

Dignity in Dying response to the call for written evidence on The End of Life Assistance (Scotland) Bill

1. Introduction

Dignity in Dying is the leading organisation campaigning for greater choice, control and access to high quality services at the end of life in the UK. We are a member-based organisation, representing 25,000 members and supporters.

Dignity in Dying believes that high-quality end-of-life care should be complemented by the option of an assisted death for terminally ill, mentally competent adults who meet strict safeguards and feel their suffering has become unbearable. The law needs to be changed to allow terminally ill people to choose the time and manner of their death, while at the same time protecting potentially vulnerable people.

2. Summary of response

The provisions in the Bill go beyond what Dignity in Dying believes to be a safeguarded assisted death. However, whilst Dignity in Dying does not agree with every aspect of the Bill, we welcome the intention to prevent needless suffering and to prevent people from taking desperate measures in order to have choice at the end of life. Dignity in Dying welcomes the debate that has been generated as a result of the consultation and formal Bill process, and we would welcome the opportunity to provide oral evidence at the next stage of the Committee process.

2.1 Key components of the Bill that Dignity in Dying *does not* support:

- i) The age level being set at 16 years plus.
- ii) That a person with a progressive condition or permanent physical incapacitation be able to request an assisted death. This is assisted suicide rather than assisted dying.
- iii) Having a time-limit of 28 days on the 'agreement' for an assisted death after the second request has been agreed.
- iv) That there is no definition of what the final act will be, other than it occurs in a private place and the medical practitioner who has been involved in the process is present. This appears to allow for voluntary euthanasia, assisted dying and assisted suicide.

2.2 Key components of the Bill Dignity in Dying *does* support:

- i) That persons must have proven mental capacity.
- ii) That the person making the request must be registered with a medical practitioner in Scotland for at least 18 months.

iii) That the process is patient-driven so the individual decides for themselves if/when life has become intolerable.

iv) That the voluntary request process is in two stages, with multi-professional involvement.

3. Terminology

The Bill uses the term 'end of life assistance' without stating specifically what it means. Our understanding is that, in the context of the Bill, it means both assisted dying (where a terminally ill patient is helped to die) and assisted suicide (where a patient with a progressive condition or permanent physical incapacitation is helped to die). The Bill also appears to allow for voluntary euthanasia (where the medical professional directly ends a patient's life). Dignity in Dying views assisted dying, assisted suicide and voluntary euthanasia to be distinct acts.

Dignity in Dying's understanding of 'assistance' is more focussed than the Bill proposes. For Dignity in Dying an assisted death is where a doctor prescribes a life-ending dose of medication to a mentally competent, terminally ill adult at their request and subject to legal safeguards. The patient then chooses to administer the medication themselves. The essence of the term 'assistance' lies in the fact that a third person only helps the person in question by enabling him or her to administer the life-ending medication themselves.

4. Jurisdictions where assisted dying is legal practice

Assisted dying practice differs in the jurisdictions where it is legal practice. In the US States of Oregon and Washington assisted dying is practiced, in Switzerland assisted dying and assisted suicide are practiced, in Belgium voluntary euthanasia is practiced and in both the Netherlands and Luxemburg assisted dying, assisted suicide and voluntary euthanasia are practiced. Whilst evidence suggests that the process in the Netherlands and Belgium works effectively^{1 2 3}, Dignity in Dying's model for assisted dying is more closely related to that of Oregon, where it became legal practice under the 1997 Oregon Death with Dignity Act (DWDA).

To qualify for assisted dying in Oregon individuals must be 18 years or over with mental capacity and be terminally ill with a prognosis of six months. Processes in Oregon are similar to that proposed by the Bill apart from at the end-stage. In Oregon the life-ending prescription is written by the physician, but this is the last stage they are involved in. In their place it is usual practice that a volunteer from

¹ Van der Heide A, Rurup M, Hanssen-de Wolf J *et al* (2007) End-of-life practices in the Netherlands under the Euthanasia Act *New England Journal of Medicine* 356(19): 1957-1965

² Regional euthanasia review committees: 2006/2007/2008 annual reports. Dutch Review Committee.

³ Smets T, Bilsen J, Cohen J *et al* (2010) Legal euthanasia in Belgium: Characteristics of all reported euthanasia cases *Medical Care* 42(2) 187-192

Compassion & Choices of Oregon (who provide emotional, social and spiritual support to terminally ill Oregonians) or a family member is with the patient when they take the life-ending prescription themselves.

Research evidence from Oregon demonstrates that the system works effectively and numbers of assisted deaths are under 0.2% of all deaths per year¹. This evidence relates only to *assisted dying for terminally ill patients* as assisted suicide is not legal practice². Evidence from Oregon and the Netherlands also demonstrates that potentially vulnerable groups (disabled, adults over 85 years, people with mental health issues, the poor etc) are not at increased risk from assisted dying legislation³.

5. Response to questions set out in the ‘Call for written evidence’

5.1 Do you agree a person should be able to request end-of-life assistance from a registered medical practitioner?

Yes, but with limitations on the person’s condition. An opt-out clause for medical practitioners who do not wish to assist those who make a request should also be inserted in the Bill.

Research by Clive Seale has found that 0.21% of deaths attended by a medical practitioner in the UK were as a result of voluntary euthanasia, and that 0.30% of life was ended without an explicit request from the patient (non-voluntary euthanasia)⁴. This demonstrates that assistance in dying is currently practiced in the UK, but without safeguards.

Furthermore, the Director of Public Prosecutions (DPP) published the *Policy for Prosecutors in Respect of Cases of Encouraging or Assisted Suicide* on 25th February 2010. The policy provides the first legal recognition that, in certain circumstances, a person who is wholly motivated by compassion should not be prosecuted for assisting someone to die. It is reasonable to suggest that the DPP’s policy demonstrates the need for a safeguarded assisted dying law across the UK.

The policy memorandum attached to the Bill states that “*The Bill imposes no element of compulsion on a registered medical practitioner to participate in the end of life assistance processes set out in the Bill*” (paragraphs 113-115) and that they have an obligation to refer patients to another doctor. Our preference would be for this to be made explicit in the Bill itself.

¹ 2009 Summary of Oregon’s Death with Dignity Act (2010)

² These figures have been misinterpreted in the Explanatory Notes (point 85) which accompany the Bill. Theoretically transporting these figures to the proposed system for Scotland, which includes broader eligibility criteria than Oregon, cannot be done.

³ Battin MP, van der Heide A, Ganzini L, van der Wal G and Onwuteaka-Philipsen BD (2007) Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ‘vulnerable’ groups *Journal of Medical Ethics* 33: 591-97

⁴ Seale C (2006) Characteristics of end-of-life decisions: survey of UK medical practitioners *Palliative Medicine* 20(7): 653-659

5.2 Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

Dignity in Dying does not agree with the age requirement but does agree with the connection with Scotland requirement.

Both the *Age of Legal Capacity (Scotland) Act 1991* and the *Adults with Incapacity (Scotland) Act 2000* define “adult” as someone who has reached the age of 16 years. However, Dignity in Dying campaigns for those who have reached the age of 18. The threshold of 18 years is in line with current policies on refusing, withholding and withdrawing treatment and with current guidelines on consent, (applicable in England and Wales).

Being registered with a medical practice in Scotland for a continuous period of at least 18 months prior to making a request ensures that ‘suicide tourism’ will not take place.

5.3 Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

Dignity in Dying believes that only terminally ill adults with mental capacity should be allowed an assisted death. Assisted dying relates to terminally ill people, whereas assisted suicide relates to people with a progressive condition or permanent physical incapacitation.

When someone is terminally ill and they have an assisted death they control the manner and timing of a death that would otherwise be unbearable to them. In effect they are substituting a bad death with a good death. If someone is disabled and not terminally ill, and wants to be assisted to die, they are having an assisted suicide because they deem the quality of their life to be poor. It is possible that measures could be taken to improve that quality of life. In effect they are substituting a life with a death.

The UK public recognizes the difference between assisted dying and assisted suicide. The 2007 BSAS survey¹ found that 80% agreed that a person with a terminal and painful illness from which they will die should be allowed an assisted death. Only 43% agreed that a person who is not in much danger of death, but becomes dependant on relatives for all their needs should be allowed an assisted death.

5.4 The Bill outlines a two-stage consent and verification process that would be required to be followed for an eligible person to receive end-of-life assistance. Are you satisfied with this process?

¹ Clery E, McLean S, Phillips M (2007) Quickening death: the euthanasia debate, in Parks A, Curtice J, Thomson K, Phillips M and Johnson M (eds.) *British Social Attitudes: the 23rd report – perspectives on a changing society* London, Sage: 35-54

Dignity in Dying does not agree with allowing people aged 16-17 years and those who are not terminally ill to have an assisted death. However, the two-staged consent and verification process will provide an effective safeguard to ensure that only those people with mental capacity, whose life has become intolerable and who voluntarily, and without undue influence, repeatedly request assistance, are able to go through with the process.

Dignity in Dying welcomes the proposed multi-professional, two-stage assessment procedure which incorporates checking that the request is voluntary and the person has capacity alongside compulsory psychiatric screening. However, we will be interested in submissions from experts in psychology and psychiatry which might shed light on whether the double psychiatric assessment is overly onerous and is appropriate in every case. Dignity in Dying supports the clear statement in the draft Bill that the patient can drop out of the process at any time.

Dignity in Dying also agrees that the medical practitioner who takes on the case should be with the patient throughout the *majority* of the process. This ensures continuity.

Dignity in Dying has three concerns with the consent and verification process: that the medical practitioner has to be present at the very end of life, that the method of ending life is not defined and that there is a 28 day expiry on the assistance agreement.

We are concerned by the provision that the medical practitioner *must be* present at the end of the person's life. This potentially forces practitioners to be involved in a stage they might not want to and doesn't allow the patient and family privacy at this sensitive time. We will be interested in submissions addressing this point from both patient and practitioner perspectives. Another point of concern is the lack of definition of the method by which life will be ended. The only guidance is that it must be in a private place and that regardless of who administers the means to bring about the end of life, the designated practitioner must be present. Restrictions should be made clearer. Dignity in Dying does not endorse voluntary euthanasia and we believe that this end-stage must be defined to ensure all participants in the process know what to deliver and expect, is applied with uniformity and can be audited.

Dignity in Dying believes that the proposed 28 days expiry of the 'agreement' to an assisted death could impact on the level of control the patient has over their end of life, pressure them into making hasty decisions and take away the element of 'emotional insurance'.

Evidence from Oregon demonstrates that patients who request an assisted death do not feel pressurised into going through with the final act. In Oregon, in 2009, 95 life-ending prescriptions were written, 53 took the medications (for which the

prescription has no expiry date), 30 died of the underlying disease and 12 were still alive at the end of the year¹. This means that 40% of patients potentially used the prescription as an 'emotional insurance'², with the final act being an option they wanted at their disposal rather than a commitment.

5.5 Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

The End of Life Assistance (Scotland) Bill moves beyond what Dignity in Dying believes to be a safeguarded assisted death. However, there are many aspects of the Bill which will provide a safeguarded system and we recognise that the responses to the consultation exercise³ to inform the Bill have been carefully considered.

Dignity in Dying supports assistance to end life forming one option at the end of life, with healthcare practitioners discussing and exhausting palliative care options with those who make a request. Legal assisted dying practice does not de-prioritise palliative care; rather it can be appropriately embedded within and complement palliative care, encourage wider discussions and investment, improve the training of professionals and improve process for the patient^{4 5 6}.

5.6 Do you have any other considerations on the Bill not included in answers to the above questions?

Whilst it is anticipated that deaths will be reported to the Procurator Fiscal, this is not clear in the wording of the Bill. There is also no reference in the Bill to a publically available annual report being produced. It might also have been helpful to list any voluntary organisations which will help patients and families during this end-of-life period (if such organisations are to be involved).

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12 May 2010

¹ 2009 Summary of Oregon's Death with Dignity Act (2010)

² Norwooda F, Kimsma G, Battin M (2009) Vulnerability and the 'slippery slope' at the end-of-life: a qualitative study of euthanasia, general practice and home death in The Netherlands *Family Practice* October 14: 1-9

³ Consultation on the draft proposal End of Life Choices (Scotland) Bill, December 2008 to March 2009

⁴ Lindsay R (2009) Oregon's experience: evaluating the record *The American Journal of Bioethics* 9(3): 19-27

⁵ Van Den Block, Deschepper R, Bilsen *et al* (2009) Euthanasia and other end-of-life decisions: a mortality follow-back study in Belgium *BMC Public Health* 9(79): 1-10

⁶ Ganzini L, Nelson H, Schmidt T, Kraemer D *et al* (2000) Physicians' experience with the Oregon Death with Dignity Act *New England Journal of Medicine* 342: 557-563