Commission *on Assisted Dying*
Lord Charles Falconer, Chair
www.commissiononassisteddying.com

> “The legal and ethical status of assisted dying in our society continues to be an unresolved public policy issue…”

THE COMMISSION ON ASSISTED DYING BRIEFING PAPER: KEY RESEARCH THEMES

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PARTNERS CREDITS

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About Demos

Demos is a think-tank focused on power and politics. Our unique approach challenges the traditional, 'ivory tower' model of policymaking by giving a voice to people and communities. We work together with the groups and individuals who are the focus of our research, including them in citizens' juries, deliberative workshops, focus groups and ethnographic research.

Through our high quality and socially responsible research, Demos has established itself as the leading independent think tank in British politics. Our work is driven by the goal of a society populated by free, capable, secure and powerful citizens.

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About the commission

The Commission on Assisted Dying is an independent commission established in order to investigate the circumstances under which it could be possible for people to be assisted to die.

The commission is to act entirely independently and the commission alone will be responsible for its conclusions, which will be formed based on the evidence received. In particular, the commission will be independent from Demos and its funders. Demos is hosting the commission and providing support as the secretariat.

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INTRODUCTION

The reason for addressing the assisted dying debate at this point in time is that the legal and ethical status of assisted dying in our society continues to be an unresolved public policy issue. The Director of Public Prosecutions' (DPP) policy for prosecutors in England and Wales has clarified the circumstances in which somebody who assists another person to commit suicide is likely to be prosecuted.

However, this policy effectively decriminalises amateur assistance with suicide (if this assistance is motivated by compassion), while stipulating that healthcare professionals who provide assistance are likely to be prosecuted. The policy therefore creates the expectation that people must rely on friends and family for assistance, with all of the practical risks that this might entail.

The policy also fails to resolve ethical questions such as whether there are some circumstances that might justify somebody wishing to end their life (for example if the person is terminally ill) and others that might not (for example if somebody is experiencing temporary and curable depression).

The Commission on Assisted Dying has been set up to independently investigate whether there are circumstances in which it should be possible for people to be assisted to die, and whether the legal status quo is adequate, or whether any changes in the law are required.

This briefing has been written by Demos to inform the Commission on Assisted Dying with key arguments and evidence and to guide the commission's programme of work by identifying key themes of enquiry for the commission to pursue during the course of its investigation. This document does not represent the views of the commission or of any individual commissioner. It is intended to provoke debate and intentionally poses more questions than it seeks to answer.

Definitions

A number of terms are used to describe actions that may be taken to assist somebody to end his or her own life. The terminology surrounding assisted dying remains contested, and different definitions tend to be used in different contexts. Therefore, to avoid confusion, the following definitions are provided to define the terms of the discussion within this briefing:

Assisted suicide

'Providing someone with the means to end his or her own life.'[1]

Voluntary euthanasia

'Ending another person's life at his or her own request.'[2]

Non-voluntary euthanasia

Ending another person's life 'when the individual is incompetent to consent to or refuse euthanasia and has made no prior decision.'[3]

Assisted dying

A compendium that can refer to voluntary euthanasia and/or assisted suicide.[4]

International Overview

The following table summarises the jurisdictions in which some form of assisted dying has been legalised, the assistance that is legal, the law and the year of legalisation.

Table 1 – Jurisdictions in which some form of assisted dying is legal

Jurisdiction	Legislation Permits	Law
Switzerland	Assisted suicide (non-medical)	Swiss Penal Code (1942)
Oregon	Physician-assisted suicide	Oregon Death with Dignity Act (1994)
The Netherlands	Voluntary euthanasia & physician-assisted suicide	The Termination of Life on Request and Assisted Suicide (Review Procedures Act) (2001)
Belgium	Voluntary euthanasia	Law on Euthanasia (2002)
Luxembourg	Physician-assisted suicide & voluntary euthanasia	Law on Euthanasia and Assisted Suicide (2008)
Washington State	Physician-assisted suicide	Washington Death with Dignity Act (2008)
Montana	Physician-assisted suicide	No Act, but the Supreme Court ruled that: 'nothing in Montana Supreme Court precedent or Montana statutes indicating that physician aid in dying is against public policy.'

1 – ASSISTED DYING AND THE STATUS QUO

1.1 - The current legal status of assisted suicide in UK law

Deliberately and directly taking the life of another person, whether that person is dying or not, constitutes the crime of murder. The Suicide Act 1961, updated by the Coroners and Justice Act 2009, makes encouraging or assisting a suicide a crime punishable by up to 14 years' imprisonment. The Suicide Act gives the Director of Public Prosecutions (DPP) discretion over whether to prosecute cases of assisting or encouraging suicide - a decision is taken as to whether prosecution is in the public interest.

There have been a number of important cases challenging this law. In 2002, Diane Pretty, who was been diagnosed with motor neurone disease, wanted her husband to assist her in committing suicide when she was no longer physically able to do so herself. She asked the DPP to grant him immunity from prosecution. The DPP refused and she subsequently took the request to court.[5] Two UK courts refused the request and the case went to the European Court of Human Rights, but again her request was refused based on the judgment that: 'though she has a right to life, she had no right to death.'[6] The European Court of Human Rights held that 'the notion of personal autonomy is an important principle underlying the interpretation' of the right to respect for private and family life found in Article 8 (1) of the European Convention on Human Rights. However, the court went on to find that any interference with Mrs Pretty's right was compatible with the saving provision in Article 8 (2) as it was necessary 'in pursuit of the legitimate aim of safeguarding life and thereby protecting the rights of others.'[7]

More recently a similar but successful challenge was made to the DPP. In 2009, Debbie Purdy, a woman with primary progressive multiple sclerosis, wanted to know if her husband would be prosecuted if he helped her commit suicide overseas.[8] Her landmark case challenged the law, arguing that the DPP was infringing her human rights by failing to clarify how the Suicide Act is actually enforced. The House of Lords (at the time the highest court; since replaced by the Supreme Court) ruled that clarification should be given and the DPP was asked to prepare an offence-specific policy to identify the facts and circumstances that he would take into account in deciding, in such cases, whether or not to prosecute.

The Crown Prosecution Service (CPS) subsequently published a 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide', that set out sixteen public interest factors in favour of prosecution and six against (see Table 2). The policy gives individuals an indication of how they are likely to be treated by police or prosecutors and for the first time gives formal recognition that in some circumstances, people should not be prosecuted for helping someone to die, making a distinction between compassionate and malicious acts of assistance.

Table 2 – DPP Prosecuting Policy - Public Interest Factors

In favour of prosecution	Against prosecution
Victim is under 18 years old. Victim did not have the capacity as defined by the Mental Capacity Act 2005 to reach an informed decision. Victim had not reached a voluntary, clear, settled and informed decision. Victim had not clearly communicated their wish to commit suicide. Victim did not seek the encouragement or assistance of the suspect personally or on his or her own initiative. Suspect not wholly motivated by compassion, but personal gain. Suspect pressured victim into committing suicide. Suspect did not take reasonable steps to ensure others had not pressured victim to suicide. Suspect had history of abuse towards victim.	Victim reached a clear, voluntary, settled and informed decision to commit suicide. Suspect wholly motivated by compassion. Actions of suspect, although fitting definitions of crime, were only minor encouragement or assistance. Suspect sought to dissuade the victim. Actions of the suspect may be characterised as reluctant encouragement or assistance in the face of determined wish of victim. Suspect reported victim's suicide to police and fully assisted in their enquiries.

Victim physically unable to undertake the act that constituted assistance himself. Suspect unknown to the victim personally, e.g. providing information via website. Suspect gave encouragement or assistance to more than one victim who were not known to each other. Suspect paid by the victim, or those close to the victim. Suspect acting in their capacity as a health or social care professional, or was another person in authority, e.g. prison officer. Suspect aware that the victim intended to commit suicide in a public place. Suspect acting in capacity of employee of organisation whose purpose is to provide the environment for another to commit suicide.	

1.2 - To what extent are assisted suicide and euthanasia already happening in the UK?

It was previously thought that covert voluntary euthanasia was a fairly widespread practice amongst the medical profession. A number of surveys were understood to demonstrate this. One survey of GPs and consultants found that 12 per cent of respondents claimed to have complied with a request to prematurely end a patient's life.[9] Another study found that one in seven GPs admitted to helping patients to die and that 'hundreds, probably thousands, of patients die each year with the help of doctors.'[10] A Medix survey in the UK in 2004 found that 45 per cent of doctors understood that their colleagues actively helped their patients die.[11]

However, more recent evidence suggests that the practice of physician-assisted dying is actually much less prevalent than previously thought. In 2004, a survey of end-of life decisions (ELDs)[12] in the UK, which asked doctors about the most recent death they had attended, found relatively low rates of voluntary and non-voluntary euthanasia and no instances of assisted suicide. [13] These results contrasted with similar versions of the survey conducted in the Netherlands, Belgium and Australia where both euthanasia and assisted suicide were found to be more common.[14] A subsequent survey of ELDs conducted in 2007-08 found that euthanasia, physician-assisted suicide and non-voluntary euthanasia continued to be relatively rare in the UK.[15] It found that 0.21 per cent of UK deaths attended by a medical professional involved voluntary euthanasia and 0.30 per cent involved ending the patient's life without an explicit request from the patient. However, there were no cases of physician assisted suicide in the UK according to this survey. This research found that even where decisions are taken with the understanding that they may accelerate death in around a third of cases, they are not regarded as actually affecting the length of a patient's life. The study concluded that the shortening of life by a significant amount is rare in UK medical practice.

Research also by Clive Seale indicates that the use of continuous deep sedation (CDS), which is a palliative practice of relieving pain or distress in the last hours or days of a terminally ill person's life, usually by means of administration of sedative drug, is relatively common. A survey of over 8,000 doctors found that just over 18 per cent of the doctors attending a dying patient reported the use of CDS.[16]

For terminally ill people who wish to die, the right to refuse life-prolonging treatment (including nourishment and hydration) is also firmly established in law.[17] [18] If a patient chose to shorten their life by refusing treatment, this would not be considered an assisted death. Clive Seale's survey of ELDs conducted in 2007-08 found that 21.8 per cent of UK deaths attended by a medical professional involved the withdrawing or withholding of treatment.[19] In the case of Airedale NHS Trust v. Bland in 1993, the House of Lords also confirmed the principle that doctors could withhold life-prolonging treatment from 'an insensate patient in a persistent vegetative state', if that patient's death would follow 'imminently' after the withdrawal of treatment.[20] However, in its ruling the court advised that if similar situations arose in the future, families and doctors should seek advice from the court before taking action, as the right course of action would need to be decided on a case-by-case basis. The court specifically distinguished the action of withholding life-prolonging treatment from euthanasia, which is a criminal offence.[21]

Are assisted suicide and voluntary euthanasia happening outside the confines of the medical profession? At least 150 UK citizens are known to have ended their lives at the Dignitas clinic in Switzerland, with up to 800 more believed to be members, the ethics of which will be discussed in the next section. Home Office statistics report that a very small number of mercy killings (around four) are identified each year.[22] There are occasional high profile cases of suicides occurring behind closed doors and of amateur assistance with suicide. Recent examples include Michelle Broad, who took her own life after she began to experience the degenerative impacts of motor neurone disease. In 2009, Michael Bateman helped his wife Margaret to die, who had been unable to leave her bed for three years. Yet accurate statistics detailing actual incidences are difficult to come by.

In summary, the legal practice of continuous deep sedation, often until death, is fairly common and may occur in almost one in five deaths. Equally, there is evidence that the practice of withdrawing or withholding treatment occurs in approximately one in five deaths. However, the most recent evidence available suggests that in the UK, cases of voluntary and non-voluntary euthanasia are relatively rare, with about 2 in every 1000 deaths involving voluntary euthanasia and about 3 in every 1000 deaths involving non-voluntary euthanasia. No cases of physician-assisted suicide were identified by this research. In addition to these practices, a small number of individuals are known to travel from the UK each year to end their lives in Switzerland, and a similarly small number of cases on mercy killing and amateur assistance with suicide are also believed to take place.

1.3 - Advantages and disadvantages of the current legal position on assisted dying

The current legal situation under the new CPS policy has been criticised for being discriminatory. Jonathan Glover from the Centre of Medical Law and Ethics, King's College London, has argued that it is 'discriminatory and objectionable that somebody who is capable of committing suicide is able to do that, but somebody who happens to lack the physical capacity to do that is denied it.'[23] Questions of equality also surround the practice of attending Dignitas for the purposes of 'suicide tourism'. Above and beyond issues surrounding the operating principles of Dignitas, this poses a serious issue of equality: is it right that those than can afford to travel to Switzerland are able to end their life whilst those that do not have the financial capability cannot and might attempt to do so at home in secret?[24]

What are the implications of the DPP policy?

The DPP 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide' was welcomed by many individuals and organisations as an important source of clarification of the law with regards to assisted suicide. Care not Killing welcomed the fact that 'the law has not changed, that no-one has immunity from prosecution, and that a prosecution will normally follow unless there are clear and compelling public interest factors to the contrary.'[25] Care not Killing and SPUC Pro-Life also both welcomed the fact that the characteristics of terminal illness or disability in the assisted person were not identified as factors tending against prosecution, which they argued would mean providing people who have disabilities or who are ill with less legal protection than other groups.[26] [27]

However, some critics have argued that the previous unofficial policy of non-prosecution in cases of 'assisted suicide-tourism' that existed before the DPP policy was preferable, as this did not risk normalising or condoning assisted suicide.[28] Other critics have argued that while the DPP policy 'does not change the law on assisted suicide' and 'does not open the door for euthanasia' the policy could be construed as 'seeking to change the law by the back door',[29] and the 'checklist approach could legalise killing because it becomes far easier for people to hide the fact if they are acting out of bad motives'.[30] Furthermore, others argue that whilst the policy does provide some much needed clarity over the law, the policy still cannot provide a safeguarded means for assisted dying;[31] and that the policy condones terminally ill people travelling abroad to die but does not allow them the choice to die at home at a time of their choosing.

Penney Lewis, Professor of Law at King's College London, has also criticised this element of the policy: 'by strongly discouraging medical involvement, the guidelines place a heavy burden on supportive friends and family' with the burden of assistance likely to fall on someone with no experience or access to relevant information.[32] In her response to the CPS consultation on the policy, Professor Penney Lewis noted how a number of the prosecution factors seem concerned with ensuring that assistance remains an amateur activity carried out by inexperienced individuals without the assistance of either medical professionals or non-medical organisations (such as Dignitas in Switzerland).

Dignity in Dying (DID) also criticised the policy on a number of issues,[33] noting in particular that the policy has shifted emphasis from the characteristics of the assisted person to the motivations of the person that assists. This means that there are no safeguards to determine who should and should not be able to receive assistance which means that there is less protection than would be offered by a change in the law. The policy is unclear about the extent of restrictions on doctors' actions and on what grounds they might be prosecuted for providing assistance. DID argue that this could not only affect doctors' willingness to provide patients with medical records should they want to go abroad, but also to engage in discussion with patients who express a desire to end their life. This could damage the patient's trust of their doctor and patients may turn instead to the internet for information if their doctor is unwilling to provide it. DID voice concerns that, as a result, assistance with suicide will remain an amateur activity conducted by inexperienced people, with the potential to expose those individuals being assisted to even greater suffering if their suicide attempt goes wrong. DID also argue that the policy's provision of retrospective checks does not protect the public, as up-front safeguards are still lacking. [34]

The Medical Protection society have voiced the concern that whilst the DPP policy may bring comfort to individuals and their loved ones facing these difficult issues, the policy 'sends a clear signal that prosecutions are more likely to be brought against healthcare professionals who may be faced with requests from patients regarding assisted suicide.'[35] Also reacting to the policy, The British Medical Association asserted their continued advice for doctors to avoid 'actions that might be interpreted as assisting, facilitating or encouraging a suicide attempt' and stated that they remain opposed to doctors taking a role in any form of assisted dying.[36]

Questions

- Does the DPP policy provide sufficient safeguards for vulnerable people, or is further clarification or a change in the law required?
- Is it reasonable to accept the principle of compassionately-motivated assistance with suicide but rely on the infrastructure in Switzerland to manage the consequences of our law? Or should the law be changed to incorporate the acceptance of this principle?
- Who should provide assistance to those who want assistance to end their lives – professionals or amateurs?

2 - THE ASSISTED DYING DEBATE – ETHICAL CONSIDERATIONS

2.1 – Personal autonomy versus sanctity of life

The assisted dying debate is often characterized as a debate between two conflicting principles: the sanctity of human life versus the importance of personal autonomy.

The sanctity of life

The principle of the sanctity of life asserts that it is always preferable for someone to be alive rather than dead and that the argument against purposefully killing another human must always outweigh all other arguments.[37] This is the primary argument against assisted dying that is supported on both religious and secular grounds. Religious arguments stem from the belief that life is God-given and therefore cannot justifiably be terminated by others, even on request. In their evidence to the Select Committee on Lord Joffe's Bill, the Church of England House of Bishops wrote that

> *The arguments presented in this submission grow out of our belief that God himself has given to humankind the gift of life. As such, it is to be revered and cherished.*[38]

Evidence from the Office of the Chief Rabbi stated that

> *Jewish tradition places at its centre the sanctity of life, viewing life as a precious gift from God, not something we can dispose of at will. Indeed, the value of human life is absolute and not relative to factors such as age and health… In addition, there is a strict prohibition against suicide in the Jewish legal code… Judaism cannot purchase relief from pain and misery at the cost of life itself.*[39]

Arguments based on the sanctity of life are not all religious; in his evidence to the Select Committee, Lord Walton of Detchant (who chaired the 1993/4 Select Committee on Medical Ethics) cited,

> *society's prohibition of intentional killing, a prohibition which is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal.*[40]

While arguments derived from religious doctrine may have little weight for those without religious faith, there is a need to address this broader 'sanctity of life' argument (also referred to in secular terms as 'crossing the rubicon'): that legal changes which have the effect of qualifying the basic principle that all human life is of equal value and should be protected could put the vulnerable in our society at risk.

Personal autonomy

The principle of personal autonomy is one of the four foundation principles of medical ethics: 'the doctor must treat his patient as a rational human being capable of making choices and possessed of free will.'[41] The principle derives from Kant, who argued humans were part of the natural world and governed by physical laws in all respects bar one: the possession of reason. The principle states that choices must not be made for another human but they must spring from one's own autonomous will.

Professor John Harris has defined autonomy as 'the ability to choose and the freedom to choose between competing conceptions of how to live'. Harris further argues that 'it is only by the exercise of autonomy that our lives become in any real sense our own….When we are denied control at the end of our lives we are denied autonomy.'[42]

However, as others have argued:

> *it is clear to most people that a limit has to be set on such self-determination through self-government (or personal restraint) or through law, in order to preserve the freedoms of others.*[43]

The question is how society can ensure that one individual's right to personal autonomy does not compromise another person's right to be protected from harm.

Weighing personal autonomy against the sanctity of life

In his evidence to the Select Committee, Lord Joffe expressed the view that 'personal autonomy trumps sanctity of life.'[44] This view was apparently shared by Professor Harris, who argued that if assisted suicide is not legalised, then the group of people who are terminally ill and require assistance to die will experience *certain harm*, whereas there is only *potential harm* to others if assisted suicide is legalised (e.g. those vulnerable who might feel pressured into having an assisted suicide for the wrong reasons).[45] Professor Harris expressed the opinion that:

> *we have to take a balanced view … but that balanced view should not be at the expense of one group always in order to offer absolute protection to another group.*[46]

However, others have expressed equally strong convictions that the risk of the *potential harm* is greater and more serious than the incidents of *actual harm* referred to above. Discussing Lord Joffe's Bill, Baroness Finlay argued that:

> *Ultimately the real question rests on balance of harms: whether it is worse for some people to live for days or weeks longer than they otherwise wish, or it is worse that some will commit suicide or have their lives ended months or even years prematurely because their decision is misinformed or their ability to project forward and accept that life can still be worth living fails them.*[47]

Baroness Finlay suggests that the latter harm substantially outweighs the former, therefore, the potential risk to the vulnerable must outweigh individuals' right to personal autonomy.

Questions

- If assisted dying legislation were to include adequate safeguards to protect people more at risk from abuse of the law, would there be an adequate balance between choice for the individual and protection for society?

2.2 - What is the rationale underpinning the legalisation of some form of assisted dying in other jurisdictions?

In the UK, those advocating a change of the law have most frequently framed their argument in terms of human rights.[48] For example, Diane Pretty's appeal against the DPP's refusal to provide assurance that her husband would not be prosecuted if he assisted her to commit suicide was based on:

> *her rights to life, freedom from torture and inhuman or degrading treatment, respect for her private and family life, freedom of thought, conscience and religion, and freedom from discrimination under the European Convention on Human Rights.*[49]

However, as Professor Penney Lewis has observed in 'Assisted Dying and Legal Change', none of those jurisdictions that have legalised some form of assisted dying have done so on the basis of rights-based claims:

> *No legislature has been forced to draft legislation legalizing assisted dying in direct response to a judgment striking down a criminal prohibition on assisted suicide, murder, or any lesser offence on the grounds of a violation of one or more constitutionally entrenched human rights.*[50]

Lewis points out that as the rationale underpinning the legalisation of assisted dying varies significantly between jurisdictions, we should bear in mind that the experiences of other jurisdictions 'do not translate directly to other jurisdictions.'[51] To highlight some important differences between jurisdictions, some key examples of the rationale and mechanisms underpinning assisted dying regimes are outlined in the box below.

Box 1 – The rationale for legalisation in other jurisdictions[52]

Netherlands and the 'Defence of Necessity'

Euthanasia and assisted suicide were effectively legalised through the use of the defence of necessity in prosecutions of (primarily) doctors. The defence is available when the doctor faced a conflict between his or her duties to preserve life and relieve suffering. The courts held that only doctors can face such a conflict of duties because only doctors have a professional duty to relieve suffering: lay-persons and nurses do not. Over some thirty years, the courts developed this duty-based defence of necessity in euthanasia cases, placing a range of conditions on the defence, conditions which became known as requirements of due care or careful practice. The Dutch legislature eventually codified the parameters of the defence in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.

Switzerland and 'unselfish motives'

According to article 115 of the Swiss Penal Code, it is a criminal offence to assist a suicide only where the assister has a selfish motive. This provision in the Penal Code has not changed since 1942. When it was originally drafted in 1918:

The attitudes of the Swiss public were shaped by suicides motivated by honour and romance, which were considered to be valid motives. Motives related to health were not an important concern, and the involvement of a physician was not needed.[53]

Unlike the situation in The Netherlands, assistance with suicide in Switzerland is not seen to be exclusively the role of doctors and the law does not distinguish between doctors and other people. 'Anyone may legally give such assistance from non-selfish motives,'[54] although a doctor's prescription will be needed to obtain lethal medication. Importantly for citizens of jurisdictions where assisted dying is illegal, the Swiss Penal Code does not specify that people who obtain assistance with suicide must be residents of Switzerland.[55]

Oregon and patient autonomy

The Oregon Death with Dignity Act (ODDA) was conceived of with the intention of supporting the autonomy of terminally ill patients who are mentally competent and wish to have an assisted suicide. A legislative approach to legal change was taken, with the State's electorate voting on the ODDA. Many US states allow legislation to be enacted if a majority votes for an initiative placed on the ballot following a petition signed by a minimum number of voters. Following two unsuccessful ballot attempts to permit physician-assisted suicide in Washington and California, Oregon voters passed the first Death with Dignity Act in 1994 by a majority of 52 per cent.

The emphasis on personal autonomy as an underpinning rationale is reflected in the fact that eligible patients remain responsible for their own suicide: 'the administration of the lethal dose must be by the patient, and not the doctor.'[56] However, importantly, the Oregon courts have not recognized a right to assisted suicide, therefore:

it is unlikely that claims using rights could be used to expand the contours of the Oregon law to dispense with, for example, the requirement of terminal illness or the limitation to assisted suicide.[57]

The differing legal basis of these jurisdictions' positions on assisted dying reflects – and has no doubt influenced – these jurisdictions' culturally embedded understanding of whether it is appropriate and ethically acceptable for doctors (and others) to be involved in some form of assisted dying as part of their role in caring for patients at the end of life. This question of the doctor's role will be explored in sections 2.4, 4.3 and 5.5.

2.3 - The Ethics of Eligibility

There are profound ethical issues surrounding the question of who – if anybody – should be eligible for an assisted death. If some form of assisted dying were to be legalised in the UK, there would arguably be a need to limit who might justifiably make use of this provision. The 2004 Assisted Dying for the Terminally Ill Bill proposed by Lord Joffe was conceived of as a compassionate response to the intense suffering experienced by many people in the final weeks and months of their lives, and an attempt to support the personal autonomy of dying patients to choose the timing and manner of their death. The Bill therefore limited eligibility to people who were terminally ill, suffering unbearably and mentally competent.

However, some commentators have questioned the basis for limiting such legislation to the terminally ill, when other groups may experience unbearable suffering and have an equally strong claim to assistance with dying. As Professor Finnis commented to the Select Committee on the Assisted Dying for the Terminally Ill Bill, people suffering from chronic debilitating conditions may have an equally strong claim to receive assistance with suicide, but would be excluded under the Bill's terms. Other commentators such as Ilora Finlay have taken the opposite view, arguing that it would be morally wrong to mark out the terminally ill for special treatment by the law, as this means making a 'value statement … that as death approaches, a person's life has less worth in our society; in this utilitarian perspective death becomes a social or health-economics expedient.'[58]

The latter view was particularly influential in the public consultation on the DPP's interim prosecution policy. This interim policy stated that if the 'victim' of an assisted suicide had 'a terminal illness', 'a severe and incurable physical disability' or 'a severe degenerative physical condition' and there was 'no possibility of recovery', this would be a factor tending against the prosecution of the person who had assisted their suicide.[59] However, this wording was removed in the final DPP policy, in response to campaigners' arguments that those groups identified by the policy may be put at risk as a result of being less protected by the law. [60] [61]

Jurisdictions that have legalised some form of assisted dying nearly all specify the characteristics of who should eligible for assistance to die, with the notable exception of Switzerland. Criteria differ between these jurisdictions but tend to include at least one of the following stipulations: being over 18 years old; experiencing unbearable suffering; being terminally ill or having been diagnosed with ‘a serious and incurable disorder’.[62] The significant variety between these different societies’ conceptions of what might constitute a legitimate reason for seeking to end one’s own life indicates the broad spectrum of opinion on this issue.

In the Netherlands, where unbearable suffering ‘with no prospect of improvement’ is the main eligibility criteria for an assisted death, there is no requirement for applicants to be terminally ill. In some exceptional cases, ‘very severe but incurable mental illness – which relates to a situation of hopeless and unbearable suffering’ has been accepted as a reasonable basis for requesting an assisted death.[63] However, a legal ruling by the Dutch Supreme Court in 2003 determined that simply being tired of life was not a justifiable reason for seeking an assisted death:

> *Doctors may not perform euthanasia or help with suicide unless the request comes from a patient suffering from a medically classifiable physical or psychiatric sickness or disorder. Simply being ‘tired of life’ is no basis for doctors to act’*[64]

This judgment shows that even in jurisdictions that are considered to have particularly liberal assisted dying regimes, there is felt to be a need to limit eligibility. However, the differing social and legal context in each jurisdiction will determine different boundaries on what is considered to be acceptable.

In the UK, surveys of public opinion suggest that if there were to be a change in the law, there would be public support for limiting the definition of who might reasonably seek an assisted suicide. The British Social Attitudes Survey in 2007 found that 80 per cent of respondents supported a change in the law to allow terminally ill people to have an assisted death, whereas only a third said that someone with an incurable - but not terminal – illness should also be able to have an assisted death.[65] The report concluded that ‘only a minority support assisted dying if someone is in pain or dependent, but not terminally ill.’[66]

Therefore, if some form of assisted dying were to be legalised, this issue of eligibility would clearly be a fundamental issue for new legislation to address. Potential options for eligibility criteria will be considered in more detail in section 5.3 of this briefing.

Questions

- If some form of assisted dying were to be legalised, who should be eligible for assistance?
- Is there a clear ethical basis for limiting eligibility for an assisted death to certain groups?

2.4 Assisted dying and medical ethics

As observed above, in the Netherlands it was the perceived conflict between the doctor's professional duties to relieve suffering and to preserve life that gave rise to the legalisation of euthanasia and assisted suicide.[67] Dutch law recognises that within specified guidelines it is ethically acceptable for a doctor to hasten a patient's death in order to relieve unbearable suffering.[68] However, non-doctors may not provide assistance with suicide, as only a doctor has a professional duty to relieve suffering.

The Swiss Penal Code, however, does not distinguish between the legality of a doctor or non-doctor providing assistance with suicide. There is an ongoing debate in Switzerland about the role of doctors in assisting suicide and in 2004 the Swiss Academy of Medical Sciences (SAMS) issued the guidelines 'Care for Patients at the End of Life', stating that:

> *assisting patients to die is not to be considered a medical activity but should not in principle be morally condemned if a physician decided to act on his or her individual conscience and if the patient was terminally ill.*[69]

A survey conducted among Swiss healthcare professionals in 2008 found that only 15.8 per cent of participants considered physician-assisted suicide to be a legitimate part of medical practice, whereas the majority thought assisted suicide to be a non-medical intervention that should not be morally condemned.[70] The unresolved issue of whether or not assisting patients to die is a legitimate part of a doctor's role has led to non-governmental organisations having a very prominent role in facilitating physician assisted suicide in Switzerland.

In England, as the DPP's prosecuting policy has recently highlighted,[71] it is not currently legally permissible for a doctor to provide assistance with suicide or otherwise act in a way that intentionally hastens a patient's death. According to the principle of double-effect, a doctor is 'entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life.'[72] Shortening life must not be an intentional consequence of the doctor's actions. Patients who are terminally ill and do not want their death to be prolonged may, however, refuse life-prolonging treatment (as can all competent patients, regardless of their medical condition).

Doctors' views on the legalisation of assisted dying

Doctors' views towards assisted dying in the UK are still poorly understood. A review of the evidence between 1987 and 2005 concluded that support for a change in the law varied from between 22 to 66 per cent with variation attributed to differences in question wording.[73] This lack of clarity has not been helped by the shifting stance of the British Medical Association who in 2005 moved to a neutral position on assisted dying for terminally ill adults, only to return to opposition the following year following criticism from members.[74] Despite this uncertainty, the evidence shows that in general, the majority of doctors are opposed to the legalisation of assisted dying. Geriatricians are more opposed than medical practitioners as a whole and GPs are less opposed than hospital doctors.[75]

An extensive survey of UK doctors found lower levels of support for all categories of assisted dying when compared to the public (as indicated by the British Social Attitudes Survey).[76] The research also shows that 90 per cent of palliative care specialists are opposed to legalisation. The evidence suggests that those with greater experience of end-of life care are more opposed to a change in the law and that greater religiosity correlates strongly with opposition to assisted dying. This research confirms that there is much less support for all categories of assisted dying amongst doctors compared to the general public.[77] This trend is consistent with findings from other countries where similar comparisons have been carried out including the USA, New Zealand, Norway, the Netherlands Australia and Finland.

Clive Seale recently conducted a study on the role of religion in affecting doctors views towards assisted suicide. This found that doctors who described themselves as non-religious were almost twice as likely than others to report having given continuous deep sedation until death, having taken decisions they expected or partly intended to end life, and to have discussed these decisions with patients who were judged to have the capacity to participate in discussions.[78]

To what extent should doctors participate in assisted dying?

Dr Michael Wilks, representing the British Medical Association, told the Select Committee on the Assisted Dying for the Terminally Ill Bill that assisted suicide and voluntary euthanasia ‘move medicine and medical care into a different field,’ and determine ‘a different type of relationship between the doctor and the patient.’[79] Fiona Randall and Robin Downie have pursued this argument further, arguing that a doctor’s role by definition cannot include involvement in physician-assisted suicide. According to this argument:

> *A doctor’s job description is to aim at the provision of treatments with health benefits in the patient’s best interests, and to avoid adverse outcomes. Death is not a health benefit and a dead patient has no health interests. Death resulting from treatment is a serious adverse outcome. It is therefore irrational to assume or argue that the provision of AS/VE could be part of a doctor’s role.*

Significantly, Randall and Downie do not argue against the legalisation of assisted suicide, but assert that if patients are to be provided with control over when and how they die, this 'in fact points to the involvement not of doctors but of legal agencies as decision makers plus technicians as agents.'[80]

Research looking at doctor's attitudes towards assisted dying shows that those in favour of legalisation frequently express concern about the involvement of medical professionals should some form of assisted dying become legal.[81] Comments included:

'If the law and patient choice dictates euthanasia I have no real objection but it should be conducted by professionals other than doctors as it may blur perceptions of doctors' role, leaving vulnerable people reluctant to seek medical help for symptom control'[82]

'I do not think euthanasia is actively a doctor's role. It is not technically difficult and if society wants this I do not see that a separate 'profession' couldn't be set up (perhaps providing employment for philosophy graduates?) so as to keep doctoring free of the express role of euthanasia'[83]

The view that the doctor's role should preclude involvement in assisted dying is not, however, shared by all doctors. Giving evidence to the Select Committee on the Assisted Dying for the Terminally Ill Bill, Professor Raymond Tallis commented that:

To me [assisted dying] does seem to be a therapeutic option, as are many other forms of treatment that may hasten people's deaths… For that reason I do feel it should be regarded as part of the therapeutic alliance between the patient and the doctor. I do see … that it is part of the whole package of care.[84]

Mary Warnock and Dr Elisabeth MacDonald have also argued that:

Assisted dying, if legalized, should remain under medical supervision, perhaps in the hands of specialist physicians who favour this approach and can offer continuity of care and a final act of friendship.[85]

Questions

- Is assisted dying compatible with the ethos and values of the medical profession?
- Are tasks such as addressing questions of coercion, spiritual issues or even symptom control better performed by nurses, social workers, clergy or lawyers?[86]

Section 5 will explore the practical implications of assisted dying, including the role of doctors or non-medical organizations, in more detail. The following section will examine arguments regarding the role of assisted dying in relation to existing frameworks of end of life care.

3 – WHAT IS THE RELATIONSHIP BETWEEN ASSISTED DYING AND PALLIATIVE CARE?

3.1 – What is the purpose of palliative care?

In 2002 the World Health Organisation (WHO) defined palliative care as:

> *An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*[87]

According to the WHO definition, palliative care specifically:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as

> chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[88]

In 2004, the House of Commons Health Committee's report on palliative care emphasised the distinction between general and specialist palliative care. General palliative care:

is provided by the usual professional carers of the patient and family, such as GPs, district nurses, hospital doctors, ward nurses, allied health professionals and staff in care homes. Most palliative care is provided by non-specialist staff such as these.

Specialist palliative care:

is provided by multi-disciplinary teams that might include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care.

Such staff are specifically trained to advise on symptom control and pain relief and 'to give emotional, psychosocial and spiritual support to patients, their families, friends and carers, both during the patient's illness and into bereavement'.[89]

3.2 – What is the availability of palliative care in the UK?

According to expert witnesses for the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, palliative care in the UK is 'of a very high quality but inadequately resourced and unevenly spread.'[90]

About 500,000 people die in England each year, with almost two thirds of people aged over 75. More than half (58%) of deaths take place in NHS hospitals, with about 18% occurring at home, 17% in care homes and 3% elsewhere.[91] In 2008 there were 175 adult inpatient specialist palliative care units in England, of which 133 were in the voluntary sector and 42 in the NHS. These provide 2645 specialist palliative care beds, of which 2141 were in the voluntary sector and 504 in the NHS. In addition to this there were 93 'Hospice at Home' services, 231 Home Care services, 225 Day Care services, 29 Hospital Support Nurses and 226 Hospital Support

Teams.[92] As these numbers show, despite recent improvements there continues to be significant under-provision of palliative care services in England.

In 2004 the House of Commons Health Committee on Palliative Care identified inequity of provision as a key issue in the delivery of palliative care. The particular inequities that were identified were:[93]

Inequity by geographical area:

The Health Committee found that in many areas there was ‘a severe mis-match between service provision and need’ and concluded that:

> *There is need for more equitable distribution of both hospices and of care at home through an assessment of the needs of the population, greater planning of services and the introduction of detailed contracting arrangements.*[94]

Inequity by patient group:

Palliative care services for adolescents and young adults were described to the Health Committee as being ‘very patchy’ and it was felt that they were not sufficiently strategically planned.[95] Age Concern expressed concern that some older patients were less likely to receive referrals to specialist palliative care services than younger patients. There was evidence of inequity by ethnicity, as a number of studies have demonstrated the under-representation of black and minority ethnic communities in palliative care. There was also evidence that patients with complex needs and especially those with learning disabilities may be less able to secure access to palliative care services.

Inequity by disease:

The Health Committee commented that ‘the lack of palliative care for non-cancer sufferers constituted a major and recurrent theme of our evidence.’[96] The Department of Health agreed that inequity by disease was the most significant inequity in palliative care services. Whereas 95% of those in hospices have cancer, cancer is the cause of death in only a quarter of the population.[97]

The Department of Health's 'End of Life Care Strategy', published in July 2008, acknowledged the continuing under-provision of palliative care services for non-cancer patients and identified 'enhanced specialist palliative care services for people with conditions other than cancer, including additional services in care homes' as a key area that requires greater investment.[98] It found that patients dying from cancer have a much greater likelihood of dying in a hospice than other patients (16 per cent of cancer patients die in a hospice compared with 4 per cent overall and less than 1 per cent of patients with circulatory or respiratory disease), despite the fact that those with cancer and those with other diseases tend to experience similar problems in the last year of life.[99]

The report concluded that:

> *The challenge for the NHS and social care services now, is to extend this quality of care from the minority of patients (mainly those with cancer) who currently come into contact with hospices and specialist palliative care services, to all people who are approaching the end of life.*[100]

3.3 – Is palliative care always effective in relieving suffering?

As the above discussion illustrates, there is now a consensus on the issue that high quality palliative care should be made available to all patients at the end of their lives, regardless of their medical condition, age, ethnicity or location. The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill found that there was also general agreement among the witnesses who presented evidence that there are limitations in the degree to which palliative care is able to relieve all dimensions of dying patients' suffering.

The evidence presented to the Select Committee suggested that in most cases, 'good palliative care … can largely relieve the symptoms of physical pain.'[101] However, witnesses including the Voluntary Euthanasia Society [102] and the British Medical Association observed that the psychological suffering that derives from some patients' distress at their irreversible loss of autonomy can be much harder to address than physical symptoms, and that it is this type of suffering that is most likely to give rise to a request for an assisted death.

The Select Committee concluded that:

The demand for assisted suicide or voluntary euthanasia is particularly strong among determined individuals whose suffering derives more from the fact of their terminal illness than from its symptoms and who are unlikely to be deflected from their wish to end their lives by more or better palliative care.[103]

However, opinion continues to be strongly divided on the subject of whether assisted dying could play a complementary role in conjunction with palliative care, or must necessarily conflict with the aims and ethos of palliative care.

Questions

- What provisions need to be and can be made for those for whom palliative care is not effective?

3.4 – Are assisted dying and palliative care complementary or in opposition?

Generally speaking, people's opinions on the relationship between assisted dying and palliative care tend to correspond with their overall position on the issue of assisted dying. As one study has noted:

VE/AS legalization advocates and palliative care providers typically have an adversarial relationship to one another regarding the question of assisted death.[104]

Those who are against the legalisation of assisted dying tend to argue that assisted dying conflicts with and undermines the principles of palliative care, while those who support the legalisation of assisted dying tend to argue that establishing a legal process to support assisted dying can work alongside, and complement palliative care. Some key arguments in support of each position are identified below.

Arguments supporting the perspective that assisted dying and palliative care are in conflict

- There is no type of suffering that cannot be relieved if patients have access to expert palliative care, provided by staff with the right training therefore assisted dying is not an appropriate response to suffering.[105]

- Governments should focus on ensuring that their citizens' needs for palliative care services are adequately met before they consider the legalisation of assisted suicide.[106]

- If some form of assisted dying is legalised in order to respond to patients' unbearable suffering, there may be less incentive to improve palliative care and palliative care could be 'underdeveloped' or 'devalued' across the board as a result.[107]

- Palliative care aims to provide people with the best possible quality of life throughout the dying process. Providing assistance for the terminally ill to end their lives prematurely implies the value judgement that dying people's lives are less valuable to our society. This contradicts and undermines the principles underpinning palliative care.[108]

- A patient's request for an assisted death is sometimes in fact a veiled request for reassurance and support in the face of considerable suffering. What the patient may actually be asking for is good palliative care.[109] In these circumstances, an assisted death would not meet the patient's real, underlying needs for support and might increase their feelings of abandonment.

Arguments supporting the perspective that assisted dying and palliative care could be complementary

- While high quality palliative care will provide an effective solution to suffering towards the end of life for the majority of people, there is a small group of people for whom palliative care is not an effective response to their suffering. Those people for whom palliative care is ineffective and who would rather end their life than continue to experience unbearable suffering, should have the option of an assisted death.[110]

- There would not necessarily be less investment in palliative care if some form of assisted dying was legalised. There might be greater investment in the development of palliative care if the alternative was that patients might want to shorten their lives.[111]

- Both palliative care and assisted dying regimes are driven by values of supporting patients' autonomy and acting with compassion, therefore they are not fundamentally in conflict with one another.[112]

- Trust in doctors could be strengthened.

Evidence from abroad

What is the relationship between palliative care and assisted dying in jurisdictions in which some form of assisted dying has been legalised? Box 3 below provides some key information on the development of palliative care services in the Netherlands, Oregon and Belgium.

Box 2 – Palliative care in jurisdictions that have legalised some form of assisted dying

Oregon

A 2001 study by Ganzini et al[113] found that since the Death with Dignity Act in 1994, 'most Oregon physicians who care for terminally ill patients report that … they have made efforts to improve their ability to care for these patients.'

Out of 2094 survey respondents, 76 per cent said that they had made efforts to improve their knowledge of the use of pain medications for the terminally ill, 69 per cent had sought to improve their recognition of psychiatric disorders including depression, and 79 per cent said their confidence in prescribing pain medications had improved.

In 2009, 59 people died under the Death with Dignity Act. Of these, most patients died at home (98.3 per cent); and most were enrolled in hospice care (91.5 per cent) at the time of their death.[114]

In 1994, 22 per cent of Oregonians who died were enrolled in hospice programmes. In 2008 this figure had risen to 52 per cent – one of the highest rates in the USA.[115]

The Netherlands

A 2007 study comparing the effectiveness of palliative care across Europe identified the Netherlands as being one of the countries with the 'highest level of development of specialized palliative care teams' (alongside the UK, Iceland, Poland, Luxembourg and Norway). This group of countries had an average of 5 palliative care beds to 100,000 inhabitants.[116]

However, the same study found that the Netherlands has a particularly low number of professionals dedicated to palliative care, with one physician per 1,160,000 inhabitants. [117] This reflects the fact that the Netherlands takes a 'generalist' approach to palliative care, through which all GPs and nurses are trained to give palliative care, usually at the patient's home. [118]

Belgium

When the Belgian Euthanasia Law was passed in 2002, an act positing 'the right to palliative care' was passed at the same time. This doubled public funding for palliative care.[119]

The Flemish Palliative Care Federation made a statement that 'Palliative care and euthanasia are neither alternatives nor antagonistic … Euthanasia may … be part of palliative care.' [120]

The first report of the Federal Control and Evaluation Commission (FCEC), which covered a 15 month period from 2002-2003, found that out of 259 reported cases of euthanasia, in only 101 cases (40 per cent) had palliative care teams been consulted by attending physicians.[121]

A 2009 study by Van den Block et al found that ‘Medical end of life decisions including euthanasia or physician assisted suicide are not related to lower use of palliative care in Belgium and often occur within the context of multidisciplinary care.’[122]

A palliative care ‘filter’?

The Select Committee on the Assisted Dying for the Terminally Ill Bill recommended that:

> *If any future bill is to claim credibly that palliative care is regarded as complementary rather than an alternative to assisted suicide, consideration must be given to finding a means by which applicants can experience the effects of good palliative care rather than simply be informed of the existence of such treatment.*[123]

However, given the resource limitations that have been identified above, there may be practical barriers to implementing this recommendation that would need to be addressed. The prospect of a palliative care ‘filter’ will be discussed in more detail in section 5.4.

Questions

- Could assisted dying have a complementary relationship to palliative care?
- What processes or safeguards should be included in assisted dying legislation to ensure that those determined in requesting an assisted death have fully explored what palliative care can offer them?

4 – POTENTIAL RISKS ASSOCIATED WITH A CHANGE IN THE LAW

4.1 – The slippery slope

Professor Penney Lewis defines slippery slope arguments as those that 'assume that all or some of the consequences that flow from permitting a particular practice are morally unacceptable.'[124] Lewis identifies two distinct categories of slippery slope arguments against the legalization of assisted dying: 'logical' arguments and 'empirical' arguments.

Logical slippery slope arguments

Logical slippery slope arguments contend that once a particular practice has been deemed acceptable on principle, we will be logically committed to subsequently accepting other related practices as there is no clear argument for rejecting the related practices once we have agreed to the principle.[125]

According to this argument, a change in the law to permit physician-assisted suicide for a certain group (e.g. the terminally ill) might logically commit us to future extensions in the law to permit other groups who are not terminally ill to have an assisted suicide (e.g. the seriously ill, disabled, or those who are 'tired of life'). If the potential extensions to the law that could take place are deemed to be too morally hazardous (e.g. failing to safeguard vulnerable people from potential abuse), it is deemed that the initial change in the law is also too dangerous to be permissible.

Logical slippery slope arguments include:

- A law that allows the terminally ill to have access to an assisted suicide will be thought to be inequitable, therefore the entitlement is likely to be extended to other groups who are not terminally ill but are suffering unbearably.[126]

- The legalisation of assisted suicide concedes the point that it is better for some people, such as the terminally ill, to end their lives. This will logically lead to a societal tolerance first for voluntary euthanasia (for those who cannot physically end their lives), and then for non-voluntary euthanasia (e.g. for mentally ill people whose lives are not deemed to be worth living.)[127]

Empirical slippery slope arguments

Empirical slippery slope arguments claim that if the law is changed to permit certain legally-defined practices, the public's perspective on the issue may change to the extent that people will go on to accept (and perform) other more morally questionable practices, despite the fact that these fall outside the legal definition of what is acceptable.[128]

Empirical slippery slope arguments include:

- The uncertainty principle: 'if a law contains terms that are impossible to define precisely, then inevitably that law will become more permissive than was at first proposed.'[129] It is difficult to define terms such as 'terminal illness' and 'unbearable suffering' sufficiently precisely.

- Elastic interpretation:[130] if the law is changed to permit assisted suicide in specific circumstances, there is a risk that the chosen criteria governing eligibility will be interpreted in an 'elastic' way to allow a wider application than was originally intended. For example, legal definitions of criteria such as 'terminal illness', 'unbearable suffering', or 'mental competence' might not be strictly adhered to in practice. The Abortion Act of 1967 is widely cited as an example of elastic interpretation.[131]

- Paradigm shift: if assisted suicide is legalized within certain strict parameters, this will cause a change in patients' expectations and medical culture, leading to a situation in which euthanasia seems increasingly acceptable.

Evidence from abroad

Those who argue that legalising some form of assisted dying in the UK would lead to a slippery slope have often pointed to the experience of the Netherlands and the frequently-cited statistic (deriving from Holland's first national survey in 1990) that 1000 deaths per year are attributable to non-voluntary euthanasia or 'termination of life without an explicit request.'[132] However, a more robust look at the Dutch data shows that while a significant number of cases of non-voluntary euthanasia do occur in the Netherlands each year, there is no evidence that numbers have risen since voluntary euthanasia became legal.

Surveys undertaken in 1990, 1995, 2001 & 2005 have shown that the rate of non-voluntary euthanasia in the Netherlands has not risen since 1990: 0.8 per cent of all deaths were caused by non-voluntary euthanasia in 1990, 0.7 per cent of deaths in 1995 and 2001[133] and 0.4 per cent in 2005.[134] There is therefore no evidence that the legalisation of voluntary euthanasia has caused a 'slippery slope' towards increasing numbers of non-voluntary euthanasia.

In Belgium, where voluntary euthanasia was legalised in 2002, a similar trend has been found to that in the Netherlands, with no evidence of a slippery slope from voluntary euthanasia to non-voluntary euthanasia. A study by Bilsen et al[135] found that in 2007, 1.9 per cent of deaths in Flanders were caused by voluntary euthanasia, showing an increase from 1.1 per cent in 1998. However, at 1.8 per cent of all deaths, the rate of non-voluntary euthanasia was lower than it had been in 1998 (at 3.2 per cent of all deaths), and had remained reasonably stable since 2001, when 1.5 per cent of all deaths were attributable to non-voluntary euthanasia. The study found that physicians were significantly more likely to discuss end-of-life practices with their patients in 2007 than they had been in 1998.

In Oregon there is also no evidence of a slippery slope. The numbers of people receiving assistance with suicide in Oregon since the Death with Dignity Act was passed in 1997 have increased each year, but have remained low. Since 1997, 460 patients have died from taking medications prescribed under the Death with Dignity

Act. In 2009, the most recent year for which data is available, assisted deaths accounted for a total of 59 deaths (an estimated 19.3 assisted deaths per 1000 total deaths).[136]

On the basis of these figures, it has been estimated that if assisted suicide was to be legalised in Britain using similar legislation to that in Oregon, around 1,000 people per year would have an assisted suicide.[137]

Questions

- Are logical extensions to assisted dying legislation inevitable?
- Is there a way of designing a law to permit some form of assisted dying in a way that would provide sufficiently well-defined safeguards to prevent the descent down a slippery slope?
- Could sufficient regulation and monitoring ensure that safeguards are not interpreted in an 'elastic' manner?
- Do regimes in which only assisted suicide is legalized provide better protection against 'elastic' interpretation and paradigm shift?

4.2 – Risk to vulnerable people

Ensuring that those requesting assistance to die are acting purely on their own will and are not being coerced by their family, friends, or those in the medical profession, is one of the most critical issues for legislation seeking to legalise some form of assisted dying. Whether or not the 'victim' had reached a voluntary decision to commit suicide is also a key factor in the DPP's prosecuting policy on assisted suicide. Yet in practice, this is a very difficult thing to retrospectively investigate.

Concerns have been widely expressed that legislation to legalise assisted dying specifically for the terminally ill would suggest that their lives are no longer of value to society. Concerns have also been voiced that terminally ill patients might feel pressured into having an assisted death when the cost of care begins to impact on their family's inheritance, for example. However, is the issue of feeling oneself to be a burden bound up with frustration at experiencing a loss of autonomy and therefore a legitimate element of a wish for an assisted death?

Lord Joffe's 2005 Bill contained a number of requirements aimed at ensuring that requests are made voluntarily. The Bill proposed that the process would begin with a written request to one's doctor for assistance to die. Thereafter the patient would have to undergo a consultation with two doctors, one of whom must be an independent consultant. If either of the doctors had concerns about the patient's mental competence he or she would be referred to a psychiatrist. The Bill also contained a minimum period of 14 days for reflection. A final safeguard in the Bill to ensure that the decision being taken is voluntary, was that the patient - not the doctor - would administer the drugs. [138] Yet despite these safeguards, evidence suggests that doctors would still feel high levels of concern about their ability to assess the extent of external pressures on those who request euthanasia.[139]

Assisted death as a cheap option?

In 2009, for the first time in the UK the number of people over 65 exceeded those under 16. This ageing population is predicted to lead to significant pressures on the state in coming years. The Treasury's 'Long term public finance report' predicts significant rises in health spending (from 6.9 to 9.5 per cent of GDP between 2003-04 and 2053-54). Age related public spending is predicted to rise from around 22 per cent of total spending today, to 28 per cent in 2030.[140] Our care system is already struggling to meet the needs of those who currently require support and is ill-prepared for the coming wave of ageing baby boomers.[141]

Those who argue that legalising some form of assisted dying as a 'treatment option' will place pressures on people near the end of their lives also argue that it could become the cheapest, quickest and simplest option; and one that is more attractive to health and social care providers than developing and providing expensive, and potentially long-term, services. Opponents of a change in the law argue that this will irrevocably damage the relationship between care givers and receivers.[142]

Discriminatory attitudes towards disability and old age

The disabled lobby has frequently voiced concerns that a change in the law to allow assisted dying would act to re-enforce public prejudice towards both disabled and old people and that if options for assisted dying were available, support for independent living might become more difficult: 'if assisted dying became legal, decisions could be made through a prism of the prejudice and inequity that does still pervade our society.'[143] There is always the potential danger of people internalising negative constructs of disability, hence feeling under pressure to choose death to avoid becoming a burden on family, friends or society.[144] Age UK also contend that pervasive ageism undermines the value given to the lives of older people.[145]

Concerns about the impact of legislation on attitudes to disabled people particularly came to light following the DPP's interim prosecuting guidelines, to which many campaigning groups responded. The EHRC argued that Factor 4 against prosecution should be limited to the victim having a terminal illness and should not include a disability:

> *To include 'having a severe and incurable physical disability, or a severe degenerative physical condition' suggests that the life of a disabled person who is not terminally ill is worth less than the life of a person who is not disabled.*[146]

The public and media perceptions of the case of Daniel James, a severely depressed tetraplegic who persuaded his mother to facilitate his suicide in Switzerland were subsequently used to illustrate this point:

> *His wish to die was considered acceptable because he was a disabled man. The same desire to die in a non-disabled person of either sex or any age would be considered to be unreasonable and a sign of mental illness.*[147]

Barbara Wilding, Britain's most senior female police officer, has argued that a change in the law to permit some form of assisted dying could lead to exploitation by families who wish to kill burdensome elderly relatives.[148] She has drawn attention to elderly abuse, asserting this as a comparable social issue to child abuse and one that is easily covered up for those elderly people without a voice. This view is shared by Age UK who point to data that shows that ageism is the most commonly experienced form of discrimination, with 23 per cent of adults reporting experiences of this type of prejudice. [149]

Research by Age UK cited by the organization Care not Killing has also found that from age 55 onwards, people were almost twice as likely to have experienced age prejudice than any other form of discrimination.[150] This research found that 'one third of people thought that the demographic shift towards an older society would make life worse in terms of standards of living, security, health, jobs and education' and that 'one in three respondents said they viewed the over 70s as incompetent and incapable.' [151] Consultation with older people by Age Scotland around the End of Life Assistance (Scotland) Bill found there to be, in general, support for assisted suicide for people with a terminal illness.[152]

The British Geriatrics Society (BGS) has also voiced concerns that many older people, because of the care given to them by society (and the NHS) will perceive themselves as a burden and feel under pressure to end their lives, should the request be available to them. The BGS believes that older people are often unduly influenced by their families and carers:

> *It is important to remember that not all these people will necessarily have the older person's well-being at heart. Even if they do, it is noteworthy that almost all requests to end life – made either directly or indirectly to us as geriatricians – come from the patients' families and not the older person themselves. Often such requests are then forgotten if such degrading symptoms as urinary and faecal incontinence, depression and unremitting pain are relieved.*[153]

Empirical evidence from the Netherlands and Oregon

A study by Battin et al in 2007[154] compared available data on the characteristics of people receiving assistance in dying in Oregon and the Netherlands to identify whether members of vulnerable groups were over-represented. Categories the study examined included the elderly, women, uninsured people, people with AIDS, people with low educational status, the poor, racial and ethnic minorities, people with non-terminal physical disabilities or chronic non-terminal illnesses, minors and patients with psychiatric illness (including depression and Alzheimers disease). The study found that there was 'no evidence of heightened risk … with the sole exception of people with AIDS.' The study identified those who were most likely to have an assisted death as 'members of groups enjoying comparative social, economic, educational, professional and other privileges.' Battin et al concluded that:

> *We found no evidence to justify the grave and important concern often expressed about the potential for abuse – namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups.*

4.3 – Impact on the medical profession and doctor-patient relationships

The doctor-patient relationship is one founded primarily on trust and opponents to a change in the law argue that by taking on the additional role of assisted dying, trust could be lost and the doctor-patient relationship damaged. The majority of medical practitioners in the UK currently oppose the legalisation of assisted dying (see Section 2.4) and the British Medical Association remains 'opposed to doctors taking a role in any form of assisted dying.'[155] In this regard, it is important that doctors with a conscientious objection to assisted dying should be exempt from taking part, an issue that will be discussed in more detail in Section 5.5.

In what ways might the legalisation of some form of assisted dying affect the integrity of the medical profession? One issue is the practicality of enacting the law if a majority of doctors conscientiously object to assisting their patients to die. The Association for Palliative Medicine, for example, have voiced concerns that legislation could cause a polarisation in the medical profession and lead to the development of a specialist assisted dying sector made up of practitioners who have no interest in offering alternatives to death. There is also the possibility that patients may lose trust in their doctors if they know that assisted death is a 'treatment' option: one survey found that 60 per cent of respondents felt that elderly people might be more nervous of going into hospital if euthanasia were to be legalised.[156]

However, evidence from other countries has as yet shown little or no evidence of these negative impacts. A survey of eleven European countries (including the UK) found that the Dutch had the highest regard and trust for their doctors.[157] Another study looking at end-of-life decisions in six countries in Europe found that the best communication between doctors and their patients and families occurred in the Netherlands.[158]

This evidence suggests that levels of trust depend on openness and communication between doctors and patients and that for many people, knowing that a doctor is able and willing to end their life if it is in their best interests would promote trust, not reduce it. Respect for patient autonomy is one of most important parts of the doctor-patient relationship and being able to openly discuss all a patient's wishes is central to this. A study by Back et al found that the best outcome for patients and their families is when the doctor is able to discuss all of the patient's concerns and requests, including any request for help to die. If the doctor cannot be open to such a discussion, the patient can feel abandoned and suffer further distress.[159]

Research in Oregon and the Netherlands has shown that where some form of assisted dying is permitted, society remains supportive of the legislation. A survey conducted in Oregon in 2004 found that 74 per cent of respondents had become more supportive since the legislation took effect.[160] A survey in the Netherlands in 2001 found that 81 per cent of respondents supported assisted dying.[161]

5 – PRACTICAL CONSIDERATIONS FOR ASSISTED DYING LEGISLATION

5.1 – Legal options going forward

Before this briefing considers the practical aspects of assisted dying legislation, it is necessary to briefly consider the different potential legal options that are available with regards to assisted dying. The main options going forward are:

1. No change in the law
2. A change in the law to revert to the previous status quo
3. A change in the law to establish a process for medically-assisted dying
4. A change in the law to establish a legally-driven process for assisted dying
5. A change in the law to legalise both medical and non-medical assisted suicide

1. No change in the law

According to this course of action, the status quo is preferable to a change in the law to establish a legal framework for permitting some form of assisted dying, or to revert to a position in which assisted suicide was less clearly decriminalised (within the criteria stipulated by the DPP policy).

2. A change in the law to revert to the previous status quo

According to this course of action, the legal status quo prior to the DPP policy (e.g. 'wilful blindness'[162]) was preferable as assisted suicide was still clearly a criminal action, but the DPP was able to exercise discretion in whether a prosecution should go ahead.

Therefore, the law should be tightened up to make it clear that assisted suicide is not condoned by the law.

3. A change in the law to establish a process for medically-assisted dying

According to this course of action, there is a strong argument for changing the law to allow some form of medically-assisted dying in some legally-defined circumstances. These circumstances would need to be defined, as would the nature of medical professionals' involvement.

4. A change in the law to establish a legally-driven process for assisted dying

According to this course of action, a tribunal would be established to consider applications for an assisted death and whether these met legally-defined criteria. This course of action would be likely to require some level of medical involvement in performing assessments and prescribing or administering medication. The extent and nature of doctor involvement would need to be defined.

5. A change in the law to legalise both medical and non-medical assisted suicide

According to this course of action, assisted suicide would be legalised in certain circumstances but the law would not specify who would be responsible for facilitating assisted suicide, or prescribe a particular process to be followed. This option resembles the current situation in Switzerland.

This paper does not take a position on whether some form of assisted dying should, or should not be legalised. However, for the purpose of framing this discussion, the following sections of the briefing paper will explore the question of what a legal framework for assisted dying ought to look like, were some form of assisted dying to be legalised.

5.2 – If there were to be a change in the law, should assisted suicide and/or voluntary euthanasia be considered?

It is not always easy to make the distinction between assisted suicide and voluntary euthanasia, yet the legality of each differs between the jurisdictions where some form of assisted dying is legal (see Box 4). What is legal varies greatly, with assisted suicide legal in Oregon but only voluntary euthanasia legal in Belgium. Lord Joffe's Bill sought to legalise not just assisted suicide, but also in cases where self-administration of lethal medication is not possible, voluntary euthanasia.

Box 4 - Overseas Experience

Switzerland

Voluntary euthanasia remains a criminal offence but assisted suicide is legal. This means that the final act must be taken by the patient. This usually involves taking a pre-prepared lethal solution from a cup on a table and drinking it themselves.

The Netherlands

Both assisted suicide and voluntary euthanasia are a legal option for doctors and patients. The medical profession in Holland makes no moral or ethical distinction between the two.[163] It is understood that many doctors prefer voluntary euthanasia for practical and clinical reasons, as it eliminates the need to cross boundaries that would usually not be crossed e.g. handing over medication to the patient for self-administration. Yet KNMG guidelines state that assisted suicide is preferable in the psychological sense for doctors because of the responsibility placed on the patient.

Belgium

Voluntary euthanasia is legal, but assisted suicide remains illegal. The omission of assisted suicide was sharply criticized by the Council of State in its opinion on the Bill.[164] But in its first biannual report, the Belgian Federal Control and Evaluation Commission accepted cases of assisted suicide as falling under the euthanasia law.

Oregon

The Death with Dignity Act (ODDA) offers the successful applicant only assisted suicide, not voluntary euthanasia. The restriction in Oregon was imposed primarily as a protection for medical professionals; firstly so that they would not have to take such an active role in assisting patients to commit suicide, but also because it was believed that the legislation would be more publicly acceptable if only assisted suicide and not euthanasia were legalised.[165] Doctors were also reportedly more comfortable with assisted suicide than voluntary euthanasia.

Washington

The Death with Dignity act legalised only physician-assisted suicide.

Luxembourg

Voluntary euthanasia and physician-assisted suicide were legalised in 2008.

Is there a difference of principle between assisted suicide and voluntary euthanasia? Mary Warnock and Elisabeth Macdonald, two respected voices in the field argue that there is no difference:

> *Whether a doctor actually administers the lethal dose by injection or places a lethal dose by his patients bed with instructions to take it orally, what is at stake is whether he should be able, within the law, deliberately to bring about the death of his patient in response to a serious request…to do so.*

Care Not Killing also argue that the two are ethically equivalent, ‘because in both cases the intention of the doctor is to end the life of the patient’.[166] They recognise little practical difference between placing medication in a patient’s hand and directly administering it.

The Select Committee on the Assisted Dying for the Terminally Ill Bill was told that ‘the medical profession in Holland makes no moral or ethical distinction between [voluntary euthanasia and assisted suicide].’[167] According to Dr Johann Legemaate of the Royal Dutch Medical Association:

> *Many doctors prefer euthanasia for practical and clinical reasons, because when it is assisted suicide you hand over the medication to the patient and he has to take it himself. It may have side effects which lead to the doctor acting anyway. For that reason most doctors prefer euthanasia.*[168]

However, many would argue that there are significant differences in principle between assisted suicide and voluntary euthanasia. Dignity in Dying make a clear distinction between voluntary euthanasia, assisted suicide and assisted dying, campaigning only for the legalisation of ‘assisted dying’, which they define as a situation in which:

> *A doctor prescribes a life-ending dose of medication to a mentally competent, terminally ill adult at their request, and the patient then chooses to administer the medication themselves.*[169]

They assert that assisted suicide should be distinguished from assisted dying as it is not limited only to the terminally ill, but may also include those with a chronic illness or disability.[170]

When comparing the practical implications of the difference between assisted suicide and voluntary euthanasia, significant differences emerge in terms of the incidences of assisted death recorded each year. In Oregon, where only assisted suicide is legal, less than 1 in 700 deaths were attributable to assisted dying in 2005, whereas in the Netherlands, the proportion of deaths that were assisted was more than one in forty, 90 per cent of which were as a result of voluntary euthanasia and 10 per cent from assisted suicide.[171] This evidence suggests that the inclusion of voluntary euthanasia in an assisted dying law may result in a far higher rate of take-up.

The Select Committee's enquiry into the Assisted Dying for the Terminally Ill Bill recognised a clear and important distinction between assisted suicide and voluntary euthanasia. Firstly, the distinction between the two provides a final piece of clear evidence (and further safeguard) that the suicide is 'completely volitional and self-administered.'[172] Secondly, it was noted that there was likely to be less opposition to a bill that contained assisted suicide but not voluntary euthanasia, as a 'slippery slope' blurring of the line between voluntary and non-voluntary euthanasia may be more likely to occur with the legalisation of voluntary euthanasia than with the legalisation of only assisted suicide. The Select Committee recommended that 'a clear distinction' should be made between the two in any future bill, to ensure that the different implications of each course of action are considered.[173]

Questions

- Can we identify a sufficiently clear distinction between assisted suicide and voluntary euthanasia?
- Is the distinction a practical or ethical one?
- Which is preferable and why? Or both?
- If only assisted suicide is legal, what about those who are physically unable to commit the act? What provisions would be required to address this?
- What is more important: protecting the medical profession and engendering public support (assisted suicide over voluntary euthanasia) or protecting the patient and ensuring a safe and complication free death (voluntary euthanasia over assisted suicide)?

5.3 – What should be the eligibility criteria for an assisted death?

Nearly all regimes in which some form of assisted dying is legal specify the characteristics of those who should be eligible for assistance to die. Switzerland, where assisted suicide is legal but not voluntary euthanasia, is a notable exception in this respect: its criteria specify the characteristics of the assister but not the person being assisted. Box 5 below outlines the eligibility criteria specified in jurisdictions that have legalised some form of assisted dying, and also those that have been proposed in previous UK assisted dying bills.

Box 5 – Precedents: eligibility criteria in jurisdictions that have legalised some form of assisted dying

Switzerland

- No specified medical conditions or terminal illness.
- Action taken by the person assisting should not be self-serving – those acting on entirely honourable, non-selfish motives will be exempt from prosecution.
- Swiss residency not required.

Oregon

- Patient must be aged 18 or over.
- Patient must be terminally ill and expected to die within six months.
- Patient must be resident of Oregon.
- Patient must have made a competent voluntary request.

The Netherlands

- The patient is at least 12 years old. A Patient between 16 and 18 years old who is 'capable of making a reasonable appraisal of his own interests' may request euthanasia or assisted suicide. Patients between 12 and 16 years of age must pass this test of capacity and also require the consent of their parents.[174]
- No requirement for patient to be terminally ill but patient must be suffering unbearably with no prospect of improvement and with no reasonable alternative.
- Patient must be capable of expressing his will.
- Residency is not mentioned in the bill but required.

Belgium

- Patient must be aged 18 or 'legally emancipated' if aged 15 or older.
- Request should be voluntary, well-considered and 'not the result of any external pressure'.
- Patient must be competent and conscious at moment of request.
- Patient must be 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.[175]
- Residency is not mentioned in bill but, in effect, is required.

Washington

- Patient must be aged 18 or over.
- Patient must be terminally ill and expected to die within six

months.

- Patient must be a resident of Washington State.
- Patient must have attained the age of majority.
- Patient must have made a competent and voluntary request.

Luxembourg

- The patient must be in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder.
- Eligible patients include: adults, emancipated minors and minors between 16 and 18 with the authorisation of their parents or the person who has parental authority.
- Patient must be competent and conscious at the moment of making the request.
- Whilst not mentioned in the Act, residency is in effect required.

Draft Bills for England and Wales, and Scotland

Assisted Dying for the Terminally Ill Bill 2005, Lord Joffe

- Patient must have a terminal illness and be suffering unbearably.
- Patient must be informed about options for palliative care.
- Patient must have mental ‘capacity’.
- Patient must be aged 18 or older.

End of Life Assistance (Scotland) Bill 2010

- Patient must be terminally ill or 'permanently physically incapacitated'.
- Patient must be aged 18 or older.
- Applicants must be registered with Scottish GP for 18 months.[176]
- Bill does not apply to those with dementia or other degenerative mental conditions.

A – Terminal illness

Should terminal illness be a required pre-condition for a patient to qualify for an assisted death? While in Oregon and Washington a patient must be terminally ill, this is not a condition in the other states in which some form of assisted dying is legal. A major issue in permitting assisted dying for those with a terminal illness is the difficulty in ensuring accuracy in both diagnosis and prognosis (the doctor's prediction of the likely outcome of the patient's disease).

In the 2004 Assisted Dying for the Terminally Ill Bill proposed by Lord Joffe, 'terminal illness' was defined as:

> *An illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will be likely to result in the patient's death within a few months at most.*

This definition of terminal illness means that it becomes very important that doctors are able to accurately predict patients' life expectancy. Professor John Saunders of the Royal College of Physicians, giving evidence to the Select Committee on this Bill, commented on the problems associated with accurate prognosis, observing that:

Prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor.[177]

Statistics show that there is a 30 per cent error rate in the medically-certified cause of death, a rate which amounts to significant error (i.e. misdiagnosis of a terminal illness resulting in inappropriate treatment) in about 5 per cent of cases.[178]

In the 2005 revision of Lord Joffe's Assisted Dying for the Terminally Ill Bill, 'terminal illness' was redefined as an illness which in the opinion of both the attending and the consulting physician:

- is inevitably progressive
- cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily, and
- will be likely to result in the patient's death within six months.

This definition of terminal illness including a predicted life-span for the patient of six months or less corresponds with the 1994 Oregon Death with Dignity Act (ODDA), in which 'terminal disease' is defined as an:

incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months.[179]

The 2010 End of Life Assistance (Scotland) Bill also uses the duration of six months life expectancy in its definition of 'terminal illness':

A person is terminally ill if the person suffers from a progressive condition and if death within six months in consequence of that condition can reasonably be expected.[180]

Questions

- How should terminal illness be defined?
- Is prognosis sufficiently accurate for terminal illness to constitute a fair and reliable criterion?
- How short a life-expectancy is sufficient to qualify as 'terminally ill'?
- Should people with non-terminal progressive illnesses also qualify for an assisted death?
- Should 'terminal illness' and other criteria such as 'unbearable suffering' be given equal weighting?

B – Disability

Like older people, disabled people are often considered to be particularly vulnerable to any change in the law that legalises any form of assisted dying. Groups representing disabled people frequently voice concern that if some form of assisted dying were legalised, public prejudice towards disabled people would be reinforced. They argue that if assisted dying were offered to disabled people then they might experience 'subtle downward pressures to avail themselves of these options and that support for independent living might become harder to obtain'.

Would such a bill offer disabled people autonomy in the same way that it might to non-disabled people? Or would if offer 'coercion dressed up as choice'?[181] There is concern amongst some disabled groups that a change in the law would lead to their lives becoming less valued than non-disabled people.

However, some academics working in the field take an opposing view. Dr Shakespeare of the PEALS research institute at the

University of Newcastle believes that disabled people would not be vulnerable to pressure to choose an assisted death: 'disabled people are not dupes ... I do not think they are going to be trotted off to die against their will'.[182] Polling has indicated that only a small proportion of disabled people would trust their doctors *less* if some form of assisted dying were legal.[183]

The End of Life Assistance (Scotland) Bill has been criticised for its 'wide catchment area' as it is not restricted to the terminally ill, but applies also to anyone who is 'permanently physically incapacitated to such an extent as not to be able to live independently'.[184] Care Not Killing have voiced their concern at the message that this sends to disabled people: 'It [the bill] says: "If you cannot live without help, you are a candidate for having your life ended." Ms MacDonald may be well intentioned, but this bill is simply too dangerous.'[185] The bill has also been criticised for suggesting that the lives of disabled people are of less value than non-disabled people and for reinforcing the stereotype that disabled people's lives are so insufferable that they must want to die.[186]

Questions

- Should legislation include assistance for disabled people?
- If so, what safeguards would be needed to protect disabled people?

C - Mental competence

Mental competence is an important eligibility criteria for those wanting assistance to die; this is a specified qualifying condition for an assisted death in the Netherlands, Belgium, Luxembourg and Oregon. In the Netherlands, 'the patient must be competent to make such a request and the attending physician must consult a psychiatrist if he or she suspects the patient is incompetent.'[187] In Belgium, the patent must be 'legally competent.'[188]

In Oregon, the attending or consulting physician must refer the patient to a counsellor if he or she suspects the patient 'may be suffering from a psychiatric or psychological disorder, or depression causing impaired judgment.' The assisted suicide may only take place under the ODDA if the counsellor decides the patient does not have such a condition.[189]

The 2005 Assisted Dying for the Terminally Ill Bill specified that the patient requesting an assisted death must have 'capacity', defined according to the 2005 Mental Capacity Act (see box 6 below):

> *A person lacks capacity in relation to being assisted to die if at the material time he is unable to make a decision for himself in relation to that matter because of an impairment of, or a disturbance in the functioning of, the mind or brain resulting from any disability or disorder of the mind or brain.*[190]

The bill specified that if the attending or consulting physician thought that the patient may lack capacity,

> *the attending physician shall refer the patient to a consultant psychiatrist, or a psychologist, who shall be independent of the attending and consulting physicians, for an opinion as to the patient's capacity.*[191]

However, is this a sufficient safe-guard to protect potentially vulnerable applicants or should assisted dying legislation require a mandatory psychiatric assessment (See section 5.4 B)?

Box 6: The Mental Capacity Act (2005)[192]

Principles

- A person must be assumed to have capacity unless it is established that he lacks capacity.
- A person is not treated as unable to make a decision unless all practicable steps to help him do so have been taken without

success.

- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done on behalf of someone who lacks capacity must be done in their best interests and regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Determining lack of capacity

- A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.
- The disturbance or impairment can be permanent or temporary.
- A lack of capacity cannot be established merely by reference to a) a person's age or appearance, or b) a condition or aspect of behaviour which might lead other to make unjustified assumptions about his capacity.

Inability to make decisions

A person is unable to make a decision for himself is he is unable to a) understand the information relevant to the decision, b) retain that information, c) use or weigh that information as part of the process of making the decisions, d) communicate his decision.

Evidence from abroad

In 2008 a study by Ganzini et al[193] explored the prevalence of depression in terminally ill patients who had pursued assistance in dying under the Oregon Death with Dignity Act. The study found that three of the participants who met the criteria for depression received a prescription for a lethal drug and all three of these participants died by ingesting the lethal drug within two months of being interviewed. The study concluded that:

> *Most patients who request aid in dying do not have a depressive disorder. However, the current practice of the Death with Dignity Act in Oregon may not adequately protect all mentally ill patients, and increased vigilance and systematic examination for depression among patients who may access legalised aid in dying are needed.*

Researchers have also found that a level of 'appropriate sadness'[194] or depression is considered normal in terminally ill patients approaching the end of their life. Further, the existence of depression does not necessarily mean that a person lacks mental capacity.

Questions

- Does the Mental Capacity Act define mental capacity in a way that would be appropriate for this purpose (taking into account the potential impact of terminal illness on mental capacity)?
- Can we trust that doctors will be able to spot treatable depression or other mental health problems that might affect capacity in all cases?
- Should safeguards include a mandatory psychiatric assessment?

D - Unbearable suffering

Professor Tallis has suggested that 'it is very important not just to confine the notion of prognosis to life expectancy but to expectancy of quality of life.[195] This is the case in the Netherlands where lawful euthanasia is not restricted to the terminally ill. In the Netherlands, the basis for acceding to a request is 'hopeless and unbearable suffering', not life expectancy.'[196]

The Select Committee on the Assisted Dying for the Terminally Ill Bill recognised the sense of illogicality in allowing some form of assisted dying for those who are likely to be relieved of their unbearable suffering by natural means (terminal illness) but denying it to those with chronic conditions whose suffering is unbearable, but likely to be prolonged.

The Select Committee also commented on the difficulties that doctors would be likely to face in identifying whether patients met a criteria of 'unbearable suffering', given that this depends on 'patients' subjective assessments of their own suffering.'[197] Therefore, to allow for more objective medical assessment, the Select Committee recommended that consideration should be given to including a test of 'unrelievable' rather than 'unbearable' suffering or distress.[198] However, an argument could be made that the point of including 'unbearable suffering' in the Bill was to allow individuals who met the other criteria to make a subjective judgement about their own suffering, not for doctors to make a judgement about this.

As observed above, this would not resolve the apparent inconsistency in allowing those in pain but likely to die naturally (through terminal illness) the right to die, but not to those whose chronic illness is causing them prolonged suffering.

Questions

- Were the qualifying criteria in Lord Joffe's bill adequate? Are there any other criteria that should be included to safeguard vulnerable people?
- Would 'unrelievable' rather than unbearable suffering provide a more objectively verifiable criterion?
- Is it possible to verify unbearable suffering based on a single consultation?

5.4 – What safeguards would be required in new assisted dying legislation to protect vulnerable groups?

Boxes 7 and 8 detail the safeguards provided in the 2005 Assisted Dying for the Terminally Ill Bill and in the 2010 End of Life Assistance (Scotland) Bill, and also the safeguards in jurisdictions where some form of assisted dying has been legalised.

Box 7: Safeguards in the 2005 Assisted Dying for the Terminally Ill Bill and Safeguards in the 2010 End of Life Assistance (Scotland) Bill

1. Only competent adults, domiciled in England and Wales, suffering unbearably from a terminal illness, can make a request to a doctor for assistance to die.
2. Only the patient, not the doctor, can initiate the process.
3. Before the patient can proceed with his request, he must be seen by two doctors one of whom must be a consulting physician who is a specialist in the patient's condition. The prognosis must be confirmed, and all other alternatives to assisted dying including palliative care must be explored.
4. Should competency be in question, the patient will be referred for a psychiatric assessment. If the patient cannot fulfill all the

criteria, his request will fail.

5. A 14 day waiting period must pass between the time when the patient made a written request to the doctor of the wish to die and any action taken by the doctor.

6. A number of safeguards were included to ensure that the patient was acting voluntarily at all stages of the process. These include a written declaration, which must be independently witnessed by two adults, one of whom shall be a practicing solicitor. At any stage the patient can revoke his request.

7. The Bill provides that a specialist in palliative care, who can be a doctor or a nurse, is required to attend any patient who requests help to die, in order to see if their needs can be met in an alternative way.

There are 6 levels of protection in the Scotland Bill:

1. Persons must be 16 or over and must have been registered with a medical practice in Scotland for 18 months; must be mentally capable of making the request and to be in one of 2 categories of person prescribed in the Bill.

2. Person must make two separate requests for assistance to ensuring that it is clear that the person is making the request themselves. These requests must be witnessed again, providing another check on the process.

3. Medical scrutiny of the requests: The person requesting an assisted death is required to make 2 requests and at both stages the person is examined by both a registered medical practitioner and a psychiatrist. The registered medical practitioner is also required to be satisfied that the person continues to meet the criteria at the point at which end of life assistance is to be provided.

4. Time constraints: second request must be made between 15 and 30 days after the first request; end of life assistance must be provided within 28 days of approval of 2nd formal request
5. Constraints upon the nature of the assistance used to end life: assistance must be such that it enables the requesting person to die with dignity and a minimum of distress.
6. Finally, under the terms of the Crown Office and Procurator Fiscal Service guidance on the reporting of sudden deaths, each death must be reported to the Procurator Fiscal. Each death will be investigated by the Procurator Fiscal to ensure all the safeguards and protections have been met.

Box 8 - Safeguards in jurisdictions where some form of assisted dying has been legalised

Oregon

- Patient can request in writing to doctor; request must be voluntary and initiated by patient.
- If in the opinion of either physician a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgement, the patient shall be referred for counselling.
- The attending physician has to ensure that the patient is making an informed decision by informing the patient of his or her diagnosis, prognosis, potential risks and probable result of taking the medication and any feasible alternatives.
- Request must be confirmed by two witnesses.
- The doctor must get a second medical opinion.

- The attending physician has to inform the patient of the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.
- If request authorized, patient must wait another 15 days to make second oral request before prescription written.
- The Department of Human Services shall require any health care provider upon dispensing medication to file a copy of the dispensing record with the Department.

The Netherlands

The law allows the medical review board to suspend prosecution of doctors who performed euthanasia when each of the following conditions is fulfilled:

- The patient's suffering is unbearable with no prospect of improvement.
- There must be ‘no reasonable alternative in light of the patient’s situation.’[199]
- The patient's request for euthanasia must be voluntary and persist over time and is a carefully considered request (the request cannot be granted when under the influence of others, psychological illness or drugs).
- The patient must be fully aware of his/her condition, prospects and options.
- There must be consultation with at least one other independent doctor who needs to confirm the conditions mentioned above.
- The death must be carried out in a medically appropriate fashion by the doctor or patient, in which case the doctor must be present.
- The patient is at least 12 years old (patients between 12 and 16

years of age require the consent of their parents).

- There are regional committees to review reported cases. The committees consist of 6 members: two legal experts, two physicians and two experts on ethical and moral issues.

Belgium

- The assessing doctor must satisfy herself of the 'durable nature' of the patient's request – the doctor must then have several conversations with the patient spread out over reasonable period of time.
- The attending physician must inform the patient about his/her health condition and life expectancy, discuss the request for euthanasia and the possible therapeutic and palliative courses of action and their consequences.
- The doctor must obtain a second opinion.
- The doctor must allow at least a month between the patient's written request and the act of euthanasia.
- Patients requesting euthanasia must be made aware of the option of palliative care, but this is not regarded as a 'filter'.[200]
- The request must be voluntary, well-considered, and repeated. A written request is needed in all cases. The patient can withdraw the request at any time.
- The attending physician must inform the patient about his/her health condition and life expectancy, discuss the request for euthanasia and the possible therapeutic and palliative courses of action and their consequences.
- The consulting physician reviews the medical record, examines the patient and must be certain of the patient's constant and unbearable suffering that cannot be alleviated.

- Any physician who has performed euthanasia is required to fill in a registration form, which will be studied by the Federal Control and Evaluation Commission. The Commission is composed of 16 members: eight doctors of medicine, four professors of law or practising lawyers and four people who deal with incurably ill patients.

Switzerland

- There are few safeguards or conditions: only condition is that those assisting with suicide should not have self-serving motives.
- The involvement of a physician in assisted dying is considered a safeguard in other jurisdictions where some form of assisted dying is legal, but this is not the case in Switzerland.

Washington

- The patient can request it in writing to doctor; request must be voluntary and initiated by patient.
- If in the opinion of either physician a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgement, the shall be referred for counselling.
- The attending physician has to ensure that the patient is making an informed decision by informing the patient of his or her diagnosis, prognosis, potential risks and probable result of taking the medication and any feasible alternatives.
- Request must be confirmed by two witnesses.
- The doctor must get a second medical opinion.
- The attending physician has to inform the patient of the feasible

alternatives, including, but not limited to, comfort care, hospice care and pain control.

- If the request is authorized, patient must wait another 15 days to make a second oral request before prescription written.
- The Department of Human Services shall require any health care provider upon dispensing medication to file a copy of the dispensing record with the Department.

A - Access to palliative care

Lord Joffe proposed that palliative care should always be the first option for someone who is terminally ill and that an assisted death should be a last resort.[201] Being aware of and having experience of palliative care may reduce the likelihood that patients should choose an assisted death for the wrong reasons, for example due to suffering that is relievable. The Belgian Act on Euthanasia makes the provision that patients who request euthanasia should be informed of the option of palliative care.[202] However, this is not considered to be a 'filter', described as:

> *A process through which applicants must go in order to see to what extent their needs can be met through good quality palliative care before deciding to have their lives ended.*[203]

In the UK, some palliative care specialists have voiced concerns that a short consultation with a patient would be insufficient to undertake a proper assessment of a patient's needs. According to Vicky Robinson, a Nurse Consultant at St Christopher's Hospice, a full assessment of 'how a person's suffering may be supported, and if possible, relieved, through palliative care' would take a minimum of a week and potentially months.[204]

Lord Joffe's Bill identified being *informed* about the options for palliative care as a necessary safeguard, but Help the Hospices has argued that:

Experience of pain control is radically different from the promise of pain control, and cessation is almost unimaginable if symptom control has been poor. On this view patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed.[205]

According to this view, information about palliative care may be an insufficient safeguard.

However, a more stringent safeguard requiring that the applicant should have *experienced* high quality palliative care may not be feasible at present. Recent analysis has found that there continues to be significant regional variation in people's place of death (e.g hospital, hospice, or at home)[206] and in the level of investment in palliative care by PCTs.[207] This suggests that access to specialist palliative care across England is still likely to be patchy. In these circumstances, a palliative care 'filter' requiring experience of palliative care could mean that access to an assisted death would mirror the current inequalities in access to palliative care.

The question of whether legal safeguards should include a palliative care 'filter', and whether this should require patients to have received information about palliative care, or to have experienced specialist palliative care, therefore requires further consideration.

Questions

- Are the safeguards used in other jurisdictions sufficient to mitigate the risks posed by assisted dying legislation on vulnerable groups? If the law were to change, what safeguards should be put in place in the UK?
- How can legislation best address the issue of ensuring that a patient is not acting on the basis of *relievable suffering*, or suffering that could be alleviated with access to the right palliative care?
- Is information about the existence of palliative care an effective safeguard?
- Should safeguards include a palliative care 'filter'?

B - Psychiatric assessment

Discussion has already touched upon the question of whether a psychiatric assessment should be a mandatory requirement for all those requesting an assisted death.

Competence of the patient rests upon being able to think clearly and make a reasoned decision, and also the ability to form a judgment unclouded by a transient or treatable psychological condition. A GP should be able to determine whether a patient is compos mentis, but determining the second condition may prove more difficult.

All those giving evidence to the select committee on this topic agreed on one conclusion: attending and consulting physicians who are the 'gate-keepers' to assisted dying could not be expected to spot impairment of judgment in all cases.[208] There may therefore be a need to stipulate that a clinical psychologist or psychiatrist should assess all applicants before a decision on eligibility is made.

Questions

- Can a GP be expected to spot more difficult cases of treatable depression as accurately as a psychiatrist?
- GPs have often received some psychiatric training, but some cases may require a specialist.
- Should all applicants for an assisted death be assessed by a clinical psychologist or a consultant psychiatrist in order to determine if their mental competence is sufficient?

C – Decision of Eligibility

This section will consider the question: who should make the decision about whether somebody who requests an assisted death is eligible for assistance? It will assess the pros and cons of decision-making by doctors, or of a tribunal model of decision-making.

Box 9 - Models of decision-making used in other jurisdictions

Switzerland

- Anyone may legally provide assistance if they are acting on non-selfish motives.
- A doctor's prescription is however needed for lethal medication.
- Voluntary organisations are heavily involved and patients' decisional capacity is assessed by trained personnel from a non-medical organisation (e.g. Exit, Dignitas) on at least two occasions.

Netherlands

- The patient's doctor must be satisfied that the patient has made a voluntary and carefully considered request and meets the legal criteria.

- The doctor must consult a second, independent physician. The second opinion increasingly comes from one of a team of Support Consultation Euthanasia Network doctors.
- The majority of requests in the Netherlands are made to GPs.

Oregon

- The attending doctor must refer the patient to a consulting doctor for confirmation of diagnosis and that the patient is competent and acting voluntarily.
- A counselling referral is made if either doctor suspects the patient is suffering from a psychological or psychiatric disorder. The assisted suicide may only take place if the counsellor confirms the patient is not suffering from such a condition.
- Doctors prescribe and pharmacists then issue lethal medication to be taken by the patient.

Belgium

- The patient's doctor determines whether the patient satisfies the criteria.
- The doctor must then seek a second medical opinion.

Washington

- The attending physician makes the initial determination of whether a patient has a terminal disease, is competent, and has made the request voluntarily.

- Patient then referred to a consulting physician for medical confirmation of the diagnosis, and for a determination that the patient is competent and acting voluntarily.
- A patient who may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment should be referred by either physician for counselling.

Doctors

Care for the terminally ill is often carried out by multi-disciplinary teams including a number of doctors and nurses etc. In such a case, who would be the primary carer or decision-maker (when often team members work as equals)? What if one member of the team has an objection and doesn't want to be implicated by the decision?

Pros

- A doctor who has a long-term relationship with the patient may be better able to assess whether an assisted death is an appropriate course of action.
- A doctor who has a long-term relationship with the patient may be better able to spot if the patient is experiencing psychological pressure from a family member.
- Doctors are trained to make decisions and diagnoses relating to terminal illnesses and unbearable suffering.
- Decision-making by a doctor may be less arduous and bureaucratic than a process involving a tribunal.

Cons

- Doctors may have a conscientious objection; indeed some argue assisted dying breaks the Hippocratic Oath.
- The responsibility for making such decisions may impose a heavy emotional burden on doctors.

A Tribunal Model

Terry Pratchett has mooted the possibility of a establishing a tribunal model to investigate the facts of a case before the assisted death takes place.[209] The tribunal would behave as an independent 'jury' acting in the interests of society to determine whether each 'applicant' fitted with the criteria, such as being of sound mind, firm in their purpose, terminally ill and not under coercion. Pratchett has suggested that such a tribunal should include at least one lawyer and a doctor with a specialism in long-term illness and end-of-life care.

A currently operating model that a tribunal for assisted dying could be based upon is the First-tier Tribunal (Mental Health). This Tribunal is an independent judicial body that operates under the provisions of the Mental Health Act 1983 (as amended by the Mental Health Act 2007). Its main purpose is to review the cases of patients detained under the Mental Health Act and to direct the discharge of any patients where the statutory criteria for discharge have been satisfied. Tribunal hearings are normally held in private (no press or media coverage) and take place in the hospital or community unit where the patient is detained.[210] The Lord Chancellor appoints tribunal judges whilst the Health Minister appoints non-legal members of the tribunal. Mental Health Tribunal panels are made up of a Judge and two other members, one of whom must be a medical specialist. The medical specialist is required to undertake an examination of the patient before the hearing. The third member provides balance to the Tribunal as a representative of the community, outside of the legal and medical practice. In practice, most have some experience of health or welfare, for example through the NHS or voluntary organisations.

Pros

- Each case would receive an independent and expert assessment of the facts prior to the event, providing checks and balances.

- This would restrict the number of doctors who would need to experience the potentially high emotional burden of decision-making.

Cons

- The process of putting each case before a Tribunal may be unnecessarily long-winded and bureaucratic. It could subject terminally ill patients to an unnecessarily drawn-out process.
- It may be difficult to recruit expert Tribunal members for what may be perceived as a 'death panel' role.

Questions

- Would a Tribunal system provide better protection to vulnerable people than a system of retrospective review of cases by a monitoring commission?
- Would a Tribunal system be feasible for the numbers of people who would be likely to apply for an assisted death?
- What would be the anticipated cost of establishing a Tribunal system for assisted dying?

D - Written statement by patient with witnesses

The 2005 Assisted Dying for the Terminally Ill Bill contained a provision that the requesting patient must sign a written declaration of intent.

Question:

- What provisions should be made for those who are physically unable to sign a statement?

E - Waiting period

In most jurisdictions where some form of assisted dying is legal, the legislation contains some form of waiting period between request, declaration and assistance, so that there is time for applicants to fully consider the immense importance of their decision. In Belgium, the waiting period is one month between a request and any act of euthanasia; in Oregon and Washington applicants must wait 15 days between their first oral request and the prescription being written; Lord Joffe's bill contained a waiting period of 14 days between a request for euthanasia and any action taken by a doctor.

Some concern was voiced over whether this period should commence after the first written request, or following the declaration. Lord Joffe explained the reasoning behind the timing of the waiting period to spare additional suffering on the part of the patient as should the waiting period only commence after the declaration, then the patient may have already died. Yet if the period begins at the point of request, then it is highly likely that these 14 days will have expired by the time that the declaration has been completed. Evidence suggests that this 'cooling off' period is less important for cases of assisted suicide, as many who receive lethal prescriptions do not immediately take them, but keep them as an 'insurance policy'.[211]

Questions

- How long should the waiting period be and when should it start?
- Should the period start from the point of request for assistance with death or should the time period be triggered once the declaration has been made?
- How can the waiting period balance the need to avoid increased suffering for determined individuals against the importance of providing time for reflection for those less certain?

F - Retrospective review of cases by a monitoring commission

Lord Joffe's Bill contained the provision to establish a monitoring commission to review the operation of the Act and to hold and monitor records of assisted deaths. It was proposed that the commission should consist of a doctor, a lawyer and a lay person with experience of end-of life care. It specified that statistics on assisted deaths would be published annually.[212]

However, concerns have been expressed about whether a retrospective review by a monitoring commission *after the event* would provide sufficient safeguards. Surveys conducted in the Netherlands, where both voluntary euthanasia and assisted suicide are legal, have found that cases that meet the definition of euthanasia are not always reported to the authorities. In cases that were not reported, the conditions of consulting a second physician and writing a report on the action taken were less likely to have been satisfied.[213] A study of reporting rates over the time period prior-to and post-legalisation shows that:

> *The reporting rate in the Netherlands has gradually increased from 18 per cent in 1990 to 80.2 per cent in 2005, indicating a trend towards more societal control over the practice.*[214]

This difficulty in bringing voluntary euthanasia within regulatory control may reflect the fact that medically-assisted dying had been effectively decriminalised in the Netherlands for several decades before the practice was legalised. Therefore, while the issue of how assisted deaths can most effectively be monitored is an important question for the legalisation debate in the UK, the same problems experienced in the Netherlands would not necessarily be encountered in the UK.

This problem with unreported cases of assisted deaths has not been identified in Oregon. Unlike the Netherlands, in Oregon there was no period prior to legalisation in which assisted suicide was effectively decriminalised. Since legalisation, the Oregon Department of Human Services (ODHS) has had responsibility for recording the uptake of the Oregon Death with Dignity Act (ODDA), for checking that requirements are being observed and for reporting discrepancies to the Oregon Board of Medical Examiners. Monitoring does not begin until the point at which the patient has been issued with a prescription for lethal medication, although the correct procedure must have been followed prior to this point. Experts consulted by the Select Committee on the Assisted Dying for the Terminally Ill Bill thought that the figures of reported deaths under the ODDA could be considered accurate, with one witness commenting that:

> *physicians … have a vested interest. If they follow the steps and report them, they are protected under the law … it is insurance for physicians to report.*[215]

While concerns about reporting rates in Oregon were not mentioned, Dr William Toffler did express concerns that patients with a known history of depression had not been referred for psychiatric assessment.[216] The Select Committee commented that ‘none of these perceived abuses had been reported formally to the OBME for investigation.’[217] This suggestion that some doctors may not be adhering to the ODDA safeguard on mental competency (according to which a patient whose judgment may be impaired by depression should be referred for counselling and further assessment) poses questions both of whether a psychiatric assessment should be made mandatory, and also whether retrospective monitoring is sufficient, or whether a formalised and monitored process of decision-making (e.g. by a tribunal) should be put in place to approve requests for assisted suicide in advance.

Questions

- Can a retrospective monitoring commission provide sufficient safeguards against abuse, or is a formalised and monitored decision-making process (e.g. by a tribunal) required to approve assisted dying requests before they are carried out?
- Are monitoring requirements significantly altered according to whether only assisted suicide or assisted suicide and voluntary euthanasia are legalised?

5.5 The role of the medical profession

Box 10 - What role do doctors take in assisted deaths in other jurisdictions?

Switzerland

- Doctors have little involvement beyond diagnosis and prescribing lethal medication.
- The majority of assisted suicides are not directly supervised by doctors. Non-medical ‘suicide organisations’ play a facilitating role.

The Netherlands

- The majority of assisted deaths occur through voluntary euthanasia, undertaken by a doctor.
- Many doctors prefer voluntary euthanasia to assisted suicide for practical reasons.
- Only a physician may carry out euthanasia, as long as he satisfies the criteria of due care.
- Where a patient opts for an assisted suicide, the doctor will usually be present and willing to perform euthanasia if the attempted suicide fails.[218]

Oregon

- The doctor will prescribe a lethal dose of medication to be taken by the patient.
- The extent of doctor responsibility beyond this prescription is difficult to assess (no provisions made in the Bill for any further relationship).
- Not all end up taking the medication. For example in 2009, 95 prescriptions were written but only 53 patients took the medication.
- The doctor's role is limited to assessment and prescription (although they may be present at the moment of death).

Belgium

The Doctor is involved in the initial assessment and also in the act of euthanasia itself – lethal medication is administered by the doctor.

Professor Penney Lewis argues that the advantages of medical involvement in assisted dying are ‘manifold’, and include: lower risk of botched suicide and suffering during suicide; greater role for screening for previously unknown mental disorders including depression.[219]

The 2005 Assisted Dying for the Terminally Ill Bill said nothing about place or means of death, but for most, this would clearly be important. Research shows that the majority of people (55 per cent) would choose their doctor as the person whom they would wish to help them to die, if it were legal: 19 per cent said they would choose a relative and 9 per cent a friend. [220]

As shown above, the nature of doctors’ role in assisted dying regimes varies significantly between jurisdictions (see sections 2.2 and 2.4 for further discussion of this issue). There are clearly some areas where medical expertise is essential but also some questions to which medical expertise can provide no answer.[221] Communication about diagnosis, prognosis and treatment options is clearly an area of expertise for doctors. However, as the Swiss model shows, while it is necessary for doctors to be involved in diagnosis and prescribing lethal medication, it is possible for non-medical organisations to be involved in facilitating assisted suicide. The following sections A and B will examine some of the practical ramifications of involving the medical profession in assisted dying.

Question

- What model of doctor involvement in assisted dying is desirable for the UK, given the views of the medical profession on assisted dying? Compare Switzerland and the Netherlands (low vs high doctor involvement).

A - What provisions would be required to protect doctors and other medical professionals who are ethically opposed to assisted dying?

As seen in section 2.4, support for introducing some form of assisted dying is much less prevalent amongst doctors than the general public as a whole, and many doctors view the procedures involved in the practice of assisted suicide and voluntary euthanasia as running counter to the ethics of their profession.

The 2004 Assisted Dying for the Terminally Ill Bill contained a provision for conscientious objection, which states that:

> *No person shall be under any duty, whether by contract or by any statutory or other legal requirement, to participate in any diagnosis, treatment or other action authorised by this Act to which he has a conscientious objection.*[222]

The bill stipulated that a doctor with such an objection

> *Shall take appropriate steps to ensure that the patient is referred without delay to an attending physician who does not have such a conscientious objection.*[223]

However, the Select Committee recommended that this referral clause should be removed from the Bill as this practice of referral might be regarded as an infringement of conscience. They recommended that the onus should be on the patient to find a doctor without an objection, rather than the other way round. The Select Committee also recommended that this protection should be extended to all healthcare professionals involved in any way, including persons working in multi-disciplinary teams.[224] These recommendations were reflected in amendments made to the 2005 Assisted Dying for the Terminally Ill Bill.

B - What provisions would be needed to regulate the doctor-patient relationship?

Length of relationship

Professor Penney Lewis has drawn attention to the disparity in practice between the Netherlands and Oregon State with regards to the length of relationship between doctor and patient that is expected to exist prior to a doctor providing an assisted death. In the Netherlands, Dutch case law requires a long-standing relationship between the doctor and patient to ensure that the doctor knows the patient sufficiently well to assess both ‘whether his request is both voluntary and well-considered, and whether his suffering is unbearable and without prospect of improvement.’[225]

However, as Lewis has noted, in Oregon the relationship between patient and doctor is less likely to be a long-standing one; a study by Ganzini at al found that 27 per cent of doctors responding to the questionnaire (38 of 143) had known the patient for less than a month at the time the patient requested assistance with suicide.[226] This shorter length of relationship may be an unavoidable consequence of doctors with conscientious objections to assisted dying referring their clients on to another doctor, or causing the patient to seek a doctor who is likely to fulfil their request; the first year in which statistics were published on the ODDA found that:

> *Six of the patients who chose physician-assisted suicide had to approach more than one physician before finding one that would start the prescription process.*[227]

The aggregate statistics on patients who died under the auspices of the Death with Dignity Act between 1998-2009 show that the median length of the doctor-patient relationship was 10 weeks, with a range of 0-1440 weeks.[228] The fact that the median is 10 weeks suggests that many patients had known their doctor for only a short period of time. The potential risk that an unfamiliar physician may be less likely to detect if the patient is lacking in capacity (e.g. due to depression or another type of impairment) or is not acting voluntarily should be taken into account in the design of safeguards.

Duty of care in cases of assisted suicide

A disparity between different jurisdictions has also been identified in the role played by the doctor at the point of death in cases of assisted suicide. In Switzerland it is most frequently a non-medical organisation that facilitates the moment of death, whereas in the Netherlands, as Warnock and Macdonald have observed:

The ethos is that physicians should be within close proximity and be willing to perform euthanasia if the patient's attempted suicide fails.[229]

They comment that this approach would be unlikely to work in the UK, where euthanasia is most likely to remain illegal. In Oregon, medical practice at the moment of an assisted suicide apparently varies significantly between cases; the first annual report on the ODDA observed that:

For eight of the fifteen persons who chose physician-assisted suicide, the prescribing physician was at the bedside when they took the lethal medications. For six of the fifteen patients, the physician was also at the bedside when they died. In instances where the physician was not present for the medication ingestion or death, times to unconsciousness and death, as well as reports of complications, were provided to the physician by persons present at the bedside.[230]

Is it right that the decision on the doctor's level of involvement should be decided between the doctor and patient, or should the doctor's duty of care to the patient require the doctor to be present at the moment of death to address any complications?

Question

- Should safeguards stipulate a minimum duration of doctor-patient relationship before an assisted death may take place?
- Should doctors who provide an assisted death be required to supervise the patient at the moment of death to address any potential complications?

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NOTES

[1] Select Committee on the Assisted Dying for the Terminally Ill Bill [HL] *Volume I: Report*' (London: The Stationary Office, 2005) p 14

[2] Select Committee on the Assisted Dying for the Terminally Ill Bill [HL] Volume I: Report' (London: The Stationary Office, 2005) p 14

[3] Lewis, P, Assisted Dying and Legal Change (Oxford: Oxford University Press, 2007) p 5

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[25] 'DPP Guidelines' http://www.carenotkilling.org.uk/?show=876 (accessed 12/10/2010)

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[42] Select Committee on the Assisted Dying for the Terminally Ill Bill [HL] Volume I: Report' (London: The Stationary Office, 2005) p 20

[43] Finlay, I, 'The flip side to 'assisted dying' – why the Lords were wise to reject Lord Joffe's Bill' Clinical Ethics 1: 118 –120 (2006)

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