End of Life Assistance (Scotland) Bill

Alzheimer Scotland

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 8\textsuperscript{th} 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\textsuperscript{1}. 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 diagnoses 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

\textsuperscript{1} Scottish Parliamentary Cross Party Group on Alzheimer’s: Charter of Rights for People with Dementia and their Carers (October 2009) see: \url{www.dementiarights.org}
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.

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