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. 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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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></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>191</td>
<td>93</td>
<td>12</td>
<td>296</td>
</tr>
<tr>
<td>%</td>
<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></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>83</td>
<td>188</td>
<td>25</td>
<td>296</td>
</tr>
<tr>
<td>%</td>
<td>28%</td>
<td>64%</td>
<td>8%</td>
<td>100%</td>
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</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></th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>83</td>
<td>84</td>
<td>24</td>
<td>191</td>
</tr>
<tr>
<td>%</td>
<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>
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</thead>
<tbody>
<tr>
<td>159</td>
<td>110</td>
<td>27</td>
<td></td>
<td>296</td>
</tr>
<tr>
<td>54%</td>
<td>37%</td>
<td>9%</td>
<td></td>
<td>100%</td>
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</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>159</td>
<td>12</td>
<td>20</td>
<td></td>
<td>191</td>
</tr>
<tr>
<td>83%</td>
<td>6%</td>
<td>10%</td>
<td></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>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>81</td>
<td>211</td>
<td>292</td>
</tr>
<tr>
<td>28%</td>
<td>72%</td>
<td>100%</td>
</tr>
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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>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>
</tr>
</tbody>
</table>