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
Submission from Care Not Killing Alliance Scotland\(^1\) to the public consultation on the End of Life Assistance (Scotland) Bill

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](http://www.carenotkilling.org.uk)) includes almost 50 professional groups, faith groups and human rights groups, including ten groups in Scotland.
euthanasia 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’.

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)
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

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\(^3\) 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

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\(^6\) 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’12, that the physician concerned must agree with the applicant ‘on the means by which that assistance is to be provided’13, that ‘the end of life assistance must, so far as reasonably practicable, be provided in accordance with the agreement’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’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,

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12 Section 1(2)
13 Section 10(1)(d)
14 Section 11(1)
15 Section 11(6)
carbon monoxide poisoning, hanging, shooting or a push over a cliff\textsuperscript{16}. 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’\textsuperscript{17} 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 an Oregon-style bill providing only for assisted suicide. For this reason the Oregon-based estimate given in the Explanatory Notes\textsuperscript{18} 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\textsuperscript{19}.

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

\textsuperscript{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.

\textsuperscript{17} Section 2(1) (‘the provision or administration of appropriate means’)

\textsuperscript{18} Paragraph 88

\textsuperscript{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. 18/01/2001), (2005) 21 EHRR 97
2 (1996) 21 EHRR 124
3 Application No 2346/02; 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 a 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 Netherlands5 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

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