END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE

AGENDA

8th Meeting, 2010 (Session 3)

Tuesday 28 September 2010

The Committee will meet at 10.00 am in Committee Room 1.

1. End of Life Assistance (Scotland) Bill: The Committee will take evidence on the Bill at Stage 1 from—

   Frank Mulholland QC, Solicitor General;

   John Logue, Head of Policy Division, Crown Office and Procurator Fiscal Service;

and then from—

   Pam Duncan, Board Member, Inclusion Scotland;

   Johanna McCulloch, Policy Information and Parliamentary Officer, Scottish Disability Equality Forum;

   Sarah Wootton, Chief Executive, Dignity in Dying;

   Gordon MacDonald, Public Policy Officer, Care Not Killing Scotland;

   David Manion, Chief Executive, Age Scotland;

   Chris Docker, Director, EXIT;

   Jan Killeen, Director of Policy, Alzheimer Scotland;

   Tanith Muller, Parliamentary and Campaigns Officer, Scotland, Parkinson’s UK;

   Sheila Duffy, Member, Friends at the End;

   John Deighan, Parliamentary Officer, Catholic Bishop’s Conference of Scotland.
The papers for this meeting are as follows—

**Agenda Item 1**

Submission from Inclusion Scotland  
Submission from Scottish Disability Equality Forum  
Submission from Dignity in Dying  
Submission from Care Not Killing Scotland  
Submission from Age Scotland  
Submission from EXIT  
Submission from Alzheimer Scotland  
Submission from Parkinson's UK  
Submission from Friends at the End  
Submission from the Catholic Bishops’ Conference of Scotland
End of Life Assistance (Scotland) Bill

Inclusion Scotland

1 Background

1.1 Inclusion Scotland is a network of disabled peoples' organisations and individual disabled people. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives and to encourage a wider understanding of those issues throughout Scotland. We are well placed to comment from the perspective of expected “beneficiaries” of the End of Life Assistance (Scotland) Bill’s provisions.

2 Questions: “Do you agree that a person should be able to request end of life assistance from a registered medical practitioner?”

2.1 No: Inclusion Scotland questions whether the State should ever give support to the idea that a person in despair be given State assistance to end their lives. Though suicide rates in Scotland have been in decline over the last decade, we still have the highest suicide rate of any of the four nations of the United Kingdom\(^1\). The Scottish rate of suicides amongst young men is twice as high as in England & Wales. Ironically the Scottish Government has just begun an expensive, high profile media campaign to dissuade people in a depressed state from committing suicide. Yet this Bill endorses the view that there are some circumstances in which suicide or “assisted death” is a valid option.

2.2 This Bill’s provisions divide society into two groups. One group would be eligible for state assistance in committing suicide; the other would not. We question the grounds on which this division has been made.

2.3 The first group eligible for assistance are those with a terminal illness and likely to die within the next six months. This group are treated as disabled people in terms of entitlement to Disability Living Allowance. The second eligible group are people who “are permanently physically incapacitated to such an extent as to not be able to live independently and who find life intolerable…” This can include all disabled people who have acquired physical or sensory impairments as well as people with congenital, progressive or irreversible conditions.

2.4 Thus all of those who would qualify for assistance would be disabled people. The vast majority of those excluded from assistance would be non-disabled people. That suggests that the lives and existence of one group are being treated as of less value than the other. Yet, with the exception of a few vocal individuals, assisted dying legislation is not supported by disabled people.
2.5 This is demonstrated by the formation of “Not Dead Yet UK” an organisation of disabled and terminally ill people opposed to assisted suicide in response to an earlier assisted suicide Bill at Westminster.

2.6 Other disabled people’s organisations opposed to assisted dying include RADAR (Royal Association for Disability Rights); National Centre for Independent Living; UK Disabled People's Council and Disability Awareness in Action.

“If as much work, effort, time and money went into improving the lives of disabled people as has been spent over the years on the idea that disabled people would be better off dead, then perhaps we would not be so disabled and would find work.” – Kenny Milne, Contact 100 member

2.7 We note that to qualify for assistance a person would also have to find life “intolerable”. Yet a non-disabled person who finds life intolerable would not receive assistance. This suggests that the “dependency” that a disabled person experiences is somehow more worthy of death. The State, in assisting their suicide, would be condoning the stereotype that disabled people’s lives are so valueless, tragic, burdensome and insufferable that they must want to die.

2.8 If this Bill succeeds it will create invidious pressure on the disabled and terminally ill to do right by their families and the state. It will be the cheapest, quickest and simplest option. The so-called safeguards in the Bill would not prevent insidious and sometimes even unconscious pressure being brought to bear on disabled people by carers, health and care professionals, as all it seeks to bar is pressure brought to bear for monetary gain.

2.9 All research studies conducted on assisted dying show "not wanting to be a burden" as the principal reason for seeking death. This point is made in the Financial Memorandum to the Bill pointing out that costs of ending disabled and terminally ill people’s lives will be significantly less than providing care & support.

2.9 Inclusion Scotland believes that the Assisted Dying Bill will begin a journey that ends in an accepted culture of "mercy killing" of disabled people. Legalising premature death of disabled people undermines their right to support to live with dignity and the State’s responsibility to ensure their access to support and care services. If this Bill succeeds, despair at disabling conditions will be endorsed as a reasonable expectation for which early state-sanctioned death is an effective remedy.

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

3.1 No. We object to the wide criteria of people who “are permanently physically incapacitated to such an extent as to not be able to live independently and who find life intolerable...” There is no attempt to define not being “able to live independently”; anyone who requires even minimal care
and assistance (e.g. meals on wheels or help in reading their mail) could conceivably fit this criteria. This is referred to within the Bill as “the dependency criteria”. Physically impaired people are categorised as “dependent” if they receive any support whatsoever.

“The morality of helping disabled people to kill themselves rather than providing care and support has to be questioned. By analogy, parents who decided that they no longer wanted their children, should be allowed to kill them, because this is cheaper than looking after and supporting them” - Marion Hersh, Contact 100 member

3.2 Disabled people object to this categorisation of “dependency” as it is demeaning and contradicts the social model of disability which states that it is society’s failure to make necessary adjustments to impairment which “disables” an individual and restricts their ability to participate fully in community life.

3.3 It would mean that over 80% of those currently receiving Attendance Allowance (116,000 people) and Disability Living Allowance (another 144,000) on the grounds of physical or sensory impairments would meet the criteria for end of life assistance. In total over 250,000 Scots would be eligible for assistance as they have either care or mobility needs to be met in order to support them in living “independently”. Please also note that an estimated 30% of those entitled to these benefits do not apply for them.

3.4 We note that the Scottish Government and COSLA endorsed a “Shared Vision of Independent Living” last December which states that “It is right for the individual….to participate within society as full and equal citizens”. The Government is therefore committed to supporting disabled people to play their full role as contributors to the economic and social wealth of society. Yet this Bill questions whether their lives are worth living at all if they have care needs.

3.5 Many disabled people’s lives are severely restricted – trapped in residential and nursing homes, isolated and segregated from their families and friends; trapped in inaccessible housing; denied an equal education and training opportunities; confined by inaccessible transport, prejudice and lack of access in the workplace; provided with support services which meet basic needs only and denied engagement in social and community life.

3.6 In such circumstances many of those 250,000 disabled people do occasionally become depressed and desperate. They should not be encouraged to consider suicide at such points in their lives. Instead Inclusion Scotland urges the Scottish Parliament to commit to safeguard and invest in care & support services that enable people live their lives to their full potential. Disabled people want the right to live, as non-disabled people do, and not the right to die.
4 Assisted Dying in Holland

4.1 According to the American experience, cited in this Bill’s Financial Memorandum, the numbers likely to take the option of assisted death will remain low. However the Memorandum fails to mention our near neighbour, Holland, where euthanasia law was liberalised several decades ago. Surely its experience of how the law and practice of assisted dying has developed is relevant?

4.2 In 1991, the results of the first official government study of the practice of Dutch euthanasia were released. The Remmelink report documents the prevalence of voluntary and involuntary euthanasia in Holland. The report indicates that despite court-approved euthanasia, guidelines developed to protect patients, abuse has become an accepted norm. In 1990:

- 2,300 people died as the result of doctors killing them upon request.
- 400 people died as a result of doctors providing them with the means to kill themselves (physician-assisted suicide).
- 1,040 people died from involuntary euthanasia, i.e. doctors killed these patients without their knowledge or consent. Of these patients 72% had given no indication that they would want their lives terminated.
- 8,100 patients died due to doctors giving them overdoses of pain medication, not for the primary purpose of controlling pain, but to hasten death. In 61% of these cases the overdose was given without the patient's consent.

4.3 According to Remmelink, Dutch physicians intentionally ended the lives of 11,840 people – accounting for over 9% of the annual Dutch death rate. The report found that the majority of all euthanasia deaths in Holland at that time were involuntary. Dutch euthanasia law has led to a climate where doctors routinely euthanise patients with or without their consent.

4.4 Figures from the Dutch official monitoring body show the number of registered cases of euthanasia in Holland rose to 2,500 in 2009. In 2007 Dutch experts said that around 80% of assisted deaths are registered with the monitoring body. This means that approximately 3,000 sick and disabled Dutch people were assisted to die last year.

4.5 If assisted dying were to be introduced in Scotland and grew over time to Dutch levels this would equate to 1000 assisted deaths a year (the Dutch population is three times our own). However if involuntary euthanasia also became more prevalent, then 9% of all Scots deaths might eventually become attributable to “mercy killing” – equivalent to 5,000 deaths per annum.

4.6 Although the Dutch law on euthanasia is liberal by British standards, it is still much more restrictive than that envisaged in the current Bill’s proposals. In 1981 the Dutch courts restricted the availability of assisted
dying to “patients experiencing unbearable pain”, a much smaller group than all terminally ill people and those disabled people dependent on some form of care.

4.7 The most frequently cited reasons given by Dutch health professionals for ending the lives of patients without their knowledge or consent were: “low quality of life,” “no prospect for improvement,” and “the family couldn't take it anymore.”

4.8 Inclusion Scotland believes that where euthanasia is an accepted medical solution to patients' pain and suffering, there is little incentive to develop programs which provide modern, available, and effective pain control for patients.

“I have cerebral palsy. When I was twenty-one I could have said to my mother that I wished to take my own life but now I am a campaigner for disabled and older people’s rights. I have been extremely successful in my life despite being in care for forty years” – Jimmy MacIntosh, Disability Activist

5 Terminal Illness, Palliative Care & Assisted Living

5.1 Scotland has an aging population and the incidence of impairment rises as age increases. Disabled and older people are at risk of being subtly pressured into contemplating ‘assisted dying’ by both their families and health professionals.

5.2 Health professionals sometimes judge whether care will be provided, rationed or withheld on the basis of a patient’s “quality of life”. This has previously resulted in “Do Not Resuscitate” notices sometimes being placed on disabled patients’ beds when neither they nor their families have made any such request. Even Baroness Jane Campbell, ex-Chair of the Disability Rights Commission has experienced difficulty in obtaining life-saving treatment because of health professionals’ attitudes.

5.3 It is acknowledged that health professionals reflect prejudices towards disabled people held in wider society. Parliament should instead foster attitudes in society that recognise the value of all people, regardless of impairment. The focus must shift from assisted dying to the more humane concept of Assisted Living, valuing all lives irrespective of impairment and the provision of high quality palliative care.

5.4 Birth and death are life events affecting everyone. There is a huge disparity in the way we treat people at the beginning and end of life. In 2008 there were 55,699 deaths and 60,041 births in Scotland. There are approximately 850 maternity beds in specialised NHS units and health visitor/midwives are attached to every general practice. In contrast, nearly all terminal care beds are wholly or in part supported by the Hospice Movement.
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5.5 Many people currently die in busy general wards where staff are overstretched, with no specialised training in terminal care and with no opportunity for spiritual and psychological support. In the community, district nurses do their best but there is under-staffing and poor out-of-hours provision. It is therefore understandable why some terminally ill people might choose to die with some dignity and relatively free from pain. However Inclusion Scotland believes very few would make that choice if good quality palliative care was genuinely available.

5.6 It is now widely accepted that a person’s state of mind can directly affect their physical health. A person who can look forward to quality terminal care and support will remain healthy longer and will use fewer resources. Many relatives and companions of terminally ill patients suffer great distress at the current ‘end days’ of their loved one. This, again, can directly affect their physical health leading to increased use of NHS resources.

5.7 Therefore Inclusion Scotland welcomes the proposed Palliative Care Bill. We believe that NHS Boards should be under a statutory obligation to provide high-quality palliative care, increasing the number of palliative care beds and district nurses with palliative care training.

6 Conclusion

6.1 Inclusion Scotland believes that this Bill’s proposals are dangerous and offensive. A person’s life should not be seen to be at an end if they have a physical impairment. We therefore wholeheartedly oppose the reasoning behind, and proposals contained within, this Bill.

6.2 The End of Life Assistance Bill will not only encourage disabled people’s suicide and, over time, their involuntary euthanasia but also gives tacit support to discrimination against disabled people within wider society by treating them as second class citizens whose lives are not worth living.

6.3 The Scottish Government’s “Independent Living Core Reference Group” (CRG) has accepted the core values of independent living as Freedom, Dignity, Choice and Control and are working together to make independent living a reality. It is ironic that these same values are being used to promote ‘assisted dying’, just as this work to create real opportunities for ‘assisted living’ is beginning.

6.4 A society which cannot first guarantee opportunities for good quality assisted living is a society where disabled people will be pressurised into feeling a burden on others, which in turn will inevitably force many to make the choice of assisted death. Let us therefore invest resources and effort into making Assisted Living for Scots disabled people a reality rather than Assisted Dying.

Bill Scott
Policy Officer
Inclusion Scotland
References:

4. Source DWP: [http://83.244.183.180/100pc/dla_ent/tabtool_dla_ent.html#infotab](http://83.244.183.180/100pc/dla_ent/tabtool_dla_ent.html#infotab)
7. Ibid., p. 15.
8. Ibid., p. 50, table 6.6.
9. Ibid., p. 58, table 7.2
10. Ibid., p. 72.
The Scottish Disability Equality Forum (SDEF) works for social inclusion in Scotland through the removal of barriers and the promotion of equal access for people affected by disability.

It is a membership organisation, representing individuals with any type of impairment, disability organisations and groups who share our values. It aims to ensure the voices of people affected by disability are heard and heeded.

SDEF promotes access in its widest sense, including access to the built and natural environment and access to the same opportunities as are enjoyed by other people in our community.

Introduction to evidence

SDEF has consulted widely on the issue of assisted suicide and the specific contents of this proposal. We would like to make it clear that the views of our members on this issue are diverse and that no consensus has been reached.

Overall, slightly more than half of those who responded to the consultation were in favour in principal of some kind of relaxation of laws criminalising assisted suicide. Of this group, very few were entirely satisfied with the Bill as it is currently presented and their views are presented below.

Some of our members who are opposed to any change to the law on assisted suicide were concerned that a response from SDEF making suggestions about either procedural or substantive changes might be seen as tacit support and approval for the principles of the Bill on behalf of SDEF. We would like to make it clear that this is not the case. With this response, SDEF merely seeks to put forward the views of its individual members.

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

Of the two categories of eligible persons it was the second which provoked the most reaction from our members. Section 4(2)(b) gives the right to make a request for assistance to those who are permanently incapacitated to such an extent as to not be able to live independently and find life intolerable.

Our members were divided on this provision. Many felt that it 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. One stated:
At the end of the day, this is a choice that everybody should be able to make themselves. I don’t want other people telling when I can and can’t end my life. It’s my choice. No-one else’s”

Another said:

“As far as I am concerned, my life belongs to me, not any elected official. Therefore, if I chose to either put my life at risk by performing a certain activity, e.g. driving a car, crossing a road, parachuting, etc. or by extension, to end my life, it is my own choice. Therefore, if I am in a condition that I am no longer able to take control of my own actions to end my life, I still feel that I have the right to make the decision to request aid to perform this function.”

Many felt 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.

“If end of life assistance is not made available I will have to end my life earlier than I wish while I still have enough physical function to carry out suicide. I am grateful beyond words to those fighting for assistance to be made available.”

Indeed, this was borne out by an example given by another member who stated:

“A friend took her life recently - probably before she needed to die. Her family was devastated and felt they had failed her. If it had been possible here in the UK (she was unable to travel abroad) they could have been involved in the decision and prepared for the event”

Despite this support for the Bill, many others were extremely concerned about use of the term, ‘incapacitated to such an extent as not to be able to live independently’

Our members clearly made the point that the barriers to independent living in Scotland are numerous and extremely complex. 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. This sentiment is eloquently expressed by Jim Elder-Woodward’s article in the Scottish Herald

“To hear Margo MacDonald use the absence of independent living as an advocate for death and dying makes the blood of many disabled people run cold. Elements of Independent Living are now enshrined as “rights” under the UN Convention of Rights of Disabled People; it is the absence of such rights which makes life intolerable, not physical incapacity. It is quite wrong of
people to think that being denied such rights to live, should give disabled people the right to be assisted to die. If this bill becomes law, it won’t be their impairments which will cause them intolerable pain and discomfort, but a society which has turned its back on them; and points to the exit door.”

One of our members also stated:

“I think society should be working to ease the lives of people with disabilities, ie free personal care, more support etc. As somebody who has been disabled for over 24 years, I feel society has stepped backwards in many of its positive attitudes to disabled people, and much of the "care in the community” support that was put in place to ensure people could live independently in the community is gradually being diminished and sometimes withdrawn making it increasingly difficult for disabled people and their families. This makes disabled people feel guilty at the cost and burden it puts on families, and it worries and scares me what the implications would be should the right to die with assistance became law.”

Some members raised the possibility of a ‘rights worker’ or ‘key worker’ being allocated to any physically incapacitated person who had asked for assistance in ending their life. This worker could help to ensure the individual was accessing all services and entitlement available to them which might assist them to live independently and make their life more tolerable.

Another issue which was raised again and again was that of disabled people feeling burdensome and sensing that there was pressure on them to end their lives. This was often the result of family members struggling to cope with caring responsibilities or financial pressures.

Some of our members stated that they themselves had experienced feeling burdensome and that at its worst it had left them wondering “whether to end it all would indeed be the best thing for everybody concerned”.

Some respondents felt that as well as looking at means of facilitating independent living was a need to address care issues, support for carers, respite care and community and social care provision for family members to allow them to live their own lives and continue with their caring responsibilities.

Furthermore several of our members commented that the only moral justification for including those who are physically incapacitated in the Bill was if they were physically incapable of carrying out the act of suicide itself. Otherwise, they felt there could be no moral distinction between able bodied and the physically disabled people in relation to assisted suicide. They suggested replacing the phrase ‘physically incapacitate to the extent that they are not able to live independently’ with the phrase ‘physically incapacitated to such an extend as they are not able to end their lives without assistance’ – or similar.
The Bill outlines a several 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?

**Time Limit**

In relation to the consent and verification process the main concern of our members appears to be the making of a second request between 15 and 30 days after the first. The majority of those who responded thought that this was an insufficient period to confirm such a decision, particularly given the risk of depression and mental health problems amongst those considering suicide. One commented that:

"you usually have 31 days to change your mind about returning a sofa and surely this was a more important decision. It also take years to convince the NHS you need a sex change. 14 – 28 [sic] days just isn’t long enough."

Many of our members who responded to our consultation on the Bill said that they had experienced deep depression and even suicidal feeling upon diagnosis but that these feeling had eventually passed and that they had adapted to their new circumstances and come to enjoy full, active and fulfilling lives. Many members stressed the need for support and counseling for those who wanted to end their lives. Again, the point was raised that more support must be given to enable disabled people to live independently. Some of their experiences are recounted below:

“Some people could have a knee-jerk reaction to their condition and without real insight or knowledge of how their life could be, may want to end it. I know from experience that I had always said that I would not want to live with any disability. Life would not be worth living and I would want it to end. When I lost my sight, I presumed my life was over. However, with good support, rehabilitation and meeting others with the same condition as me, I realised that life was indeed worth clinging on to. It is important in these cases to ensure that all support is offered. Especially psychological support. That every possible programme has been offered to that person, before any consideration to assisted suicide can be made."

Another commented:

“As somebody who became paralysed at the age of 21, now over 24 years ago, I felt deeply disturbed when the young rugby player who had been paralysed ended his life with assistance. I look back to when I found myself paralysed, vulnerable and feeling as if my whole world had come to an end, and feel very relieved that there did not seem to be the acceptable choice to consider ending my life with assistance at that point in time. My experience of spinal rehab in the 80's was firm but positive, trying to prepare you for future life with a particular disability. I would be lying if I said I had never considered suicide, but this wasn't until about 10 years on, at a time of feeling isolated and down, but with help and support it became easier. As a disabled person you are at times very vulnerable, and I am deeply troubled by the debate that
is going on about the end of life assistance especially when at the same time so many cuts and changes are being made in the help and support to both the disabled and the elderly.”

In relation to terminal illness there was less comment on time periods. However, one member did state that:

“The window being offered for providing assistance is apparently small. First someone has to be deemed to have less than 6 months to live, then the process has to be concluded, which appears to take at least a month. It would be better to focus on optimising terminal care and quality of life for that time. The highest profile example of life expectancy assessment has proven woefully inadequate. The Lockerbie bomber was repatriated on compassionate grounds, with less than 3 months to live, 6 months ago. He is still alive! We do not choose to be born, nor do we expect to choose what conditions affect us during our life. Death should remain at that same level of mystery, beyond our choosing.”

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

**Procedure**

Many members that no safeguard or procedures would ever be sufficient to eliminate the risks involved in assisting people to end their lives. One member commented:

“This proposed bill to me would very soon lead to massive abuse. The bill does not have the safeguards that the 1967 Abortion Act has and yet we know how meaningless they have become. How many of those who might say that they wanted to die would in fact simply have needed diagnosis and treatment of depression? Would the doctors or the psychiatrist who may never have met the person take the time for a proper examination or evaluation taking everything into account? “

Some felt that there was also a risk that mistakes would be made, particularly where people with extreme communicative difficulties are involved. One stated

“This is an extremely dangerous route to follow, particularly with relation to disabled people. Although there is much in the bill about safeguards, it is likely that many potential users will have extreme communication difficulties, and the possibility of misunderstanding, or misinterpretation has to be there, especially if someone goes through the process then changes their mind.”

SDEF would like to reiterate the point that if any law relating to assisted suicide is passed it is essential that all information relevant to the Bill be made available and publicised in a range of formats including BLS, Easy read, audio, video etc. This should be the case with any documents involved in the process of requesting assisted suicide.
The other major concern amongst some of our members was that medical doctors were not in the best position to make decisions relating to assisted suicide. Some felt that medical doctors do not always have a sufficient appreciation of disability and the lives of disabled people. A small minority said that the medical profession was representative of a certain sector of society – namely ‘middle-aged, middle-class and able-bodied’. They felt that certain doctors might not always attach sufficient value to the life of a disabled person or understand what it can mean to live independently and how this can be achieved. The group felt that there was a need for any doctors involved in the process to receive training in disability awareness and independent living.

Others were against doctors making decisions about who should be eligible for assisted suicide because they felt that to have such wide and subjective applicability criteria – such as inability to live independently - put an unreasonable burden on the doctors who would have to make the decisions.

“These decisions would not be based on a physical medical prognosis but rather on a judgement as to whether a person’s life was tolerable or not.”

Others felt that a wider range of people should be involved in making what were “essentially moral, value based judgments”. One stated that, “there should be an independent committee set up that consisted of people from all strands of the disability and equality sector. Whether that be made up of charity groups, professional groups, voluntary groups and patient focus groups from NHS. A bit like jury service where the evidence is heard and the independent committee sat in judgment of the facts.”

This view was by no means universally held. One members stated,

“Should I choose to end my life, I feel to have to have a group of people, who do not know me, stand in judgment and decide if I can or not somewhat insulting!”

Thank you for this opportunity to present the views of our members

Johanna McCulloch
Policy Information and Parliamentary Officer
Scottish Disability Equality Forum
12 May 2010
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.
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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 focused 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 Luxembourg 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 Compassion & Choices of Oregon (who provide emotional, social and spiritual support to terminally ill Oregonians) or a family

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\(^3\) Smets T, Bilsen J, Cohen J \textit{et al} (2010) Legal euthanasia in Belgium: Characteristics of all reported euthanasia cases \textit{Medical Care} 42(2) 187-192
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 year\(^1\). This evidence relates only to *assisted dying for terminally ill patients* as assisted suicide is not legal practice\(^2\). 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 legislation\(^3\).

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 25\(^{th}\) 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.

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\(^1\) 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.
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 survey 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 dependent 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?

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

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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 year\(^1\). This means that 40% of patients

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\(^1\) 2009 Summary of Oregon’s Death with Dignity Act (2010)
potentially used the prescription as an ‘emotional insurance’\(^1\), 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 exercise\(^2\) 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\(^3\)\(^4\)\(^5\).

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).

Sarah Wootton
Chief Executive
Dignity in Dying
12 May 2010


\(^2\) Consultation on the draft proposal End of Life Choices (Scotland) Bill, December 2008 to March 2009


End of Life Assistance (Scotland) Bill

Care Not Killing Scotland

Care Not Killing (CNK) is a national Alliance, bringing together almost 50 organisations including professional associations, faith groups, human rights groups and healthcare providers. We endeavour to promote more and better palliative care, to oppose changes in the law to allow assisted suicide or euthanasia and to contribute to the debate on end of life issues.

We aim to work with MSPs, MPs, Peers and other UK leaders to improve the quality and accessibility of palliative care throughout the UK, to change attitudes and improve services for people with disabilities and to promote programs that identify and eliminate any despair that might be felt by those approaching the end of their lives.

We enclose the following:

1. Our response to the consultation on the End of Life Assistance (Scotland) Bill
2. Our card outlining our position on the bill and so far signed by 12,000 Scottish citizens
3. Our earlier letter on the bill to the Presiding Officer of the Scottish Parliament

We wish the Committee all the best in its deliberations and would be very willing, if required, to provide oral evidence.

Dr Gordon Macdonald
Public Policy Officer
Care Not Killing Scotland
12 May 2010
Executive Summary

This is a Dutch-style Euthanasia Bill with the potential to put large numbers of Scottish people at risk of self-harm. It should be rejected because:

- it is full of euphemisms and ambiguities and it does not define what sort of 'end of life assistance' would, and would not, be legal under its provisions;
- it is so widely drawn that tens of thousands of seriously ill and disabled people throughout Scotland would fall within its ambit;
- it places responsibility for providing 'end of life assistance' on the shoulders of Scottish doctors, for whom it contains no 'conscience clause' and the majority of whom would not be prepared to participate in implementing it;
- its so-called safeguards are seriously defective.

The Bill assumes the existence of a perfect world – a world in which all seriously ill or disabled people know their own minds without doubt, all relatives are 'loved ones' and all doctors have limitless time and knowledge of their patients to be able to assess requests for 'end of life assistance' accurately and dispassionately. In the real world, serious illness and disability are often accompanied by depression or feelings of being a burden. While many families provide loving care, others can be manipulative. And doctors are hard-pressed professionals whose proper role is to treat illness or relieve its symptoms. We have here a Bill which has been drafted around the wishes of a small minority of strong-minded and highly determined people but which could easily end up being applied to much larger numbers of others who are less than resolute about having their lives ended but feel they should 'do the decent thing'.

We thank the Scottish Parliament for this opportunity to comment on the current Bill, and now respond to the Committee’s specific questions:

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

No. The Bill is founded on a false assumption – namely, that it should fall to the medical profession to implement it. The only connection between this Bill and the practice of medicine is that it is targeted at people with prescribed clinical conditions. While it is the role of doctors and other health care professionals to diagnose and treat such conditions, it does not follow that, if some of those who fall within the Bill's ambit wish to have their lives ended, responsibility for performing the act should belong to their doctors. This is not just an academic point. Unlike in the Netherlands, where the legalisation of

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1 CNK (www.carenotkilling.org.uk) includes almost 50 professional groups, faith groups and human rights groups, including ten groups in Scotland.
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elation was founded on a 30-year history of medical collaboration, in Britain the Medical Royal Colleges, the British Medical Association and the majority of practising physicians are opposed to legalisation and only a small minority could be expected to consent to carrying out the Bill's provisions. Yet there is no 'conscience clause'.

Even if such a clause were to be inserted, the only way that the Bill could be implemented is by applicants going 'doctor shopping' in order to find a compliant physician. This is what has been happening in Oregon since that State's assisted suicide law was enacted in 1997, with the result that applications are being assessed in many instances by doctors who have little knowledge of the applicant beyond the case notes and who are personally sympathetic to the notion of assisted suicide. It is debatable just how much reliance can be placed on the objectivity of such assessments. It is, however, known from independent research that Oregonians with depressive disorders are getting through the net without being diagnosed during the assessment process. Is this the sort of thing we want to see happening in Scotland?

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

No. The bill states that

(1)A person may make a formal request for end of life assistance under this Act only if the person
(a) is 16 years of age or over at the time of making the first formal request;
(b) has been registered with a medical practice in Scotland for a continuous period of at least 18 months immediately prior to making that request;

While 16 is the age of majority in Scotland, in a matter of such gravity it is surely prudent and responsible to err on the side of safety with regard to the maturity of applicants. While the sub-section on registration seems to have been designed to obviate 'death tourism', it is not by any means certain that it would be effective in that regard. Registration with a medical practitioner in Scotland requires continuous residence of three months. The Bill states\(^2\) that 'it is not necessary that the requesting person should have been registered with the same medical practice throughout the [18 month] period'. It would not be difficult for a person from England to take a lease on an apartment located near to a 'sympathetic' GP or to move in with a friend or relative in Scotland and reside at that address for a period of 18 months.

We expect that most Scottish doctors would not wish to provide 'end of life assistance' and that a few compliant medical practitioners would provide the 'assistance to die' in the majority of cases. It is likely, therefore, that those wishing to avail themselves of such assistance would need to move house and change their doctor at least 3 months before the 'assistance' was provided or alternatively that some GPs would have to accept patients from outside their normal catchments. It would be therefore unlikely that the doctor concerned would have a detailed knowledge of the patient and would make it

\(^2\) Section 4(3)
difficult for the doctor to assure himself that the patient was not acting under duress. The ‘so called’ protection in the Bill which requires the doctor to be satisfied that no duress is present would, thus be no more than a formality.

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

No. The Bill’s catchment area is truly breathtaking. Section 4(2) says that, to be eligible for ‘end of life assistance’, a person must either have been ‘diagnosed as terminally ill’ or be ‘permanently physically incapacitated to such an extent as not to be able to live independently’. These two categories cover most people in Scotland who are moderately or seriously ill or disabled. They include not only those who may expect to die within the next six months, which is how the Bill defines terminal illness, or others who have degenerative illnesses such as Parkinson’s or multiple sclerosis but also people with very common conditions such as, for example, insulin-dependent diabetes, heart or lung disease or arthritis and anyone with a disability, ranging from tetraplegic paralysis to blindness, deafness and immobility, that makes them dependent on support from other people. Its requirement that an applicant must also ‘find life intolerable’ provides no effective safeguard. Such a condition is not objectively verifiable and the Explanatory Notes are candid enough to admit\(^3\) that this is a purely subjective criterion. The Explanatory Notes contain a revealing statement\(^4\). They tell us that ‘persons able to live independent lives without the need for any assistance would not qualify under the provisions of the Bill’. This makes clear that the Bill’s real target is dependency and that it is, in effect, saying to people who cannot live without support that having their lives ended is a course of action they might reasonably contemplate. Legislation can and does change social attitudes. Many people are guided in their views of what is acceptable and unacceptable by what they see the law prohibiting or allowing. This Bill risks creating a social and moral climate in which seriously ill and incapacitated Scottish people are seen as potential candidates for having their lives terminated. Is this the message that Parliament wants to send to the tens, if not hundreds, of thousands of people throughout Scotland who depend on the support of others to live their lives?

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?

No. The Bill’s so-called safeguards consist largely of its requirement that an applicant for ‘end of life assistance’ must make two witnessed applications and be assessed on each occasion by a physician and a psychiatrist. On closer inspection, however, it becomes clear that the actors in both stages of the assessment process are, to a large extent, the same people. The Bill specifies\(^5\) that the second request ‘must be addressed to the designated

\(^3\) Paragraph 21

\(^4\) Paragraph 22

\(^5\) Section 8(2)(b)
practitioner’, who has been defined earlier\(^6\) as ‘the registered medical practitioner to whom a first formal request has been made’. There is no provision, therefore, for a second and independent medical opinion: it is simply the same doctor assessing the same patient on two different occasions. It is more than likely that, having recently approved the first request, the ‘designated practitioner’ will approve the second one.

Similarly, the Bill prescribes\(^7\) that the psychiatrist who examines the applicant at the second stage ‘need not be the psychiatrist who acted in relation to the first formal request’. However, if the referral is made by the same ‘designated practitioner’, it is likely to be to the same psychiatrist who sees the applicant at the second stage, unless the applicant should insist on seeing someone else. The same principles apply to the witnessing of the second application. With the same actors involved at each stage, the assessment process lacks proper rigour: the second stage will be no more than a rubber-stamping of the first.

The Bill requires that the second application should be made no more than 30 days after the first one has been approved\(^8\). Such a timetable may perhaps suit a very small number of strong-minded applicants who have thought long and hard about seeking ‘end of life assistance’ and are fully determined to proceed. But it risks pressuring less resolute people to press ahead in order to avoid having to start the process all over again. Moreover, the Bill is making assumptions about the availability of psychiatric resources which may well be unfounded. Psychiatrists have waiting lists of other patients and it must be doubtful whether, without queue-jumping, an applicant for ‘end of life assistance’ could be examined at the short notice that the Bill requires.

The psychiatrist is required to assess whether the applicant ‘has capacity to make the relevant request’\(^9\) and to confirm that he or she ‘is not suffering from any mental disorder which might affect the making of such a request’\(^10\). Here the Explanatory Notes refer\(^11\) the reader to Section 328 of the Mental Health (Scotland) Act 2003 and on this basis they define mental disorder as comprising ‘mental illness, personality disorder or learning difficulty’. It is not clear whether this definition covers people who are in all respects mentally healthy except that they are depressed – a common enough condition generally but particularly common among people who are seriously ill.

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

No. In addition to matters raised in the previous section another important question arises: is the Mental Health Act an appropriate psychiatric tool for assessing whether lives should be ended? The Explanatory Notes make clear, for example, that the 2003 Act does not include within its definition of

\(^6\) Section 2(2)
\(^7\) Section 9(6)
\(^8\) Section 8(1)(c)
\(^9\) Section 9(3)
\(^10\) Section 9(4)
\(^11\) Paragraph 64
mental disorder ‘dependency or use of alcohol or drugs’. Are we to understand therefore that a psychiatrist would be required to disregard the presence of an addiction to drugs or alcohol in assessing whether a person has the capacity to have his or her life ended? Mental health legislation exists primarily to protect people from self-harm, not as a vehicle for enabling them to kill themselves or to be killed. This is surely a misuse of the 2003 Act.

The psychiatrist is also required to assess whether a request for ‘end of life assistance’ is being made voluntarily and without external influence. This in itself is far from being a straightforward and infallible process. But it is much more difficult, yet equally necessary, to ensure that an applicant is not acting as the result of internalised pressures, such as a sense of duty to remove him or herself as a care burden on the family or to avoid consuming in nursing home fees money that is ‘needed’ by children. Such requests for ‘end of life assistance’ may possibly be voluntary and free from external coercion, but they may well not stem from a wholehearted and determined wish to die.

These and other weaknesses of the Bill’s so-called safeguards share a common feature. They rest on an assumption that those who will request ‘end of life assistance’ will know their own minds beyond doubt and will be thoroughly resolute about carrying out their intent. This is a false assumption. In today’s individualistic society the pressures on sick, disabled and elderly people to avoid placing what they may see as unfair burdens on others are such as to open the way for this Bill to be used by many less-than-serious applicants whose underlying but concealed motivation is a wish to spare others rather than to end their own lives. Maintaining the law’s protection of this silent and vulnerable majority is more important than giving choices to a minority of strong-minded and highly resolute people.

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

The Bill is vague about precisely what it is seeking to make legal. It purports to legalise ‘end of life assistance’ for people who are seriously ill or disabled. It does not, however, specify what that assistance might be. We are told that it includes ‘the provision or administration of appropriate means’\textsuperscript{12}, that the physician concerned must agree with the applicant ‘on the means by which that assistance is to be provided’\textsuperscript{13}, that ‘the end of life assistance must, so far as reasonably practicable, be provided in accordance with the agreement’\textsuperscript{14}, that it must be provided ‘before the expiry of 28 days’ and that ‘the designated practitioner must be present at the end of the requesting person’s life’\textsuperscript{15}.

The Bill is silent, however, on precisely what manner of ‘end of life assistance’ is to be legalised. The reader may assume it to be the prescription or administration of lethal drugs, but there is nothing in the Bill as it stands to exclude other forms or killing or assistance with suicide, such as suffocation,

\textsuperscript{12} Section 1(2)
\textsuperscript{13} Section 10(1)(d)
\textsuperscript{14} Section 11(1)
\textsuperscript{15} Section 11(6)
carbon monoxide poisoning, hanging, shooting or a push over a cliff. This worrying silence probably stems from a desire on the part of the Bill’s authors to avoid causing concern by spelling out what is involved – handing out suicide pills or injecting people with lethal drugs. Whatever the reason, the Bill in its present form is unacceptable as a legislative instrument. Euphemisms and verbal evasions have no place in the rigorous practice of law-making, particularly when life-or-death issues are involved.

It is clear from the Bill’s definition of ‘end of life assistance’ that it is intended to cover both assisted suicide (where a patient is provided with lethal drugs by a physician for self-administration) and euthanasia (where a physician administers lethal drugs to a patient directly). This is therefore a Dutch-style euthanasia bill rather than an Oregon-style bill providing only for assisted suicide. For this reason the Oregon-based estimate given in the Explanatory Notes that the Bill would result in some 55 deaths a year in Scotland is considerably wide of the mark. Based on the experience of The Netherlands, where a similar euthanasia regime operates, the number of Scottish deaths caused annually would be many times this figure – perhaps as many as 1500.

The Bill’s purpose at 1(2) is said to be ‘to enable a person to die with dignity and a minimum of distress’. However this is properly the role of good palliative care. The proposed simple discussion of the alternative of palliative care is not sufficient. Help the Hospices said this to the House of Lords select committee on Lord Joffe’s Assisted Dying for the Terminally Ill Bill five years ago: ‘Experience of pain control is radically different from the promise of pain control, and cessation is almost unimaginable if symptom control has been poor. On this view patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed’. Under Belgium’s euthanasia law, those requested to administer euthanasia are entitled to make their agreement conditional on the applicant first undergoing a course of palliative care. Most who experience this ‘palliative care filter’ withdraw their applications for euthanasia.

Conclusion

This Bill is flawed both in detail and in principle. Care Not Killing calls upon the Scottish Parliament to reject this Bill at the earliest opportunity.

Gordon MacDonald
Public Policy Officer
Care Not Killing Scotland
12 May 2010

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16 It is interesting that Paragraph 8 of the Explanatory Notes states that assistance ‘may include the provision or administration of appropriate means of ending life’. The significance of ‘may’ is not at all clear.
17 Section 2(1) (‘the provision or administration of appropriate means’)
18 Paragraph 88
19 See House of Lords Report 86-I (Session 2004-05), Paragraph 243, which contrasts death rates from physician-assisted suicide in Oregon (1 in 700 deaths) with those from physician-administered euthanasia in Holland (1 in 40 deaths).
Mr Alex Fergusson MSP  
Presiding Officer  
The Scottish Parliament  
Edinburgh  
EH90 1SP

Dear Presiding Officer,

Re: Proposed End of Life Choices (Scotland) Bill

I am aware that you will presently be considering the competence of the End of Life Choices (Scotland) Bill prior to it potentially being dealt with by the Scottish Parliament. I would like to take this opportunity to express Care Not Killing’s deepest concerns about this Bill. We are advised that particular features of the Bill conflict with the European Convention on Human Rights. As you know such conflict would, under the terms of the Scotland Act, place the proposed legislation outside the competence of the Scottish Parliament.

Suicide in itself is not lawful in Scotland or in the United Kingdom; it has however, for reasons of compassion to victims and their family members, been decriminalised in England and Wales and has not been prosecuted for such reasons in Scotland. The unlawfulness of suicide is the basis for the severe penalties which attach to assisting suicide which is regarded as a form of homicide.

Article 2 of the European Convention on Human Rights provides that:

1. Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:
   a. in defence of any person from unlawful violence;
   b. in order to effect a lawful arrest or to prevent escape of a person lawfully detained;
   c. in action lawfully taken for the purpose of quelling a riot or insurrection.
The positive obligations under this article which have arisen in the jurisprudence of the European Court of Human Rights in Strasbourg, notably since the McCann v UK case, provide clear guidance that States bound by the terms of the convention are obliged not only to refrain from depriving persons of life within their territory but also must take actions to prevent threats arising within society which place the lives of persons within their jurisdiction at risk.

In the case of Osman v United Kingdom the European Court of Human Rights stated that:

"The Court notes that the first sentence of Article 2(1) enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction. It is common ground that the State’s obligation in this respect extends beyond its primary duty to secure the right to life."

Thus, Article 2, as set out above, contains a negative restraint on the State but also requires the State to take active steps for the protection of life.

In Pretty v United Kingdom, the European Court of Human Rights state that:

"The consistent emphasis in all the cases before the Court has been the obligation of the State to protect life. The Court is not persuaded that the ‘right to life’ guaranteed in Article 2 can be interpreted as involving a negative aspect ... it is unconcerned with issues to do with the quality of life or what a person chooses to do with his or her life ... nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life."

The Parliamentary Assembly of the Council of Europe has made known its policy on the matter which was quoted in the consideration of the Diane Pretty Case where the applicant sought permission for assisted suicide.

"The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects ... (c) by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while (i) recognising that the right to life, especially with regard to a terminally ill or dying person, is guaranteed by the member states, in accordance with Article 2 of the

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1 McCann and Others v UK, (App. 10264/91), (1995) 21 EHRR 97
2 (1999) 21 EHRR 12
3 Application No. 23944/02, 26 April 2002
European Convention on Human Rights which states that ‘no one shall be deprived of his life intentionally’; (ii) recognising that a terminally ill or dying person’s wish to die never constitutes any legal claim to die at the hand of another person; (iii) recognising that a terminally ill or dying person’s wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death."\(^4\)

I draw to your attention the fact that legal regimes which permit forms of assisted dying inevitably give rise to threats to the lives of vulnerable people resulting in deprivation of life contrary to the protection guaranteed by Article 2. This in itself places a responsibility on authorities within State Parties to take action to prevent the threat arising. Moreover, Article 14 of the Convention establishes that the rights in the Convention should be applied in a non-discriminatory manner. This (combined with Article 2) suggests that legislation which is likely to disproportionately threaten the lives of people who are disabled or who belong to other groups would be contrary to the Convention.

The Human Rights Committee of the United Nations has explicitly raised concern over the legal system’s oversight of euthanasia in the Netherlands\(^5\) which has been cited publicly by the Ms Macdonald as a model for safeguards in her proposed Bill.

Care Not Killing requests you to reject this Bill as being under the terms of the Scotland Act, ultra vires for consideration by the Scottish Parliament as it contravenes the European Convention of Human Rights. I realise these concerns touch on important issues and look forward to your consideration of such a serious matter. I am willing to ensure that further information can be provided should you require it.

Yours sincerely

Dr Gordon Macdonald
Policy Officer, Care Not Killing Scotland


End of Life Assistance (Scotland) Bill

Age Scotland

Please find attached Age Scotland’s submission to the End of Life Assistance Bill Committee’s call for evidence on Margo McDonald MSP’s End of Life Assistance (Scotland) Bill.

Also attached is an analysis of a survey we did of readers of our member publications. Unfortunately it was impossible to keep the length of this document to six pages so it exceeds the maximum length asked for by the Committee. I offer our apologies for that but there really was no way to make it shorter without losing the detail that the survey found.

About Age Scotland

Age Scotland welcomes the opportunity to respond to the Committee’s consultation on Margo McDonald’s End of Life Assistance Bill.

Formed by a merger of Age Concern Scotland and Help the Aged in Scotland, Age Scotland has a vision of a Scotland and a world where older people flourish as valued and equal citizens. We will act to help all older people, present a strong and effective voice and reduce the challenges for those facing serious and multiple disadvantages as they grow older.

Introduction

Assisted suicide is one of the most emotive and divisive issues that the Scottish Parliament has ever considered and Age Scotland does not feel able to support or oppose what is for many people a matter of individual conscience. Given the sheer weight of opinion on either side and the lack of a clear and decisive, objective answer to the issue of assisted suicide, we carried out a survey to enable us to represent the full range of views of our members to the Committee. Analysis of the survey is included as an accompanying document.

As an organisation we have treated the bill even-handedly and objectively as we see our role as helping MSPs find areas of the Bill that would benefit from amendment if, and only if, MSPs themselves choose to support it. It would be folly if we were to ignore the Bill or avoid engaging in the legislative process because of the controversy around the issue of assisted suicide; if the Bill was passed without scrutiny from organisations such as Age Scotland we would be in a weak position if we wished to criticise any aspect of it.

Detailed analysis of the Bill

Beyond the moral and ethical objections that many people have and, equally, the reasons people have for supporting the Bill, there are a number of areas where the Bill could require more detail or could potentially create ambiguity.
Ability to communicate

The Bill states that a person who has a lack or deficiency in their ability to communicate should not be considered as lacking capacity to request end of life assistance, provided that lack or deficiency can be made good by human or mechanical aid. This in itself is not necessarily a problem, but the Bill specifies that this can include aid of an “interpretative nature”. There is a great deal of controversy around a form of interpretative communication known as facilitate communication. The evidence for the accuracy and reliability of this method of communication is weak and there is a great deal of evidence to suggest that the ‘interpreters’ are influencing the content and form of the communication far more than the person supposedly communicating\(^1\). Obviously, in the context of end of life assistance it would be remiss to allow a request to be made through a largely discredited form of interpretative communication.

A lack of specific detail around what forms of assistance are available

It is logical that the Bill would avoid listing the forms of end of life assistance because it would set in legislation a fairly rigid list of potential means of end of life assistance that could only be amended through further legislation. The policy memorandum accompanying the Bill notes, however, that the means and method of delivery have not been specified as it “reflects an individual’s choice, acknowledges medical development and accepts expertise is best left to registered medical practitioners.” This may be problematic in that – even in contentious issues such as end of life assistance – there will undoubtedly be best practice considerations. Some means of end of life assistance will be ‘better’ than others (better being taken to mean quicker, less painful etc) and it would be useful to at least attempt to offer evidence to allow doctors to make an informed decision.

Doctors will not necessarily know what the best means of offering end of life assistance are in particular circumstances and if the Bill is passed it would presumably be preferable to offer some form of advice. Some doctors will be content without it, but it would provide some evidence for doctors to support their proposals during discussions about the actual method of end of life assistance provided to an individual who has requested it.

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\(^1\) For more on a recent high profile case of assisted communication:
http://www.livescience.com/strangenews/091201-coma-victim.html
Evidence from studies of the method can be found here:
http://www.dcsf.gov.uk/research/data/uploadfiles/RR77.pdf
The views of the National Autistic Society on assisted communication are available here:
http://www.nas.org.uk/nas/jsp/polopoly.jsp?%3ca%3d%22http%3a%2f%2fwww.nas.org.uk%2fnas%2fjsp%2fpolopoly.jsp%3f%3ena%3d1384%26a%3d%22%26d%3d1384%22%3e%22http%3a%2f%2fwww.nas.org.uk%2fnas%2fjsp%2fpolopoly.jsp%3f%3ena%3d1384%26a%3d%22%26d%3d1384%22%3e
End of life choices for people with dementia

It has been noted by some of our survey respondents that they would wish to make use of the provisions of the End of Life Assistance (Scotland) Bill if they were suffering from dementia or Alzheimer disease. This is not something that the Bill's provision would likely enable.

If someone in the early stages of developing dementia was to request end of life assistance, it is unlikely that they would meet the criteria in that they would not be “permanently physically incapacitated to such an extent as not to be able to live independently.” By the time an individual did meet that criteria, it is highly unlikely that they would be able to give informed consent and so would not meet the criteria for having capacity.

This is not necessarily a flaw in the Bill but it is one that should be borne in mind given the perception among some members of the public that the Bill would allow assisted suicide, or even euthanasia, for people with dementia.

People with rapidly deteriorating conditions

The accompanying documents make clear that the Bill would not necessarily prevent people suffering extended periods of pain or indignity before their death and one area where this is particularly the case regards people who have an illness that deteriorates rapidly. An individual may have a progressive disease (i.e. a non terminal disease) during the latter stages of which their health deteriorates rapidly. Until their health deteriorates to the point that they meet the criteria for non-terminal illness they would be ineligible to apply for end of life assistance, but once they reach that point they may die before the process can be completed.

Again, this is not necessarily a flaw in the Bill but it is important that expectations of what the Bill could achieve are realistic.

Difficulties with the definition of ‘terminal illness’

It has been mentioned by some commentators that there is not a clear distinction between terminal and non-terminal illnesses. In some cases of cancer, the final cause of death is an infection or other health problem exacerbated by the cancer and/or treatment. Similarly, an individual diagnosed with Aids can reasonably expect to live a relatively healthy life, albeit with significant medical intervention. The potential ambiguity about whether illnesses are terminal could potentially lead to legal challenges as to whether or not an individual is eligible for end of life assistance. This is exacerbated by the possibility that an individual may choose to refuse treatment in order to bring their life expectancy to within the six month period required to be eligible for end of life assistance. The Bill does not appear to address this possibility, and it may well be that it is the intention to allow individuals that choice.
Ambiguity around the definition of “living independently”

The Bill would allow people who are permanently physically incapacitated to the extent that they can no longer live independently and find their life intolerable to seek end of life assistance. However, this criterion potentially covers a very wide range of circumstances because of ambiguity about the precise circumstances in which an individual is considered to be able to “no longer live independently.”

“Independent living” is a concept frequently used by disability advocates to describe the circumstance where an individual who has a disability is enabled to live in their own home, albeit with whatever support, adaptations or equipment they require. Similarly, Government, charities and social care workers often refer to free personal care as allowing older people “to remain living independently in their own home.” However, as far as it is possible to tell this is not defined in law. As such it would be possible to argue that “living independently” could mean “living in one’s own home without any support.”

This could prove problematic in some circumstances. For example, an individual who lives in their own home but requires the delivery of meals on wheels on account of severe arthritis could be argued to be “permanently physically incapacitated to the extent that they can no longer live independently”, which would mean that they would be eligible for end of life assistance if they felt their life to be intolerable. It seems likely that this is somewhat at the lower end of the scale of severity envisioned by the authors of the Bill, although it may well be the case that they have already considered this.

Alternatively, if “living independently” is taken to simply mean “living in your own home” the consequence is to entirely restrict access to end of life assistance for people living at home who are not terminally ill. It would mean that an individual with, for example, severe mobility problems who is cared for in a nursing home and feels their life is intolerable would be eligible to request end of life assistance but an individual with the same mobility problems being cared for by their partner at home would not. In this sense it would make eligibility for end of life assistance more about where someone lived than about their health. It seems unlikely that this is the intention of the Bill.

This ambiguity could place medics in the invidious position of making decisions that are outwith their professional expertise.

Potential conflict of interest in witness requirements for care home residents

The Bill provides that care home residents seeking end of life assistance would require one of their two witnesses to be an employee of the care home appointed by the care home manager, and that this witness must be able to attest to the lack of any pressure or undue influence on the person making the request. This could be problematic in cases where an individual was being pressured by care home staff to request end of life assistance. It seems likely
that this set of circumstances would be extremely rare but it is a potential hole in one of the safeguards set out in the Bill. It may well be that the designated medical practitioner and psychiatrist would pick up such a circumstance during their own investigations but it places a great deal of responsibility on their shoulders to be the arbiter of aspects that lie outwith their professional expertise in medicine and psychiatry respectively.

Some of the time limits are vague

The Bill’s Policy Memorandum offers some guidance on the length of time in which the designated medical practitioner and psychiatrist are expected to approve formal requests for end of life assistance. It states that there is no particular time limit but that the designated practitioner and psychiatrist should be mindful that the person requesting end of life assistance is doing so because they feel their life is intolerable. This is somewhat vague and would potentially allow a designated medical practitioner who opposes the availability of end of life assistance to deliberately slow down or delay the process. The Bill would, of course, allow any medical practitioner (including anyone who would be involved in providing the end of life assistance itself) to decline to be involved on the grounds of moral objection and it is highly likely that the vast majority of nurses, doctors etc who oppose it would take this route. However, it would seem wise to provide a definite time limit on consideration of requests to close this potential obstruction.

Similarly, there is no time limit specified for a care home manager to appoint a member of staff to act as witness although the Bill does provide for a disregard of that requirement if none is forthcoming within a reasonable time scale. This again could be more tightly defined as it is not entirely clear who would have responsibility for deciding how long to wait for a care home witness – presumably it would be the designated medical practitioner – and it places a great deal of responsibility on them to decide precisely how long is reasonable.

Nick Waugh
Senior Policy and Parliamentary Officer
Age Scotland
12 May 2010
End of Life Assistance Bill survey

Introduction
In advance of the introduction of Margo McDonald MSP’s End of Life Assistance Bill, Age Scotland took the opportunity to survey the views of its members on the principle of assisted suicide.

In November 2009 we sent out a survey with our member magazine. 970 copies were distributed by this means and we received 296 returns. However, many older people’s groups photocopied the survey sheet so it is likely that the actual number of copies distributed is far higher than 970.

It is important to note that Age Scotland does not have a position on the Bill. The purpose of this survey was to gauge the opinion of our membership (although many recipients will not actually be members) and to allow the views of older people on the issue to be represented in their entirety.

This is a basic survey and we would caution against considering its findings to be an entirely accurate representation of the views of older people in Scotland.

Key findings
- 65% of respondents support legalising assisted suicide for people with a terminal illness and 31% oppose it.
- 28% of respondents support assisted suicide for people who are not terminally ill and 64% oppose it.
- 54% of respondents said they would consider assisted suicide as a means to end their own lives.
- 89% of respondents who opposed legalising assisted suicide report that they are religious. However, 50% of all respondents who said they were religious supported legalising assisted suicide for people with a terminal illness.

Detailed analysis of responses

Question 1
Do you support the principle of legalising assisted suicide for people with a terminal illness?
As Table 1 shows below, a majority (65%) of respondents support the principle of legalising assisted suicide for people with a terminal illness. A significant minority (31%), however, oppose it. A very small proportion (4%) said they don’t know whether they support or oppose it.

The nature of the survey means that people who would answer ‘don’t know’ are perhaps less likely to respond. As such the proportions of people who say they support or oppose the principle may be higher than if the survey had been more representative of the older population at large.
Table 1: All responses to Question 1
Do you support the principle of legalising assisted suicide for people with a terminal illness?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>191</td>
<td>93</td>
<td>12</td>
<td>296</td>
</tr>
<tr>
<td>65%</td>
<td>31%</td>
<td>4%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Question 2
Would you support allowing assisted suicide for people who are not terminally ill?

Support for the principle of allowing assisted suicide for non-terminally ill people was markedly lower than for terminally ill people.

Table 2: All responses to Question 2
Would you support allowing assisted suicide for people who are not terminally ill?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>83</td>
<td>188</td>
<td>25</td>
<td>296</td>
</tr>
<tr>
<td>28%</td>
<td>64%</td>
<td>8%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 2 shows that 28% of all respondents said they would support assisted suicide for people who were not terminally ill in comparison to the 65% who supported assisted suicide for terminally ill people.

As might be expected, all the respondents who opposed legalising assisted suicide for the terminally ill also opposed its legalisation for people who were not terminally ill.

Table 3: Of the 191 who said 'yes' to question 1
Would you support allowing assisted suicide for people who are not terminally ill?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>83</td>
<td>84</td>
<td>24</td>
<td>191</td>
</tr>
<tr>
<td>43%</td>
<td>44%</td>
<td>13%</td>
<td>100%</td>
</tr>
</tbody>
</table>

The most interesting responses to this question were from the 191 respondents who answered yes to question 1, which can be seen in Table 3. Of these respondents, 13% said they didn’t know whether people without terminal illnesses should be able to access assisted suicide, 44% opposed assisted suicide for non-terminally ill people and 43% supported it. This strongly suggests that even among people who support the principle of assisted suicide for the terminally ill there is significant opposition to assisted suicide for people who are not terminally ill.
However, there is an important point to be made about the responses to this question. The survey was distributed before the Bill was published and so the question about assisted suicide for people who are not terminally ill does not reflect the precise circumstances in which the Bill would make assisted suicide available (i.e. a chronic condition that prevents them from living independently and has led to a life they deem to have be unbearable).

The survey question also does not take into account the safeguards and procedures that a person requesting assisted suicide – whether terminally ill or not – would have to go through. It is possible that some respondents may have answered differently if the provisions of the Bill had been explicitly referenced in the survey.

**Question 3**
*Would you ever consider assisted suicide as a means to end your own life if you were terminally ill?*

This question does not differentiate between whether people would consider assisted suicide as a means to end their own life under the system proposed by Margo McDonald, under another legalised system or even if it remained unlawful. We did not ask a similar question about assisted suicide if respondents were not terminally ill because we did not at that point know enough about the precise wording of the Bill.

*Table 4: All respondents*
*Would you ever consider assisted suicide as a means to end your own life if you were terminally ill?*

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>159</td>
<td>110</td>
<td>27</td>
<td>296</td>
</tr>
<tr>
<td></td>
<td>54%</td>
<td>37%</td>
<td>9%</td>
<td>100%</td>
</tr>
</tbody>
</table>

As can be seen in Table 4, a slim majority of 54% said they would consider assisted suicide as a means to end their own lives if they were terminally ill, 37% said they would not and 9% did not know.

*Table 5: Of the 191 respondents who answered yes to question 1*
*Would you ever consider assisted suicide as a means to end your own life if you were terminally ill?*

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>159</td>
<td>12</td>
<td>20</td>
<td>191</td>
</tr>
<tr>
<td></td>
<td>83%</td>
<td>6%</td>
<td>10%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Perhaps unsurprisingly, all those who opposed legalising assisted suicide said they would not consider it for themselves. As can be seen in Table 5, of the 191 respondents who answered yes to question 1, 83% said that they would consider assisted suicide for themselves if they were terminally ill, with a further 6% saying they would not and 10% saying they didn’t know.
Demographics and representativeness
The demographics of responses are slightly out of line with the overall population of older people in Scotland but roughly in line with what we would expect from members of older people’s groups and forums, in as much as the majority of respondents were female. However, we would warn against considering the survey to be representative of older people’s views on the issue for a number of reasons.

Firstly, we don’t know which part of Scotland responses came from and we have not weighted responses according to factors such as socio-economic status, age, gender or religion. Similarly, only those with strong views either way are likely to return such surveys meaning that the number of people with ambivalent feelings on the issue is underrepresented. As such the results should only be taken as an insight into the views of our members rather than an accurate dissection of them.

Male/female split
The responses were disproportionately from women, something that backs up consistent observations that members of older people’s forums are more likely to be female than male.

Table 8: All responses to demographic questions

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>81</td>
<td>211</td>
<td>292</td>
</tr>
<tr>
<td>28%</td>
<td>72%</td>
<td>100%</td>
<td></td>
</tr>
</tbody>
</table>

Religious belief
We asked respondents about their religious belief – or otherwise – as a means to see if there was any significant difference in the distribution of religious belief in responses to the questions. This will be explored later in the analysis.

As can be seen from the table below, the majority of respondents (62%) consider themselves to be religious. The next most common category is ‘agnostic’ with 13%, followed by ‘atheist’ with 10%, ‘don’t want to say’ on 9% and ‘don’t know’ with 6%.

Table 9: All responses to demographic questions

<table>
<thead>
<tr>
<th></th>
<th>Atheist</th>
<th>Agnostic</th>
<th>Religious</th>
<th>Don’t know</th>
<th>Don’t want to say</th>
</tr>
</thead>
<tbody>
<tr>
<td>28</td>
<td>39</td>
<td>180</td>
<td>18</td>
<td>27</td>
<td></td>
</tr>
</tbody>
</table>
End of Life Assistance (Scotland) Bill

Preamble and position statement

We are delighted that this issue, and hopefully legal reform, is being given serious consideration. EXIT* supports a relatively conservative approach to law reform on end of life issues. With proper legislation, we do not accept that fear of ‘inevitable abuse’ is at all well-founded. But we do accept that unfounded fear might conceivably occur, and that it could be distressing. With that in mind; and also to allay some of the concerns of critics; and also in the interests of superior legislation; we favour a system whereby End of Life Assistance is of the nature of an exception to the rule of existing law, and as such may be argued on an individual case-by-case basis. The objective would be to bring about a system under which such individual exceptions could be permitted for exceedingly deserving cases. The extent and remit of such exceptions to the rule can then move with the light of experience and public opinion. The alternative is creating in advance a system of check-boxes, under which assistance will be allowed, which we would argue is far less desirable.

Future scenarios cannot always be predicted with accuracy. Public interest might suggest initial cases be handled through the judicial system, with public scrutiny, and until sufficient examples create a consensus on which exceptions to the rule should be allowed. Even if the bill does not approach legislation exactly in this manner, some degree of flexibility might perhaps be considered so that any new law can be reviewed, refined and modified in the light of experience.

Concerning specific points raised in the Call for Written Evidence:

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

Yes. But it must be clear that the registered medical practitioner is willing to consider such request without pre-judging the options. Only in this way could a patient feel a) assured that the request will be considered without prejudice, b) that the practitioner is examining palliative care options with the patient without prejudice and is open to the eventual wishes of the patient, c) an atmosphere of trust is in evidence within which to explore all available options. The practitioner must also consider the request without predetermination in order to make an initial assessment of whether the patient has capacity (In other words: not assume that a request for end of life assistance implies delusional or depressed states; and certainly not that incapacity in one sense implies incapacity to make a competent request).
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Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

Partially. The attitude of consent in Scotland, and the Age of Legal Capacity (Scotland) Act are important. At 16 years of age, a person may or may not fully understand the implications of a decision to end her or his life. It is a situation more exceptional than when a person is over the age of 21. EXIT has debated the age question at length in relation to provision of information on suicide (even though such information is commonly available in bookstores). For a person who is over the age of 21, we feel that an adult can be assumed to have capacity and the right to make such decisions, unless ‘alarm bells ring and there is evidence to the contrary.’ Although the Bill makes provision for psychiatric assessment, we would like to see especial care and consideration given to any request by someone who is under 21. We are particularly mindful that many teenagers go through a ‘phase’ of feeling suicidal, or that life is not worthwhile. This does not mean that such a person can not make a competent request, but simply that there are extra factors to be considered with great care. Just as they do for persons over 21, the requests need to be handled openly, responsibly, with transparency and lack of bias, and with full compassion. In this way public feeling – often even more sensitive when the life of a person in the full bloom of youth is concerned – can also be properly satisfied.

Imagine, for instance, a borderline case of a teenager who has a terminal and unbearable disease. Denied the opportunity to speak about end of life assistance openly and without bias, she or he feels compelled to make a decision alone – and with whatever gruesome end that might entail. Perhaps, given proper legislation and open scrutiny, the situation might have led him to ‘weather the storm.’ On the other hand, were there no possible respite, he could be availed of dignified, certain assistance – rather than an ignoble and possibly botched attempt that could serve to increase his physical, mental and emotional torment during his last moments even further.

Consideration of borderline cases can also help when applying tests to adults. The young and the very old may have similarities in feeling they are not allowed complete control of their own life. EXIT's most common letter of thanks is along the lines of, “Thank you for giving me the knowledge so I know what to do, should I ever need to.” For most of our members, the information on how to end their lives is never used; but it gives them immense reassurance, hope and courage to face an uncertain future. It gives back a sense of control.

It is this very sense of owning one's own life that an effective end of life assistance bill could and would provide. Following on from this, EXIT feels less than comfortable about the 28-day cut-off (section 11(2)). The knowledge of ‘a way out’ is one of the major benefits of such legislation. The experience of EXIT is mirrored by granting of requests in Netherlands and in Oregon, where many patients who have had a request granted do not go on to actually use it. This does not mean the request was pointless: on the contrary. Immense comfort is derived from the knowledge that there is someone there
who is willing to help in the last resort (in the way the patient wants). Many illnesses can be unpredictable. Additionally, where pain is the issue (often it isn’t, but it is one that is much feared), then the pain which is often the most difficult to palliate occurs in the final phase just before death. If the patient has gone to the trouble of making a request which has been granted, it might be inhumane to suddenly withdraw it. It could even precipitate untimely action on behalf of a desperate patient. Therefore we would recommend other safeguards if there are concerns over a time period.

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

The criteria we think of are ‘unbearable and unrelievable.’ Public knowledge has broadened our understanding, especially with cases such as that exhibited by Debbie Purdy, that being terminally ill is an inappropriate restriction. We could envisage certain cases of mental anguish even, that were unrelievable and unbearable by any reasonable standard, such as have been exhibited in test cases abroad. But these cases might best provide the necessity fully to review and modify legal provisions rather anticipating them. Law is sufficiently flexible to have responsible review periods written into a statute, after all. This is sometimes better than trying to envisage the particular anguish of a case that has yet to occur.

The Bill outlines a several 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?

It is important that at least one person who knows the eligible person well is able to give evidence. In some cases it might be hard to find sufficiently suitable persons, and in such cases the judicial system, or a review process set up under it, must be able to determine a lack of selfish interest and so on. A similar consideration has been put forward by the DPP of England & Wales in setting forth reasons not to prosecute (persons assisting those who travel to Switzerland).

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

Although the involvement of a psychiatrist is welcomed, it should not be forgotten that capacity is ultimately a legal test, not a medical one; and that the decision is based on proper consideration of medical evidence, not ultimately made by medics. Para 9(4) does not strike me as clear enough. Capacity requires that the eligible person retains the information upon which the decision is made, not simply remembers making it.

Another important point is to ensure that any assessment of capacity takes into consideration, and provides where at all possible, optimum situations or scenarios where an eligible person’s capacity is enhanced (much work has been done on this by the professions).
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We would also prefer to see the bill framed along the lines set out in our preamble - providing for a system of exceptions to the present rule of law rather than just saying in advance who qualifies. With the law as it stands, the courts have no power to make such an exception; even if there were to be a general rational consensus within the professions, and even backed by public outcry. The present lack of clear legislation for exceptional cases leaves the Procurators Fiscal in a potentially embarrassing situation. Compassionate ‘crimes’ have in some cases been handled by the courts very lightly. It is hardly good enough to lump a doctor (or other person acting compassionately, unselfishly, and at the competent and persistent request of another) with a common murderer.

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

I would like to see guidance included with the bill to set forth its aims and principles, of respecting autonomy, of compassionate motivation, of making available through medicine the options to relieve suffering, of openness and transparency, of a default to respect life but a willingness to accept that in some exceptional cases the person may place the relief of suffering above continued existence.

The primary objective and underlying principle should be to relieve suffering, and that (as with any medical intervention) by the least intervention necessary to achieve the aim.

Only by making clear at the outset the principles upon which any bill is passed, can we ensure that sufficient guidance is provided to those responsible for implementing it, and ensuring its proper observance and interpretation. Otherwise we could face a quagmire of future ambiguities, uncertainties and tussling over semantics. Guiding principles must be clear, both to avoid abuse, and to avoid legal wrangles – perhaps while a patient suffers. They are also necessary to ensure compassionate consistency. Finally the fear of abuse, even if groundless, must be properly addressed by showing requests can only be granted in exceptional circumstances, when they are persistent, and when the eligible person has a clear case, in full knowledge of all other options and, with that knowledge, able to decide whether to make a request.

General statement

Whether one believes in a religion or not (and we maybe have to accept that a large proportion of Scots do not), there isn't anyone who doesn't appreciate kindness and compassion. Kindness and willingness to help another may also result in harm of course, and the law places reasonable limits. But 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. It has been argued that death cannot be included in this pursuit since it negates life itself: but this misses the point. Death might
not be ‘part of life’ but the dying process certainly is. People have a legitimate wish to be able to control that in their own way.

It has also been suggested that there is a wider danger – to other members of society. That they will become fearful of their doctors. Or feel pressured. Due vigilance and openness must ensure that no request is ever granted where there is a suspicion of nightmarish influence from malicious doctors or greedy relatives. But the distress of imaginary fears can be treated in extreme cases by the psychiatric profession. The distress of a person suffering excruciating indignity from very real and present end-stage physical disease is not just equally deserving of having it attended to; it trumps the vague imaginings of someone who just needs reassured and protected.

This is not about protecting adults from themselves: it’s about giving adults proper respect at a time when they need it most.

Exit thanks the members of the Committee for kindly taking the time to consider our points made above. We would be happy to answer further questions if the committee wish us to do so.

Chris Docker M.Phil (Law & Ethics in Medicine)
Director
EXIT
Introduction
1 Alzheimer Scotland is Scotland’s leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people with dementia and carers in getting their views and experiences heard. We have a membership of 4000, including carers, people with dementia, professionals, professional bodies and a range of voluntary and private agencies. We provide specialist services such as day care, home support and carer support (through training programmes and support groups) in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website and our wide range of publications.

2 Alzheimer Scotland welcomes the opportunity to submit evidence to the Committee. Our comments have specific regard to issues relating to people with dementia. It is clear that the eligibility criteria for requesting assisted suicide excludes people with a mental disorder (including dementia) and we welcome this for the reasons set out in this response. Our response is informed by: our multi-disciplinary Standing Committee on Rights and Legal Protection; the views of people with dementia through the Scottish Dementia Working Group (a campaigning group run for and by people with dementia, supported by Alzheimer Scotland); those of our individual members who responded to our briefing and questionnaire; and the concerns raised in its response to the Bill by the Scottish Partnership for Palliative Care, of which we are a partner.

Background - the Adults with Incapacity Act and Human Rights
3 Alzheimer Scotland has a strong commitment to promoting and safeguarding the rights of people with dementia and their carers. We campaigned vigorously for the reforms to adult protection and mental health legislation, in particular the Adults with Incapacity (Scotland) Act 2000. During the legislative process we set up a major seminar and consultation with our members on the most controversial part of the then Bill i.e. Part 5 on Medical Treatment and Research. We approved the carefully worded clauses which were inserted to avoid any potential interpretation that the Act that might allow euthanasia (voluntary or otherwise) in relation to an adult with incapacity. Advance directives were not included in the legislation.

4 However, that was 10 years ago and we felt it was important to test out the current views of our members. We produced a briefing on the Bill and a questionnaire. The questions we asked differed from those of the Committee and focused on the status of advance directives. Two-thirds of our 170 respondents, three quarters of whom were carers expressed the view that advance directives should be given legal recognition and that they would want to be able to request physician assisted suicide in specific circumstances that would be set out in the directive. However a third of respondents felt that it
would be impossible to have strong enough safeguards to protect people who lack capacity or ability to communicate from misinterpretation (if they changed their minds - which have devastating consequences), or from abuses such as undue pressure. (Other respondents included one person with dementia and the rest were either professionals or did not specify their interest). Because of the small return to the questionnaire we are unable to reach conclusions about the views of our members, but the response received indicates an interest towards giving advance directives legal recognition. This could be an issue for future consideration within the Scottish Law Commission’s 8th legislative reform programme which includes the Adults with Incapacity (Scotland) Act 2000.

5 Last year we played a leading role within the Scottish Parliamentary Cross Party Group on Alzheimer’s in the production of the Charter of Rights for People with Dementia and their Carers. We have been pressing for the Charter to be embedded in the Scottish Government’s forthcoming Dementia Strategy. We believe that the adoption of the Charter should profoundly affect the way in which people with dementia are treated and in turn influence attitudes towards how end of life for people with dementia is valued.

The importance of post-diagnostic support
6 In the early stages of dementia it is not unusual for people who are newly diagnosed to become depressed and feel that life is not worth living, they are very vulnerable. Alzheimer Scotland believes that no one with dementia should feel that they are a burden to others or to society. This can be avoided by ensuring that they and their family/friends receive personalised support from an early stage. It is crucial that services are transformed to support the person with dementia to maintain their normal life for as long as possible and help to sustain their sense of self-esteem and self-worth. Current traditional services, often offered too late (e.g. inflexible day care) have an inherent tendency to reinforce a sense of dependency and offer little choice or improvement to quality of life. Members of the Scottish Dementia Working Group are strong advocates for peer support, awareness raising in the community and promoting training amongst professionals with the aim of spreading the message that it is possible, with the right sorts of support, to live a full and enjoyable life with dementia. With the increased use of advance care plans and powers of attorney it is possible for people with dementia to take more control over their lives and what they would like to happen in the future.

Palliative Care
7 The sensitive subject of end of life and palliative care is not a new one. The palliative care needs of people with dementia are not well understood and Alzheimer Scotland has made this a priority area for attention. For several years we have been developing palliative care training and this is currently being delivered to care homes across Scotland (known as the ‘Beyond
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Barriers’ project\(^2\) funded by the Scottish Government). We welcomed the Scottish Government’s recommendations in its report *Living and Dying Well* (2008), because, for the first time, the palliative care needs of people with dementia are recognised in health policy document. We anticipate that the Scottish Government’s National Dementia Strategy will also address the issue of palliative care.

The Bill gives rise to a number of concerns:

- we fear that the use of the term ‘end of life assistance’ may be confused with end of life palliative care and that this could have devastating consequences;
- a doctor must talk to the requesting person about alternatives to end of life assistance, including the choice of palliative care. **We strongly believe that palliative care should not be a ‘choice’ – it should be provided as of right to everyone with a progressive condition and provided as part of routine practice**;
- we fear that the introduction of this legislation could have a deterrent effect on investment in palliative care, and until it is in place for everyone who needs it there can be no real choice for people to make.

**Inadequate safeguards**

8  We are concerned that the safeguards in the Bill are not strong enough with regard to designated practitioners and psychiatrists, and we agree with the responses from the SPPC and the Mental Welfare Commission on this point. We have serious concerns about how and by whom capacity assessments might be carried out. There is a danger that a ‘business’ interest could emerge amongst doctors willing to consider and accept requests for assisted suicide.

**Our position**

9  We fully respect the right of individuals to express their personal views on this topic and the strong views expressed both in favour of the principles of the Bill and those against it. However, as an organisation representing the interests of 70,000 people with dementia in Scotland and their carers, it is our duty to ensure that they receive the highest possible quality of support and care from the onset of the illness until the end of life, and in accordance with the principles embedded in the Adults with Incapacity Act. At the present time this is very far from the case and as a consequence people often experience despair and depression. All too often carers are influenced in their views by witnessing poor nursing care and the distress caused to their loved one towards the end of life. Our mission is to reverse this situation.

10  **We therefore hold strongly to the position that it entirely right that adults with a mental disorder should be excluded from the Bill.** They represent the most vulnerable group of adults within our society and their right to access high quality care under the Convention for the Rights of Persons with Disabilities must be a key objective for the Scottish Parliament.

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11 For all of the reasons set out in this response, we believe that it would be unethical to introduce legislation which allows physician assisted suicide even for people who do not lack capacity but fear that they might at some future point.

We shall be happy to answer any queries that may arise from our response.

Jan Killeen
Director of Policy
Alzheimer Scotland
12 May 2010
Introduction

Parkinson’s UK welcomes the opportunity to respond to this consultation.

We have held a neutral position on end of life decisions for some years, taking the view that wherever possible, and within the framework of the law, the decisions and wishes of people with Parkinson's should be respected.

We are working with people who are affected by Parkinson's to make sure our position reflects the current context and the full range of views in this area.

Opinion polls show that people in the UK have differing views about end of life decisions, informed by personal, social and cultural factors. Parkinson's affects individuals from all backgrounds. We believe that it is important that we support everyone affected by Parkinson's, whatever their standpoint.

Our response is framed around the questions asked by the Committee, and highlights the issues that are of particular relevance to people with Parkinson’s, their families and carers. It should not be read as implying either support for, or opposition to, the Bill.

About Parkinson’s

About 10,000 people in Scotland people have Parkinson’s.

Parkinson’s is a progressive, neurological disorder, with no known cure. The three main physical symptoms associated with Parkinson’s are tremor, muscle rigidity and slowness of movement. However not everyone will experience all three. Non-motor symptoms and medication side effects can also cause sleep disturbance, difficulties with balance, incontinence, problems with altered posture, speech and swallowing difficulties, pain and mental health problems such as dementia, hallucination and depression. Parkinson’s UK, believes that with the right care and support many people with Parkinson’s can have a good quality of life for years after diagnosis. However, the later stages of Parkinson’s can be challenging to live with, as symptoms progress and medication side effects become harder to manage.

Parkinson’s affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson’s is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in twenty will be diagnosed before the age of 40.
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Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

It is possible that people with advanced Parkinson’s could be included in both of the categories defined in the draft Bill, yet there are requirements which might rule them out. It can be very hard to predict what will happen to a person with Parkinson’s, because the condition affects all individuals in different ways. This would make it difficult to say whether someone would be expected to survive for six months or more. It is similarly difficult to define a fluctuating condition such as Parkinson’s as a “permanent” incapacitation.

In addition, many people with Parkinson’s need ongoing support in their daily activities for a long time before their condition progresses to the advanced stages. People with Parkinson’s commonly experience significant mental health symptoms. These can include depression, which affects about half of all people with Parkinson’s, as well as compulsive behaviours and psychotic symptoms. Parkinson’s UK is concerned that people with Parkinson’s who experience mental health symptoms could decide to opt for assisted suicide or voluntary euthanasia as a result of these mental health issues. If the Bill were to proceed, this underlines the importance of strong safeguards and expert knowledge when capacity is assessed.

It might be helpful to consider whether these definitions would need to be changed to reflect these issues, which are likely to be shared with other progressive neurological conditions.

The Bill outlines a several 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?

Parkinson’s UK is concerned that the limit of 28 days after receipt of the second request may put undue pressure on the requesting person to act to end their life. We recognise the need to ensure that a person retains capacity between making a request and taking action, but feel that there are risks in stipulating such a tight timescale.

We have specific concerns about the provisions for residents of care homes, and specifically the requirement for one witness to be a member of care home staff. Although we recognise that many care workers have a good relationship with and knowledge of residents, and that some care home residents may lack a circle of friends or acquaintances who could act as disinterested witnesses, we are concerned about the minority of care homes which provide poor care. In the Care Commission’s recent rankings one in ten care homes for older people were ranked poor or inadequate, and we are concerned that it staff in those homes may not have a sufficiently high quality relationship with residents for this to provide an adequate safeguard against abuse.

We are also concerned that there is potential for conflict of interest, for example if care home managers wished to offer a place to another resident for any reason.
Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

Parkinson’s is a complex condition. The recent NHS QIS Clinical Standards for Neurological Health Services make clear that people should have access to support from a specialist multi-disciplinary team. We believe that the attending physician should also be required to consult with the person’s Parkinson’s specialist clinical team. This additional safeguard would ensure that the attending physician would be aware of alternative treatment options which might offer symptomatic relief and of medication side effects that could be addressed by altering the timing, dosage or composition of an individual’s medication regime.

We believe that the requirement for a psychiatrist to assess capacity would be an essential safeguard. Issues of capacity are of particular importance for people with Parkinson’s, and for those with other neurological conditions. Accurate and sensitive assessment of capacity is particularly important for people with advanced Parkinson’s, who are likely to experience communication difficulties in addition to mental health symptoms and medication side effects. These may include depression, dementia, compulsive behaviours and psychotic symptoms.

Parkinson’s UK agrees with the Bill’s specification that communication difficulties should not be considered to indicate a lack of capacity, where human or mechanical aids can be used to overcome difficulties. If the Bill proceeds, we would like to see a duty to involve a speech therapist where people have significant communication difficulties.

Depression affects up to half of all people with Parkinson’s, and psychotic symptoms and compulsive behaviours frequently occur caused both by the condition itself and as side effects of the medications used to manage it. The latest evidence suggests that cognitive decline and dementia are very common in Parkinson’s, and become more common as the condition progresses. However, there is also evidence that these symptoms are under-diagnosed and under-managed, and there is a danger that capacity may not be assessed accurately as a result. In a recent training needs analysis, some seven in ten health and social care professionals said that they needed training on Parkinson’s Disease dementia.

In view of the complex communication and psychiatric issues in late Parkinson’s, Parkinson’s UK believes that a general psychiatrist without knowledge of Parkinson’s may not be able to assess capacity accurately without input from the Parkinson’s specialist team, especially in cases where medication side effects may be involved. We also question whether the legislation might also provide for assessment by a clinical neuro-psychologist, in line with recommendations made in guidance accompanying the Adults with Incapacity (Scotland) Act.
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Do you have any other considerations on the Bill not included in answers to the above questions?

The Bill lacks detail explaining the ways in which the requesting person might receive assistance, and both assisted suicide (where the requesting person administers the treatment designed to end their life) and voluntary euthanasia (including instances where a third party administers the treatment) are permitted. Parkinson’s UK believes that the Committee and the Parliament should explore the implications of such a broad definition of action when considering the legislation. In particular, the reasons for allowing any person to administer life-ending methods to a requesting person, requiring the designated practitioner to act as witness should be carefully considered, as the potential for administration errors increases if the person is not trained.

Parkinson’s UK believes that any discussion of assisted dying legislation should be supported by a framework of high quality and accessible palliative care. There are very serious areas of unmet need in Parkinson’s care at the end of life, particularly with regard to the management of non-motor symptoms such as pain, depression and incontinence.

Clinicians’ awareness of the non-motor symptoms of Parkinson’s remains lower than the motor symptoms, yet many people find that the non-motor symptoms have a greater impact on their quality of life. If such symptoms remain untreated, it means that people are more likely to find their lives intolerable.

There is also good evidence that there is a lack of palliative care support for people with Parkinson’s: Parkinson’s UK has identified that that the needs of people with Parkinson’s at the end of life are not always identified or satisfied. Problems include:

- fragmented services characterised by a poor knowledge and understanding of Parkinson’s
- diminished access to services as Parkinson’s progresses, and treatment becomes less effective
- lack of information about the condition, medications, financial and other available support
- lack of face-to-face personal support
- providers focusing on the age of the person, rather than the stage of the condition
- failure to address fears about the future, or offer future planning.

The recent Audit Scotland Review of palliative care services in Scotland showed that there are particularly significant gaps in the provision of appropriate end of life support for people with neurological conditions like Parkinson’s compared with conditions like cancer and organ failure. In addition, the finding that people aged over 75 may be less able to access specialist palliative care is also of concern, as the incidence of Parkinson’s increases with age.
Whether or not this Bill proceeds, it is essential to address these gaps in services.

**About Parkinson's UK**

For more information, please contact the Scotland Parliamentary and Campaigns Officer, Tanith Muller, email: tmuller@parkinsons.org.uk, telephone 0844 225 3726.

Every hour, someone in the UK is told they have Parkinson’s. Because we’re here, no one has to face Parkinson’s alone. We bring people with Parkinson’s, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson’s. As the UK’s Parkinson’s support and research charity we’re leading the work to find a cure, and we’re closer than ever. We also campaign to change attitudes and demand better services. Our work is totally dependent on donations.

Find out more about us at parkinsons.org.uk

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1 Goetz CG, Koller WC, Poewe W et al. (2002) Treatment of depression in idiopathic Parkinson’s disease. Movement Disorders. 17(s4):s112–s119
7 Parkinson’s Disease Society (unpublished) results of training needs analysis.
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End of Life Assistance (Scotland) Bill

Friends at the end

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

Strongly agree but there must be provision for alternatives to the need for the two formal requests to be in writing for those whose illness or disability makes writing impossible.

Are you satisfied with the requirements for age and connection with Scotland?

Persons aged between 12 and 16 should be able to make a request if supported by a parent or guardian. Persons should be registered with a medical practice in the United Kingdom for 12 months, the latest of which must be in Scotland. Persons who are terminally ill or seriously disabled may move to be near relatives/friends who could be involved in their care.

Are you satisfied with the categories of people?

Yes, in full agreement.

Stages of consent and verification process

Yes but the second designated medical practitioner should not be required to be a psychiatrist. He/she should be a medical practitioner who has been registered for at least 10 years. General practitioners are dealing daily with patients with mental health and mental capacity problems and ordinarily are considered capable of making sound judgements on these issues. Psychiatrists are very expensive (£250/300 for an OP consultation, £500 for domiciliary visit twice). Appointments have to be made many weeks ahead. Psychiatry is not a popular career option nowadays so the situation is likely to become worse.

If the designated medical practitioner had any doubts about the mental health or mental capacity of the person, the second designated medical practitioner should be psychiatrist (in line with normal medical practice).

Are the level and nature of the safeguards adequate?

Evidence from Oregon (USA), where provisions are comparable, shows no evidence of slippery slopes or abuse. We think they are adequate.
Any other considerations?

Numerous opinion polls in Scotland and the UK have shown that four out of five of the electorate believe that the law should be revised to allow assisted dying.

Friends at the end
5 May 2010
Overview

In common with all people of good will, the Catholic Church seeks to assist those at the end of their natural life to achieve a dignified and pain-free completion of their life. Indeed throughout history, the Church has had a special mission to the care of the dying, founding hospices to care for the terminally ill and supporting religious orders with this vocation.

It is important to state clearly at the outset that the Catholic Church does not take a “vitalist” mentality. In other words the Church does NOT hold that life must be preserved at all costs. Rather the Church recognises that discontinuing medical procedures that are burdensome, dangerous, extraordinary or disproportionate to the expected outcome can be legitimate. Such a decision is simply the acceptance of one’s own mortality.

However there is a clear and dramatic difference between allowing someone to die with dignity and taking a decision to bring their life to an end, either by interrupting their feeding and hydration or by direct intervention to kill them by medical means. It is for this reason that the Bishops’ Conference of Scotland firmly opposes the End of Life Assistance (Scotland) bill. The proposals in the bill are contrary to the rule of law which requires the uniform protection of all human life. The bill, however, is intrinsically discriminatory by identifying classes of people whose lives are not to be provided full protection under the law. This is aggravated by the frail procedures which will permit many lives to be put at risk through varying degrees of psychological, social or cultural coercion. The proposals therefore strike at the basic principle of human solidarity by abandoning those most likely to be in need of support.

Definitions

There appears to be some confusion as to whether the bill is intended to introduce only assisted suicide or euthanasia and assisted suicide. Assisted suicide involves providing the means or assistance for a person to take their own life. Euthanasia involves a person directly taking the life of another person through an act or omission which is intended to cause death. This should not be confused with withholding or withdrawing futile or over-burdensome treatment which is morally and legally licit. The bill states: “In this Act “end of life assistance” means assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress.” The definition clearly permits a third party to administer lethal means and therefore the bill would permit euthanasia and assisted suicide.

Dignity of all human life

1 C.f. Pope John Paul II, Evangelium Vitae 65
2 The bill does not require the doctor to administer the means of death but merely to be present
The value of human life is the common foundation for all those who have concern for the wellbeing of every person. Proponents of assisted suicide and euthanasia, frequently claim that they wish to support human dignity. However, seeking to avoid the possibility of suffering or of loss of control is not based on an adequate or objective vision of the dignity of the human person. The Church maintains that every human life, irrespective of the capacities or state of health of the person, has an intrinsic dignity which must be respected and that their life must be protected.

**Duty of State to protect every human life**

It is a duty of the State to protect the lives of all of its members. This duty arises from the value of human life created in God’s image. It is a duty which is also recognised by those who do not believe in God. Throughout history and across cultures the inviolability of human life has been upheld\(^3\), such that the intentional killing or hastening of death is contrary to the law. This is the basis of the right to life which is protected by homicide laws and by article 2 of the European Convention on Human Rights.\(^4\)

The protection provided by Article 2 entails positive obligations such that states bound by the terms of the convention are obliged to take actions to prevent threats against life arising within society.

Permitting an individual to request and receive help to end their life is therefore contrary to this duty of protection. This is affirmed in the comments of the Parliamentary Assembly of the Council of Europe which has stated:

> "The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects . . . (c) by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while: (i) recognising that the right to life, especially with regard to a terminally ill or dying person, is guaranteed by the member states, in accordance with article 2 of the European Convention on Human Rights which states that 'no one shall be deprived of his life intentionally'; (ii) recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person; (iii) recognising that a terminally ill or dying

\(^3\) For example c.f. St Augustine, City of God Book I, Chapter 20

\(^4\) ECHR Article 2

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
2. Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is no more than absolutely necessary:
   a. in defence of any person from unlawful violence;
   b. in order to effect a lawful arrest or to prevent escape of a person lawfully detained;
   c. in action lawfully taken for the purpose of quelling a riot or insurrection.
person’s wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death”

Suicide

Since many of the supporters of assisted suicide make reference to suicide being permissible as a logical basis for permitting assisted suicide, we wish to comment briefly on suicide. Suicide is always a tragedy, both for those actively involved, and those of their loved ones who are left to grieve. Laws which ostensibly decriminalise suicide are not based on an acceptance of the rightness of choosing to end one’s own life, but typically on compassion for the victim who needs support rather than prosecution.

It is relevant to note that depression and other mental health problems are factors for a very high proportion of attempted suicides. This underlines the need for compassionate support for those who feel tempted to suicide and to those who suffer from illnesses and conditions which make them prone to feel suicidal. This in fact is the natural response to those who have suicidal feelings as exemplified by organisations such as the Samaritans and the campaigns aimed at avoiding suicide by successive Scottish Governments.

Assisted Suicide

Laws which decriminalise suicide do not undermine the basic requirement of law that human life must be protected. Hence the provision of assistance to permit a person to commit suicide is contrary to this basic protection and is rightly a criminal act to which a severe penalty is attached. The proposal to permit assisted suicide is therefore contrary to the inalienable respect that must be given to every human person.

The terrible consequences of the use of this provision more widely than envisaged by the bill’s proposer must be considered. That is, the benefit that a minimal number of people may believe they obtain from assisted dying cannot outweigh the concern for the grave dangers that are thereby raised for the whole of society from the abuse or widening of the practice of assisted killing.

Consent and Verification Process

The bill’s practical arrangements for processing requests to die are not proportionate to the level of power which is to be given to those who would administer the proposed process. If passed the bill would enable the termination of life and therefore, if such a power could be legitimately conferred, it would require the most stringent control of the process. The process therefore would have to be more akin to that used for implementation of the death penalty rather than the meagre consultation requirements proposed by the bill. The proposed two-stage request process gives little confidence that serious and detailed consideration could be given to ensure that applicants were not suffering from depression or mental illness; and were not subject to any undue influences arising from family, carers or general

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5 Pretty v DPP [2001] UKHL 61 at 823, Article 9.c. of the Council of Europe Parliamentary Assembly Recommendation 1418 (1999)
social attitudes. The window within which someone can die from their first request under the bill is between 19 and 60 days. This is a startling fact which raises many concerns about the haste over which a decision may be taken and the level of seriousness that alternative solutions are given in response to a person’s wish to die.

**Safeguards**

Access to euthanasia/PAS is typically described in the context of a loved one helping a family member to implement their autonomous choice. The cases of assistance motivated by compassion may be one aspect, but another, neglected aspect, is the extent of abuse that takes place against those who are vulnerable. For instance the House of Commons Select Committee on Health has noted that in England estimates propose that 500,000 to 900,000 elderly people are victims of abuse typically by members of their family or other carers and that psychological, financial and physical abuse account for the most common types of such abuse. In Scotland members may be familiar with the local campaigns to highlight the extent of exploitation and abuse that is inflicted on elderly people by family members. These routinely identify that vulnerable people are targeted by family members eager to procure money and property. Similarly, it is pertinent that abuse of disabled people by carers is reported to be extensive. These social concerns provide a context where vulnerable people face grave danger of being manipulated by those with a financial or emotional interest in their death.

A further concern is that the nature of the doctor-patient relationships makes it difficult to ensure absolute probity and competence in assessing the relevant factors. For example, doctors may not be competent in giving palliative care, may misdiagnose or give wrong prognosis or may miss depression. The legalisation of assisted suicide and euthanasia will greatly affect the relationship of trust between patient and doctor. A change in the law would

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9 For example the ‘Uncomfortable Reading’ campaign supported by Renfrewshire Council, Strathclyde Fire and Rescue and Strathclyde Police, see [http://news.bbc.co.uk/1/hi/scotland/glasgow_and_west/8241488.stm](http://news.bbc.co.uk/1/hi/scotland/glasgow_and_west/8241488.stm) (last accessed 21 April 2010)


also undermine the doctor’s right not to be drawn into activities contrary to Hippocratic ethics which have guided medicine for centuries. It is a concern compounded by the absence of a conscience clause in the bill; which therefore raises the prospect of doctors being compelled to participate in killing patients.

Cultural change

An important point to consider when examining a proposal to change important principles in society is the cultural message that it promotes. Once a particular principle is established as acceptable then it is natural that some people will seek to build on this principle. It is not difficult to envisage that a system of ending lives of people may eventually become one that is far removed from that envisaged by those who believe that only a small number of people in hopeless positions and in terrible suffering will be provided with assistance to die.

Making one particular decision, in this case that some should permitted to be killed, can change the moral or empirical assumptions about further courses of actions which are presently not acceptable, or people can become desensitized to such actions.\(^{13}\)

It is the progression from one activity to another which is important in assessing the risk of state approving the ending of innocent lives. For example the Netherlands has witnessed the move from ending the lives of individuals who are terminally ill, to those who are chronically ill, to those who are not physically ill at all.\(^{14}\) Also they have seen a move from acceptance of physical suffering, to mental suffering, to apathy for life as justifying euthanasia.\(^{15}\) The pool of potential candidates has also grown from competent adults to minors and newly born children.\(^{16}\) Around a thousand people a year, without requesting, have their lives ended in the Netherlands.\(^{17}\)

There are also changes in the dynamics of the environment in which care is provided, for example euthanasia or assisted suicide may appear a tempting solution when there are financial pressures; or the demand for improved quality of care may be lessened if a means of avoiding providing care by ending the life of the patient is an option.\(^{18}\)

Advocates for assisted dying, it is submitted, are too quick to reject the famous warning of Leo Alexander, commenting on the holocaust, who observed that “It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be


\(^{14}\) John Keown, Euthanasia, Ethics and Public Policy (Cambridge University Press, 2002) at p114


\(^{16}\) Ibid at 75

\(^{17}\) Ibid

\(^{18}\) For example as in the case of Barbara Wagner denied funding for treatment of cancer in the U.S state Oregon, but offered funding for assisted suicide. See http://abcnews.go.com/Health/story?id=5517492&page=1 (Last accessed 6 May 2010)
lived... But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitable sick”. The likelihood of moving to the practise of previously unacceptable behaviour once the principle of killing is accepted is strongly affirmed by the experience of the Netherlands.

The danger is not lost on those who may be first to be exposed to the inherent eugenic practice of deciding which persons are right to want to die. Campaigners for the disabled have noted that: “In 1939, Hitler authorised Aktion-T4, a programme of mass-murder targeting disabled people. T4, combined with unstructured so-called “wild euthanasia”, killed more than a quarter-of-a-million disabled people, yet this history is largely forgotten”. In light of the public efforts to promote euthanasia, it is submitted, that it is understandable that there should exist a determined effort to dismiss this history lesson.

Conclusion

The bill effectively aims at enabling people to act in a manner incompatible with the basic good of the human individual. It will strike a blow against the fundamental sanctity of human life and against human solidarity. Support of the bill would be a misguided support for those who want to exercise exaggerated control over their own lives and will sacrifice the sanctity of life in general and the protection of vulnerable people in particular. The role of the law in restraining the malicious or those of ill intent cannot be ignored because of the special pleading of those who wish absolute control over their lives. The moral law, upon which the law ultimately finds its source, ensures that the weak are not placed at the mercy of the powerful. The proposals for ‘end of life assistance’, as it is euphemistically called, are truly a path which places the weak at considerable risk. It is appropriate to consider that in no way can such a law be described as compassionate. “True compassion leads to sharing another’s pain; it does not kill the person whose suffering we cannot bear”.

John Deighan
Parliamentary Officer
Catholic Parliamentary Office

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21 ‘T4: Hitler's holocaust rehearsal’, Disability Now, see http://www.disabilitynow.org.uk/living/features/t4-hitlers-holocaust-rehearsal (last accessed 5 May 2010)
22 John Paul II, Evangelium Vitae, 66