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## SPICe Briefing

# End of Life Assistance (Scotland) Bill

2 September 2010

10/51

Jude Payne and Sarah Harvie-Clark

The [End of Life Assistance \(Scotland\) Bill](#) (the Bill) was introduced in the Scottish Parliament on 20 January 2010, by Margo MacDonald MSP. The Bill seeks to permit assistance to be given to persons who wish their lives to be ended, under certain conditions.

This briefing is split into three parts – the current law, the position in other jurisdictions and a discussion of the Bill itself.



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# INTRODUCTION

The [End of Life Assistance \(Scotland\) Bill](#) (SP Bill 38) (the Bill) was introduced in the Scottish Parliament on 20 January 2010, by Margo MacDonald MSP (the Member). It is accompanied by [Explanatory Notes](#) and a [Policy Memorandum](#).

The Bill seeks to permit assistance to be given to persons who wish their lives to be ended. Its main purposes are to:

- allow registered medical practitioners in Scotland to assist patients who wish to bring their own lives to an end – known as “an assisted death”
- establish who is eligible to receive an assisted death from a registered medical practitioner
- establish the process by which someone qualifies to receive an assisted death
- establish the responsibilities and duties of the registered medical practitioner and psychiatrist in response to a request for an assisted death

The Bill followed a [consultation](#) (MacDonald, 2008) on the draft proposal, which ran from 8 December 2008 to 9 March 2009. In April 2009, the Member published a [summary](#) (MacDonald, 2009) of the consultation responses. In total the consultation received 405 formal responses from a wide range of identifiable groupings, including those with a relevant personal experience, religious groups and those with a professional medical background.

This briefing is split into three parts – the current law, the position in other jurisdictions and a discussion of the Bill itself. There is cross referencing between all three, and, as a result, they have been published together in one briefing. However, the briefing is designed so that readers can be selective if they wish.

Before moving to these discussions, the briefing first deals with the issue of terminology and information on the End of Life Assistance (Scotland) Bill Committee and its call for evidence.

## TERMINOLOGY ASSOCIATED WITH THE BILL

End of life issues suffer from a confusion of terminology which is likely to be apparent in the course of any debate surrounding the current Bill. Whilst there is no universally agreed usage of any of the terms in question, this section defines them for the purposes of this briefing.

In the first place, there are three terms which do not appear in the Bill itself but which are most likely to be heard in the course of debate on the Bill. They are as follows:

- **euthanasia** (also sometimes referred to as ‘mercy killing’) involving the deliberate taking of another person’s life, to relieve unbearable suffering
- **assisted suicide** describing the situation where a competent person has expressed a desire to end his or her life but wants the assistance of another person to perform the act, for example by providing the means to do so. However, unlike the situation with euthanasia, it is the person seeking death who carries out the final act of putting to death
- **physician assisted suicide** referring to the situation where the person providing assistance with a person’s suicide is a doctor

Although at first glance the distinction between euthanasia and assisted suicide seems clear cut, it should be noted that in practice the boundary becomes somewhat blurred in relation to severely disabled people who may need assistance to commit suicide which goes significantly beyond providing the means to do so.

Some academic authors (Mason and Laurie 2005, pp 599–601; Earle and Whitty 2006, para 381; Patel 2004, p 39; Lewis 2007a, pp 4–5) refer to a classification of euthanasia that has six possible sub-sets of the term. Although quite technical, the six-part classification will be referred to in places in this briefing where this is thought helpful to the reader. From the perspective of

the individual seeking death, euthanasia is divided into the categories of:

- **voluntary** meaning carried out at the request of the person in question
- **non-voluntary** which refers to the situation where the person is unable to express a decision on the matter, for example because of severe brain damage or dementia or because they are in a permanent vegetative state
- **involuntary** which refers to the situation where the person in question is competent to consent to his or her own death but does not do, either because he or she was not asked or because his or her choice to live was ignored
- From the perspective of the person bringing about death euthanasia is divided into:
  - **active** where there a positive action to end life, such as injecting a lethal substance into a person
  - **passive** where there is an omission to act. Included in the definition of an omission to act is the withdrawal or withholding of treatment

The distinction between active and passive euthanasia has been criticised (see, for example, McLean and Morgan 2009, pp 132–133) but is still widely used. Under the six-part classification, **active voluntary euthanasia** is the type of activity that is typically the focus of impassioned debate, along with assisted suicide.<sup>1</sup>

**Assisted dying** is used in this briefing as a collective term for assisted suicide (including physician assisted suicide) and voluntary active euthanasia. It appears to be used that way as well in the [Policy Memorandum](#) to the current Bill (e.g., the Annex, p 25-27).

**End of life assistance** is the term used in the Bill itself. It is defined in section 1(2) as:

“assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress.”

Section 11(6) of the Bill highlights that the medical practitioner only has to be present, as opposed to participating in, the act of putting a person to death. Accordingly, the combined effect of section 1(2) and section 11(6) is to treat ‘end of life assistance’ as including active voluntary euthanasia and assisted suicide (including physician assisted suicide), as the aforementioned terms are defined in this section of the briefing.

## THE END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE

The [End of Life Assistance \(Scotland\) Bill Committee](#) (the Committee) was created following a [decision of the Parliament on Wednesday 10 February 2010](#) (Scottish Parliament, 2010). It has the remit of considering and reporting on the general principles of the Bill.

On 3 March 2010, the Committee issued its [call for written evidence](#) on the Bill. This closed on 12 May 2010, and received a total of 601 submissions.

### Overall analysis of the call for evidence

The SPICe [Committee briefing](#) which summarised submissions to the call for evidence was published on 17 June 2010 (Payne, 2010). This paper was not a systematic review of the evidence received. Rather, it was a largely qualitative analysis designed to alert Committee Members to some of the substantive discussion points that arose from the submissions. It shall be referred to when discussing the key provisions in the Bill.

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<sup>1</sup> Note that under some versions of the six-part classification, passive voluntary euthanasia includes assisted suicide and physician assisted suicide (see, for example, Mason and Laurie 2005, Figure 17.1). This blurs the basic

The submissions received came from a wide variety of interests, and were split into a number of respondent categories. These, together with the response rate and position, are outlined in Appendix 1. Overall, 521 (86.89%) of respondents held a position opposed to the Bill, 39 (6.49%) were supportive of the Bill or at least the principle behind it, and 41 (6.82%) had no position on the Bill. The largest respondent category was 'Private Individual' (57.1% of submissions), an overwhelming proportion of which were opposed to the Bill. This is followed by 'Professional – Medical', which comprised of doctors and doctors in training from various specialties, most of whom were responding as individuals. These made up of 19.5% of submissions, and again, the vast majority were opposed to the Bill.

Of those that were supportive of the Bill the majority (n=25) came from private individuals, followed by 'Professional – Medical' (n=5), 'Voluntary Organisation' (n=4), 'Academic' (n=3) and 'Humanist Organisation' (n=22). In terms of submissions that held no position, these responses were divided fairly evenly across the different respondent groups. They made up all of the local authority (n=4), NDPB (n=4), NHS Board (n=1) and Regulatory Body (n=2) submissions and half of those from 'Representative Body – Health' (n=8 out of 16).

As discussed above, nearly a fifth of all responses were identified as being from the medical profession. In 21 of these submissions the specialty background of the respondent was not clear. However, of the remaining 96 the largest specialty represented was general practice (n=45), though this includes two trainees and 12 retirees, followed by medical students (n=24), typically in their third or fourth year, and then palliative care specialists (n=11). Analysing all 117 'Professional – Medical' submissions, 110 (94%) were against the Bill. Of the remainder, five were in support – including three from general practice and one psychiatrist.

# PART 1: THE CURRENT LAW

## REFUSAL OF MEDICAL TREATMENT

### The general position

Refusal of medical treatment by a mentally competent adult (a form of passive voluntary euthanasia) is a right in England and Wales and in Scotland, even where refusing treatment means certain death (*Re T (Adult: Refusal of Treatment)* [1993] Fam 95; *Law Hospital NHS Trust v Lord Advocate* 1996 SC 301).<sup>2</sup>

### Advance statements

Advance statements (also sometimes called ‘living wills’ or an ‘advance directives’) are a means by which a person’s wishes in relation to medical treatment are communicated before there is a medical need for any decision but in anticipation of that need. The statement, usually an advance refusal of (particular types of) medical treatment, is made while the patient is mentally competent, with the intention being that its terms should be honoured if and when the patient is no longer competent (*Earle and Whitty* 2006, para 379).

In England and Wales, by virtue of the Mental Capacity Act 2005 (c 9) (sections 24–26), an advance statement is legally binding. In Scotland, there is no comparable legislation or reported cases on the issue.<sup>3</sup> Under the Mental Health (Compulsory Treatment)(Scotland) Act 2003 (asp 13) an advance statement will be ‘given effect’ to by the [Mental Health Tribunal for Scotland](#) (and other specified medical professionals performing certain functions under the Act) in the context of compulsory treatment for mental disorders, although such a statement is not legally binding (Mental Health (Compulsory Treatment)(Scotland) Act 2003 (asp 13), sections 275–276) (*Earle and Whitty* 2006, para 379).

## WITHHOLDING OR WITHDRAWING TREATMENT

A person is in a permanent vegetative state (PVS) where they do not have and are never going to recover awareness of their surroundings or who show no response to tactile, visual, auditory or noxious stimuli, or have no awareness of language or ability to communicate (*Earle* 2007, p 156).

Withholding or withdrawing treatment from individuals in a PVS (a form of passive non-voluntary euthanasia) is permitted in England and Wales and in Scotland where it is in the patient’s best interests not to prolong life because further treatment would be futile (*Airedale NHS Trust v Bland* [1993] AC 789, [1993] All ER 821; *Law Hospital NHS Trust v Lord Advocate* 1996 SC 301). ‘Treatment’ includes the administration of nutrition and hydration.

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<sup>2</sup> The law in England and Wales is discussed in more detail in the [Memorandum from the Attorney General](#) (Attorney General 2005) at paras 20–25. (The Memorandum was produced to support parliamentary committee consideration of the [Assisted Dying for the Terminally Ill Bill \[HL\]](#) in 2004/2005).

<sup>3</sup> However, the case of *Law Hospital NHS Trust v Lord Advocate* (1996 SC 301) arguably does involve recognition by a Scottish court of a role for a type of advance statement in a specific set of circumstances. In that case the Court of Session set out the procedure which should be followed in cases where what is sought from the court is authorisation for the withholding or withdrawing of medical treatment from individuals in a permanent vegetative state. In Law the court stated that one of the documents that should be lodged with the court in such instances should be a statement of any views on treatment decisions that the patient may have expressed before going into a permanent vegetative state (see further *Earle* 2007, p 160).



## ACTIVE VOLUNTARY EUTHANASIA

This section considers the criminal charges which might be brought in relation to cases of active voluntary euthanasia, ie where somebody takes positive action to bring about the end of another person's life with the agreement of that other person.

### England and Wales

There are two relevant offences: murder and manslaughter.

#### *Murder*

Murder is defined as 'unlawful killing with malice aforethought'. It requires intention to kill or to cause grievous bodily harm. It is not relevant whether the person in question consented to that act or that that person was dying anyway. The penalty for murder is life imprisonment (Attorney General 2005, para 4).

#### *The doctrine of 'double effect'*

Where the accused person is a member of the medical profession, the principle of double effect may provide a defence. If a doctor can show that his or her primary intention was to alleviate suffering rather than hasten the death of the patient, the administration of potentially lethal drugs will not be criminal. This applies even where the doctor realises that a likely consequence of alleviating pain is that this will result in the death of the patient (R v Adams ([1957] Crim LR 365; Attorney General 2005, para 5).<sup>4</sup>

#### *Manslaughter*

Active voluntary euthanasia may also be charged as manslaughter. Manslaughter is an offence which includes homicides that would otherwise amount to murder but the charge is reduced to manslaughter because one of the special defences provided for by the Homicide Act 1957 apply (Attorney General 2005, para 6).

The special defences include diminished responsibility (section 2 of the Homicide Act 1957) and killing in pursuance of a suicide pact (section 4 of the Homicide Act 1957). Diminished responsibility is a state of mind falling short of insanity but which is such that the law considers the accused should only have partial responsibility for his or her actions. Section 4(3) of the Homicide Act 1957 defines a suicide pact as follows:

“a common agreement between two or more persons having for its object the death of all of them, whether or not each is to take his own life, but nothing done by a person who enters into a suicide pact shall be treated as done by him in pursuance of the pact unless it was done while he has the settled intention of dying in pursuance of the pact”

Aside from situations where the aforementioned special defences apply, it is unclear whether other acts of euthanasia legally amounting to murder might be prosecuted in practice as the lesser offence of manslaughter. In July 2010 Tony Nicklinson, who suffers from 'locked in' syndrome, launched a judicial review action based on various articles of the European Convention of Human Rights and seeking confirmation from the Director of Public Prosecutions that his wife will not be prosecuted for murder if she gives him a lethal injection. For an example of the associated press coverage surrounding the case see [Locked-in man seeks right to die](#) (BBC news release 2010).

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<sup>4</sup> This can be contrasted with the situation in R v Cox ((1992) 12 BMLR 38), where a doctor was found guilty of attempted murder. He was not able to rely on the defence of double effect because the drug with which he injected his patient, potassium chloride, had no pain-killing purpose.



## Scotland

There are two main relevant offences in Scots law: murder and culpable homicide. These are discussed in more detail below. However, it should be noted that acts connected with assisted dying may be relevant to other offences under common law or statute. For example, the common law offences of assault, reckless endangerment and breach of the peace may be relevant, as well as various statutory offences under the Misuse of Drugs Act 1971 (c 38).

### *Murder*

Murder has been defined as:

“[A]ny wilful act causing the destruction of life, whether intended to kill, or displaying such wicked recklessness as to imply a disposition depraved enough to be regardless of consequences” (Macdonald 1948, p 89)

Whilst intent to kill or wicked recklessness is required, the accused person’s motive for taking the life of another person (for example, to alleviate suffering) is irrelevant to the issue of the accused person’s criminal liability. Furthermore, the fact that the victim may have consented to being killed, or even urged the accused to carry out the fatal act, is not a valid defence to the charge of murder (HM Advocate v Rutherford 1947 JC 23). Likewise, the fact that a person is killed a short time before they would have died anyway is of no relevance to the issue of criminal liability (Gordon and Christie 2000–2001, para 23.03; Earle and Whitty 2006, para 382).

### Culpable Homicide

Culpable homicide may be the appropriate charge where there was intent to kill but an accused person was suffering from diminished responsibility. In euthanasia cases, where the accused had strong emotional ties to the deceased person, it has been suggested that a court may be persuaded that the accused was suffering from diminished responsibility, on the basis that witnessing the suffering of the deceased may have significantly affected the accused’s state of mind (Fergusson 1998, p 294).

Even if it may amount to murder in legal terms, in practice an act of euthanasia might be prosecuted as the lesser offence of culpable homicide (Gordon and Christie 2000–2001, para 25.03; Earle and Whitty 2006, para 382; McCall Smith and Sheldon 1997, p 173; Fergusson 1998, p 294). There are a couple of Scottish unreported cases typically referred to by academic authors in this context, for example, HM Advocate v Brady (October 2006), where the accused killed his brother who was in the final stages of Huntington’s disease and was found guilty of culpable homicide and admonished (see the discussion at Fergusson 1998, pp 294–295). However, in the absence of Scottish reported cases on euthanasia and culpable homicide and/or specific guidance for prosecutors on euthanasia cases, this area of law and practice is uncertain. (For a discussion of the issue of guidance for prosecutors in relation to assisted suicide see p 10 and p 11 below).

### *The doctrine of ‘double effect’*

As mentioned above, the doctrine of double effect provides a possible defence for the medical profession in England and Wales if they can show the primary intention was to provide pain relief, rather than to end life. Some academic authors have suggested that this doctrine probably also applies in practice in Scotland (Fergusson 1998, p 295; Gordon and Christie 2000–2001, para 23.03 (footnote 13)), although the position is uncertain because of the absence of reported Scottish case law.

## ASSISTED SUICIDE

This section considers the criminal charges which might be brought in relation to cases of assisted suicide (including physician assisted suicide).

### England and Wales

#### *The Suicide Act 1961*

The traditional attitude of the law of England and Wales was to treat suicide as contrary to criminal law. Section 1 of the Suicide Act 1961 ('the 1961 Act') changed the law to provide that suicide is not a criminal offence. However, section 2 (along with sections 2A and 2B) of the 1961 Act makes it a statutory offence to encourage or assist a suicide or attempted suicide.<sup>5</sup> The offence carries a penalty of up to fourteen years' imprisonment.

#### *Key Cases on the Role of the Director of Public Prosecutions*

Under section 2(4) of the 1961 Act, the consent of the Director of Public Prosecutions (DPP) is required to initiate proceedings for a prosecution relating to the above offence. The following discussion considers two important cases relating to the role of the DPP under section 2(4).

The first such case was that of Diane Pretty (Pretty v DPP and Secretary of State for the Home Department [2001] UKHL 61; Pretty v United Kingdom 2346/02 [2002] ECHR 427). Ms Pretty suffered from motor neurone disease and was unable, without help, to take her own life. She sought an advance undertaking from the DPP that, if her husband aided her, the DPP would not consent to a prosecution under section 2(4) of the 1961 Act. She challenged his refusal to give this advance undertaking citing various articles of the European Convention of Human Rights ('the Convention') namely article 2 (right to life – she argued this included the right to self-determination in respect of life and death); article 3 (freedom from inhumane and degrading treatment); article 8 (right to respect for private life); article 9 (freedom of conscience) and article 14 (freedom from discrimination).

The House of Lords unanimously dismissed her appeal in respect of the case, finding that none of Ms Pretty's Convention rights were infringed by the DPP's failure to give the advance undertaking she desired. Ms Pretty then took her case to the European Court of Human Rights which ruled unanimously that the UK Government had not violated the Convention.

The second key case relating to the role of the DPP under section 2(4) was that of Debbie Purdy (R v DPP ex p Purdy [2009] UKHL 45; 2010 1 AC 345). Ms Purdy suffers from multiple sclerosis, for which there is no known cure, and she is confined to a wheelchair. She has said that when her condition becomes unbearable, she hopes to end her life at the Dignitas clinic in Switzerland. Her husband has indicated that he is willing to help her and, if necessary face a prison sentence. However, she does not wish to put him in that position and thus sought guidance from the DPP on what approach would be taken in relation to the possibility of prosecution.

The DPP stated that he would not create a specific policy for cases of assisted suicide but would consider each case individually in deciding whether or not to prosecute. Ms Purdy sought judicial review of the DPP's refusal to create this policy, on the ground that her right under article 8 of the Convention (right to respect for private life) had been violated. Article 8(2) requires any interference with the right to respect for private life be "in accordance with law". To meet this requirement, a number of tests must be satisfied including:

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<sup>5</sup> The wording of section 2 of the 1961 Act was substantially amended in February 2010 by the coming into force of section 59 of the Coroners and Justice Act 2009 (c 25). Section 59 also inserted sections 2A and 2B into the 1961 Act.

“whether the law or rule in question is sufficiently accessible to the individual who is affected by the restriction, and sufficiently precise to enable him to understand its scope and foresee the consequences of his action so that he can regulate his conduct without breaking the law”. (R v DPP ex p Purdy UKHL 45 at para 40; 2010 1 AC 345 at 390 per Lord Hope)

The House of Lords found that the then approach of the DPP to assisted suicide cases fell short of what was required to satisfy the Convention tests of accessibility and foreseeability and ordered the DPP to formulate a specific policy for cases of assisted suicide.

### *Policy for Prosecutors in Assisted Suicide Cases*

Following the successful legal challenge by Debbie Purdy in 2009, the DPP issued a [Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide](#) (February 2010) replacing an Interim Policy (September 2009) on the same topic.<sup>6</sup> The policy identifies sixteen public interest factors in favour of prosecution and six public interest factors against prosecution.

It should be noted that the policy emphasises that the act of suicide requires the victim to take his or her own life:

- 33 It is murder or manslaughter for a person to do an act that ends the life of another, even if he or she does so on the basis that he or she is simply complying with the wishes of the other person concerned
- 34 So, for example, if a victim attempts to commit suicide but succeeds only in making himself or herself unconscious, a person commits murder or manslaughter if he or she then does an act that causes the death of the victim, even if he or she believes that he or she is simply carrying out the victim’s express wish

Further information on the law relating to assisted suicide in England and Wales (including a detailed discussion of recent cases) can be found in the House of Commons Library briefing on [Assisted Suicide](#) (Almandras 2010).

## **Scotland**

### *Relevant offences*

In Scotland it is not a criminal offence to attempt to commit suicide. Consequently, it is thought that a person cannot be guilty ‘art and part’ of suicide or attempted suicide (ie of aiding and abetting such acts) as suicide and attempted suicide are not crimes in Scots law in the first place (Mason and Laurie 2006 p 611; Earle and Whitty 2006, para 384). There is no reported Scottish case law on the application of the criminal law to cases of assisted suicide; however there would appear to be a number of possible offences in Scots law, including murder, culpable homicide and reckless endangerment (Fergusson 1998 p 298; Earle and Whitty 2006, para 384; McCall Smith and Sheldon 1997, p 172). This would not preclude other charges depending on the circumstances. These are considered in more detail below. However, as mentioned earlier in this briefing, acts associated with assisted dying may be relevant to other offences under common law or statute, such as assault, breach of the peace and various offences under the Misuse of Drugs Act 1971 (c 38).

Reckless endangerment can be charged when the accused has recklessly exposed another to the risk of harm, even if no harm has actually resulted. Jones and Christie have noted that charging an individual with this offence seems a sensible option for the Crown in cases in which “the causal link between the accused’s reckless conduct and actual injury to another is weak or

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<sup>6</sup> The policy published in February 2010 replaced the [Interim Policy for Prosecutors in respect of Cases of Assisted Suicide](#) (September 2009).

difficult to prove” (Jones and Christie 2008, para 9.28). Murder and culpable homicide are crimes in which the prosecution must prove a causal link between the acts of the accused and the death of the victim; in other words, that the accused’s behaviour caused the death.

In relation to murder and culpable homicide academic authors have explored whether the victim’s act of taking his or her own life amounts to a ‘novus actus interveniens’ (ie an act breaking the chain of causation between the accused’s assistance and the victim’s death) (Fergusson 1998, pp 299– 305; McCall Smith and Sheldon 1997, pp 171–172; Earle and Whitty 2006, para 384; McLean *et al* pp 278–280). Reference has been made in this regard to a separate strand of Scottish case law on culpable homicide, not involving assisted suicide (or indeed any intention that someone should die) where the allegedly criminal act was the supply of controlled drugs and similar substances (Fergusson 1998, p 304–305; McLean *et al* 2009, pp 278–280). The latest key case in this regard is *MacAngus v HM Advocate; Kane v HM Advocate* ([2009] HCJAC 8) which clarified that “the adult status and deliberate conduct” of a person to whom the drugs were supplied can, but does not necessarily, sever the causal link between that person and the accused. Discussing this case from a general criminal law perspective, Stephen (2009, p 30) has suggested that this leaves the way open for “a cautious case by case approach” by the courts. However, as there are no reported Scottish cases on assisted suicide, it remains to be seen how this branch of case law would be applied in the context of assisted suicide.

The doctrine of double effect referred to above may also provide the medical profession with a defence to the criminal charges where they have assisted with a suicide (Earle and Whitty 2006, para 385). However, in the absence of reported Scottish case law on the doctrine the position is uncertain.

#### *The Implications of the Debbie Purdy case for Scotland*

In Scotland, there is no published prosecution policy specifically relating to assisted suicide cases. Instead, as was formerly the case in England and Wales, there is a general [Prosecution Code](#) (Crown Office and Procurator Fiscal Service 2001) which sets out a list of public interest factors to be taken into account both for and against prosecution.

As referred to above, the House of Lords ruling in the case of Debbie Purdy in 2009 resulted in the DPP issuing a [Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide](#) (February 2010), replacing an Interim Policy (September 2009) on the same topic. On the same day the Interim Policy was issued in respect of England and Wales the Lord Advocate issued the following statement in relation to Scotland:

“The guidance issued by the Director of Public Prosecutions for England and Wales will only apply to cases where an offence of assisted suicide takes place within England and Wales. It will not apply to Scotland.

The DPP’s guidance follows the decision of the House of Lords in the English case of Purdy. This case applies only to England and Wales and to the statutory offence of assisting the suicide of another under section 2 of the Suicide Act 1961. This offence does not apply in Scotland, where, depending on the particular facts and circumstances of the case, the law of homicide may apply.

The Crown Office and Procurator Fiscal Service will give careful consideration to the implications of the DPP’s guidance, the outcome of his public consultation and developments in other jurisdictions.

The Crown recognises the importance of this issue, but any change in the current law related to homicide is properly a matter for the Scottish Parliament”.<sup>7</sup>

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<sup>7</sup> The statement was reproduced in MacQueen and Wortley 2010, p 12.

The case of Debbie Purdy and the statement by the Lord Advocate have been the subject of some academic commentary in Scotland (Chalmers 2010; McLean *et al* 2009). For example, Chalmers argues:

“Were Ms Purdy and Mr Puente Scottish residents, they would face an even more unpalatable risk that Mr Puente’s potential prosecution for complicity in suicide: a potential prosecution for murder (...) it surely cannot be the case that because the potential consequences for an individual are *more* severe in Scotland than under English law, the case for prosecutorial guidelines is weakened (...)

(...) the only relevant difference between the position in England and Scotland is that the Director of Public Prosecutions has been obliged by court order to produce guidelines on the prosecution of assisted suicide, and the Lord Advocate has not. Given that the order made by the House of Lords was a consequence of the application of the ECHR, it should be self-evident that this difference cannot and does not justify the absence of such guidelines in Scotland.” (Chalmers 2010, pp 299–300)

In a similar vein McLean *et al*, have observed:

“(...) if we accept that art 8 rights are engaged in cases of assisted suicide, this must equally be the case in respect of citizens of Scotland, since the 1998 Act applies throughout the United Kingdom. It follows logically that Scottish prosecutorial policy should be in accordance with art 8(2), thereby demanding a certain level of clarity...

At present, those who assist in a suicide *in Scotland* would – without modification or further elucidation of the current situation – remain vulnerable to the exercise of a prosecutorial discretion as to whether or not to bring charges that is opaque and is, therefore, potentially in breach of the human rights legislation”. (McLean *et al* 2009, pp 281–282)

## **PART 2: POSITION IN OTHER JURISDICTIONS**

A number of jurisdictions across the world have introduced legislation to legalise various forms of euthanasia and/or assisted suicide or have policies of not prosecuting cases of assisted suicide under certain conditions. A selection of these together with a brief overview of their position on euthanasia and/or assisted suicide can be found in Appendix 2.

However, as the Policy Memorandum and a significant number of submissions to the Committee's call for evidence referred to the situation in the Netherlands and the US state of Oregon, these will be the focus of this briefing.

### **THE NETHERLANDS**

Tiedemann and Valiquet (2008, p 8) state that in the Netherlands the term "euthanasia" has a single meaning and is not normally qualified through the use of "voluntary" or "involuntary" or "non-voluntary". It is the practice of deliberately terminating a patient's life by a physician acting on the patient's request and according to strict guidelines. As a result, using the terminology outlined at the start of this briefing, euthanasia in the Netherlands context will be referred to as active voluntary euthanasia (AVE). The Netherlands also allows physician assisted suicide (PAS), but this is separately acknowledged in the research discussed below.

#### **Background**

Under the 1886 Netherlands Penal Code it is a criminal offence to either: a) terminate the life of a person upon his or her express request, or b) assist a person to commit suicide. Whilst these provisions remain in force, beginning in the 1970s courts found that doctors who performed active voluntary euthanasia or assisted suicide could use the statutory defence of necessity. Lewis (2010, p 1) notes that:

"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: laypersons (who include relatives) and nurses do not."

Over time the Courts began to place conditions on doctors using such a defence. In 1986 the Royal Dutch Medical Association (RDMA) produced 'due care' criteria, which attempted to take account of these conditions. These were approved by the Dutch Government, which meant that as long as a doctor followed them they would not be criminally liable for the practice of AVE or PAS. Following this, there were a number of developments, which are worth noting. In 1990 the Dutch Government set up the Remmelink Commission, to investigate AVE and PAS. As well as providing the first official estimate of euthanasia in the Netherlands, it made a number of recommendations, including on reporting procedures for doctors. A further key development was the controversial Chabot Case, which led to the Courts accepting that assisted suicide could be justifiable in cases where, although no physical illness was present, the patient was experiencing intense emotional or mental suffering. Following this were two similar cases, but this time involving severely disabled infants, which led to an acceptance of euthanasia when requested by the parent where the infant is experiencing unbearable and hopeless suffering.

Finally, in 1998, following concerns about doctors not reporting AVE and PAS, the responsibility for reviewing cases was given to five Regional Review Commissions. Doctors were required to report all cases of euthanasia and PAS to the relevant Commission, who in turn decided whether the requirements of due care had been followed, before reporting the case to the public prosecutor regardless of the findings. (Janssen (2002, p 261-262)).



## Termination of Life on Request and Assistance with Suicide (Review Procedures) Act

In 1999 the Dutch Government proposed legislation to codify existing practice. The Termination of Life on Request and Assistance with Suicide (Review Procedures) Act (the 2001 Act) was passed in 2001, coming into force in 2002, and whilst it did not legalise AVE or PAS, it did provide statutory defences for each when the procedures laid out are followed (Patel, 2004). In the Act the due care requirements, previously outlined in guidance, were spelled out in greater detail (see Figure 3, below).

As Patel (2004, 40-41) notes the 2001 Act also included a number of other provisions. Firstly, it applies to children as well as to adults - between the ages of 16 and 18 young people can make their own decision (though this must be done with the involvement of their parent / guardian), whilst between the ages of 12 and 16 children must have parental consent. Secondly, the Act set out the membership and role of the five regional Committees, namely:

- a) they must be composed of an uneven membership of at least three, and must include a doctor, a legal expert and an expert in ethics or philosophy
- b) their main task is to assess whether the physician complied with the due care criteria. If the Committee believes the physician did comply then no further action is taken. However, if they do not then the case is referred to the public prosecutor
- c) the public prosecutor has the power to initiate their own investigation if they suspect a criminal act has been committed
- d) the Committee is required to notify the physician of its findings within six weeks of receiving the initial report

### Figure 3: Due care requirements under the Termination of Life on Request and Assistance with Suicide (Review Procedures) Act

- be satisfied that the patient's request is voluntary and well considered
- be satisfied that the patient's suffering is unbearable and that there is no prospect of improvement
- inform the patient of his or her situation and further prognosis
- discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution
- consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the criteria for due care
- exercise due medical care and attention in terminating the patient's life or assisting in his or her suicide

(Source: Tiedemann and Valiquet (2008, p 11))

Thirdly, the law allows patients to leave a written request or advance statement for AVE. This gives doctors the discretion when patients become too physically or mentally ill to decide themselves. Again, these cases must meet the due care criteria, and they are also reviewed by the Regional Committees.

## Empirical evidence of euthanasia and PAS in the Netherlands

In terms of the Bill, and the submissions received by the Committee, a number on both sides of the debate pointed to empirical evidence from the Netherlands to support their argument. One problem for analysing the data is that many of the reports are published in Dutch. In addition, much of the data is based on surveys of physicians or reports filed by them. The use of surveys means that different methodologies are employed by different researchers, which can lead to varying results (see Patel, 2004).

However, the key studies that tend to be referred to are those commissioned by the Dutch Government. Beginning with the Rummelink study in 1991, there have been a further three published studies for the years 1995, 2001 and 2005, with similar methodologies and the same core of researchers. The data comes from answers to an anonymous questionnaire sent to physicians that attended deaths. The deaths were identified through death certificates for the given year. In 2007 the data for 2005 was published in English in a journal article, which compared it to the previous studies ([van der Heide et al, 2007](#)). Also published in 2007 was an



evaluation of the legislation, undertaken on behalf of the Netherlands Government (Onwuteaka-Philipsen et al, 2007). The evaluation involved many of the researchers involved in the van der Heide study, and used the data from 2005 and 2001. Unfortunately, only a [summary](#) of this report is available in English.

### *Practice of euthanasia and PAS*

Van der Heide et al (2007) considered the frequency of AVE, PAS and other end of life practices, which are reproduced in Table 1. Table 2 presents the same data for 2001 and 2005 as in Table 1, but includes an estimate of the absolute numbers involved.

Table 1: Frequencies of Active Voluntary Euthanasia, Physician Assisted Suicide and other end of life practices in the Netherlands, according to given year

<b>Variable</b>	<b>1990</b>	<b>1995</b>	<b>2001</b>	<b>2005</b>
No of studied deaths:	5197	5146	5617	9965
No of questionnaires	4900	4604	5189	5342
Most important practice that possibly hastened death (% of all deaths):				
Active Voluntary Euthanasia	1.7	2.4	2.6	1.7
Physician Assisted Suicide	0.2	0.2	0.2	0.1
Ending of life without explicit request of the patient	0.8	0.7	0.7	0.4
Intensified alleviation of symptoms	18.8	19.1	20.1	24.7
Withholding or withdrawing of life-prolonging	17.9	20.2	20.2	15.6
<b>Total</b>	<b>39.4</b>	<b>42.6</b>	<b>43.8</b>	<b>42.5</b>
Continuous deep sedation	-	-	-	8.2

Source: Van der Heide et al (2007)

Table 1 shows that the frequency of PAS has remained fairly stable over the time period, though latterly falling slightly from 0.2% in 2001 to 0.1% in 2005. The frequency of euthanasia saw an increase from 1.7% in 1990 to 2.4% in 1995, and then a further slight increase to 2.6% in 2001. However, in 2005, the number reduced significantly back to the 1990 level of 1.7%. Withholding or withdrawing life-prolonging treatment saw a similar trend. The ending of life without specific request of the patient has declined steadily over the time frame from 0.8% in 1990 to 0.7% in both 1995 and 2001, falling to 0.4% in 2005. The only practice which has seen a study by study rise has been 'intensified alleviation of symptoms', where death is a possible side effect. The table also shows the number of cases in 2005 where patients were continuously and deeply sedated (8.2%) before death.

As demonstrated in Table 2, below, this can be broken down further. Such sedation was provided in tandem with decisions that possibly hastened death (e.g. withholding hydration or nutrition) in 7.1% of all deaths, which is a slight increase on the 2005 figure. In the remaining 1.1% the sedation was not provided along with such decisions (there is no figure available for 2001). Onwuteaka-Philipsen et al (2007, p 7) also note that the survey data shows a decrease in the numbers of requests for euthanasia. Those requests made 'in due course' decreased from 34,700 in 2001 to 28,600 in 2005, and those 'within the foreseeable future' decreased from 9,700 in 2001 to 8,400 in 2005.

Table 2: Estimated frequencies of medical end-of-life decisions and continuous deep sedation in the Netherlands in 2001 and 2005

	2001		2005	
	No	%*	No	%*
<b>Medical decision on end of life:</b>				
Active Voluntary Euthanasia	3500	2.6	2325	1.7
Physican Assisted Suicide	300	0.2	100	0.1
Ending of life without explicit request of the patient	950	0.7	550	0.4
Intensified alleviation of symptoms	29000	21.0	33700	25.0
Withholding or withdrawing life-prolonging treatment	28000	20.0	21300	16.0
<b>Continuous deep sedation:</b>				
With medical end-of-life decisions	8500	6.0	9700	7.1
Without medical end-of-life decisions	-	-	1500	1.1

\* Of all deaths

Source: Onwuteaka-Philipsen et al (2007)

### *Patient and practice characteristics of euthanasia and PAS*

Van der Heide et al (2007) considered a number of patient and practice characteristics as regards AVE and PAS, as well as those cases where life was ended without an explicit request by the patient. The results are outlined in Table 3, which shows that the highest rates of AVE or PAS were found for patients aged 64 years or younger, for men, and for patients with cancer. In addition, general practitioners were the most likely clinicians to be involved in AVE and PAS cases. The researchers considered that the data indicated that demographic changes may be one reason behind the falling rate of AVE and PAS. They noted that whilst the absolute number of deaths in the Netherlands in 2005 was less than in 2001, the proportion of persons aged 80 and over was greater, an age group less likely to seek AVE and PAS.

Table 3: Rates of AVE or PAS and ending life without an explicit request by the patient, in 2001 and 2005, by characteristics of patients

Characteristic	Deaths in 2005 studied (No.)	% of all deaths	AVE or PAS		Ending of Life without Explicit Request by	
			2001	2005	2001	2005
<b>Age:</b>						
0-64 yr	2583	19.2	5.0	3.5	1.0	1.0
65-79 yr	3462	32.4	3.3	2.1	0.4	0.3
≥ 80 yr	3920	48.4	1.4	0.8	0.7	0.2
<b>Sex:</b>						
Male	5371	49.7	3.1	2.0	0.7	0.4
Female	4534	51.3	2.5	1.5	0.7	0.4
<b>Cause of death:</b>						
Cancer	2760	28.8	7.4	5.1	1.0	0.3
Cardiovascular	4882	31.9	0.4	0.3	0.6	0.2
Other or unknown	2323	39.3	1.2	0.4	0.5	0.6
<b>Type of physician:</b>						
General practitioner	5135	41.3	5.8	3.7	0.6	0.2
Clinical Specialist	2891	32.3	1.8	0.5	1.2	0.7
Nursing home	1458	24.5	0.4	0.2	0.4	0.3
<b>Total</b>	<b>9965</b>	<b>100.0</b>	<b>2.8</b>	<b>1.8</b>	<b>0.7</b>	<b>0.4</b>

Source: Van der Heide et al (2007)

The study also considered more detailed analysis involving the discussions with patients and relatives, the drug used and the time by which life was shortened, which are outlined in Table 4. This shows that in both 2001 and 2005 physicians discussed AVE and PAS with all patients whose death was caused by either act. In 2001, 96% of cases were discussed with a relative or friend and just over 90% with at least one other physician. However, both these rates decreased in 2005, most significantly the rate of discussion with relatives. In terms of those cases where life was ended without the explicit request of the patient, there was a significant increase in the rate of discussions taking place with the patient themselves, from 26.5% in 2001 to 60% in 2005. In 2005, of the remaining 40% of cases where discussions did not take place, the study found that this occurred because the patient was unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%).

Table 4: Discussion of ending-of-life practices; use of drugs in the ending of life; and time by which life was shortened; in 2001 and 2005

Variable	AVE or PAS		Ending of Life without explicit request by patient	
	2001	2005	2001	2005
No of deaths studied	335	258	58	24
Discussion of practice (%):				
With patient (or previous wish of patient)	100.0	100.0	26.5	60.0
With relative or friend	96.0	75.5	100.0	80.9
With ≥ other physician	90.7	87.7	65.2	65.3
Drugs administered (%):				
Neuromuscular relaxants	63.2	65.4	1.7	22.9
Barbiturates	10.8	8.5	2.3	5.3
Opioids	21.6	16.2	74.7	58.5
Benzodiazepines	0.0	6.6	2.3	2.7
Other drugs	0.9	0.3	0.0	4.5
Unknown	3.5	2.9	19.0	6.0
Shortening of life (%):				
By < 1 week	45.9	44.8	77.3	85.5
By ≥ 1 week	54.1	53.9	18.1	11.6
Unknown	0.0	1.3	4.7	2.9

Source: Van der Heide et al (2007)

In terms of drugs administered, in cases of AVE or PAS, the principal drugs used were neuromuscular relaxants, and usage increased slightly from 63.2% in 2001 to 65.4% in 2005. Opioids were used in 16.2% of cases in 2005, down from 21.6% in 2001. For situations where life was ended without the request of the patient, opioids were used in three quarters of cases in 2001, though this had decreased to 58.5% in 2005. This appears to have been largely in favour of using neuromuscular relaxants, which increased in usage from 1.7% of cases in 2001 to 22.9% in 2005. As part of the study, physicians were asked to estimate the amount of time by which life was shortened owing to the use of lethal drugs. For cases involving AVE or PAS, the rates have remained largely stable between 2001 and 2005, where in around 45% of cases life was shortened by less than a week, and 54% of cases were lessened by one week or more.

## Discussion

The debate over the findings (and the conclusions that can be reached) when analysing data from the Netherlands is an emotive and complex one. This section of the briefing does not seek to evaluate the various arguments put forward by both sides of the debate. Instead, it aims to provide a synopsis of some of the key points from the literature on the Netherlands experience.

A key argument concerns the critics view that by legalising AVE there has been a slide to permit non-voluntary active euthanasia (NVAE) (where a person is unable to express a decision on the matter). This argument is multi-faceted and several of the areas of debate are discussed in this part of the briefing.

### *The 'slippery slope' – through legislation*

One argument is that greater numbers of people become eligible to take advantage of a law because the enabling legislation is reformed (either by case law or further primary legislation). In a number of submissions to the Committee critics of the Bill believed the Netherlands was an example of this type of slippery slope because the practice began in cases where there was deemed to be intolerable physical pain and distress. However, after the Chabot case it was extended into the realm of emotional distress, and, one year after the Chabot case, children, including newborn babies. Proponents would argue that it was not so much that the process was being gradually reformed in order to take in more groups; rather the statutory defence of necessity was being tested and applied by the courts in cases brought before it.

### *The 'slippery slope' – AVE to NVAE*

In 2005 there were 8,400 direct and explicit requests for AVE and PAS in the Netherlands. The number of actual cases was 2,425, which would mean that 5,975 requests were not granted. Proponents use such data to show the benefits of a controlled system of AVE and PAS. In addition, taking account of the recent downward trend in AVE and PAS cases (see Tables 1 and 2), proponents would argue that this is evidence against the notion of a 'slippery slope'. However, Keown (2006, p5) contends that, based on the number of refused requests, it is already the doctor who is deciding whether someone should die or not. He argues that a logical extension of this practice would be for a doctor to then decide the fate of those without capacity to decide, given they already make the decision for those with capacity.

For critics this is evidenced empirically by referring to the number of cases of AVE and PAS that occur without the express consent of the patient. As Table 1 shows there were 950 such cases in 2001 and 550 cases in 2005. When analysing this further Van der Heide et al (2007) found that that there had been discussion of the act or there was an awareness of the previous wish of the patient in 60% of these cases in 2005, when it was only 26.5% in 2001. For proponents this is a sign that the 2001 Act is having a positive effect on such practices. However, critics will then point to the further analysis done by Van der Heide et al (2007), as discussed on p 17 above, that the reasons given by physicians for not expressly seeking the wishes of the patient was due to the patient being unconscious or incompetent due to young age, but there was also a significant "other" category. Both Fenigsen (2004, p 75) and Keown (2006, p 6-7) also refer to the Dutch Government commissioned studies from 1995 and 2001 which stated that it was the patient who was responsible for avoiding termination of their life and that if they did not wish this then they should state it clearly in advance. This suggests a form of presumed consent, which is of great concern to critics. Opponents to such AVE and PAS legislation also point to the increase in practices of "intensified alleviation of symptoms" and the use of "continuous deep sedation", as evidence of cases where drugs are used to keep the patient in a coma without nutrition or hydration until death.

Lewis (2007b, 199) argues that caution is required when debating the 'slippery slope' argument using empirical evidence from the Netherlands. She contends that the argument is only effective if: a) it can be demonstrated that legalisation causes the 'slippery slope', and, b) if it is used comparatively to demonstrate that the slope is "more slippery" in the Netherlands than it is in jurisdictions that have not legalized suicide or euthanasia. The problem with using the data from the Netherlands is that it does not cover the period before effective legalisation with the result that it is not possible to say whether non-voluntary euthanasia was higher or lower than after legalisation. Therefore it is difficult to demonstrate that legalisation causes the slippery slope. Lewis (2007b) also compares the available rates of ending life without the patient's explicit consent from a range of countries which have and have not legalized voluntary

euthanasia. She concludes that:

“Evidence in relation to other jurisdictions are mixed, while rates of non-voluntary euthanasia in some prohibitive jurisdictions are higher than the Dutch rate, in other prohibitive jurisdictions the rates are lower. Lacking solid baseline evidence the current evidence does not support the drawing of inferences that that legalisation causes an increase in the rate of non-voluntary euthanasia or that such rates are higher under a prohibitive approach.” (2007, p 205).

#### *Evidence negating the need for euthanasia*

Fenigsen (2004), considering evidence from the 2001 study found that in 48% of such cases the practice was not carried out because the patient died before it could be performed. The 2005 data considers the estimated amount of time by which life was shortened owing to the use of lethal drugs (see Table 4) and showed that in many of the cases studied life was shortened by less than one week. This could be seen to back some critics' view that any form of euthanasia or assisted dying is unnecessary. However, Dignity in Dying (2010b) consider that discussions around end of life choices is important regardless of whether or not someone goes through with them as it helps the person feel in control and can be a form of 'emotional insurance'.

Van der Heide et al (2007) also make reference to research showing that increasing numbers of Dutch physicians are using high-quality end-of-life care as an alternative to AVE or PAS, at least in some cases. Such findings are used by critics to argue that good quality palliative care negates the need to consider euthanasia and PAS. On the other hand Dignity in Dying (2010b) contend that assisted dying legislation can provide an impetus to enhancing palliative care, pointing to the cases of Belgium and Luxembourg where voluntary euthanasia legislation was introduced alongside palliative care legislation.

#### *Drugs used*

Both van der Heide et al (2007) and Onwuteaka-Philipsen et al (2007) considered that the change in the drugs used for AVE and PAS was one reason for the decrease in rates (see Table 4, above). They both reflected on a body of evidence that suggested that the life-shortening effects of opioids were overestimated, and noted that the Review Committees had disapproved of the use of opioids for euthanasia because of this. This meant that physicians were probably less inclined to attribute a life-shortening result to morphine. Van der Heide et al (2007, p 1963) note that: “the decrease in the percentage of cases of euthanasia in which opioids were used in 2005 as compared with 2001 may at least be partly the result of variation in the attribution by physicians of their acts, not only from an actual change in practices”.

Fenigsen (2004, p 76) considers this matter more generally and is concerned that terminal sedation (TS) may be used alongside the withdrawal of treatment and be recorded as the latter. Using 2001 data he found that terminal sedation was used using benzodiazepines, barbiturates and/or morphine in 43% of cases without the patient's consent. In 69% of cases without the patient's consent it was combined with withdrawal of food and fluids. He argued that depending “on the doctors' intentions, the presence or absence of a patients request, and the dosage of drugs, some cases in which TS was applied qualify as active voluntary or involuntary euthanasia, or intentional overdose of drugs”. Therefore cases of euthanasia may be underestimated.

#### *Questions over the monitoring systems in the Netherlands*

Van der Heide et al (2007) note that physician reporting rates for AVE and PAS increased from 18% in 1990 to 80.2% in 2005, which they believe is a result of the gradual changes in policy and legislation, to a position where euthanasia and assisted suicide are no longer legally questionable. For proponents this demonstrates the increased transparency and openness over end-of-life decision making that a controlled system can bring. Onwuteaka-Philipsen et al (2007) concluded that data from 2005 showed that the Review Committee system was generally

working well and conforms to the intentions of the law.

Van der Heide et al (2007) discussed how, for the first time, the 2005 study examined the reasons given by physicians for non-reporting. They found that a large majority of non-reported cases involved acts to end life but were not labelled by the physicians as AVE or PAS. These cases mostly involved drugs with uncertain lethal effects eg opioids (see above). This meant that the Review Committees mainly evaluated cases where death was hastened by neuromuscular relaxants or barbiturates, where physicians virtually always adhered to the requirements for careful practice. Van der Heide et al (2007, p 1964) considered this showed that “the transparency that is envisaged by the Dutch law apparently does not extend to all cases of euthanasia”.

This point was also made by Fenigsen (2004), who considered the data on how often a physician who had undertaken AVE or PAS had, as per the due care criteria, consulted with another physician. As Table 4 shows, in the vast majority of cases this happens. However, in 2001, Fenigsen (2004) found that the number of cases where it did not happen was 500. As Table 4 shows the rate of consultation decreased in percentage terms between 2001 (90.7%) and 2005 (87.7%). For Fenigsen, situations like this leave the system in the Netherlands open to serious criticism about the lack of control there is both before and after the fact.

A related criticism is made by Keown (2006, p 7) who noted that it is rare for a doctor to be prosecuted in the Netherlands for performing non-voluntary euthanasia and that lenient punishments imposed when in even rarer cases a doctor has been convicted of murder or assisted suicide.

## **OREGON**

### **Background**

The development of legislation in Oregon was very different from that in the Netherlands. The Death with Dignity Act (the DWDA) was passed through Motion 16 of a state-wide ballot in November 1994, by 51% to 49%. This followed unsuccessful attempts to have the state legislature pass a similar law (Patel, 2004), and two narrowly defeated ballots in the states of Washington and California (Lewis, 2010). Also, unlike in the Netherlands, the law is quite restrictive and, using the definitions in the ‘Terminology’ section, above, would be described as having a system of physician assisted suicide (PAS). In addition it is interesting to note that unlike in the Netherlands where the momentum for a change in the law came through the medical profession, in Oregon the impetus was civilian based, and the key medical body in Oregon was opposed to the legislation. As discussed by the Oregon State Government: Department of Human Services (OSG: DHS) (2006a), implementation was delayed by a legal injunction, but after proceedings, that included a petition denied by the United States Supreme Court, the Ninth Circuit Court of Appeals lifted the injunction in October 1997. The following month Measure 51, emanating from the state legislature, and asking voters to repeal the DWDA, was placed on the general election ballot. This was rejected by a margin of 60% to 40%, and the DWDA was able to come into force. Since then, whilst the DWDA has remained in force, there has been another challenge at US federal level, but this failed (see [OSG: DHS \(2006a\)](#)). The eventual result was that the DWDA was allowed to continue intact.

### **The DWDA provisions**

As OSG: DHS (2006b) notes, the DWDA allows terminally ill adults with a prognosis of less than six months to live, to obtain a prescription for medication for the purpose of committing suicide. It specifically prohibits euthanasia. To request a prescription for lethal medication, the DWDA requires that a patient must be:



- 18 years of age or older
- a resident of Oregon
- capable (defined as able to make and communicate health care decisions)
- diagnosed with a terminal illness, ie “an incurable and irreversible disease that has been medically confirmed”, that will lead to death within six months

If a patient meets these criteria, they can then request a prescription for lethal medication from a licensed Oregon physician. The process required is described in Figure 5.

To comply with the law, physicians must report to the DHS all prescriptions for lethal medications, but this is not required if patients begin the request process but never receive a prescription. Patel (2004, p 47) notes that the law also requires a record of “all of the oral and written requests of the patient, attending physician’s diagnosis and prognosis, outcome and determination made during counselling, physician’s determination that the patient is competent and acting voluntarily and had made an informed decision, etc.” Following an amendment to the DWDA in 1999, pharmacists must also be informed of the prescribed medication’s intended use.

**Figure 5: Process for dispensing prescription under the DWDA**

- The patient must make two oral requests to his or her physician, separated by at least 15 days.
- Following the second oral request, the patient must provide a written request to his or her physician, signed and dated in the presence of two witnesses.
- An additional 48 hours must pass before the physician can write a prescription, though the patient can revoke the request any time by any means.
- Neither of the witnesses can be: a relative by blood, marriage or adoption; an heir; or, employee, owner or operator of a healthcare facility that the person is receiving care. At the time of the request a witness must also not be the prescribing physician approached by the person.
- The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
- The prescribing physician and a consulting physician must determine whether the patient is capable.
- If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychological examination.
- The prescribing physician must inform the patient of feasible alternatives to DWDA, including comfort care, hospice care, and pain control.
- The prescribing physician must request, but may not require, the patient to notify his or her next-of-kin of the prescription request.
- Once the prescription has been accepted by the pharmacy, the patient decides when, where and in what manner with who present to self-administer. Neither the prescribing physician nor anyone else can administer the medication.

(Source: OSG: DHS (2006b) and Patel (2004))

Other provisions include that physicians and patients who adhere to the requirements of the Act are protected from criminal prosecution, and using the DWDA cannot affect the status of a patient's health or life insurance policies. In addition, there is a conscientious objection clause for physicians, pharmacists, and health care systems The DWDA also specifies that action taken in accordance with the Act does not constitute “suicide, assisted suicide, mercy killing or homicide, under the law.” However, the Oregon Health Division must report any non-compliance with the law to the Oregon Board of Medicine.

**Data connected with the DWDA**

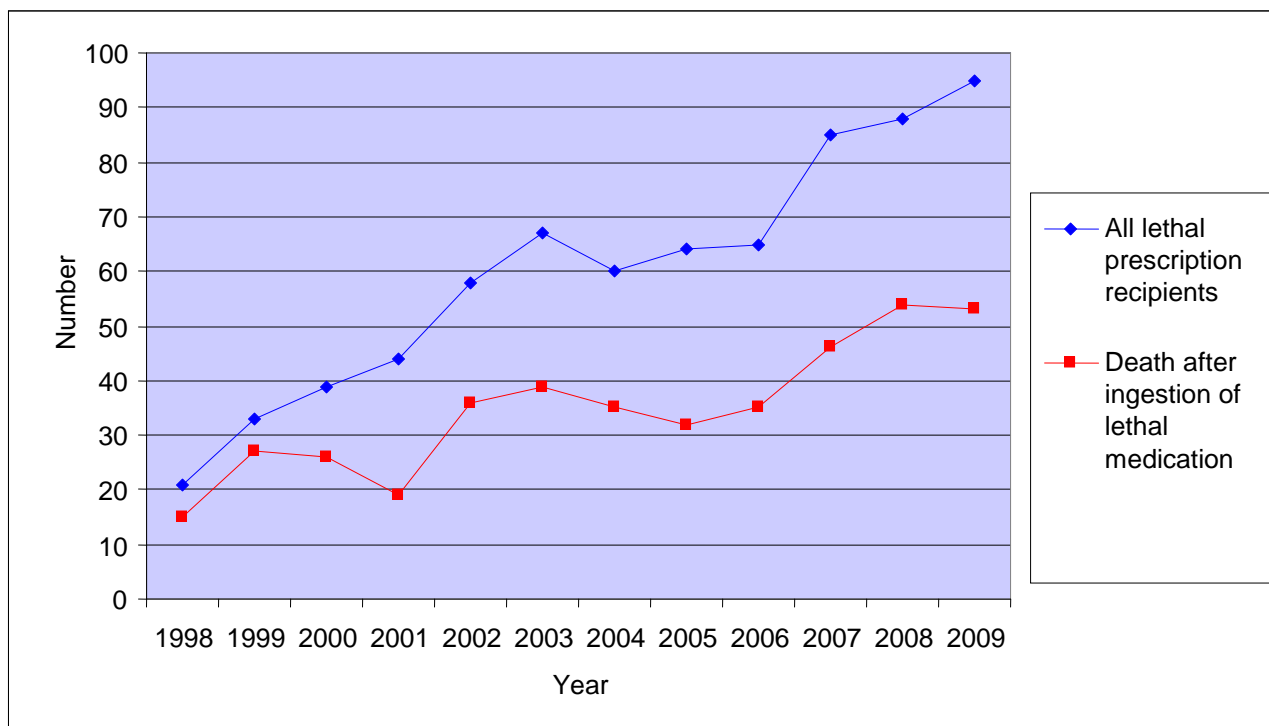
The DWDA provides that the Oregon Department of Health must publish an annual report. All of the Annual Reports are published on the OSG: DHS [‘Death with Dignity Act Annual Reports’](#) web page. In the first five years (1998 to 2002) of the DWDA’s operation, the annual reports were published in medical journals. Thereafter the reports began to shorten, so that for example the 2009 report (published in 2010) contains far less discussion of the results than the earlier reports. One group of data which is consistently reported is the overall number of



persons that were eligible for and received a lethal prescription, and those that administered the lethal drugs and died.

Figure 6, below, shows that the number of recipients of lethal prescriptions has risen fairly consistently between 1998 (21) and 2009 (95), apart from a slight drop in 2004. In 2007 the total number of prescriptions increased to 85 from 65 in 2006. In relation to the number of people who have then self-administered the lethal medication. Figure 6 shows that whilst there has been a similar upward trend, there remains a significant gap between the number of prescriptions which are self-administered and the number of prescription recipients. Indeed, the proportion of those choosing to self-administer the lethal medication has decreased from 71.4% in 1999 (the earliest year with data presented in this way) to 55.8% in 2009, though there have been several years within that period which go against the overall downward trend. Overall a total of 406 people have died between 1998 and 2009 by taking lethal medication prescribed under the DWDA. However, given the total number of deaths in that time period was over 366,000 (see *Estimating the demand for end of life assistance*, below), this remains a very small proportion of the total number of people that have died in Oregon over that time period.

Figure 6: Number of DWDA Prescription Recipients and Deaths by Year, Oregon, 1998-2009



Source: OSG: DHS (Online) [‘Death with Dignity Act Annual Reports’](#)

As already illustrated above, the data has not always been consistently reported over the 12 annual reports. One issue concerns the number of people who did not die from self-administering the lethal medication. This category includes those who died from their illness during the calendar year reported, and those who have survived to the end of that calendar year without (yet) self-administering the lethal medication. As regards the number of those who died due to their illness, the year on year reports showed that this increased from 15% in 1999 to 31.6% in 2009, though it was an undulating trend. In terms of those who did not die from their illness but survived (at least to the end of the calendar year) without taking the lethal medication, this rose from 1% in 1999 to 12.6% in 2009, though, again, the overall upward trend was not constant.

When considering some of the other data sets collected for the Annual Reports, the problem of consistency of reporting makes it difficult to provide a year on year analysis or even a selection of dates over the time period. Therefore, data from the 2009 report, which provides data for that

year and also a figure for the combined years of 1998 to 2008 will be used.

Table 5 details the data on various characteristics of those who died after ingesting lethal medication prescribed under the DWDA.

Table 5: Characteristics of persons who died after ingesting lethal medication, Oregon, 1998-2008 and 2009

Characteristics	2009 (N=59)		1998-2008 (N=401)		Total (N=460)	
	N	%	N	%	N	%
<b>Sex:</b>						
Male	31	52.5	213	53.1	244	53.0
Female	28	47.5	118	46.9	216	47.0
<b>Age:</b>						
18-34	2	3.4	4	1.0	6	1.3
35-44	1	1.7	11	2.7	12	2.6
45-54	2	3.4	32	8.0	34	7.4
55-64	9	15.3	85	21.2	94	20.4
65-74	13	22.0	114	28.4	127	27.6
75-84	24	40.7	112	27.9	136	29.6
85+	8	13.6	43	10.7	51	11.1
Median years	76	-	70	-	71	-
<b>Underlying illness:</b>						
All cancers	47	79.7	326	81.3	373	81.1
Amyotrophic lateral sclerosis *	5	8.5	30	7.5	35	7.6
Chronic lower respiratory disease	3	5.1	15	3.7	18	3.9
HIV/AIDS	0	0.0	8	2.0	8	1.7
Other ^	4	6.8	22	5.5	26	5.7
<b>End-of-life concerns #:</b>						
Losing autonomy	57	96.6	357	89.9	414	90.8
Less able to engage in activities making life enjoyable	51	86.4	347	87.4	398	87.3
Loss of dignity	54	91.5	228	83.8	282	85.2
Losing control of bodily functions	31	52.5	233	58.7	264	57.9
Burden on family, friends, carers	15	25.4	152	38.3	167	26.6
Inadequate pain control or concern about it	6	10.2	95	23.9	101	22.1
Financial implicaitons of treatment	1	1.7	11	2.8	12	2.6
<b>NB:</b>						
* A form of Motor Neuron Disease						
^ Includes: alcoholic hepatic failure, corticobasal degeneration, diabetes with renal complications, hepatitis C, organ-limited amyloidosis, scleroderma, Shy-Drager Syndrome, multiple sclerosis, meningioma, chronic heart failure and Huntingdon's disease						
# Affirmative answers only ("Don't know" included in negative answers)						

Source: OSG: DHS (2010)

In the first instance, Table 5 shows that from 1998 to 2009 a total of 460 people have died after ingesting lethal medication. It also shows that slightly more men (53%) have died as a result of ingesting the medication, and this has remained fairly constant over the time period. Over the whole timeframe the median age has been 71, although in 2009 this was higher (76). Overall, the majority of those dying through PAS have been in the 65-74 (27.6%) and 75 to 84 (29.6%) age groups, though a significant percentage have also come from the 55-64 age group (20.4%). However, as an illustration of how this can change year on year, in 2009 the 75-84 age group accounted for 40.7% of these deaths. Table 5 also shows that cancer is the predominant illness for those dying through PAS and this has been consistent across the DWDA's operation. Finally, the table shows the concerns given by those choosing to end their lives through PAS. People have tended to give more than one reason over the time period, with the vast majority of people identifying a loss of autonomy (90.8%), being less able to engage in activities that make life enjoyable (87.3%) and loss of dignity (85.2%). Just over a quarter of people said they felt

they were a burden to family, friends and carers, which is one of the discussion points which will be addressed in the section below.

Table 6 details some of the key data on the PAS process itself. As noted above, a psychiatric assessment is not an essential part of the process unless it is considered necessary by the prescribing physician. The Table shows that only 8.4% of all those that died received such an assessment across the time period and in 2009 none of those who died received one. In relation to this specific point Dignity and Dying (2010b) point out that the official data only records those people who have received a prescription, and not the numbers of people rejected. It argues that each year people apply to use the DWDA and are refused permission following the psychiatric assessment. Therefore, it should not be concluded from this figure alone that doctors are becoming more permissive about mental health problems.

Table 6: PAS process characteristics for those that have ingested lethal medication under the DWDA, Oregon, 1998-2008 and 2009

PAS Process	2009		1998-2008		Total	
	N	%	N	%	N	%
<b>Initial process:</b>						
Referred for psychiatric evaluation	0	0.0	38	9.6	38	8.4
Patient informed family of decision *	52	89.7	309	94.2	361	93.5
<b>Hospice:</b>						
Enrolled	54	91.5	350	87.7	404	88.2
Not enrolled	5	8.5	49	12.3	54	11.8
Unknown	0	0.0	2	-	2	-
<b>Patient died at:</b>						
Home (of patient, family or friend)	58	98.3	377	94.0	435	94.6
Long term care, assisted living or foster care facility	0	0.0	19	4.7	19	4.1
Hospital	0	0.0	1	0.2	1	0.2
Other	1	1.7	4	1.0	5	1.1
<b>Lethal Medication:</b>						
Secobarbital (Barbiturate)	50	84.7	211	52.6	261	56.7
Pentobarbital (Barbiturate)	9	15.3	186	46.4	195	42.4
Other ^	0	0.0	4	1.0	4	0.9
NB:						
* First recorded beginning in 2001						
^ Includes combinations of secobarbital, pentobarbital and/or morphine						

Source: OSG: DHS (2010)

Table 6 also shows that the vast majority (93.5%) over the time period informed their family of their decision. It goes on to detail that, across the time period, 88.2% of those that died were enrolled with a Hospice at the time of their death, and given that in 94.6% of all cases death took place in the home it can be surmised that many of these were receiving home care service through a hospice provider. As regards the lethal medication prescribed, two medicines from the Barbiturate class of drugs have been the primary medication used in the vast majority of cases (99.1%). The 2009 Report (OSG: DHS, 2010) notes that over the time since the DWDA has been in force, in 95.5% of cases there has been no complication recorded when using the medication. In the remaining 4.5% of cases, complications were due to regurgitation.

Table 7, below, considers the various data on timings of the PAS event for those that decided to die through assisted suicide. Overall the median number of weeks a patient has known the assisting physician is 10 weeks, though as can be seen from the range; there were people who had known their doctor for very long periods of time, in at least one case 27 years. As the figure for 2009 shows, the length of relationship varies considerably.

Table 7: Timing of PAS event for those that have ingested lethal medication under the DWDA, Oregon, 1998-2008 and 2009

Timing of PAS event	2009	1998-2008	Total
<b>Duration (weeks) of patient/physician relationship:</b>			
Median	9	10	10
Range	0-863	0-1440	0-1440
Unknown (number)	1	19	20
<b>Duration (days) between 1st request and death:</b>			
Median	46	43	43
Range	15-527	15-1009	15-1009
<b>Minutes between ingestion and unconsciousness:</b>			
Median	5	5	5
Range	1-30	1-38	1-38
Unknown (number)	2	36	38
<b>Minutes between ingestion and death:</b>			
Median	45	20.5	25
Range (minutes - hours)	2min-104hrs	1min-83hrs	1min-104hrs
Unknown (number)	2	31	33

Source: OSG: DHS (2010)

Table 7 also shows that the median number of days between a patient's first request for PAS and death was 43 days. The range shows that there were some deaths after the minimum waiting period required by the DWDA (15 days), while other deaths did not occur until nearly three years after the first request. As will be discussed in the next section, this is another point of debate. Table 7 also shows the length of time it took between the ingestion of the lethal medication and unconsciousness. The median was 5 minutes with the range showing a maximum of 38 minutes and a minimum of 1 minute. The median time between ingestion and death was 25 minutes, though it is noticeable that if 2009 is not included, the median is nearly 5 minutes less. This is due to a median of 45 minutes in 2009. However, when considering the range, the maximum length of time was 104 hours, which also occurred in 2009.

The final area from the Annual Reports worth noting is the data on the number of physicians assisting patients through the DWDA. Taking into account the figures from the reports from 2001 to 2009, the median over that timescale was 40. However, the range was from a minimum of 33 to a maximum of 59, and the trend is an upward one.

Over the entire time period of the DWDA's operation, the prescribing physician was present at the time the lethal medicine was ingested in 23.8% of cases (OSG: DHS, 2010). In the majority of cases (59.1%) another health care provider was present, and in 17.1% no health care provider was present. On average, fewer prescribing physicians continue to be present at death (20.3%), though it is more likely that there will be another health care provider present (61.5%) than for there to be no provider (18.2%) Finally, the Annual Reports show that a total of 22 infringements of the law by physicians have been reported to the Oregon Medical Board. There were no referrals in 1998, 2002 or 2007. The infringements have tended to be for errors in recording, or for not following proper procedures in terms of witnesses. However, what is less clear from the reports is whether or not any actions have been taken as a result of these referrals. In the [2006 Report](#) (OSG: DHS, 2007) and the [2008 Report](#) (OSG: DHS, 2009), there were a total of 12 infringements. These two reports made clear that in all cases the Board: "...found no violations of "good faith compliance" with the Act and did not sanction any physicians for "unprofessional conduct" regarding the Act" (e.g. OSG: DHS, 2007, p 9). The [1999 Report](#) (Sullivan et al, 2000, p 12) did note a concern that there may be under-reporting because physicians were concerned about being referred to the Medical Board but this does not appear to have been investigated in subsequent Annual Reports. Therefore, unlike in the Netherlands where such data on reporting rates is available, it is not possible to consider trends or possible reasons for this.

## Discussion

### *The 'slippery slope' argument*

As with the Netherlands, a key concern of opponents is that the DWDA will, over time, lead to an increase in numbers of people taking advantage of the legislation, and that the legislation will gradually be diluted to allow more categories of people to take advantage of it. At present the data still shows very small numbers of people choosing PAS under the DWDA, and there has been no amendment of the legislation. This, suggests proponents, provides evidence that there are no such trends in Oregon. Opponents may point to the gradual increase in prescribing physicians, lethal prescriptions and the fact there has been more than a three-fold increase in the number of patients ingesting the lethal medication.

### *Reasons given for choosing PAS*

A concern that arose a number of times in submissions to the Committee was the extent to which people gave as a reason for choosing PAS, that they considered themselves a burden to family, friends and carers. As noted in the section above this was stated by 26.6% of all those who died in this manner during the DWDA's operation. Proponents will argue that, as shown in Table 6, above, the vast majority who gave other reasons for choosing PAS, principally that they wish to regain autonomy over their own life and decisions. Though for opponents the concern is that this could include people who may be facing coercion, either directly or indirectly, to end their life.

### *The length of time between the first request and death*

This is another concern of opponents to PAS. As noted in Table 7, above, whilst the median length of time between the first patient request for PAS and death is 43 days, there are cases where patients are choosing not to administer the lethal medication until a much longer period has passed. For proponents this can suggest that some people are reassured by the knowledge that they can end their life at a time of their choosing. However, for critics it may also suggest that there are patients with terminal illnesses who are living beyond the six month stipulation of the DWDA. This may raise concerns about the original diagnosis but is more likely to illustrate that predicting the length of a terminal illness is very difficult.

### *Issues connected with physicians*

As shown in the section above the number of physicians who have chosen to be involved in the PAS of terminally ill patients is small. For proponents this is another sign that the 'slippery slope' phenomenon has not been seen in Oregon. However, for opponents it raises the prospect that patients may be 'doctor shopping', evidenced by the short median length of relationship between the patient and the assisting physician, as shown in Table 7, above. Proponents may also consider the range and that there are obviously patients who have known the physician for a long period.

Another issue relates to the regulation of physicians under the DWDA. As noted above, whilst infringements of the law are reported to the Oregon Board of Medicine it is not clear from the Oregon Annual Reports what the outcome of approximately half of these referrals have been. Given that it is known that the other half faced no sanction, opponents may argue that this suggests a fairly lax system.

### *Palliative care*

As with the Netherlands, there is some discussion suggesting that better palliative care is helping to keep the numbers of PAS cases low in Oregon. Considering the situation in the Netherlands and the United States as a whole Hendin and Foley (2008, p 1635) found:

“Efforts at educating physicians appear to be making a difference in both the

United States and the Netherlands. The more physicians know about palliative care, the less they favour assisted suicide; the less they know, the more they favour it.”

However, as with the Netherlands experience this is interpreted differently. Proponents argue that this demonstrates that PAS is only intended for and chosen by a small number as a last resort. Opponents use the data to question the need to allow PAS in the first place.

A concern for some critics of this legislation (reiterated in submissions to the Committee concerning the Bill), particularly among those involved in palliative care, is that hospices may become used for PAS. Table 6 shows that whilst, ultimately, the vast majority choose to die in a home environment and not in a hospice, some do and for some critics this is inappropriate because they do not believe that PAS should be linked in any way to palliative care. As is discussed, below, in relation to the Bill, this relates to a concern that legalising PAS or other forms of euthanasia view will erode trust in health professionals and services.

### *Limited data*

The level of reporting and monitoring is also an issue in Oregon. Hendin and Foley (2008) have found that Oregon Health Division officials have no way of knowing the exact number of PAS cases due to a reluctance by some doctors to report. They also note there is no enforcement mechanism for dealing with doctors who do not comply with guidelines. These authors argue that the law would have to be amended in order to grant full immunity to physicians as in the Netherlands to get a fuller picture of the situation.

Despite the annual reports, there are no anonymous prevalence surveys like those undertaken in the Netherlands, and it is difficult to obtain the real rate of PAS in Oregon, or any data on those patients dying as a result of other end-of-life processes such as the withholding of treatment or intervening in such a way that a hastened death will be a known side-effect of the treatment. Hendin and Foley (2008) also point to other problems, including the assertion in the Annual Reports, without substantiating data, that patients who request PAS receive adequate end-of-life care. They argue that this does not appear to match with surveys and interviews with family members, nurses and physicians. However, Dignity in Dying (2010b) point to research<sup>8</sup> which indicates that the relatively low use of the DWDA is a result of a high quality of care provided by hospices in Oregon. This example may illustrate a wider debating point on the level of data and analysis that should be provided through official reports.

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<sup>8</sup> Ganzini L et al (2002) Experiences of Oregon nurses and social workers who requested assistance with suicide *New England Journal of Medicine* 347(8): 582-8



## **PART 3: THE END OF LIFE ASSISTANCE (SCOTLAND) BILL**

The aim of the Bill is to “enable persons whose life has become intolerable and who meet the conditions prescribed in the Bill to legally access assistance to end their life (Policy memorandum, 2010). Whilst there is an acceptance that good quality palliative care can ensure a dignified and peaceful death for most people, it maintains that this is not so for a small number of people, thus recognising their autonomy and rights to seek assistance to die. The Policy Memorandum (para 45) states:

“The Bill is positioned at the interface of privacy, individual morality and belief and public policy. It addresses a sensitive issue, and seeks to establish the legal perimeters inside which a person will not be committing an offence in giving end of life assistance to a person who has requested such assistance.”

The Bill defines what end of life assistance would be and goes on to provide for a range of eligibility residency, age and medical condition criteria for requesting persons. It then provides for a range of further safeguards to ensure:

- the person is making the decision themselves and without coercion
- medical scrutiny of the requests
- time constraints so that the process is not lengthy given the suffering being endured by the requesting person on the one hand, and giving sufficient time for due consideration to the enormity of the decision
- constraints upon the nature of end of life assistance

This part of the briefing considers the proposals in the Bill in greater detail. As well as using information from the Bill and its accompanying documents, submissions to the Committee will also be utilised, and in particular the key findings from the summary of written evidence carried out for the Committee (Payne, 2010). As discussed above, the Bill prompted a very large number of submissions with 88% being against the proposals. In discussing the Bill the aim is to alert Members to the key issues that were raised by those responding to the Bill from both sides of the debate. It is therefore a more qualitative discussion rather than a quantitative one.

### **PHILOSOPHICAL DEBATE**

Before considering the Bill itself, it should first be recognised that many of those who submitted to the Committee’s call for evidence did so from a strong philosophical position. There were two key strands to the discussion on this basis– “dignity” and “personal autonomy”. It should be noted that often one of these terms would be used as an example of the other and it was not always clear what respondents meant when they were referring to them. They also meant different things to different people.

#### **Dignity**

A key point made by several respondents was that “dignity” was a difficult concept to define, and its use in the Bill itself (see section 1(2)) was questioned, leading to calls for greater clarification in the Bill as to its meaning.

For many of those supporting the Bill, there was not an explicit discussion of “dignity”, though in considering their arguments it is clear they were raising arguments similar to those contained in the Bill’s Policy Memorandum (para 56-66), where it is argued that the current legal process is inhumane because it forces people to have to leave the country and go elsewhere to obtain assistance to end their life, perhaps resulting in an earlier death than would otherwise be the case. In addition, a person having the ability to end their life in this country would be able to die in more comfortable circumstances with support of family and friends. It is also argued that it would lessen the suffering of those who are facing a prolonged and intolerable end of life experience. In some submissions discussing personal experiences it appeared that a link was



being made between the suffering of those whose pain could not be adequately dealt with through medical care and a lack of dignity in the way they died. To allow this to continue even when a person was making their wishes clear was considered inhumane.

Opponents to the Bill tended to reflect on what they considered to be an apparent acceptance in the Bill that the only dignified way of dealing with suffering was through ending life. The Scottish Council on Human Bioethics (2010) summed up many of the arguments in this regard stating:

“It is incorrect and disturbing to suggest that any person can ever lose his or her human dignity. Though human dignity is not a scientific concept, it is something that everyone should always accept is found in every person to an equal extent. Legalising euthanasia would mean that society would accept that some individuals can actually lose their inherent human dignity and have lives which no longer have any worth, meaning or value. It would give the message that human dignity is only based on subjective choices and decisions and whether a life meets certain quality standards.”

This was a theme that ran through many submissions from private individuals, stemming from a belief that everyone regardless of support needs could play a valuable role in society. It was also a key theme in the vast majority of religious submissions, where there were reflections on human dignity flowing from the belief that all life was God given, that it was fundamentally wrong to kill another person, and that true respect and compassion was to care for those who were suffering.

## **Personal autonomy**

As regards autonomy, the basic argument used by those supportive of the principle espoused by the Bill is that everyone should be able to make decisions over their own lives. Some questioned why death was not treated like other momentous occasions in a person's life. There was a concern amongst a small number of respondents that religious and other cultural traditions were unfairly discriminating against those who wished to make this choice. In some cases it was felt this led to people seeking desperate ways to end their lives. For others the issue was one of control. Macfie (2010, p 1) argued that there were those with a terminal illness who “hate the very idea of having to endure the ordeal of their inevitable decline, their dependence on others and their loss of control over their own circumstances.” As discussed above, one of the findings of the Oregon experience was that the loss of autonomy was the key factor in the vast majority of people choosing to end their life through PAS.

However, there was some reflection on limits to this autonomy even amongst those who supported the Bill. EXIT (2010, p 4) noted that “rational thinkers on all sides eventually tend to agree that we should allow a person, if not interfering with the liberty of others, to be free to pursue her or his own good in her or his own way”. Brassington (2010, p 1) considered those that were physically incapable of carrying through their wishes, arguing that this placed them in a position of: “...’double jeopardy’, whereby the exercise of those rights is hampered by their condition when that condition is plausibly a contributing factor to their wanting to end their own lives to begin with.” He argued such people should be able to call on assistance to end their lives but argued there should be no moral or legal compulsion on anyone to do it.

However, it is the effect on others which was fundamental to the reflections on autonomy by those opposed to the Bill, and is summed up in the joint submission by the Church of Scotland, the Methodist Church in Scotland and the Salvation Army (2010, p 2):

“One of the specific concerns about this Bill is that sometimes an individual may want to make a choice that is so damaging to the society in which we live that making that choice is wrong. Appeals to autonomy, while superficially seductive, fail to take into account the interconnectedness of communities, and the fact that the concept of a person being a burden to society is inimical to autonomy, as somebody who is truly autonomous by definition cannot be a burden.”

There was a broad concern amongst those opposed to the Bill that a choice of such magnitude would have an effect on those around the requesting person, including family, friends, health professionals and others who may care for them. Other points raised in this regard included that the Bill was discriminatory as it only granted such autonomy to certain groups of terminally ill or the disabled, and that whilst personal autonomy is important, this must be balanced against the need to protect the vulnerable.

## PROVISIONS WITHIN THE BILL

### Section 1: Lawful to provide assistance under the Act

Section 1(1) provides that it would not be a criminal offence or a delict<sup>9</sup> for a person to provide: a) end of life assistance under the Bill, or b) provide assistance or participate in the process provided for in the Bill thereby enabling another person to provide or obtain end of life assistance. As regards the latter, the Explanatory Notes (para 9) states that this provision aims to cover any participation in any step required by the Bill, eg where a person participates in the process as a witness, designated practitioner or psychiatrist. Section 1(2) defines “end of life assistance” as:

“...assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress.”

The Explanatory Notes (para 8) note that such assistance may include the provision or administration of appropriate means of ending life.

There was significant discussion in submissions to the Committee about the implications of this section.

#### *The breadth of the Bill*

A number of respondents considered that the wording of section 1(1) could be interpreted as proposing the introduction not only of PAS but also voluntary euthanasia (eg Lord Mackay of Clashfern (2010)). However, if one utilises the definitions outlined at the start of this briefing then it could be argued that the Bill would introduce PAS, assisted suicide and active voluntary euthanasia. This would explain why some respondents concluded the Bill went beyond both the systems in the Netherlands and Oregon. Laurie and Mason (2010, p 1) felt that what was being proposed was “largely uncharted territory for any jurisdiction... and has to be treated with exceptional care”.

For many of those that supported the Bill there appeared to be a general acceptance of what was being proposed, though for some there were concerns at the breadth of the Bill, for example Dignity in Dying (2010a) who preferred the model adopted in Oregon. Indeed there were a couple of supportive submissions that felt the Bill may have garnered more support if it has been drafted along the lines of a PAS system. However, it should also be noted that there were some who believed the Bill may be too restrictive.

#### *Use of the phrase “end of life assistance”*

Section 1(2) also raised some debate among respondents who were critical of the Bill. Several respondents from a palliative care background felt that the definition used described what palliative care sought to do. As a result there was a concern this could cause confusion amongst patients and the public, namely that the Bill concerned palliative care when it was proposing various forms of euthanasia. This, together, with the points raised on the breadth of the Bill above, led to calls for the phrase to be changed or better defined.

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<sup>9</sup> An act or omission by one party usually resulting in loss or injury to another party and which give rises to a legal remedy (most commonly financial compensation).

## Section 2: Need for two formal requests

Section 2(1) stipulates that end of life assistance could only be provided under the Bill if the person wishing the assistance made two formal requests for the assistance to a registered medical practitioner, both of which would have to be approved by that medical practitioner. This is one of the key protections in the Bill to ensure the individual is certain in making the request. There is further discussion of these, below, when considering the further provisions proposed in the Bill for the two requests.

Section 12 defines a “registered medical practitioner” as a person registered in the register of medical practitioners referred to in section 2 of the Medical Act (1983 ) (c 54). Section 2(2) proposes that this medical practitioner be known as the “designated practitioner”, and also stipulates that they be the practitioner who receives the first formal request by the requesting person. In essence this means that this one practitioner must see the requesting individual through the consent and approval process.

### *The proposed role for doctors*

There was little discussion of this section per se in the submissions to the Committee. However, as the designated practitioner has a pivotal role in the Bill, it is appropriate to discuss views on this proposed role.

The majority of medical professionals that submitted to the Committee were opposed to doctors having such a role. There was some concern that there had not been sufficient consultation with the profession as to whether or not they were the right profession to undertake this role. For some the role proposed by the Bill was not explicit enough and there was a need to consider this further before such discussions could take place (e.g. Royal College of General Practitioners (2010)). It should be noted that the Member in charge of the Bill sent the original consultation on the proposed Bill to a range of representative bodies of the medical profession, including the Royal College of General Practitioners and BMA Scotland. However, for many practising doctors and those in training who responded, the role proposed was contrary to the reasons they went into medicine and to the role of the doctor as understood exemplified by the Hippocratic Oath. For some individual doctors it was wrong to ask another person to assist someone else to die. However, the key concern of those who were opposed - across respondent groups - was the belief that the Bill would fundamentally alter the existing patient/doctor relationship of trust. Not just in terms that patients may not perceive doctors as always acting in their best interests, but also because vulnerable patients may be reluctant to disclose their fears and concerns to doctors and other healthcare professionals.

As regards those who supported the Bill or the principle behind it, most supported the role proposed for medical practitioners, though this was clarified in some cases. EXIT (2010, p 1), reflecting on the needs of the requesting person, felt that it must be clear that the registered medical practitioner is willing to consider such a request without any pre-judgement, fully willing to explore all options. Several felt there should be further provision in the Bill for medical practitioners unwilling to undertake the role. This is discussed in the ‘Further considerations’, below. In addition, when considering this role for medical practitioners, some proponents (e.g. Dignity in Dying, 2010) discussed research that showed there were small numbers of deaths attended by a medical practitioner in the UK that were as a result of voluntary euthanasia, and non-voluntary euthanasia. Given there is no legalised process in the UK, for such respondents this demonstrated that assistance in dying was currently being practiced without safeguards, unlike in other jurisdictions such as the Netherlands.

In common with the debate concerning the Netherlands, above, there was also some concern about the power that the Bill was giving to doctors. McLean (2010) felt giving the designated practitioner the sole role of approving the requests could give excessive power to doctors, and may allow them to impose their own view in deciding whether or not to allow the patient’s request. She suggested this could be overcome by including an obligation to refer for a second

opinion. The Policy Memorandum (para 85) states that the involvement of psychiatrists in the process (see below) would have the “additional benefit of imposing another check on the work of registered medical practitioners”. Other respondents from both sides of the debate questioned the reason behind nominating a medical practitioner to undertake the process, as ultimately medical considerations were only part of it. Other suggestions were made, such as lawyers, social workers, panels of carefully selected and trained lay people.

There was also some debate surrounding the provision that the same designated practitioner see the whole consent and verification process through from beginning to end. Whilst welcomed by some, others felt this was quite onerous and could place pressure on resources, particularly given the time it would take to meet the various criteria and time constraints that are involved in the process. There were suggestions that the designated practitioner should be able to co-opt another medical practitioner into the process as long as this had the agreement of the requesting person.

This led some respondents to argue for the Bill to stipulate that the designated practitioner be someone with whom the requester had been registered with or treated by. Otherwise the doctor would not have the familiarity with the person’s medical condition, their psychological state and family background. However, on the other hand the objectivity of the designated practitioner was a crucial point for some who supported the Bill. EXIT (2010) felt it would be the only way a patient would feel assured that the request would be considered without prejudice, and be open to the eventual wishes of the patient. Others wanted the Bill to stipulate that doctors who provided normal care for a patient should not be permitted to be actively involved in the process, even if they wished to.

Other comments relevant to this section of the Bill included a belief that a doctor should have a level of experience before being able to be the designated practitioner under the Bill (eg Laurie and Mason (2010), and that the term “registered medical practitioner” be revised to take account of the new licensing procedure that had been brought in by the General Medical Council (eg General Medical Council, 2010).

### *Role of other health professionals*

The only other specific reference to a health professional in the Bill, other than doctors, is to a psychiatrist, and this was commented on by a number of respondents. Several noted that the Bill failed to recognise the involvement of other professionals such as nurses, pharmacists, social workers and carers. This was either because feasibly they could be called upon to provide the final assistance or because they may find themselves being involved in terms of patients approaching them for advice (eg Association for Children's Palliative Care, 2010 and Community Pharmacy Scotland, 2010). The Independent Association of Nurses in Palliative Care (2010) noted that in other countries where euthanasia is available there is a significant role for nurses as they are in more contact with dying people than any other professional group. It called for further clarification about who can and cannot be part of this process.

### **Section 3: Revocability of request for assistance**

Section 3(1) proposes that the process of end of life assistance must cease if the requesting person gives notice, however informal, to the designated person that they no longer wish it to continue. Section 3(2) makes clear that such revocability would not prevent a person making a subsequent request under the Bill. However, it is likely that the person would have to start the whole process from the beginning.

### *Discussion*

There was very little comment on this particular section in submissions to the Committee, though the overall provision was welcomed by those that discussed it. However, as will be outlined below, issues were raised over whether it is necessary for a person to have to start

from the very beginning should they decide to stop the process for any reason.

#### **Section 4: Eligibility requirements – age and connection with Scotland**

Section 4 was a pivotal provision for many respondents to the Committee. Therefore this section will consider the criteria relating to age and connection to Scotland, and the following section will consider the criteria relating to medical conditions.

Section 4(1) stipulates that a person may only make a formal request for end of life assistance under the Bill if they:

- a) are 16 years of age or over at the time of making the first formal request
- b) have been registered with a medical practice in Scotland for a continuous period of at least 18 months immediately prior to making the first request
- c) satisfy the requirements on medical condition (see next section of the briefing)

Section 4(3) states that it is not necessary for the requesting person to have been registered with the same practice throughout the period.

Both these provisions received much comment.

#### *Age*

The majority making detailed comment were opposed to the proposal that someone aged 16 or over should be able to seek assistance to end their own lives. Discussion tended to concentrate in particular on the 16 to 18 age group. The key arguments against the inclusion of this age group were:

- the age of 16 is too young to make such a decision
- young people are not emotionally mature enough nor have enough life experience to make the decision
- young people may be at risk of undue pressure being placed upon them
- the law does not allow people to drive until they are 17, or smoke, drink alcohol and vote until they are 18, so they should not be allowed to take such a decision

Some could understand why age 16 was chosen, given it is the age of majority in Scotland, but felt the decision was such that it would be prudent and responsible to err on the side of caution (eg Care not Killing, 2010). In addition, the Royal College of Psychiatrists (2010) noted that the Mental Health (Care and Treatment) (Scotland) Act 2003 (asp 13) requires NHS Boards to provide “age-appropriate” mental health services for those under 18. It contends that if the Bill was passed, psychiatrists undertaking assessments in 16- and 17-year olds would need to be specifically trained in adolescent mental health. It therefore considered that the age of eligibility should be 18.

Fewer people agreed with the provisions in the Bill, with arguments tending to centre on 16 being the age of majority, and that if, for example, a person was considered old enough to marry and have the responsibility of caring for a child, they must also be old enough to take decisions relating to their quality of life, including ending their life. There were respondents, though very few in number, who argued that provision should be made for those aged 12 to 16 if supported by a parent and guardian as in the Netherlands, and would be similar to the law on organ donation. However, there were also those supporting the Bill who believed that for the younger end of the eligibility scale there should be a special system for those aged 16 to 21 (e.g. EXIT, 2010).

This variety of opinions on the proposed age provision mirrors the result of the consultation on the original proposal (MacDonald, 2008) for the Bill. The [consultation summary](#) (MacDonald, 2009, p 8) notes that the consultation did not state a preferred age, though it did draw the attention of respondents to the definition of an adult within the Adults with Incapacity (Scotland)

Act (asp 4), which defines an adult as someone who has reached the age of 16. Of that responded to the issue of age in the original consultation the consultation summary states that “overall, the greatest number of respondents appear to have a preference for the minimum age to be set at 16”. Therefore, the age of 16 was proposed in the Bill.

### *Connection to Scotland*

A number of respondents were content with the provisions and felt they would be sufficient to prevent “suicide tourism” (eg Dignity in Dying, 2010), although there were a few calls for the provision to be 12 months and not 18 months. There were a number of respondents who were concerned that the provision could discriminate against those who moved to Scotland for perfectly legitimate reasons, for example those who are terminally ill or severely disabled who move to be closer to relatives (Royal College of Physicians of Edinburgh, 2010).

The majority of those who discussed this issue did not believe the provision was sufficient. A number of reasons were presented, including:

- that the type of practice is not defined in the Bill, meaning there is no requirement to be registered with a NHS practice. This could lead to the establishment of private practices for the purpose of assisted dying (eg Dying Well, 2010)
- there may be an avenue to obtain registration through temporary residence (eg Care Not Killing Scotland, 2010)
- a concern that 18 months will not be long enough to prevent “suicide tourism” (eg Church of Scotland et al, 2010)

Whilst not addressing the issue of private practice, the Policy Memorandum (para 90-91) does not envisage many of the problems that have been identified. As regards registration it states that it is not necessary for the person to be registered with the same GP practice in Scotland, and indeed accepts that people may indeed wish to move to be closer to family and friends on the onset of their condition, albeit already being resident in the country. Given the way modern GP practices operate it noted that people are more likely to see the first available GP rather than the same GP repeatedly and also noted the likelihood of GPs retiring or moving to another practice. As regards “suicide tourism” the Policy Memorandum noted that a GP Practice can reject a request to be registered on the grounds that the person is not resident in the area. In addition it discusses that those people who emigrate from the UK, but return sometimes for visits are not entitled to free NHS treatment from a practice. The precise policy is outlined in a [leaflet](#) published online by Health Rights Information Scotland, which states that, an individual can get health care from the NHS when in Scotland if they spend at least nine months of the year in the UK, and have been in the UK for at least six months before making a claim.

## **Section 4: Eligibility requirements – medical conditions**

Section 4(2) of the Bill states that to be eligible, the person must fall into one of the following categories:

- a) the person has been diagnosed as terminally ill and finds life intolerable; or
- b) the person is permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable

Section 4(4) defines “terminally ill” as “if the person suffers from a progressive condition and if death within six months in consequence of that condition can reasonably be expected”.

The Explanatory Notes (paras 21 and 21) explain that “intolerability” under both conditions has not been further defined as the test should be a subjective one determined by the person themselves, though adds that the requester would be subject to a psychiatric assessment. They also explain that the second condition will “encompass persons who have been the subject of a trauma as well as persons with progressive and irreversible conditions, provided the dependency and intolerability criteria are met”. The Policy Memorandum (para 96) clarifies that



permanent physical incapacity “is not in itself enough to qualify for an assisted death, it is necessary that as a result of the incapacity they are unable to live independently and that they find life intolerable”.

The Policy Memorandum (para 83-84) notes that the original proposal in the consultation document on the Bill was that there be three eligibility grounds, with the third being “ person who are not terminally ill, suffering from a degenerative condition, or unexpectedly incapacitated but who find life to be intolerable”. However, due to the reaction against this, on the grounds that it was permissive and would place vulnerable people at risk, the Member in charge of the Bill removed it.

Nevertheless these provisions proved to be the most contentious within the submissions received by the Committee. Concerns were raised on all sides of the debate, and these will be discussed in the following subsections. However, it should be noted that a number of those who were classed as supportive of the Bill were in turn largely supportive of the medical categories as proposed. There were also a small number of respondents that believed the categories could be widened to take account of ‘living wills’ and ‘advance statements’, as in the Netherlands, for people with early stages of dementia.

### *The categories in general*

Amongst those supportive of the Bill or the principle there was support for the criteria as they stood (eg British Humanist Society, 2010 and Friends at the End, 2010). Others felt they should be extended further, including Brassington (2010), who, on the basis of the submission, would have been in favour of including the original third criteria (see above) which was not included in the Bill.

Some respondents considered that the scope of the conditions in the Bill was too broad, although aimed at a small number of people who were finding life intolerable would in fact cover often vulnerable people with a range of physical conditions. This concern was shared amongst some of those supporting the principle, for example Dignity in Dying (2010) considered that assistance should only be available to those with a terminal illness who had capacity.

Others were concerned with achieving clarity over the position of certain conditions. For example, Age Scotland (2010), wanted it clarified that dementia would not be an eligible condition.

For many respondents who were opposed to the Bill the proposed medical categories led to concerns about the numbers of people who would be eligible. Often, respondents would discuss the Netherlands in this context, with particular reference being made to the ‘slippery slope’ debate and their concern for the most vulnerable, such as older people. The Policy Memorandum (para 52) states that the Member in charge of the Bill was keen to ensure that such a trend did not take place, and is the reason for “providing a tightly defined and clear process and into incorporating detailed protections”. At several points in the Policy Memorandum, the Member states their view that only a small number of people will be likely to take advantage of the Bill.

### *The use of the term “intolerable”*

There was widespread dis-satisfaction from across respondent groups with the lack of definition of “intolerable” in both condition categories. For many respondents from both sides of the debate, the term was too subjective with questions raised as to how it would be judged and measured (eg Dr Iain Brassington, 2010 and Care Not Killing Scotland, 2010). Some noted how much any judgement would depend on many unspecified factors eg psychological, emotional, physical and social, and as a result each individual’s state of mind will fluctuate over time. Some respondents referred to the [findings](#)<sup>10</sup> of the House of Lords Select Committee on the

<sup>10</sup> House of Lords Assisted Dying for the Terminally Ill Bill Committee (2005)



Assisted Dying for the Terminally Ill Bill, which was introduced by Lord Joffe. Lord MacKay of Clashfern (2010) who chaired this Committee noted that Lord Joffe proposed the term “unbearable suffering” in his Bill but the Select Committee considered after hearing evidence that more objectivity was required and instead suggested “unrelievable” or “intractable” suffering as a more satisfactory criterion, as long as it was associated with a suitable test. This suggestion of having a suitable test indicates that someone else would determine how the person is feeling, whereas, as noted above, the Bill intends that this would be a matter for the requesting person themselves. Laurie and Mason (2010, p 3) suggested that the concept of ‘unbearable suffering’ should replace ‘intolerability’, “...on the grounds that something that is intolerable, cannot, by definition, be tolerated whereas ‘unbearable suffering’ more accurately reflects the subjective experience of the patient and his/her choice to end that suffering”. They also felt this took account of recent English case law. The summary of written evidence (Payne, 2010, p 12) outlines the other suggestions that were made in this regard.

### *Permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable*

The major concern voiced by many respondents was the breadth of this provision and the large number of people that could feasibly be covered. Examples were given by a number of respondents including progressive neurological disorders, heart disease, paralysis and diseases of the lung (eg Age Scotland, 2010 and Care Not Killing Scotland, 2010). The British Psychological Society in Scotland (2010, p 3) argued that the inclusion of the physically disabled, “...seems haphazard and there appears to be little thought about how those with a disability who are dying differ from those with a life-time of chronic physical disability”.

Other concerns that were raised in terms of the provision included that:

- it could be interpreted as allowing some people to end their life for social, rather than health, reasons and that would be entirely wrong (eg West Dunbartonshire Council, 2010)
- it is imprecisely worded to the extent that it result in multiple and widely varying interpretations. Insufficient clarity could leave both doctors and persons seeking voluntary euthanasia/assisted suicide in unsatisfactory positions (eg Scottish Partnership for Palliative Care, 2010)
- the concept of physical incapacity and the related lack of ability to live independently do not reflect the complex dependence-independence relationship which is a normal facet of growing up and maturing (eg Association for Children's Palliative Care, 2010)

As a result of such points, there were a number of calls for this provision to be revised or considered further.

### *Terminal illness*

The Policy Memorandum (para 95) states that the definition of terminal illness with a prognosis of death within 6 months “follows the general understanding of members of the medical profession“. However, it was a point of concern particularly amongst responses from medical the profession and palliative care groups. The key point made was that this is extremely difficult to predict particularly in non-cancer, non-malignant conditions (eg Scottish Partnership for Palliative Care, 2010 and Royal College of General Practitioners, 2010).

### *The issue of disability*

There was much discussion amongst those with disabilities about how these provisions could affect the perception of disabled people amongst wider society,

The Scottish Disability Equality Forum (SDEF) (2010) based its submission on the results of a survey of its members and found that just over half of those that responded were, in principle,

favourable of a relaxation of laws criminalising assisted suicide. However, even amongst this group few were not entirely satisfied with the Bill as introduced, and the proposal for the eligible medical conditions was a significant area of debate, particularly the second eligible condition. Some felt that this provision would “bring the rights of those who are physically incapacitated in line with those of able bodied people, in that they would be able to choose when to end their lives” (2010, p 1), which is very much in line with arguments posed in the Policy Memorandum (eg para 3). SDEF continued that “many felt that there should be as much choice as possible, as early as possible for those who had disabilities or degenerative conditions. They felt in many cases that legislation might extend rather than shorten lives.” (2010, p 2).

However, a key concern amongst SDEF members was the terminology within “incapacitated to such an extent as not to be able to live independently”. SDEF stated that this issue was raised as a result of the complex nature of the barriers to independent living:

“It is not always illness or incapacity that makes independent living impossible, but rather societal and physical barriers and a lack of care and support. Some of our members related this to a need for government and society to embrace and understand the social model of disability. They felt that to accept that a person’s life would not be worth living because of their disability or condition was not acceptable when many of the factors that make people’s lives intolerable and prevent them from living independently are in fact external and improvable.” (2010, p 2).

Similar concerns were made by other groups, such as Independent Living Scotland (2010). Inclusion Scotland (2010, p 2) state that the Bill could lead to a situation where most of those who would qualify for assistance would be people with disabilities, whilst the vast majority of those excluded from assistance would be people without disabilities, which suggested to it that...the lives and existence of one group are being treated as of less value than the other”. It also noted the reference in the Explanatory Notes (para 22) to the word “dependency”, used as part of the discussion of the second medical condition. It felt this condoned “the stereotype that disabled people’s lives are so valueless, tragic, burdensome and insufferable that they must want to die” (2010, p 2).

## **Section 5: Requirements relating to designated practitioners and psychiatrists**

The Bill imposes constraints upon who can act as a designated practitioner or psychiatrist with regard to the processes set out in the Bill. Firstly, neither can be a relative of the requesting person (this is defined in the Bill). Secondly, neither can personally benefit, or have a relation that will benefit, from the requesting person’s estate, though this would not apply to any reasonable fees for work done in relation to the application or its assessment.

### *Discussion*

There were not many comments concerning this specific section in the submissions to the Committee’s call for evidence. However, West Dunbartonshire Council (2010) felt there should be a provision requiring the medical practitioner and the psychiatrist to state formally that they have no such links to the patient.

There was some concern about the possibility through this section that a designated practitioner could charge reasonable fees for the application and its assessment. GPs are currently able to charge for various services not covered by the General Medical Services contract, such as travel vaccines and medical assessments for insurance purposes. However, there was particular concern that given there is no requirement in the Bill for the designated practitioner to be within the NHS, it could lead to the development of specialist private services (eg Scottish Partnership for Palliative Care). The Financial Memorandum (Explanatory Notes, para 108) states there is nothing in the Bill to prevent a requesting person going to a medical practitioner working in private practice, as “time and availability may be significant constraints on who can

be consulted". However, there is a belief this is more likely to affect consultations with a psychiatrist rather than a medical practitioner. The Financial Memorandum attempts to estimate the cost of four consultations (two for each request) with a psychiatrist from private psychiatrist. Using advertising costs of a range of psychiatrists operating in the UK, it states this is likely to be in the region of £675.

## **Section 6: Requirements relating to the first formal request**

Section 6(1) requires that the first formal request be in writing and signed by the requesting person as well as two witnesses. Section 6(2) stipulates that as well as witnessing the requesting person's signature the witnesses must also certify, that to the best of their knowledge and belief the requesting person:

- a) understood the nature of the request
- b) was making the request voluntarily
- c) was not acting under any undue influence in making the request

Section 6(4) adds that a witness could not knowingly be related to the requesting person, be a beneficiary of their estate or have another interest in the person's death and cannot be the designated practitioner. Section 6(3) provides that, for requesting persons living in care homes, an employee of that establishment would have to be one of the witnesses if practicable with the proviso that they knew the person well. The Policy Memorandum (para 102) that this person should be in a position to judge whether or not the requesting person was being influenced or coerced into seeking help to die. However, in order that the process should not be obstructed by a failure on the part of a care home to find a suitable witness in a reasonable period of time, then this requirement is removed though there would still be a need for two witnesses.

### *Discussion*

A number of respondents felt the stipulation about the first request being in writing could prevent eligible people requesting end of life assistance who have capacity, but do not have the physical ability to make a written request due to their condition. It was felt provision should be made for such people to make a request (eg Association of Chief Police Officers in Scotland, 2010 and McLean, 2010). In addition, SDEF (2010) raised the possibility of whether a 'rights worker' or 'key worker' could be allocated to any physically incapacitated person who had asked for assistance in ending their life, to guide them through the process.

As regards witnesses in general, the Royal College of Physicians of Edinburgh (2010) felt there needed to be clarity on how close and knowledgeable witnesses needed to be and on what basis they would be judged to have made a "reasonable" decision. There were also points raised on the exclusion criteria for witnesses. For some respondents the criteria were not stringent enough, and suggestions were made for additional groups to be excluded, such as close friends on the grounds that they may lack objectivity, or a staff member at the same medical practice as the designated practitioner. However, for others there was a concern that the criteria may be too strict, and were concerned that strangers who did not know the person well were far less likely to be able to determine whether a risk of internal or external undue influence existed. Some respondents queried why witnesses from care homes needed to have knowledge of the person when other witnesses did not. EXIT (2010) felt that at least one witness should know the person well and if that is not practicable there may need to be a review process put in place for such cases.

The provisions over care home witnesses also caused some comment. There were concerns that this could expose care home residents to (albeit a minority of) unscrupulous staff and that they could be pressured to request end of life assistance (eg Age Scotland, 2010 and Parkinson's UK, 2010).

## **Section 7: Consideration of the first formal request by the designated practitioner**

Section 7 of the Bill makes it clear that the designated practitioner would be unable to approve the first formal request unless certain requirements were met. Under section 7(1) they would need to meet with the requesting person and discuss with them:

- a) their medical condition that makes them eligible for assistance
- b) all feasible alternatives including palliative care and hospice care
- c) the consequences of approval together with the ability to revoke the request at any time, and
- d) the forms of the assistance that will be available

Secondly, under section 7(2) the designated practitioner would have to be satisfied that:

- a) the person met all other eligibility criteria
- b) the person was acting voluntarily and without undue influence
- c) they had received a psychiatrist's report concerning the person under section 9 of the Bill (this report must include a statement from the psychiatrist that they are satisfied that the person is acting voluntarily and without undue influence)

Finally, under section 7(4), should the designated practitioner approve the request, they must do so in writing, and sign and date the document.

### *Discussion*

A number of respondents questioned whether all doctors agreeing to participate (GP or hospital based) would have the necessary knowledge and experience to discuss end of life issues with patients, and confirm that eligibility criteria were met, particularly with regard to discussing all feasible alternatives (eg Royal College of Physicians of Edinburgh (2010)). There were also questions raised as to how the doctor could be sure that the person was not under undue pressure and how they were to assess that person was acting "voluntarily" (eg Catholic Bishops Conference of Scotland, 2010). Allied to this were concerns that inexperienced and young medical doctors could be asked to facilitate the process, which led to calls for clarification on what these competency levels should be.

Another key issue concerned the discussion of palliative care with the requesting person. For a number of respondents this was not sufficient, and there were calls for the person to first experience palliative care before making a request (eg Care Not Killing Scotland, 2010). In addition, largely as a result of concerns that the Bill did not mention the feasible role of other health and social care professionals, a number of respondents noted that assessments in palliative care took place on a multidisciplinary basis involving a whole range of professionals including, doctors, palliative care specialists, nurses, pharmacists, social workers, psychologists, psychiatrists and spiritual care providers. Calls were made for this process to be acknowledged, but in addition to consider the role some of these may inevitably play in the process should the Bill be passed (eg Scottish Partnership for Palliative Care, 2010).

As with other parts of the process there was some concern that there was a lack of scrutiny and reporting mechanisms to ensure all the procedures were being followed, and also a few calls for an appeals mechanism in the event that a request is turned down.

## **Section 9: Consideration of capacity etc by a Psychiatrist**

Given that section 7 makes reference to the psychiatric assessments it would seem appropriate to discuss section 9, which sets out the provisions in this regard, before analysing the requirements connected with the second formal request in section 8.

Section 9(1) proposes that psychiatric assessments would be required as part of the process for consideration of the first and second formal requests. This is different from Oregon, where such

an assessment is only required if requested by the attending physician. Section 9(1) also would require that a psychiatrist meet the requesting individual in person after the making of the requests, to discuss with them the following matters that are described in section 9(2):

- a) the person's medical condition that makes them eligible for assistance
- b) the availability of all other alternatives including palliative and hospice care
- c) the nature of the request and the revocability of the request; and,
- d) the person's feelings and reasons for making the request.

Under section 9(3) discussions must also cover what is required for the report to the designated practitioner, namely: that the person has capacity to make the request; is doing so voluntarily; and is not under undue influence. Section 9(4) stipulates that in assessing capacity, all reasonable efforts would need to be made to communicate with the person in an appropriate way before arriving at a decision eg the assistance of an independent interpreter who is familiar with the person's means of communication could be considered as well as any necessary equipment. A person would be deemed to have capacity if they are not suffering from any mental disorder, which might affect the decision to make such a request. A "mental disorder" is defined in section 328 of the Mental Health (Care and Treatment) (Scotland) Act 2003 (asp 13)<sup>11</sup>. In addition, the person must be capable of communicating, understanding and remembering such decisions. Finally, there are provisions stating the same psychiatrist "need not" undertake the assessments for both formal requests (s 9(6)), and that the report to the designated practitioner must be in writing, addressed to the designated practitioner, signed and dated by the psychiatrist (s 9(7)).

As noted in 'Eligibility requirements – medical conditions', above, the Member in charge of the Bill originally intended the two medical condition eligibility criteria to include a third where a person felt their life to be intolerable without being terminally ill, suffering from a degenerative condition or unexpectedly incapacitated. The Policy Memorandum (para 85) notes that, originally, only this criteria would have required the involvement of a psychiatrist. However, as respondents to the Member's consultation argued that this provided insufficient safeguard and risked doctors missing co-morbidity<sup>12</sup>, the Member decided to extend this to all requests.

Many of the matters that the psychiatrist must discuss with the requesting person are the same as those which relate to the designated practitioner, and as such many of the issues raised were similar. The following section covers only those points specifically raised about the psychiatric assessments.

### *Discussion*

As regards psychiatrists themselves, a number of respondents called for a definition of a "psychiatrist", eg in terms of whether they are appropriately licensed and registered (eg Laurie and Mason (2010)). There was also some discussion as to whether all psychiatrists would have the right skills and experience to deal with the all the matters stipulated in the Bill. This included particular concerns that whilst psychiatrists can competently diagnose, for example, major depression, the diagnosis and management of depressions in people who are seriously physically ill is more specialised (eg Scottish Partnership for Palliative Care, 2010). The British Psychological Society in Scotland (2010) stated that it was satisfied that psychiatrists, psychologists and other specialist professionals did have the skills to make the assessments outlined in the Bill with regards to capacity.

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<sup>11</sup> Section 328 defines "mental disorder" as any mental illness, personality disorder, or learning disability, however caused or manifested. However, it also expressly states that person cannot be considered as mentally disordered by reason only of any of the following – sexual orientation; sexual deviancy; transsexualism; transvestism; dependence on, or use of, alcohol or drugs; behaviour that causes, or is likely to cause, harassment, alarm or distress to any other person; or acting as no prudent person would act.

<sup>12</sup> A concomitant but unrelated pathologic or disease process; usually used in epidemiology to indicate the coexistence of two or more disease processes.

However, there were those who argued for a more multidisciplinary approach to the assessments. Lord MacKay of Clashfern (2010) in discussing the scrutiny of provisions in Lord Joffe's Bill, noted that the House of Lords Select Committee was concerned that there should be a thorough psychiatric evaluation, with other professionals, such as neuropsychologists or palliative care physicians, being involved as necessary. This was in line with a number of respondents who called for a multidisciplinary approach involving health and social services. As an example the process in evaluating capacity under the Adults with Incapacity (Scotland) Act 2000 (asp 4) was often referenced (eg West Dunbartonshire Council, 2010 and the Royal College of Physicians of Edinburgh, 2010).

There was also some comment as to whether the assessment process in the Bill would be sufficient. A number of respondents noted that while severe mental disorder or blatant coercion may be readily detectable, a potentially common combination of factors affecting a requesting person (mild depression, mild cognitive impairment and an internalised perception that they are a burden to relatives) may be more difficult to identify without a much more thorough process (eg Scottish Partnership for Palliative Care, 2010 and Royal College of Physicians of Edinburgh, 2010). As regards depression, in particular, there was a concern raised that the definition of mental disorder in the Bill may not cover depression and there were calls that there should be specific screening for this (eg Care Not Killing Scotland, 2010). Others were concerned that in using the definition of mental disorder under section 328 of the Mental Health (Care and Treatment) (Scotland) Act 2003, drug or alcohol dependency could not be included as a mental disorder. Given the particular needs of such individuals it was felt inappropriate not to take their dependence into account in relation to their capacity (eg Dying Well, 2010).

In terms of the test of capacity, there were those who felt it was an essential part of the legislation and would ensure the protection of the most vulnerable in society (eg University of West of Scotland: Faculty of Education, Health and Social Sciences). However, some problems were identified with the test, including EXIT (2010) which considered that capacity is ultimately a legal test, not a medical one. The Royal College of Psychiatrists (2010), which based its submissions on a survey of its members, described a concern of many respondents, namely that the Bill

“..assigned to psychiatrists the assessment of capacity in requesting persons *without* mental disorder. As the Adults with Incapacity Act 2000 and its associated Code of Practice make very clear, assessing capacity is intended to be a *generic* responsibility of clinicians in all areas. Where it is a matter of assessing capacity to consent to (or decline) specific medical or surgical treatments, then the responsibility for assessing capacity falls on the doctor primarily responsible for the treatment in question – in this case the doctor offering end –of-life assistance. The Act and its Code also make it clear that there is a general presumption of capacity: in other words all adults are presumed to have capacity for all decisions, until proven otherwise; and the burden of proof falls on those who would deny it. The Bill reverses these presumptions.... There was a general reluctance amongst respondents to accept these responsibilities, at least in these terms.” (p 4-5)

In addition, the lack of a requirement in the Bill for separate psychiatrists to carry out the assessments for the first and second formal requests was also criticised by some. It was felt that given the nature of the request different psychiatrists should be involved at each stage. Other issues raised included:

- the need for a resolution mechanism should there be separate psychiatric reports for the first and second formal request which disagree
- the lack of a requirement for the psychiatrist and the designated practitioner to agree on the course of action
- a concern that psychiatric and psychological resources are scarce and the affect this could have on the assessment process
- the report is not required to include the evidence on which the psychiatrist has based



their opinion

## **Section 8: Requirements relating to the second formal request**

Section 8(1) of the Bill stipulates that the second formal request for assistance may not be made unless: a first formal request has been approved by the designated practitioner; the requesting person has been informed of the approval of the first formal request; and a period of not less than 15 and not more than 30 clear days have elapsed since the requesting person was informed. The Policy Memorandum (para 105) states that this delay is designed to provide the person with a reasonable time to consider whether they wish to continue. The Explanatory Notes (para 81) state that failure to submit a second formal request within the 30 days period would have the effect of ending the process. Where this occurs the requesting person, should they still wish end of life assistance under the Bill, would be required to start the process afresh.

Section 8(2) states that the second formal request would have to be addressed to the designated practitioner, who must be the same practitioner who considered the first formal request, and it must be in writing, signed by the requesting person and by two witnesses. Exactly the same requirements as in the making and consideration of the first formal request apply in relation to the second formal request eg in relation to the form of the request, witnessing, the need for a psychiatrist's report and the consideration of that request by the designated practitioner (s 8(3)). However, the witnesses to the second request are not required to be the same as those to the first request (s 8(4)).

### *Discussion*

Again many of the issues raised in relation to the first formal request are pertinent to this section; they will not be reiterated.

The key issue here was the proposed 30 day timescale. Those opposed to the timescale felt that it was too short. A number of reasons for this were given, including:

- it would put extra pressure on vulnerable people and lead to them feeling unduly pressured
- there was an insufficient waiting period to allow for the effectiveness of any potential therapeutic interventions (including treatment for depression) to be assessed, for any improvements in care and symptoms or for the person coming to terms with an illness or condition

However, it should be noted that there were those supporting the Bill who were in agreement with the Policy Memorandum that that the person is making the request because they find their life intolerable and as such the process should not be unnecessarily prolonged. However, there were also those supportive of the Bill that wished the process to be shorter. This included the Humanist Society of Scotland (2010), which reflected on the timescale in this section together with the other timescales provided for in the Bill. Although accepting the need for necessary safeguards it felt that someone in severe pain who knew they were likely to die in the short term would have to wait the best part of 3 months, which it felt to be too long. It also thought it would be problematic for someone with a degenerative condition who may want to set up the process whilst still capable but not wanting to enact it within the total time period allowed for in the Bill.

Similarly as in the discussion concerning psychiatrists, a number of respondents wished to see consideration of the second formal request by a different designated practitioner or suggested that a second opinion should be sought. The Royal College of Physicians and Surgeons of Glasgow (2010) considered this to be essential, believing that doctors were neither qualified nor skilled in conducting the background searches which would be necessary to establish the eligibility of all participating personnel. SPUC Scotland (2010) felt that because, potentially, only one medical practitioner and one psychiatrist had to be involved in the two formal stages, it was likely that on the second occasion both designated practitioner and psychiatrist would be conditioned to more readily accept a request. Some respondents felt that the best way of dealing with such matters would be to have the final decision being made by a panel.

## **Section 10: Agreement on provision of assistance**

Section 10(1) of the Bill details the requirements that must be agreed between the requesting person and the designated practitioner, once the second formal request has been approved and before end of life assistance can be provided. These are:

- a) that end of life assistance is to be provided
- b) who is to provide the end of life assistance
- c) the place where that assistance to be provided
- d) the means by which that assistance is to be provided

Section 10(2) stipulates that the agreement must be in writing, signed by both the requesting person and the designated physician, and be dated. The Policy Memorandum (para 106) considers that “the recording of this information provides a further safeguard and clarity to the process”. Finally, section 8(3) stipulates that the agreement does not become effective until the expiry of at least two clear days from the date of its conclusion. The Policy Memorandum (para 111) states this is to allow the requesting period a final opportunity to consider whether not they wish to continue.

### *Discussion*

Submissions to the Committee concerning this particular section were quite varied, and included:

- there is no necessity for the designated practitioner and requester to meet and discuss the agreement
- consideration should be given to the agreement stating what action the designated practitioner (or others) are to take in the event of complications (eg failure to die, unexpected side effects)
- the provision places no obligation on the designated medical practitioner and requesting person to involve the person nominated to undertake the final act of assistance in any of the advance discussions leading to the decision of method/place/time nor to oversee any of the legislative requirements relating to designated practitioners or psychiatrists
- it is far from clear whether there is an expectation that normally the “designated practitioner” would be expected to take an active role in the act of assisted death in addition to being in attendance

There were also some comments concerning the two day “cooling off” period. A number of respondents felt it was too short a period either because of the gravity of the decision, or because it did not take into account any concerns that might be raised about the whole procedure or other late-onset factors. There were suggestions that it should be extended to a minimum of seven days or a working week after the conclusion of formal proceedings. However, some respondents who supported the Bill questioned the need for the cooling off period, querying the necessity of the provision given the other checks and balances.

## **Section 11: Requirements relating to the actual provision of assistance**

Section 11 is concerned with the requirements relating to the actual provision of assistance, and stipulates that:

- 1) The end of life assistance must, so far as reasonably practicable, be provided in accordance with the agreement between the requesting person and the designated practitioner.
- 2) The end of life assistance must be provided before the expiry of 28 clear days from the date when the requesting person was informed of the approval of the second formal request.
- 3) End of life assistance may be provided only if the designated practitioner is satisfied that

the requesting person is still acting voluntarily, is still not acting under any undue influence and still wishes to proceed.

- 4) Only a person who is not connected to the requesting person in any of the ways mentioned in section 5(1)(a) to (c) when read with section 5(2) may provide end of life assistance under this Act.
- 5) The place where the end of life assistance is to be provided must not be one to which the public has access at the time when the assistance is being provided.
- 6) Where end of life assistance is provided under this Act, the designated practitioner must be present at the end of the requesting person's life.

There were a number of comments made concerning separate parts of this provision, which are outlined below.

#### *The 28 day provision*

Of those that responded in detail on this provision, there was a general feeling that 28 days was too short. For others the issue was connected with the possibility that putting such a short timescale on the process may lead to the person feeling pressured to carry it through (eg Dignity in Dying, 2010). For others the issue was that should the timescales not be met, then the requesting person, should they still wish to, would have to start the process again. A range of suggestions were made to combat this problem, including leaving the commitment open-ended with a proviso that the request be simply reaffirmed within 12 months of the approval of the first request; and, a provision to allow a further 28 days if needed. McLean (2010) considered the case of Oregon where no such deadline exists. She argued there was evidence to suggest that some people are comforted by knowledge they can end their life at time of their choosing and may in fact live longer than if forced to take medicine within a specified time limit.

However, it is clear from the Policy Memorandum (para 17) that a key concern is that the person is making the request because they are finding their life intolerable and as such the process should not be unnecessarily prolonged.

#### *Who should undertake final assistance*

In general, there were calls for greater clarity on who this should be.

#### *The place of end of life assistance*

The Policy Memorandum (para 110) states that the place chosen "must be private and not one to which the public would have access at the time". A number of respondents felt this needed to be further clarified. One discussion point related to whether or not the final act should be allowed to take place in a NHS hospital, with arguments on both sides. Others were concerned that palliative care premises could be used. A number of respondents were concerned that hospices and hospitals could be the place of end of life assistance, with one point being made that it might make many vulnerable people reluctant to enter them. Another point raised was whether or not the places chosen would be regulated in any way.

#### *Presence of the designated practitioner*

A number of issues were raised concerning this provision. A number of respondents considered that in certain circumstances it may not be possible for a doctor to be present (e.g. Jeffrey, 2010). It is important to note that under section 3 of the Bill the requesting person can revoke the request at any stage up to the point of that assistance being given, but only the designated practitioner can receive notice of it (section 3). Therefore, the designated practitioner would have to be present. However Dignity in Dying (2010a) was concerned that this would force the designated practitioner to be involved when they may not wish to be, adding that it didn't allow the patient and family privacy at a sensitive time. The Independent Association of Nurses in

Palliative Care (2010) questioned the applicability of the provision if a requesting person self-administers the medication, and called for greater clarification as it considered the provision could give the impression that the designated practitioner would be administering the assistance to die). Clarity was also sought by the Royal College of Physicians of Edinburgh (2010) as it was unclear whether the designated practitioner was expected to supervise and intervene in the event of complications (eg unexpected side effects or failure to die).

The Association of Chief Police Officers in Scotland (2010) considered there to be ambiguity in the wording of this section over whether the designated practitioner is required to be present only at the point of death or throughout the process to the actual provision of assistance to end life. It believed that there should be clarity over the role of the designated practitioner to pronounce life extinct and certify the process complete.

### *Means of assisting death*

The Policy Memorandum (para 107-108) states that means of death “must be humane and minimise the distress to the person receiving end of life assistance”, adding that the means and method of delivery is not specified, as this “reflects an individual’s choice, acknowledges medical development and accepts expertise is best left to registered medical practitioners”. However, this was a significant issue for many respondents. The majority of those who discussed this issue looked for greater clarity on what the means would be. Others were quite specific in the issues they raised, including:

- it is not clear from the Bill how medicines required to end life will be sourced; concerns were raised about the Medicines Act 1968 and the Misuse of Drugs Act 1971 (as amended). Given these are matters reserved to the UK Parliament there is a need to examine where precedence lies and if supplies for this purpose are permitted (Community Pharmacy Scotland, 2010)
- there is a need to consider how the risk of complications and untoward events could be minimised during the actual provision of voluntary euthanasia / assisted suicide (Scottish Partnership for Palliative Care , 2010)
- whilst understanding why a definite method has not been stipulated, once this is coupled with the option of nominating a person who is not a regulated clinician to deliver the final act, there is concern that the Bill cannot adequately ensure that the clinical intervention chosen will be delivered by a suitably competent person (Royal College of Nursing Scotland, 2010)
- the Bill assumes that doctors would know what to do in providing the final assistance, which is not true. Neither does it stipulate who would provide appropriate education and training (St Columba's Hospice, 2010))
- a lack of clarification may be problematic in the event of an inquiry (Association of Chief Police Officers in Scotland, 2010)
- although not endorsing voluntary euthanasia believes that this must be defined to ensure all participants in the process know what to deliver and expect, and to ensure it is applied with uniformity and can be audited (Dignity in Dying, 2010)

## **FURTHER CONSIDERATIONS**

Respondents to the Committee’s call for evidence also raised a number of additional issues.

### **Additional safeguards**

In general terms those that were supportive of the Bill or its principle considered that safeguards were appropriate, and indeed, a number of these felt the approach was perhaps too cautious though they understood why. For those opposed to the Bill there was a widespread concern that the safeguards would not protect the most vulnerable from being exploited or pressured,

and that whatever safeguards there were, they would be easily circumvented by doctors or relatives that were determined to do so. In a significant number of cases there would never be adequate safeguards. As will have been noted from the discussion of other jurisdictions, this was a common theme amongst opponents of the Netherlands and Oregon regimes.

However, there were two key matters that arose from respondents in addition to these – a lack of overall monitoring and safeguards for doctors and other health professionals.

### *Overall monitoring*

The Explanatory Notes (para 104) discuss the likelihood that the Crown Office Procurator Fiscal Service would investigate any assisted death under the Bill. However, for many respondents this was not sufficient, and many from across respondent groups criticised the Bill for not proposing proper reporting, monitoring and oversight processes (eg Dignity in Dying, 2010 and Independent Association of Nurses in Palliative Care, 2010). It might also be argued that the lack of monitoring and reporting is one of the key differences between the Bill's proposals and the regimes in Oregon and the Netherlands.

The reliance on the Crown Office Procurator Fiscal Service to investigate was commented on by some. Dignity in Dying (2010a) was concerned that the process outlined in the Explanatory Notes was not specifically referenced in the Bill itself. The Royal College of Physicians and Surgeons of Glasgow (2010) considered that the requirement for the death to be reported to the Procurator Fiscal, together with the simple expectation that an inquiry would follow was insufficient. It felt that an inquiry should be mandatory if there was to be any meaningful scrutiny of the procedures. However, the Association of Chief Police Officers in Scotland (2010) noted that if the Bill was passed there would be an increase in the overall number of investigations carried out by the police as a result of additional enquiries into deaths where assistance had been provided. It noted this would be likely to be protracted and resource intensive. The Royal College of Psychiatrists (2010) considered that the Procurator Fiscal had insufficient powers of oversight where criminal offences had not been committed. As such this may be inadequate to prevent a psychiatrist working in this area unsupervised. Other points raised included:

- there is no provision concerning the requirements for completion of death certificates or cremation papers
- it would be much better for a patient's case to be scrutinised by a review panel prior to death
- as the Bill contains no external check or regulation of the medical opinions there would need to be a new independent safeguarding body and such a function would have cost implications for the Bill

### *Safeguards for doctors and other professionals*

In terms of submissions to the Committee, there was concern that whilst the Policy Memorandum (para 113) stated that no element of compulsion would be imposed on a registered medical practitioner to participate in any end of life assistance processes, this was not explicit in the Bill itself. As a result there were a large number of calls for a specific opt-out or conscience clause to be included in the Bill. Similar calls were made amongst other professions, particularly nursing and pharmacy. Lord MacKay of Clashfern (2010) noted that the House of Lords Select Committee had considered this matter as part of its scrutiny of Lord Joffe's Bill and recommended such a clause for doctors and any other health and social service staff.

Specifically for doctors, there was concern that even where they objected to undertaking any actions under the Bill, they would be expected to refer patients on to doctors who were prepared to accept the role. A number of respondents considered the Policy Memorandum (para 114-115), which discussed the General Medical Council (GMC) guidance on personal beliefs and

how this would link with any objection amongst doctors to undertaking processes in the Bill:

“The GMC guidance is clear, however, and there would be a duty on registered medical practitioners who object to participating to make arrangements to see a registered medical practitioner who would be prepared to consider a request for end of life assistance.”

In its submission on the Bill, the GMC Scotland (NP, 468) clarified this slightly:

“..our guidance does not impose a duty on doctors to do this unless the patient is unable to make those arrangements him or herself.”

The GMC also noted that the same paragraph stated: “The GMC guidance states that registered medical practitioners should not share their personal view with the patient and should make them aware of all options”. GMC Scotland further clarified this point:

“Doctors should, in fact, tell the patient (in advance where practical) if they don’t provide a particular procedure because of a conscientious objection. Doctors must, however, be careful to be respectful of the patient’s dignity and views, whatever their (the doctor’s) personal beliefs about the procedure in question.”

### **Implications for the regulation of the medical and other health professions**

Several doctors who submitted evidence considered whether or not the Bill raised any issues for the regulation of the profession. Under the Scotland Act 1999 (c 46), whilst the regulation of any newly created health profession following devolution was a matter for the Scottish Parliament, the UK Parliament retains the regulation of those professions that already existed, including doctors and nurses. The regulation of doctors is designated to the GMC through the Medical Act 1983 (c 54) (as amended), whilst the regulation of nurses is delegated to the Nursing and Midwifery Council, through the Nursing and Midwifery Order 2001 (as amended) (which itself was made under the Health Act 1999 (c 8). The query being raised is that if the Bill is passed with no similar provision in the rest of the UK, would the GMC as a reserved body be able to take account of the Scottish law in its Guidance? Or, could a situation arise whereby a doctor in Scotland would be legally entitled to offer end of life assistance to a person under the Bill, but then face being ‘struck off’ the medical register and losing their license because they have breached the GMC’s codes of practice? Similar questions could be asked of other professions such as nursing and pharmacy.

GMC Scotland (2010, p 1) stated in its submission that it requires doctors to observe the law and as such its guidance will always be consistent with the law. As a result it has not developed a policy or issued guidance on assisted suicide as to do so on an issue which is currently illegal would undermine both the guidance and its authority to provide it. It added:

“...if the law were to change to allow assisted dying and we had previously expressed the view that it was morally or ethically unacceptable, we would either be unable to discipline such a doctor, or we would have to set ourselves above the will of Parliament.”

In its submission to the Committee the Nursing and Midwifery Council (2010, p 1) stated:

“Any move towards legislation in this direction would have a significant impact on nurses and their practice and their adherence to our code of practise. As a healthcare regulator operating across the four UK countries, you will also appreciate that any legislation of this nature affecting Scotland would have considerable implications for the NMC in its setting of UK-wide standards.”



## Discussion of the Financial Memorandum

Concerns were raised that the Financial Memorandum (Explanatory Notes, para 82-11) does not quantify the majority of cost implications there may be as a result of the Bill being passed.

### *Estimating the demand for end of life assistance*

The Financial Memorandum begins with an attempt to estimate the demand in Scotland for end of life assistance as proposed in the Bill. It discusses the difficulties in doing this, not least that there is no indication of how many people may choose such assistance if it was to be available. Therefore, it considers the situation in Oregon where there is data on the number of deaths through PAS under the DWDA. It then takes the total number of PAS deaths between 1998 and 2008 and calculates what this is as a proportion of all deaths. It then uses the resulting figure to estimate what the number in Scotland may be using the 2007 GROS population statistics, arriving at an estimate of 55 deaths per year in Scotland.

It is possible to update these figures using the Oregon State Government's '[Death Data](#)' from 1998 to 2009 (though it should be noted that the data for 2007, 2008 and 2009 is still preliminary and subject to change). According to this data there were a total of 366,605 deaths between 1998 and 2009 in Oregon. As already discussed, the data on the number of those dying through PAS under the DWDA in that time period is 417. This means that across the time period 0.11% of all deaths in Oregon were due to PAS. However, as discussed above, there is not the same level of analysis of non-reporting in Oregon, as there is in the Netherlands. Therefore it is difficult to ascertain whether this is the true prevalence or not.

To make an estimate of what the equivalent figure may have been in Scotland, using the same proportion, population figures for the same time period in Scotland were taken from the '[2009 Births, Marriages and Deaths - Preliminary Annual Figures](#)' (the 2009 report) from the General Register Office for Scotland (GROS). Between 1998 and 2009 there were a total 638,770 deaths in Scotland, resulting in an average of 53,231 deaths per year over that time frame. Using the proportion calculated from the Oregon data, it could then be estimated that the adoption of a similar system to Oregon in Scotland may result in around 59 deaths per annum.

The Financial Memorandum (90-91) appears to accept that using such calculations may not produce the most robust of data, and notes that that there will be a range of economic, social and cultural factors that would ultimately influence any rate in Scotland if the Bill was to be passed. However, it maintains that given available data from abroad, it is likely the numbers in Scotland would be small.

Only a minority of submissions commented on the Financial Memorandum. Those that did, came mainly from those opposing the Bill, with the biggest criticism being the use of Oregon as the model for estimating a number of potential deaths arising from the Bill in Scotland if it was passed. This argument was founded on the belief that what the Bill was proposing was much wider in scope than the Oregon PAS system, and, as discussed above, could feasibly be interpreted as allowing PAS, assisted suicide and active voluntary euthanasia. Therefore, the Financial Memorandum completely underestimates how many people may die through the mechanisms proposed in the Bill. Instead, it is argued, the Financial Memorandum should have used the model of the Netherlands which is more akin to the system proposed in the Bill (eg Care Not Killing Scotland, 2010, Dying Well, 2010 and Independent Association of Nurses in Palliative Care, 2010). A number of figures were proposed. However, it is possible to undertake a similar exercise as that for Oregon, above, this time using the prevalence data from the Netherlands. Table 1, above, shows that the Netherlands Government sponsored research found that a total of 1.8% in 2005 of deaths in the Netherlands were a result of PAS or euthanasia. If this was extrapolated to the average annual figure for Scotland for the period 1998 to 2009 this would suggest there could be as many as 958 deaths in an average year. Using the GROS 2009 Report the estimated deaths for 2005 (based on 55,747 deaths) would be 1003, and for 2009 (based on 53,856 estimated deaths for that year) the figure would be

However, again, these are crude figures, and without far greater information it will remain extremely difficult to estimate demand for assistance under the Bill.

*Costs to the Scottish Government, Health Boards and other public bodies*

The Financial Memorandum shows no significant costs to the Scottish Government should the Bill be passed, other than in terms of any public information campaign, which it is envisaged could be met from existing budgets. It envisages no costs on local authorities.

The main bulk of the costs, it is envisaged, would fall within the NHS, most probably within GP Practices, as the Financial Memorandum considers it will be GPs who are most likely to be approached. However, it offers no estimate of what this may cost, and assumes that much of the work that would be required under the Bill would fall within what a GP would normally do. However, as noted above, there was some concern voiced by a number of respondents to the Committee's call for evidence that the demands of the Bill on the designated practitioner could be significant, particularly if they are one of a very few medical practitioners prepared to provide assistance under the Bill. This could place the burden on a small number of practices. There was also some comment that GPs are part of a wider health care team and there would undoubtedly be an impact on other professionals around them. This goes back to the argument, by some respondents, that the Bill does not recognise the role that other health professionals may have in end of life assistance under the Bill.

There was some concern noted about paragraph 97 of the Financial Memorandum which states that "the costs required to deliver an assisted death will be minimal and will inevitably be less than those associated with providing ongoing medication and care". This was interpreted by some who opposed the Bill as an indication of the true purposes behind the Bill - that the proposal is about cost saving and encouraging those perceived as a financial burden to consider ending their life. This charge is refuted by those who support the Bill or its principle. It is extremely difficult to quantify what any potential savings may be, given the discussion above, particularly when bearing in mind the quite disparate data from the Netherlands in Table 4 which considered by how many weeks it was estimated life had been shortened for those deaths involving euthanasia or PAS. It was estimated that just under half of such deaths were shortened by less than a week and around a half shortened by more than one week.

The Financial Memorandum recognises that there may be costs to NHS Education for Scotland given its role in the training of health staff. However, it contends these would be minimal. However, some from the medical profession argued that new training modules would be required in formal medical training, which would need to be clarified and costed. Similar arguments were made by other healthcare professionals.

Finally, the Financial Memorandum considers the possible cost to the Crown Office Procurator Fiscal Service (COPFS). It accepts that there will be an increase in workload for COPFS, but given the small number of expected deaths following assistance under the Bill expects this to be minimal in the context of the current workload of the Service.

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## APPENDIX 1: OVERVIEW OF THE SUBMISSIONS TO END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE CALL FOR EVIDENCE

Respondent Category	Total	Oppose	Support	No Position
Academic	13	5	3	5
Hospice	5	5	-	-
Humanist Organisation	2	-	2	-
Local authority	4	-	-	4
NDPB	4	-	-	4
NHS Board	1	-	-	1
Political	3	2	-	1
Private Individual *	343	317	25	1
Professional - Medical	117	110	5	2
Professional - Other Health	23	22	-	1
Professional - Social Care / Social Work	3	3	-	-
Regulatory Body	2	-	-	2
Religious - Body	12	11	-	1
Religious - Group	9	8	-	1
Religious - Individual	22	22	-	-
Representative Body - Health	16	8	-	8
Representative Body - Other	5	-	-	5
Voluntary Organisation	17	8	4	5
<b>Total Number (Percentage)</b>	<b>601</b>	<b>521 (86.69%)</b>	<b>39 (6.49%)</b>	<b>41 (6.82%)</b>

**NB:** \* - One response from a Private Individual was submitted as “Anonymous”. A further 35 have been published by the Committee as “Anonymous” to ensure that the Committee complies with the provisions of the Data Protection Act 1998 regarding issues such as the protection of the personal data of individuals and protecting the identity of third parties, where details about individuals are published without their consent.

‘Religious – Body’ – representation on behalf of a whole faith or religious denomination (eg the Muslim Council of Scotland and the Free Presbyterian Church of Scotland)

‘Religious – Group’ - a group that exists within a particular or faith or denomination (eg Kemnay Parish Church of Scotland) or from submissions from a cross group of churches or faith bodies (eg Scottish Interfaith Council and Scottish Churches' Disability Agenda Group)

‘Religious – Individual’ - someone who holds a position in a faith or denomination (eg an individual Minister)

## APPENDIX 2: SUMMARY OF POSITION IN VARIOUS JURISDICTIONS

Country	Summary of position
Australia	<p>For a brief period of time, euthanasia was legalized in Australia's Northern Territory, by the Rights of the Terminally Ill Act 1995. The main provisions were:</p> <ul style="list-style-type: none"> <li>• the patient had to be over 18 and be mentally and physically competent to request his or her own death</li> <li>• the request had to be supported by three doctors, including a specialist who confirmed that the patient was terminally ill and a psychiatrist who certified that the patient was not suffering from treatable depression</li> <li>• a nine-day <i>cooling-off period</i> before the death could proceed.</li> </ul> <p>It was nullified two years later, in 1997, by the Federal Parliament. However, before they did this, three people had already utilized the legislation.</p>
Belgium	<p>Belgium legalized euthanasia in 2002. Unlike the law in the Netherlands, the Belgian Act does not regulate physician assisted suicide but only euthanasia. Euthanasia is defined as an act of a third party that intentionally ends the life of another person at that person's request. The legislation establishes conditions that must be met by both the person seeking euthanasia and the physician who performs it. The physician is required to fill out a registration form each time he or she performs euthanasia; this form is then reviewed by a Commission whose role it is to determine whether the euthanasia was performed in accordance with conditions and procedures of the legislation. If two-thirds of the Commission are of the opinion that the conditions were not fulfilled, the case is referred to the public prosecutor.</p>
Switzerland	<p>Article 114 of the Swiss Penal Code prohibits active voluntary euthanasia (ending a person's life at his or her request), although it has a lesser sentence than other acts deemed homicide: murder carries a mandatory minimum sentence of 10 years' imprisonment, and manslaughter carries a mandatory minimum sentence of one year's imprisonment, while Article 114 provides only that an individual who kills a person for compassionate reasons on the basis of that person's serious request will be sentenced to a term of imprisonment (the duration is not specified).</p> <p>Assisted suicide is addressed in Article 115, which provides that someone who, for selfish reasons, incites someone to commit suicide or assists a suicide will be sentenced to imprisonment. Thus, assisted suicide is permitted if the person assisting the suicide does so for unselfish reasons. Article 115 does not require that a physician be the person to assist a suicide, nor does it require the involvement of any physician whatsoever, which is a significant departure from legislation in other countries where assisted suicide is permitted.</p> <p>There have been recent moves in Switzerland to further clarify the legal position in order to prevent "euthanasia tourism", an issue which has raised some concern in the country over recent years.</p>
Luxembourg	<p>Luxembourg is the most recent country to have passed a law legalizing euthanasia and assisted suicide. The law stipulates that doctors who carry out euthanasia and assisted suicide will not face penal sanctions of civil lawsuits as long as they meet the various criteria including:</p> <ul style="list-style-type: none"> <li>• the patient must be suffering from a terminal or incurable illness</li> <li>• the request must be made repeatedly</li> <li>• the consent of two doctors and a panel of experts is required</li> </ul> <p>The act was passed in February 2008 and came into force in 2008.</p>

Sources: Tiedemann and Valiquet (2008), British Medical Journal (2009), Britton (2010) and Lewis (2010)

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