

**Equality and  
Human Rights**  
Commission

**Scotland**  
[equalityhumanrights.com](http://equalityhumanrights.com)

# Equal to the End?

A discussion paper on End of Life Choices and Issues



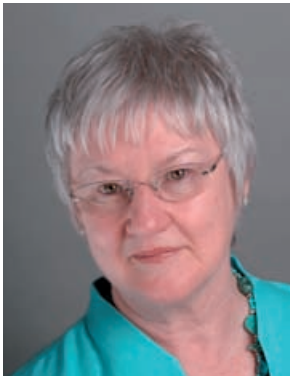
This report follows the **Equal to the End? Question Time** event held by the Equality and Human Rights Commission Scotland in March 2009.

The views expressed in this document are those of the authors, Cambium Advocacy, and reflect opinions expressed at a discussion event. They do not necessarily represent the policy or views of the Equality and Human Rights Commission.

# Contents

<b>Foreword</b>	<b>2</b>
<b>Summary</b>	<b>3</b>
<b>Introduction – Equal to the End?</b>	<b>4</b>
<b>The Current Context</b>	
Terminology	
The legal position	
Scottish Parliament/Government	
Public/Medical opinion	
<b>The Panel</b>	<b>7</b>
<b>The Debate</b>	<b>8</b>
<b>Views from the Panel</b>	
The Themes from the Debate	
Assisted Suicide – Rights and Risks	
Wider impacts: Doctors and Families	
Wider impacts: Disability Discrimination	
Pressure	
A slippery slope	
Palliative Care	
Safeguards	
<b>Conclusions</b>	<b>17</b>
<b>Table 1 - A Summary of concerns and responses</b>	
<b>Appendices</b>	<b>20</b>
<b>Oregon 11 year report</b>	

# Foreword



**“All human beings are born free, equal in dignity and human rights” states the Universal Declaration of Human Rights.**

The Equality and Human Rights Commission’s daily task is to create a Scotland where people are treated fairly with dignity and respect. I believe that dignity applies equally to how we die as well as how we live.

It was a privilege for the Equality and Human Rights Commission to host the ‘Equal to the End?’ event. Unsurprisingly, death and dying are not topics we talk about much in daily life, but they are important subjects and ultimately relevant to us all. The debate was intelligent and articulate, at times emotional and consistently thought provoking.

The Commission is proud to have brought people together for such a difficult yet timely discussion. Debate, discussion and the respectful sharing of opinions can help us shape the Scotland we want to live in.

There are currently two proposals for private members Bills’ considering end of life issues and choices before the Scottish Parliament. We hope that this Policy Discussion Paper presenting the main issues raised in the debate will assist not only MSPs but all interested people and parties in considering ways forward.

A handwritten signature in black ink that reads "Morag Alexander". The signature is written in a cursive, flowing style.

Morag Alexander  
Scotland Commissioner  
Equality and Human Rights Commission

# Summary

This 'Question Time' style event organised by the Equality and Human Rights Commission on 24 March was designed to debate the main issues surrounding voluntary euthanasia and Assisted Suicide (AS) and to facilitate the expression of people's views.

The main issues raised during the debate are presented in this report. For the sake of clarity they are presented thematically rather than how they chronologically developed on the night. At the end of each section is a list of 'issues requiring further consideration' and/or 'options' for possible policy responses to the points raised.

The debate centred on two interlinked questions.

Firstly, was there a 'right' to choose to end one's life? There were a variety of responses covering arguments on 'human', 'intrinsic' and 'negotiated' rights.

Opinions expressed included:

- there is already a human right to choose and this includes the right to choose death,
- there is currently no such right but there ought to be,
- no such right exists and any attempt to create one would undermine the 'right to life'.

Secondly, if there was such a right would the exercising of it lead to the risk of abuse? Linked to this second question was the belief that the very framing of such a right in law would inevitably have wider negative social impacts. Beyond this is the question of whether such risks are substantial and insurmountable, and whether they justify limiting any 'rights' to choose death.

Table 1 on page 18 summarises the main risks raised and responses to these.

# Introduction

## **Equal to the End?**

The Equalities and Human Rights Commission was established in October 2007 and has a remit to champion equality and human rights for all, work to eliminate discrimination, reduce inequality, protect human rights and to build good relations, ensuring that everyone has a fair chance to participate in society.

To this end the Commission will facilitate a series of debates tackling some of the policy issues that impact upon this remit and require attention due to the changing social, political, cultural and legislative contexts in which we live. The Commission will use these debates as part of a process to ensure that:

- all points of view and opinions are able to be expressed; and
- all interest groups have the opportunity to participate in the formulation of Commission policy which will allow it to effectively drive wider public debate whilst shaping policy, legislation and regulation.

The first debate is on end of life choices incorporating issues around euthanasia and assisted suicide. The timing of the debate is apposite. There are currently two proposals for private members Bills before the Scottish Parliament. MSP Margo MacDonald's End of Life Choices (Scotland) Bill and MSP Gil Paterson's Palliative Care (Scotland) Bill, initially tabled by Rosanna Cunningham MSP.

In addition there have been a series of high profile cases related to assisted dying involving the Dignitas Clinic in Switzerland. These cases were followed by an unsuccessful attempt by Patricia Hewitt MP to amend the UK Parliament's Coroners and Justice Bill in order to protect people from prosecution if they have taken a patient abroad for the purposes of assisted suicide.

This report will be submitted to the Scottish Parliament's Health and Sport Committee to assist in its deliberations on both of the proposed private members Bills'.

A verbatim record, summary and a DVD of the debate are available from [scotlandcommunication@equalityhumanrights.com](mailto:scotlandcommunication@equalityhumanrights.com) or by phoning 0845 604 5510, or text phone 0845 604 5520.

## The Current Context

### Terminology

It is important to distinguish between the different terms used in relation to the choices made at the end of life. Euthanasia may be conducted with consent (voluntary euthanasia) or without consent (involuntary euthanasia). Involuntary euthanasia is conducted where an individual makes a decision for another person incapable of doing so. Euthanasia by omission is where it is the intention to cause death by not providing necessary and ordinary care or food and water. Assisted Suicide (AS) is where someone provides an individual with the information, guidance and means to take his or her own life with the intention that they will be used for this purpose. Assisted Suicide is often used interchangeably with the term assisted dying and it has been argued that this term better reflects the process of hastening the natural ending of life. Physician Assisted Suicide (PAS) is where a doctor takes this role.

### The Legal Position

Currently, assisting suicide is illegal in the United Kingdom and this has been a contributing factor in a number of British citizens going to the Dignitas clinic in Switzerland to end their life. In October 2008 Dignitas claimed that of the 870 people it had helped end their lives 100 of them were from Britain and that 650 Britons were at that time members of Dignitas<sup>1</sup>.

In Scottish Law suicide is not illegal. Assisting in another's suicide is not covered in law but a statement in 2004 by the Deputy Minister for Health and Community Care made it clear that "an act of euthanasia by a third party, including Physician Assisted Suicide, is regarded as the deliberate killing of another, and would be dealt with under the law relating to homicide<sup>2</sup>."

### Scottish Parliament/Government

- 1 Dignitas; Euthanasia Research and Guidance Organisation.
- 2 Scottish Parliament Official Report - 11.11.04: [www.scottish.parliament.uk/business/officialReports/meetingsParliament/or-04/sor1111-02.htm#Col11876](http://www.scottish.parliament.uk/business/officialReports/meetingsParliament/or-04/sor1111-02.htm#Col11876)

In Scotland a proposal to legalise assisted suicide through a private members Bill by Jeremy Purvis MSP in 2005 failed to attract enough support. The issue has been revived recently with the MacDonald proposal for the End of Life Choices (Scotland) Bill. The proposal seeks to clarify the laws in Scotland relating to the assistance given to end the life of a person requesting such help and that on the request of the patient, and conditional on legal requirements being adhered to, a physician assisting a patient to die will not be guilty of an illegal act.

The proposed Paterson Bill on Palliative care would place a statutory duty on Health Boards to ensure that needs-based palliative care was available on demand<sup>3</sup>. The proposal is based on the premise that access to palliative care services across Scotland is variable. This is supported by Audit Scotland which criticised the inconsistency of the provision of palliative care services in a review published in August 2008<sup>4</sup>.

In October 2008 the Scottish Government published *Living and Dying Well: A national action plan for palliative and end of life care in Scotland* which aimed to ensure there was a framework in place to support a person-centred approach to delivering consistent palliative and end of life care in Scotland<sup>5</sup>.

### Public/Medical Opinion

The British Social Attitudes Survey 2007 reported that four out of five people in Britain believed that the law should 'definitely' or 'probably' allow a doctor to end someone's life **at the person's request** if they have an incurable and painful illness from which they will die. Attitudes varied and support for euthanasia dropped below 45 per cent where the person did not have a terminal illness. In relation to PAS, 80 per cent of people said they were in favour of the law allowing a doctor to end

- 3 Gil Patterson, MSP, Proposed Palliative Care (Scotland) Bill Statement of Reasons.
- 4 Review of palliative care services in Scotland.
- 5 *Living and Dying Well: A national action plan for palliative and end of life care in Scotland*.

a patient's life at their request<sup>6</sup>. In the most recent study comparing doctors attitude with those of the public it was found that a change in the law to legalise euthanasia is supported by 34 per cent of doctors (general public: 82 per cent), with 35 per cent backing PAS (general public: 62 per cent).

The British Medical Association's current policy is that:

- the ongoing improvement in palliative care allows patients to die with dignity,
- PAS should not be made legal in the UK,
- voluntary euthanasia should not be made legal in the UK,
- non-voluntary euthanasia should not be made legal in the UK,
- if euthanasia were legalised, there should be a clear demarcation between those doctors who would be involved and those who would not<sup>7</sup>.

The Royal College of Nursing (RCN) will shortly consult with its members on the issue of assisted dying. When last debated at the RCN's Annual Conference in 2005 strong arguments were made from all sides, but the RCN leadership did not allow members to vote on the issue and insisted that the College maintain its traditional position of being opposed to assisted dying.

On the day of the Commission debate, a poll by Scottish Television reported that 61 per cent believed doctors should be legally allowed to prescribe drugs to assist suicide and 58 per cent said others should have the right to make a decision for someone who has expressed the will to end their life.

Research carried out by Market Research Services (MRS) in 2005 for the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill found that<sup>8</sup>:

**“... opinion polls purporting to show that a large majority of people would favour a change in the law are misleading. They are generally based on answers to ‘yes/no’ or ‘either/or’ questions without any explanatory context and without other options – for example, good quality palliative care – being offered.”**

The MRS report concluded that the research carried out up to this point into public and health sector attitudes to the legalisation of euthanasia is **“limited in value and cannot be accepted at face value as an authentic account of opinion within the United Kingdom”**.

MRS did note that **“the apparent groundswell in public agreement with the concept of euthanasia cannot be dismissed”** and that **“it is evident that there is much sympathy at a personal level for the concept of legally releasing those wishing to die from their pain and those willing to help them from legal consequences”**.

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<sup>6</sup> British Social Attitudes Survey 2007.

<sup>7</sup> [www.bma.org.uk/images/Endoflife\\_tcm41-146693.pdf](http://www.bma.org.uk/images/Endoflife_tcm41-146693.pdf)

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<sup>8</sup> House of Lords Select Committee for The Assisted Dying of the Terminally Ill Bill; Volume 1 report, April 2005. [www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf](http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf)

# The Panel



## **Edward Turner**

Edward is a director of Dignity in Dying and joined the campaign for greater patient choice after witnessing the deaths of both of his parents from degenerative neurological disorders. His mother had an assisted death at the Dignitas clinic in January 2006.



## **Professor Sheila Maclean**

Professor MacLean is the first holder of the International Bar Association Chair of Law and Ethics in Medicine at Glasgow University. Her most recent book, *Assisted Dying: Reflections on the Need for Law Reform* was awarded the Minty Prize of the Royal Society of Authors and the Royal Society of Medicine in 2008.



## **John Deighan**

John is the Parliamentary Officer for the Catholic Bishops' Conference. The main focus of his job is dealing with issues at the interface between faith and politics. He has wide experience in the political arena through his involvement in the Trade Union Movement, pro-life work and the Movement for Christian Democracy



## **Peter Brawley**

Peter is the Manager of the Scottish Personal Assistant Employers Network, A Scotland-wide organisation supporting disabled people employing their own Personal Assistants and managing their self-directed support. He is a staunch believer in equal citizenship and the values and principles underpinning the Independent Living Movement.

# The Debate

A 'Question Time' style debate was opened by the Chair, Alex Bell, which began with general opening remarks from the panel. The debate was then opened up to questions from the floor. What follows is an analysis of the main issues raised on the night, organised into themes.

## Views from the Panel

The Commissioner, Morag Alexander, in her opening remarks gave her view that:

**“The universal declaration of human rights states that ‘All human beings are born free, equal in dignity and human rights’, and I believe that dignity applies equally to how we die as well as to how we live.”**

Edward outlined how he had become involved in the campaign for greater choice at the end of life through personal experiences. In particular he pointed out that while his father had a ‘traditional’ death where eventually he starved and dehydrated himself to death, his mother’s assisted suicide at Dignitas was a much better death for her.

He concluded that it was:

**“...extraordinarily ironic that my mother’s peaceful death was front page news and the horror of my father’s death passed completely unnoticed because that is, unfortunately, too normal.”**

He argued that people should have a limited right to end their own lives when terminally ill through Physician Assisted Suicide (PAS), but does not support euthanasia.

John was against both euthanasia and PAS. He argued that modern medicine is such that no one needs to die in agony. It is care and treatment which, he argued, we should focus on:

**“People who want to die need help and care ... I**

**think we need to support them and convince them death is not something to be frightened of, it is not something that means withering away over a long period of time.”**

He argued therefore that the debate is about autonomy, and whether we should have a right to choose the way we die. He argued that any rights to end one’s own life must be weighed against the impacts this might have on wider society. He raised concerns about the direct effect this might have on family, friends and doctors, and on wider society where other peoples lives may be put at risk.

Sheila gave examples of inconsistencies in the current legal position, where it was shown to be legal:

- for the withdrawal of treatment from a baby against the will of relatives (baby OT),
- for a patient without a terminal illness but in a Persistent Vegetative State to have treatment withdrawn without consent (Anthony Bland),
- for a patient to refuse treatment for a non-terminal illness on the basis they found their life to be intolerable.

All of these actions were taken in the knowledge they would lead to death and all were upheld by the courts.

These cases were contrasted with the case of Diane Pretty who wanted assistance to end her life. In this case the court ruled it was illegal to assist a fully competent person, with a degenerative terminal illness, to commit suicide.

She believed it was such inconsistencies that had to be dealt with, along with the ability of a competent person to make autonomous decisions:

**“...the question is whether or not we should prevent people making the choice for themselves.”**

Peter noted that, while having no mandate to speak on behalf of all disabled groups, he was personally against euthanasia and PAS.

**“There’s plenty of evidence ... that disabled people who have conditions which cannot be cured or treated are scared to go into hospital because they’re scared that their treatment would be worse. Even Baroness Campbell had a No Resuscitation order slapped on her without her consent, without her knowledge.”**

He believed this uncertainty would become worse if euthanasia or assisted suicide was to become an option and we should instead focus our attention on palliative care.

**“We’re supposed to be a society that cares for one another, why not do that first and foremost rather than put forward an agenda that history has taught us is a slippery slope that would lead to the demise of people ... we can’t support that as a society that cares.”**

## **The Themes from the Debate**

### **Assisted Suicide – Rights and Risks**

Much of the debate surrounding euthanasia and PAS revolved around ‘rights’.

**“I believe it’s my right ... to choose to go in dignity, in peace. At the moment some people... can make that choice because they can afford to go to Switzerland ... The bulk of people ... who wish to make that choice cannot afford it, so then they are left in Britain where they can go through a very distraught, a very undignified route of trying to get out of it...It’s about a person making their own choice for themselves to go in dignity...”**

(speaker from the floor)

### **A right to Assisted Death**

Professor Maclean argued that we have a ‘human right’ to make autonomous decisions and that this includes the right to choose euthanasia or assisted suicide. As this is based upon the belief in a human right to autonomy, the only limitation on the exercise of this right is that we must be competent to come to such a decision.

Edward Turner, however, believed rights are culturally derived and we as a society decide which rights are conferred:

**“We do not [currently] have a right to ask other people to end our lives, and I think that is what this debate really needs to be about. It’s under what circumstances are we going to negotiate that.”**

Although disagreeing on who should be covered by any such right, both these view points agree that we should develop a legal right to choose death and to have assistance to do so.

### **Against the right to Assisted Death**

Set against these views is the opinion that our fundamental right is our ‘intrinsic’ right to life, and any right to choose death would be **‘an antithesis of a right’**. In this view there is, and can be, no right to choose death.

It was further argued that any change to allow assisted suicide will put that right to life at risk.

John Deighan believed:

**“...this (assisted suicide) would put people’s lives at risk, I have no doubt about that, and would inherently infringe my right to life by meeting this demand for people to have the right to terminate their life.”**

This concern is generally based upon the belief that pressure may be brought to bear upon people who are vulnerable to choose assisted suicide or euthanasia against their will. Beyond this, concern was expressed during the debate that the process may become non-voluntary.

Peter Brawley argued:

**“Safeguards cannot prevent people who don’t want to die from ... being put to the sword.”**

There were other concerns raised such as the emotional impact upon doctors and families, a construction of negative perceptions of disability, and a detrimental impact upon palliative care funding. These are covered on page 15.

However, many of the objections raised did not attempt to deny that people may have a right to choose assisted suicide. Rather that the exercise of that right (or a law supporting it) would put others’ rights and lives at risk and have wider negative impacts.

Therefore, if adequate safeguards and checks can be developed and implemented the main arguments against the exercise of this ‘human’ or ‘negotiated’ right may be overcome. Such safeguards are discussed below. However, if one’s objection is based upon a belief that a right to life is ‘intrinsic’ and there is no right to choose death, then no safeguards will overcome this objection.

### Options

- Support euthanasia or PAS on the basis that individuals have a human right to make autonomous decisions regarding their life and death and allow choice for all competent individuals.
- Support euthanasia or PAS based upon negotiated right to control one’s life and process of dying and agree limitations.
- Reject euthanasia or PAS on the basis that there are wider insurmountable and substantial negative social impacts.
- Reject euthanasia or PAS on the basis that any right which negates an intrinsic right to life cannot be a right.

### Wider Impacts: Doctors and Families

**“...to facilitate that choice [of PAS] means bringing all of us into it as well. It doesn’t just impact on a person in isolation, it impacts on society.”** (John Deighan)

It was argued that the exercise of any rights to access PAS would have a series of wider negative impacts which justify a constraint upon individual liberty.

#### Doctors

One such impact was that the right to assisted suicide would require doctors to involve themselves in this process.

John Deighan put it thus:

**“We have to turn other people in society into killers...”**

The concern is that medical professionals may be required to act against what they believe to be right whether due to religious belief, their interpretation of the Hippocratic Oath, or general matters of conscience.

In Holland there is no requirement for a doctor to assist in a suicide or euthanasia. The ability to opt out of any such process could be built into any proposed system.

#### Families

It was also argued that euthanasia or PAS has such a negative impact upon family and friends that the feelings of those left behind should be weighed against the wishes of the person seeking death.

However, Edward Turner related his experience of his parents’ deaths and clearly felt that his mother’s assisted suicide was a ‘better death’ than his father’s.

Professor Maclean pointed out all deaths have an impact upon the remaining family and there is no need to assume euthanasia or PAS is worse. On the contrary:

**“There is some research that suggests that the process of seeking an assisted death can often engage the entire family and the network of friends in the discussion and actually ease the problems that they confront in grieving, so I’m not sure that we can be quite as confident as you seem to be that an assisted death necessarily is worse.”**

This research, comparing the experiences of 500 Dutch families, concluded that:

**“The bereaved family and friends of cancer patients who died by euthanasia coped better with respect to grief symptoms and post-traumatic stress reactions than the bereaved of comparable cancer patients who died a natural death<sup>9</sup>.”**

Professor MacLean went on to argue that:

**“The question is what is the greater... [concern] to society, is it defeating people’s well-considered choices or is it a grieving family left behind?”**

### Options

- In line with the practice in Holland, and as advocated in Margo MacDonald’s proposals, no doctor need have a duty to grant a request for euthanasia or to assist in the process.

### Issues for further consideration

- Clarity must be sought as to whether the impact of euthanasia or PAS is necessarily negative for the family or, as the research mentioned suggests, that the process may in fact have a positive impact.
- Beyond this the question remains as to whose feelings are given priority – the individual concerned or the family.

### Wider Impacts: Disability discrimination?

Another concern is that a change in law may create a negative perception of those groups allowed access to euthanasia or PAS.

The concern is that if only some have the legal right to assistance this in itself devalues their lives, as some lives may be seen to be worth living and some not. This was a particular concern of some disabled people.

**“The point ... is that our lives as disabled people in society [are] different ... because we’re perceived as different...”** (Peter Brawley)

This raised two major concerns. Firstly, disabled people themselves may come to feel they are a burden and choose assisted suicide because of this, rather than any deep conviction that they would prefer to die.

Secondly, there is a fear that doctor’s may discriminate against people by steering them towards assisted suicide as they may feel disabled people’s lives are of less value. This is known as ‘diagnostic overshadow’: the tendency of some medical professionals to medicalise disability, and to therefore allow diagnosis and prognosis to be tainted by unwarranted assumptions about a disabled person’s quality of life.

Disabled people, it was argued, should be concerned:

**“Because they feel as if they are outside so often and suddenly ... you can get to the front of the queue to be killed.”**  
(John Deighan)

Against this it is argued that a negative construct of disability does not necessarily follow a change in the law.

<sup>9</sup> Swarte, NB, Marije, L., et al, ‘Effects of euthanasia on the bereaved family and friends: a cross sectional study’ *British Medical Journal* Vol 327, 26 July 2003.

### Limited access

Edward Turner argued:

**“...I don’t support the idea of assisted dying for people who are disabled ... I think that is a morally different situation from somebody who is terminally ill who is naturally at the end of their life and they are fighting a different battle.”**

The limited right to PAS proposed by Dignity in Dying (the campaign group supported by Edward Turner), would require certain conditions are met before access to the process is allowed.

**“What are the symptoms and circumstances under which we would feel comfortable allowing some people to end their life? My position is when the natural process of dying has started, that is when we should avoid the moral fudge whereby we will stand by somebody’s bedside and allow them to waste away in varying degrees of distress but not give them the option of self determination to deliver themselves from their own symptoms.”**

(Edward Turner)

In the US State of Oregon, where assisted dying is legal, a terminal illness with a prognosis of death within 6 months is required. In Holland the requirement is for ‘intolerable suffering’ rather than terminal illness.

There are a therefore a variety of limitations which could be developed which do not include disability as a qualifying criteria.

### Unlimited access

In the proposal based upon a right to autonomy put forward by Professor Maclean euthanasia or PAS should not be limited but available to all people equally:

**“...I would not restrict death only to those who are terminally ill ...it seems to me if the fundamental issue is autonomy then it is autonomy that we are concerned about.”**

In this proposal access is based upon competence and autonomy with no mention of impairment. In neither Holland nor Switzerland is there a requirement for terminal illness.

A concern may remain though that even in systems which do not include disability as a qualifying criteria a disabled person’s request for PAS or euthanasia may be more likely to be granted because of value judgments of physicians. However, one study from Utah University, analysing evidence from 20 years of euthanasia and assisted dying in Holland and 8 years in Oregon, concluded that disabled groups did not access assistance at a disproportionate rate<sup>10</sup>.

### Equal access

As suicide is not currently illegal we all have a legal right to commit suicide. However, there are people who would find it physically incredibly difficult, if not impossible.

**“... if we are talking about assisted suicide ... then the issue is that the sufferer is needing assistance, everybody has the right to go out and end their life if they so desire, this is for the people who are unable to help themselves enact their own wishes.”** (speaker from the floor)

Libby Wilson from Friends at the End asked:

**“Why are groups representing people with disabilities so against assisted suicide? Surely [they] ... should have the same choices as the able-bodied.”**

In this view the current law discriminates against people with certain impairments and restricts them from equal access to their legal right to end their life.

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<sup>10</sup> Battin MP, van der Heide A, Ganzini L, et al. *Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ‘vulnerable’ groups.* J Med Ethics 2007.

### Options

- Avoid exacerbating a negative construct of disability by setting limiting criteria which do not include disability.
- Do not set any limitations on access to assistance beyond autonomy and competence.

### Issues for further consideration

- Would disabled people's requests for assistance be granted more easily? There is some evidence which suggests this has not been the case elsewhere.
- Does current law discriminate against some disabled people due to their inability to commit suicide on their own?
- What are the options for supporting people who have limited capacity to make and express their choices about dying?

### Pressure

**“... I’ve spoken to probably enough people to fill this auditorium who have genuinely felt that they are a burden and after a short conversation with their family realised that that’s not the case and their life is instantly improved.”**

(speaker from the floor)

Concern was expressed that the legalisation of assisted suicide or euthanasia may bring internal or external pressures on people to choose death. This may come from feelings such as being a burden on family, friends, the health service or general society, or from direct pressure from families.

Peter Brawley expressed his concern that:

**“...people can be easily swayed and believe that they are a burden on society, and that’s why I’m worried ...”**

John Deighan pointed to the experience of Oregon: **“One of the issues we have to address is vulnerability. In Oregon in 2005, in 42 percent of the cases, the fear of being a burden on carers and their family was one of the reasons people opted for assisted suicide.”**

Further analysis of more recent figures shows that the factors listed as shaping the decisions of the 401 people who had died under Oregon’s Death With Dignity Act between 1998 and 2008 were as follows (App 1);

- Loss of autonomy (90 per cent).
- Less able to engage in activities making life enjoyable (87 per cent).
- Loss of dignity (84 per cent),
- Losing control of bodily functions (59 per cent).
- Burden of family/care givers (38 per cent).
- Inadequate pain control/or concern about it (24 per cent).
- Financial implications of treatment (3 per cent).

Therefore the feeling of being a burden, while relevant in many cases, should not be seen as the main factor in 38 per cent of cases. Rather it is one of many factors in each individual’s decision, the most common of which are related to autonomy, dignity and enjoyment of life.

Additionally, Professor McLean argued:

**“The feeling of being a burden may be a factor in deciding whether to choose death.”**

### Vulnerable groups

Whether people from ‘vulnerable’ groups may be more likely to be pressurised was also raised as a concern. Looking at this issue the study from Utah University examined evidence in an attempt to assess concerns regarding the impact of physician assisted deaths upon 10 vulnerable groups<sup>11</sup>.

It concluded: **“... that physician-assisted death does not kill disproportionate numbers of people who are poor, uneducated, racial and ethnic minorities, minors, or people with chronic physical or mental disabilities or chronic but not terminal illnesses<sup>12</sup>.”**

<sup>11</sup> *Op. cit.*

<sup>12</sup> *It was noted that there was a greater rate of AIDS patients choosing Physician Assisted Deaths. However, this was thought to reflect the greater rate of AIDS sufferers accessing assisted suicide illegally in other jurisdictions.*

and further noted:

**“Those who received physician-assisted dying ... appeared to enjoy comparative social, economic, educational, professional and other privileges ...”**

In Oregon those most likely to access the process were white (98 per cent), married (46 per cent), educated (67 per cent), elderly (mean = 70 years old), men (53 per cent) suffering from terminal cancers (82 per cent) and enrolled in a hospice (88 per cent) (App 1).

Concern about people with complex mental health problems was also expressed by Charlie McMillan from the Scottish Association for Mental Health who said :

**“... we’ve not heard the discussion of people with significant mental health problems and people who choose to die who may well recover from that choice and those feelings ...”**

#### Issues for further consideration

- The risk that people will choose death due to the feeling that they are a burden would require that adequate palliative care is in place. The evidence from Oregon should also be borne in mind when assessing how much weight to give to this factor.
- The concern that pressure may be brought to bear, especially on groups thought to be ‘vulnerable’ should be considered in light of the evidence.
- Is it possible to develop a system of safeguards to ensure people are not acting under duress or being manipulated?

#### Slippery slope

There is also the argument that any moves towards legalisation of voluntary euthanasia or assisted suicide for a limited group of people would lead ‘inevitably’ to involuntary euthanasia for an increasingly wide group of people.

Amidst talk of World War II John Deighan argued that the ‘circle’ which encompasses those covered by an Act would grow:

**“It grows from the terminally ill to the chronically ill, to the people physically suffering to people mentally suffering. It widens. The fundamental question is: Who decides? Who decides who is the group that are right to want to die.”**

He also pointed out that during an evidence session on euthanasia in the House of Lords:

**“...a representative of the ministry of health in the Netherlands accepted before that committee that a thousand people a year are involuntarily killed by euthanasia.”**

Edward Turner clarified his view that:

**“the group does not extend ... [I] do not accept that just because you start with assisted dying for the terminally ill you inevitably move to the disabled and ... death on demand for anybody who is tired of life and has failed their exams.”**

The historical perspective pointing to Nazi Germany was challenged by Professor Maclean and current international perspectives offered instead:

**“Hitler’s agenda was never about autonomy. We’re not talking about slippery slopes towards genocide. We are talking about some people, and there are not many of them, and certainly the experience in Oregon is that there are not many of them at all, who would seek assisted suicide...”**

It was argued there had been no evidence of a ‘slippery slope’ in the international examples. In Oregon in the 11 years to 2008, 401 people committed suicide under the Death With Dignity Act. As outlined above, evidence suggests there

is no expansion of the groups covered by, or accessing assistance through, the Act.

It was also noted in relation to the involuntary euthanasia in Holland that this occurs in the UK too. One study from Brunel University suggesting there were around 2000 cases of involuntary euthanasia, and 1000 cases of voluntary euthanasia in the UK in 2005<sup>13</sup>.

### Options

- Frame any legislation to specifically require full Parliamentary scrutiny of any proposed changes.

### Issues for further consideration

- Although there are recorded cases of involuntary euthanasia in countries where euthanasia is legal, such as Holland, evidence points to a similar situation in the UK. This suggests that a different debate – including consideration of process and safeguards – around involuntary euthanasia and the current situation is needed.

### Palliative care

It was argued that if there was an adequate palliative care system there would be no need for euthanasia or assisted suicide. The view is that it is the lack of support, rather than any medical condition, which causes a person to prefer death as an option.

The lack of access to palliative care was expressed thus by one member of the audience:

**“...I’ve lost four of my immediate family in the past couple of years. Only one of them received the proper palliative care. One died in hospital, one died at home, one died in a nursing home and one died in a hospice and the only one that received the proper care was in a hospice ... older people [are] very much afraid of being at the end of life and not having the proper care. We don’t seem to have that in our society today.”**

It is argued that without such care people may well choose the option of assisted suicide if it is available, not necessarily because they have come to a freely developed determination that they want to die but that due to loneliness, pain, fear of pain and lack of care that death is a preferred option.

Professor Maclean argued:

**“I think no one is suggesting we should not better fund palliative care and the hospice movement, but as I’ve said before, it doesn’t seem to me these are mutually exclusive events.”**

John Deighan argued that euthanasia would only serve to reduce palliative care funding:

**“Surely you would see that if there was that easy option out, the demand for palliative care would be reduced and if demand was reduced surely supply would be reduced.”**

### Issues for further consideration

- There is clearly a requirement for a properly funded palliative care system to ensure people would not take decisions in the context of inadequate care. It is not clear however that this is inconsistent with access to assisted suicide or euthanasia.
- Would there be such an uptake of euthanasia or assisted suicide that demand for palliative care would be substantially reduced, and if so does it follow that capacity must then also reduce?
- There may be the opportunity to explore how a person-centred approach – a key aim of the National Action Plan – in relation to palliative care can help to alleviate concerns related to PAS or euthanasia. This would be particularly useful in relation to pressure and safeguards.

<sup>13</sup> Seale, C. (2006) *National survey of end-of-life decisions made by UK medical practitioners. Palliative Medicine* 20: 1-8.

## Safeguards

There are a range of safeguards normally suggested to reduce the risk of abuse or a decision being based upon inadequate care.

The list is not exhaustive but can include:

- A requirement for the person to request assisted suicide in multiple instances over a period of time and in varying formats.
- An assessment of their competence to make such a request.
- An assessment of the autonomy of their decision,
- An assessment that they meet whatever other qualifying criteria are laid down.
- A requirement for a medical assessment of their current circumstances including access to care, pain relief, familial circumstance, along with a full exploration of alternatives.
- A psychiatric report.
- A requirement for a second opinion.
- A report based on the above.

Whilst a comprehensive set of safeguards can be put in place risk of abuse may still exist.

**“... in countries where assisted suicide or euthanasia is permitted there is acknowledgment that the safeguards and processes don’t give absolute protection against the illegal termination of life.”**

(speaker from the floor)

Although, as Professor MacLean argued:

**“We don’t have fail-safe safeguards in any aspect of life [but] if we look for absolute safeguards we’re unlikely to do anything other than stagnate ... there are quite good safeguards in place in places like Oregon...and I think we could learn something from those safeguards, but in the long run I don’t think any law is capable of preventing some kind of abuse and the question has to be: What interest are you balancing in making that decision ...”**

## Issues for further consideration

- To what extent can the risk of abuse be avoided by the development and implementation of safeguards?
- Whether any residual risk is sufficient to justify blocking people from exercising a ‘right’ to choose assisted death as an option.

# Conclusions

The debate surrounding euthanasia and assisted suicide is based upon the idea of rights. A right, as proponents would describe it, to die with dignity, to end your life when it has become intolerable to you; the right of an informed and competent person to make an autonomous choice regarding the process of their own death. They argue that a change in the law to facilitate assistance with this choice to die is required and justifiable because of this right. Opponents argue against this on two grounds.

Firstly, they argue there is a right to life but no such right to choose death. It is described as an 'antithesis of a right' as it infringes upon the right to life.

This objection is based upon a view about how rights are conferred. If rights are seen either as 'intrinsic' in a secular sense, or granted by a God, then positions are likely to be entrenched as they are based on belief systems. A rejection of the right to choose death based upon a belief system, secular or religious, will tend to be non-negotiable as it is formed from one's world view.

The question here is whether those particular world views should limit the actions of those who do not hold to them. If so then the debate needs go no further, except perhaps to look to Scotland's current law which has not criminalised non-assisted suicide.

If however, this is not accepted then opponents put forward a second argument. The second argument accepts there may be a right to choose death, largely based on one's right to choose generally. However, it is argued any such right should be limited as it puts everyone else's right to life at risk. What must be considered here is whether there are such risks and if so, can they be effectively guarded against?

Table 1 summarises the main concerns put forward in the debate along with responses to these. There are clearly some solutions. However it is not certain that all risk can be overcome.

In coming to a decision, then one must consider whether we do, or should have, a right to choose death and get assistance with the process. If so then the risks of exercising this right must be weighed against it. We must ask whether a law can be constructed in such a way that it avoids exacerbating negative perceptions of disability, and guards against any moves towards non-voluntary euthanasia or an expansion of those covered by it. We must also consider to what extent regulation, guidance, safeguards and processes can provide protection and guard against abuse.

If at the end of these considerations it is believed all concerns can be either guarded against or are based on false assumptions, and one believes in the right of self determination in this instance, then support for euthanasia or assisted suicide should follow.

If it is felt that the concerns cannot be fully guarded against and that residual risks remain, the question then must be whether these residual risks are sufficient reason to prevent people seeking assistance with the process of their deaths.

Table 1. A summary of concerns and responses

Concerns	Responses
<p>Doctors forced to act against their conscience.</p> <p>A negative impact on the remaining grieving family.</p>	<ul style="list-style-type: none"> <li>■ Allow them to opt out. This is the case in Holland and part of Margo MacDonald’s proposals.</li> <li>■ Research suggests that the impact of an assisted death may actually be more likely to be positive than a natural death.</li> <li>■ It must be considered whether the right of an individual to choose to die is more relevant than the potential for a negative impact upon the remaining family.</li> </ul>
<p>The formulation of a law which makes it legal for some to access assistance to die and illegal for others will create a negative view of those covered. This is a particular concern of some disabled people.</p>	<ul style="list-style-type: none"> <li>■ Don’t create any limits or qualifying criteria beyond competence and autonomy and allow individuals to decide when their life is intolerable. This is the case in Holland.</li> <li>■ Create qualifying criteria such as terminal illness but do not include ‘disability’. This is the case in Oregon.</li> </ul>
<p>Disabled people will be disproportionately represented among PAS or euthanasia patients.</p>	<ul style="list-style-type: none"> <li>■ The evidence from Holland and Oregon shows no higher rates among disabled groups.</li> </ul>
<p>People will be put under pressure to end their lives to serve the convenience/ambitions of others.</p>	<ul style="list-style-type: none"> <li>■ Develop a system of safeguards which ensures as far as possible that the person is acting autonomously, this could include psychiatric assessment.</li> </ul>
<p>People will request death merely because they feel they are burdensome.</p>	<ul style="list-style-type: none"> <li>■ The statistics from Oregon suggest that concerns about dignity, autonomy and lack of enjoyment in life are the greatest drivers.</li> <li>■ The feeling of being a burden may be a legitimate factor in deciding whether to choose death.</li> </ul>
<p>People may request euthanasia or assisted suicide due to passing feelings.</p>	<ul style="list-style-type: none"> <li>■ Ensure desire is persistent – this is one of the tests in Holland, and in Oregon the median numbers of days between first request and actual death is 43.</li> </ul>
<p>People may choose to die because they are lonely, receiving poor treatment/ inadequate pain relief, or are ill-informed of their options and consequences.</p>	<ul style="list-style-type: none"> <li>■ Ensure all reasonable care and support is provided before granting request.</li> <li>■ Ensure a system of background and medical checks are developed, implemented and reported on.</li> </ul>

Concerns	Responses
<p>Palliative care funding will decrease as demand drops because of euthanasia or assisted suicide.</p>	<ul style="list-style-type: none"> <li>■ It is not certain that the number of people accessing any system would be sufficient to substantially undermine demand for palliative care. In Oregon, less than 40 people per year die under their process from a population of around 4 million.</li> </ul>
<p>Any moves toward limited and voluntary euthanasia or assisted suicide will inevitably lead to the inclusion of a wider group of people accessing assistance.</p>	<ul style="list-style-type: none"> <li>■ Analysis of Holland and Oregon systems found no evidence of this.</li> <li>■ Qualifying criteria can be set in primary legislation and therefore require any expansion to go through the parliamentary process.</li> </ul>
<p>Non-voluntary measures will develop as a next step.</p>	<ul style="list-style-type: none"> <li>■ Legislate to ensure the process of euthanasia or assisted suicide is voluntary.</li> <li>■ Ensure through stringent safeguards that the process of euthanasia or assisted suicide is in fact voluntary.</li> </ul>
<p>Non-voluntary euthanasia currently goes on in Holland and Oregon.</p>	<ul style="list-style-type: none"> <li>■ This is true in jurisdictions with and without euthanasia or assisted suicide through Do not Resuscitate order and administration of drugs. It is therefore a different issue and different process, and needs to be dealt with separately.</li> </ul>
<p>No system of safeguards can guarantee to deal with all risk.</p>	<ul style="list-style-type: none"> <li>■ Systems can minimise risks but ultimately a judgement is required to assess whether the remaining risk is sufficient to justify limiting other people's choice over their death.</li> </ul>

# Appendices

**Appendix 1. Characteristics and end-of-life care of 401 DWDA patients who died after ingesting a lethal dose of medication, by year, Oregon, 1998-2008**

Characteristics	2008 (N=60)		1998 (N=341)		Total (N=401)	
	N	(%)	N	(%)	N	(%)
<b>Sex</b>						
Male	30	(50.0)	183	(53.7)	213	(53.1)
Female	30	(50.0)	158	(46.3)	158	(46.9)
<b>Age</b>						
18-34	0	(0.0)	4	(1.2)	4	(1.0)
35-44	1	(1.7)	10	(2.9)	11	(2.7)
45-54	1	(1.7)	31	(9.1)	32	(8.0)
55-64	12	(20.0)	73	(21.4)	85	(21.2)
65-74	21	(35.0)	93	(27.3)	114	(28.4)
75-84	14	(23.3)	98	(28.7)	112	(27.9)
85+	11	(18.3)	32	(9.4)	43	(10.7)
Median years (range)	72	(44-93)	69	(25-96)	70	(25-96)
<b>Race</b>						
White	59	(98.3)	332	(97.4)	391	(97.5)
Asian	1	(1.7)	6	(1.8)	7	(1.7)
American Indian	0	(0.0)	1	(0.3)	1	(0.2)
Hispanic	0	(0.0)	2	(0.6)	2	(0.5)
African American	0	(0.0)	0	(0.0)	0	(0.0)
Other	0	(0.0)	0	(0.0)	0	(0.0)
<b>Marital status</b>						
Married	31	(51.7)	154	(45.2)	185	(46.1)
Widowed	12	(20.0)	73	(21.4)	85	(21.2)
Divorced	10	(16.7)	86	(25.2)	96	(23.9)
Never married	7	(11.7)	28	(8.2)	35	(8.7)

Characteristics	2008 (N=60)		1998 (N=341)		Total (N=401)	
	N	(%)	N	(%)	N	(%)
<b>Education</b>						
Less than high school	3	(5.0)	27	(7.9)	30	(7.5)
High school graduate	8	(13.3)	95	(27.9)	103	(25.7)
Some college	13	(21.7)	79	(23.2)	92	(22.9)
Baccalaureate or higher	36	(60.0)	140	(41.1)	176	(43.9)
<b>Residence</b>						
Metro counties †	29	(48.3)	140	(41.1)	169	(42.1)
Coastal counties	5	(8.3)	25	(7.3)	30	(7.5)
Other western counties	19	(31.7)	151	(44.3)	170	(42.4)
East of the Cascades	7	(11.7)	25	(7.3)	32	(8.0)
<b>Underlying illness</b>						
Malignant neoplasms	48	(80.0)	280	(82.1)	328	(81.8)
Lung and bronchus	14	(29.2)	65	(19.1)	79	(19.7)
Pancreas	3	(6.3)	30	(8.8)	33	(8.2)
Breast	5	(10.4)	30	(8.8)	35	(8.7)
Colon	4	(8.3)	23	(6.7)	27	(6.7)
Prostate	3	(6.3)	20	(5.9)	23	(5.7)
Other	19	(39.6)	112	(32.8)	131	(32.7)
Amyotrophic lateral sclerosis	4	(6.7)	26	(7.6)	30	(7.5)
Chronic lower respiratory disease	4	(6.7)	15	(4.4)	19	(4.7)
HIV/AIDS	1	(1.7)	7	(2.1)	8	(2.0)
Heart Disease	1	(1.7)	5	(1.5)	6	(1.5)
Other (listed on page 23) <sup>1</sup>	2	(3.3)	8	(2.3)	10	(2.5)
<b>End-of-life care</b>						
Hospice						
Enrolled	59	(98.3)	291	(85.8)	350	(87.7)
Not enrolled	1	(1.7)	48	(14.2)	49	(12.3)
Unknown	-		2		2	
Insurance						
Private	53	(88.3)	212	(62.9)	265	(66.8)
Medicare or Medicaid <sup>2</sup>	5	(8.3)	122	(36.2)	127	(32.0)
None	2	(3.3)	3	(0.9)	5	(1.3)
Unknown	-		4		4	

Characteristics	2008 (N=60)		1998 (N=341)		Total (N=401)	
	N	(%)	N	(%)	N	(%)
<b>End-of-life concerns<sup>3</sup></b>						
Losing autonomy	57	(95.0)	300	(89.0)	357	(89.9)
Less able to engage in activities making life enjoyable	55	(91.7)	292	(86.6)	347	(87.4)
Loss of dignity <sup>4</sup>	55	(91.7)	173	(81.6)	228	(83.8)
Losing control of bodily functions	37	(61.7)	196	(58.2)	233	(58.7)
Burden on family, friends/caregivers	20	(33.3)	132	(39.2)	152	(38.3)
Inadequate pain control or concern about it	3	(5.0)	92	(27.3)	95	(23.9)
Financial concerns about treatment	2	(3.3)	9	(2.7)	11	(2.8)
<b>DWDA process</b>						
Referred for psychiatric evaluation	2	(3.3)	36	(10.7)	38	(9.6)
Patient informed family of decision <sup>5</sup>	56	(93.3)	253	(94.4)	309	(94.2)
Patient died at:						
Home (patient, family or friend)	58	(96.7)	319	(93.5)	377	(94.0)
Long term care, assisted living or foster care facility	2	(3.3)	17	(5.0)	19	(4.7)
Hospital	0	(0.0)	1	(0.3)	1	(0.2)
Other	0	(0.0)	4	(1.2)	4	(1.0)
Lethal Medication						
Secobarbital	35	(58.3)	175	(51.6)	210	(52.6)
Pentobarbital	25	(41.7)	161	(47.2)	186	(46.4)
Other <sup>6</sup>	0	(0.0)	5	(1.2)	5	(1.0)
<b>Health-care provider present when medication ingested<sup>7</sup></b>						
Prescribing physician	11	(18.3)	74	(27.3)	85	(25.7)
Other provider, prescribing physician not present	40	(70.2)	140	(52.8)	180	(55.9)
No provider	6	(10.5)	51	(19.2)	57	(17.7)
Unknown	3		6		9	
<b>Complications</b>						
Regurgitated	0	(0.0)	19	(5.7)	19	(4.9)
Seizures	0	(0.0)	0	(0.0)	0	(0.0)
Awakened after taking prescribed medication	0		1 <sup>8</sup>		1 <sup>8</sup>	
None	58	(100.0)	314	(94.3)	372	(95.1)
Unknown	2		8		10	

Characteristics	2008 (N=60)		1998 (N=341)		Total (N=401)	
	N	(%)	N	(%)	N	(%)
<b>Emergency Medical Services</b>						
Called for intervention after lethal medication ingested	0	(0.0)	0	(0.0)	0	(0.0)
Calls for other reasons <sup>9</sup>	0	(0.0)	4	(1.2)	4	(1.0)
Not called after lethal medication ingested	60	(100)	337	(98.8)	397	(99.0)
Unknown	-		4		4	
<b>Timing of DWDA Event</b>						
Duration (weeks) of patient-physician relationship						
Median	8		12		10	
Range	0-916		0-1440		0-1440	
Unknown	1		18		19	
Duration (days) between 1st request and death						
Median	42		43		43	
Range	15-436		15-1009		15-1009	
Minutes between ingestion and unconsciousness						
Median	5		5		5	
Range	1-20		1-38		1-38	
Unknown	5		24		28	
Minutes between ingestion and death						
Median	15		25		25	
Range (minutes - hours)	2 min-25 hrs		4 min-48 hrs		1 min-48 hrs	
Unknown	6		25		31	

• Unknowns are excluded when calculating percentages.

† Clackamas, Multnomah, and Washington counties.

1 Includes alcoholic hepatic failure, corticobasal degeneration, diabetes mellitus with renal complications, hepatitis C, organ-limited amyloidosis, scleroderma, Shy-Drager syndrome, multiple sclerosis, and meningioma.

2 As only form of health insurance coverage.

3 Affirmative answers only (“Don’t know” included in negative answers). Available for 17 patients in 2001.

4 First asked in 2003.

5 First recorded beginning in 2001. Since then, 12 patients (3.7%) have chosen not to inform their families and 7 patients (2.1%) have had no family to inform.

6 Other includes combinations of secobarbital, pentobarbital, and/or morphine.

7 The data shown are for 2001-2008 since information about the presence of a health care provider/volunteer, in the absence of the prescribing physician, was first collected in 2001.

8 In 2005, one patient regained consciousness 65 hours after ingesting the medications, subsequently dying from their illness 14 days after awakening. The complication is recorded here but the patient is not otherwise included in the total number of DWDA deaths.

9 Calls included three to pronounce death and one to help a patient who had fallen off a sofa.





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