END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE

END OF LIFE ASSISTANCE (SCOTLAND) BILL: SUMMARY OF WRITTEN EVIDENCE

INTRODUCTION

This briefing outlines the issues arising from submissions received as a result of the Committee’s call for written evidence on the End of Life Assistance (Scotland) Bill. It first analyses the respondents themselves, before considering responses to each of the key provisions in the Bill.

This paper should in no way be considered a systematic review of the evidence received. Rather, it is a largely qualitative analysis designed to alert Members to some of the substantive discussion points that arose from the submissions, and to be an aid in selecting witnesses.

A full SPICe briefing on the Bill will be made available to Members over the summer recess, which will further explore a number of issues that are not addressed in this paper (eg the international comparisons and resource implications associated with the Bill). Members may wish to consider this paper along with the Policy Memorandum and Explanatory Notes accompanying the Bill.

ANALYSIS OF RESPONDENTS

In total, 601 submissions were received by the close of the call for evidence on 12 May 2010. The submissions came from a wide variety of interests, and these have been split into a number of categories. These, together with the response rate and position, are outlined in Table 1 below. Overall, 521 (86.89%) of respondents held a position opposed to the Bill, 39 (6.49%) were supportive of the Bill or at least the principle behind it, and 41 (6.82%) had no position on the Bill.

Table 1 also shows that the largest respondent category was ‘Private Individual’ (57.1% of submissions), an overwhelming proportion of which were opposed to the Bill. This is followed by ‘Professional – Medical’, which is comprised of doctors and doctors in training from various specialties (see below), most of whom were responding as individuals. These made up of 19.5% of submissions, and again, the vast majority were opposed to the Bill.

Of those that were supportive of the Bill the majority (n=25) came from private individuals, followed by ‘Professional – Medical’ (n=5), ‘Voluntary Organisation’ (n=4), ‘Academic’ (n=3) and ‘Humanist Organisation’ (n=22).

In terms of submissions that held no position, these responses were divided fairly evenly across the different respondent groups. They made up all of the local authority (n=4), NDPB (n=4), NHS Board (n=1) and Regulatory Body (n=2) submissions and half of those form ‘Representative Body – Health’ (n=8 out of 16).
Table 1: Respondent category, response rate and position

<table>
<thead>
<tr>
<th>Respondent Category</th>
<th>Total</th>
<th>Oppose</th>
<th>Support</th>
<th>No Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic</td>
<td>13</td>
<td>5</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Hospice</td>
<td>5</td>
<td>5</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Humanist Organisation</td>
<td>2</td>
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<td>-</td>
</tr>
<tr>
<td>Local authority</td>
<td>4</td>
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<td>-</td>
<td>4</td>
</tr>
<tr>
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<td>-</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>NHS Board</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Political</td>
<td>3</td>
<td>2</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Private Individual *</td>
<td>343</td>
<td>317</td>
<td>25</td>
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<tr>
<td>Professional - Medical</td>
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<tr>
<td>Professional - Other Health</td>
<td>23</td>
<td>22</td>
<td>-</td>
<td>1</td>
</tr>
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<td>Professional - Social Care / Social Work</td>
<td>3</td>
<td>3</td>
<td>-</td>
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</tr>
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<tr>
<td>Representative Body - Other</td>
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<td>-</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>Voluntary Organisation</td>
<td>17</td>
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<td>5</td>
</tr>
<tr>
<td><strong>Total Number (Percentage)</strong></td>
<td><strong>601</strong></td>
<td><strong>521 (86.69%)</strong></td>
<td><strong>39 (6.49%)</strong></td>
<td><strong>41 (6.82%)</strong></td>
</tr>
</tbody>
</table>

NB:
* - One response from a Private Individual was submitted as “Anonymous”. A further 35 have been published by the Committee as “Anonymous” to ensure that the Committee complies with the provisions of the Data Protection Act 1998 regarding issues such as the protection of the personal data of individuals and protecting the identity of third parties, where details about individuals are published without their consent.

‘Religious – Body’ – representation on behalf of a whole faith or religious denomination (eg the Muslim Council of Scotland and the Free Presbyterian Church of Scotland)

‘Religious – Group’ - a group that exists within a particular faith or denomination (eg Kemnay Parish Church of Scotland) or from submissions from a cross group of churches or faith bodies (eg Scottish Interfaith Council and Scottish Churches' Disability Agenda Group)

‘Religious – Individual’ - someone who holds a position in a faith or denomination (eg an individual Minister)

As discussed above, nearly a fifth of all responses were identified as being from the medical profession. In 21 of these submissions the specialty background of the respondent was not clear. However, it was in the remaining 96 and these are outlined in Figure 1.

Figure 1 shows that the largest specialty represented was general practice (n=45), though this includes two trainees and 12 retirees, followed by medical students (n=24), typically in their third or fourth year, and then palliative care specialists (n=11). The one ‘mixed’ case represents a submission from a group of doctors from a range of specialties.

Analysing all 117 ‘Professional – Medical’ submissions, 110 (94%) were against the Bill. Of the remainder, five were in support – three from general practice, one psychiatrist and one from the ‘unclear’ group. This left two which contained no stated position – one psychiatrist and one from general practice.
Personal testimony

A large number of the ‘Private Individual’ submissions illustrated their views on the Bill by referring to experiences that, in most cases, involved members of their own family or friends. In a few submissions individuals responded according to their own personal experiences. The majority of these were opposed to the Bill, though several did come from those in support. Such testimony also extended to professionals, who, in the main, tended to discuss the value of current end of life care practice.

Adherence to the questions in the call for evidence

In general, most respondents regardless of position followed or answered the questions in the Committee’s call for evidence. However, significant numbers did not. This was particularly the case for those writing as private individuals, who tended to state their position (usually in opposition to the Bill), and accompany this with reasons for it. This also happened with significant numbers from the ‘Professional – Medical’ group. It was also evident amongst those from across respondent groups who had no stated position. In some cases this was due to them being in a role which they felt inappropriate to articulate a view at all. For others membership based organisations, although they could not articulate a single view on behalf of their whole membership did feel able to make comment on specific aspects of the Bill, but this sometimes meant they did not follow the questions in the call for evidence.

In general, those who were opposed to the Bill were opposed to all aspects of it, though some of these did consider the Bill on the basis of what they would prefer to see if the Bill was passed. Proportionally, those supporting or having no position on the Bill tended to consider the various proposals in the Bill and comment on each.

KEY PHILOSOPHICAL DEBATES

This section outlines the key philosophical debates, which were central to many of the respondent’s submissions. In this and the following sections, a reference key is being used along with each respondent mentioned so that Members can easily identify their overall position on the Bill, along with the submission number it has been allocated. The key to the overall position of the Bill is:
Thus, Prof's Laurie and Mason is referred to as: (NP, 52); and, Ardgowan Hospice as (O, 399).

**Philosophical debate**

There were two key strands to this – “dignity” and “personal autonomy”. It should be noted that often one of these terms would be used as an example of the other and it was not always clear what respondents meant when they were referring to them. They also meant different things to different people.

**Dignity**

A key point made by several respondents was that “dignity” was a difficult concept to define, and its use in the Bill itself (see section 1(2)) was questioned as a result (eg Prof's Laurie and Mason (NP, 52) and Dr J Walley (O, 096)). This led to calls for more clarification on what was meant by “dignity” (eg Association of Hospice and Palliative Care Chaplains (O, 106), Ardgowan Hospice (O, 399) and the Evangelical Alliance (O, 413).

For many of those supporting the Bill, there was not an explicit discussion of “dignity”, though in considering their arguments it is clear they were raising arguments similar to those contained in the Bill’s Policy Memorandum (para 56-66). In some submissions discussing personal experiences it appeared that a link was being made between the suffering of those whose pain could not be adequately dealt with through medical care and a lack of dignity in the way they died (eg E Duncann (S, 027), Dr K Mitchell (S, 330)). To allow this to continue even when a person was making their wishes clear was considered inhumane. Such arguments were also clear in other submissions such as Dignity in Dying (S, 398) and the Humanist Society of Scotland (S, 187). With many there was a direct link between the notion of “dignity” and personal choice and autonomy which is discussed in the next section.

Opponents to the Bill tended to reflect on what they considered to be an apparent acceptance in the Bill that the only dignified way of dealing with suffering was through ending life. The Scottish Council on Human Bioethics (O, 322) summed up many of the arguments in this regard stating:

“It is incorrect and disturbing to suggest that any person can ever lose his or her human dignity. Though human dignity is not a scientific concept, it is something that everyone should always accept is found in every person to an equal extent. Legalising euthanasia would mean that society would accept that some individuals can actually lose their inherent human dignity and have lives which no longer have any worth, meaning or value. It would give the message that human dignity is only based on subjective choices and decisions and whether a life meets certain quality standards.”

This was a theme that ran through many submissions from private individuals, stemming from a belief that everyone regardless of support needs could play a valuable role in society. It was also a key theme in the vast majority of religious submissions, where there were reflections on human dignity flowing from the belief that all life was God given, that it
was fundamentally wrong to kill another person, and that true respect and compassion was to care for those who were suffering.

From a health care perspective there was a concern that the Bill was promoting a view that the only dignified death was one based on assisted suicide when it could be achieved through good palliative care (eg McGettrick et al (O, 107), J Elliott (O, 204) and Highland Hospice (O, 275). A few respondents questioned the evidence that an assisted death would be more dignified (eg A Walker (O, 179) and Prof JV Forrester (O, 318)).

**Personal autonomy**

As regards autonomy, the basic argument used by those supportive of the principle espoused by the Bill is that everyone should be able to make decisions over their own lives. Some questioned why death was not treated like other momentous occasions in a person’s life. There was a concern that religious and other cultural traditions were unfairly discriminating against those who wished to make this choice (eg E Duncann (S, 027), and GP McGovern (S, 305)). In some cases it was felt this lead to people seeking desperate ways to end their lives (eg R Imes (S, 171). For others the issue was one of control. Dr JA Macfie (S, 253) reflected on those with a terminal illness arguing that there were those who “hate the very idea of having to endure the ordeal of their inevitable decline, their dependence on others and their loss of control over their own circumstances”. He felt that doctors should be respectful of that and accept that some people will wish to end their own lives under their own control rather than the control of others.

However, there was some reflection on limits to this autonomy even amongst those who supported the Bill. EXIT (S, 350) noted that “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”. A similar point was made by the British Humanist Association (S, 245). Dr Iain Brassington (S, 010) related this to those able to make a choice but physically incapable of carrying through their wishes. He said this placed them in a position of “‘double jeopardy”, whereby the exercise of those rights is hampered by their condition when that condition is plausibly a contributing factor to their wanting to end their own lives to begin with.” He argued such people should be able to call on assistance to end their lives but argued there should be no moral or legal compulsion on anyone to do it.

However, it is the effect on others which is fundamental to the reflections on autonomy by those opposed to the Bill, and is summed up in the joint submission by the Church of Scotland, the Methodist Church in Scotland and the Salvation Army (O, 297):

“One of the specific concerns about this Bill is that sometimes an individual may want to make a choice that is so damaging to the society in which we live that making that choice is wrong. Appeals to autonomy, while superficially seductive, fail to take into account the interconnectedness of communities, and the fact that the concept of a person being a burden to society is inimical to autonomy, as somebody who is truly autonomous by definition cannot be a burden.”

A range of groups and individuals made similar comments including: Free Church of Scotland (O, 146), Dr H Gray (O, 042), Rev Dr D MacDonald (O, 057), Association of Hospice and Palliative Care Chaplains (O, 106), I & R Waldram (O, 231), Scottish Council on Human Bioethics (O, 322), and Rev G Thain (O, 371). There was a widely felt concern that the choice of such magnitude would have an affect on more than the person
themselves, but would include family, friends, health professionals and others who may care for them. Other points raised in a similar vein included:

- any right to autonomy is limited in that it does not include the right to consent to harm from another (Association for Palliative Medicine (O, 262))
- a right to die is not the same as a right to be killed. Patient autonomy is effectively a negative right, designed to protect patients from unwanted medical intervention rather than put them in a position to dictate a course of treatment (Dr F Downs (O, 198))
- the Bill is discriminatory in this regard as it only grants such autonomy to certain groups of terminally ill or the disabled and not others who may wish it (Leeza Mundaden (O, 074))
- whilst personal autonomy is important, this must be balanced against the need to protect the vulnerable (BMA Scotland, (O,154), CARE Scotland, (O, 390), and Equality and Human Rights Commission Scotland (NP, 412)

CALL FOR EVIDENCE QUESTIONS

Requesting end of life assistance from a registered medical practitioner

Many respondents began answering this question on the basis of issues of morality, dignity and personal autonomy, which have been largely covered above. As per the overall response rate the majority across most respondent groups was opposed, with many referring to issues covered by other questions. Nevertheless there were some general matters discussed in relation to this question.

The need for a debate

Some used the opportunity to welcome the debate, for example West Lothian Council (NP, 100) noted that “the debate around the Bill is welcomed, and it is hoped that the process can lead to greater clarity in the law and in public policy on end of life choices.” This call for clarity was endorsed by the Royal Society of Edinburgh (NP, 449) which called for Parliament to come to a clear view on whether it should be legally permissible for anyone to assist another person to die: “It must be recognised that this Bill has ramifications for both individuals and society that are far from ordinary”.

The breadth of the Bill

A number of respondents noted that the Bill goes further than legalising physician assisted suicide but would also legalise voluntary euthanasia (Lord Mackay of Clashfern (NP, 058) and Dr David Jeffrey (O, 048). Some described this in terms of the existing legislation in other jurisdictions, describing it in terms of the systems in Oregon and that of the Netherlands (eg S McGettrick et al (O, 107), Free Church of Scotland (O, 146) and CARE for Scotland (O, 390)). Professors Laurie and Mason (NP, 052) felt what was being proposed was “largely uncharted territory for any jurisdiction. As such, it is a leap into the unknown and has to be treated with exceptional care”.

Some of those who supported the principles of the Bill did raise concerns at the breadth of the Bill, for example Dignity in Dying (S, 398) who preferred the model adopted in Oregon1. Dr C Lunan (S, 300) felt the Bill needed to be more explicit as to what it proposed as if it only wants to legalise assisted dying (where the physician provides the means of dying) rather than euthanasia, there may be more support amongst the medical profession. However, others that thought it was too tightly drawn (eg J & J Raven (S, 078).

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1 Death with Dignity Act 1994 permits the provision of a prescription for lethal medication to be self-administered by the patient.
Use of the phrase “end of life assistance”

Others used the question to scrutinise what the Bill actually proposed overall and whether this was clear from the title of the Bill and the terminology used. Key to this was the definition of “end of life assistance” as stated in section 1(2) of the Bill:

“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.

Several respondents from a palliative care background felt this was essentially what palliative care sought to do. Given the Bill concerned forms of euthanasia, which was not part of the role of palliative care, they were concerned about the confusion this may cause particularly in patients (eg Scottish Partnership for Palliative Care (NP, 259), Association for Palliative Medicine (O, 262), I Maccormick (O, 356), Association of Chief Police Officers (NP, 386), Care Not Killing Scotland (O, 391) and Alzheimer’s Scotland (O, 462).

This, together, with the points raised on the breadth of the Bill above, led many to call for the phrase to be changed or better defined to take account of what the Bill actually proposed. (eg Catholic Bishops’ Conference of Scotland (O, 293), Dignity in Dying (S, 398), Ardgowan Hospice (O, 399), Evangelical Alliance (O, 413) and Royal Society of Edinburgh (NP, 449)). The same criticism was made in relation to the use of the phrase in the title of the Bill (eg J Elliot (O, 204), Pro-Life - All Party Parliamentary Group (O, 241) WE Thomas (O, 377), MC McGinley (O, 430).

The proposed role for doctors

The Bill proposes a pivotal role for a ‘registered medical practitioner’, in terms of the handling and consideration of end of life requests, the decision making process and agreeing the provisions of assistance. Many of the issues raised by respondents were covered in other parts of the call for evidence (eg training for the profession and how would competence to carry out such requests be decided). However, there were a number of key themes raised at this point.

The majority of medical professionals stated their rejection of doctors having such a role. For many practising doctors and doctors in training this was contrary to the reasons they went into medicine and to the role of the doctor as understood through the Hippocratic oath (eg BMA Scotland (O, 154)). For some individuals it was wrong to ask another person to assist someone else to die (eg A Byrne (O, 203)). However, the key concern of those who were opposed - across respondent groups - was the belief that the Bill would fundamentally alter the existing patient/doctor relationship of trust (eg Dr D Buchanan (O, 013), Dying Well (O, 030), Dr J Leiper (O, 137), M Murphy (O, 208), Association for Palliative Medicine (O, 262), Evangelical Alliance (O, 413). This argument is made on a number of grounds including:

- patients may look differently on the profession as a whole, given doctors take an oath to preserve life yet will at the same time have the powers in the Bill
- patients may perceive doctors will not always be acting in their best interests
- vulnerable patients may be reluctant to disclose their fears and concerns to doctors and other healthcare professionals.

Another key argument centred on the extent the profession had been consulted on such a proposal and whether they were the right people to undertake the role (eg (S McGettrick et al (O, 107) and Highland Hospice (O, 275)). For some the role proposed by the Bill was not explicit enough and there was a need to consider this further before such discussions could take place (eg Royal College of General Practitioners (O, 446)). Dr C McArthur (S,
062) who was supportive of the principle behind the Bill accepted that it should not be imposed on a profession that did not want it, which raises the issue about who else would be appropriate to undertake it.

Some respondents reflected on the likelihood that only a minority of doctors would undertake such a role should the Bill be passed. It was noted that the Bill did not specify that the doctor needed to be a person’s GP and that section 5(2) of the Bill allowed for “reasonable fees for work done in relation to the provision of end of life assistance”. These issues led to a number of concerns, including:

- patients may ‘shop around’ until they found a doctor willing to handle their request (eg Dying Well, (O, 030) and Care Not Killing Scotland (O, 291))
- could in theory lead to small numbers of services undertaking a significant amount of work without enough independent safeguards (eg Mental Welfare Commission for Scotland (O, 169) and (Faculty of Education, Health and Social Sciences, University of the West of Scotland (S, 192))
- the development of such specialist services will have a significant effect on how doctors are perceived in society (eg Dr J Keith (O, 050))
- the allowance of fees may lead to specialist private practice (Scottish Partnership for Palliative Care (O, 259)) or raise charges of a conflict of interest (St Columba’s Hospice (O, 288))

Finally there was some comment on the use of the term “registered medical practitioner”, with some respondents pointing out that a new licensing procedure had been brought in by the General Medical Council for all doctors. The General Medical Council itself (NP, 468) stated that the term should be “licensed and registered medical practitioner”, particularly as only a licensed doctor could prescribe medicines.

**Role of other health professionals**

The only other specific reference to a health professional in the Bill, other than doctors, is a psychiatrist, and this was commented on by a number of respondents. Several noted that the Bill failed to recognise the involvement of other professionals such as nurses, pharmacists and carers. This was either because feasibly they could be called upon to provide the final assistance or because they may find themselves being involved in terms of patients approaching them for advice (eg Association for Children’s Palliative Care (O, 291), Community Pharmacy Scotland (NP, 144), EM Grant (O, 303), Morgan Dr T R M (O, 408).

The Independent Association of Nurses in Palliative Care (O, 203) noted that in other countries where euthanasia is available there is a significant role for nurses as they are in more contact with dying people than any other professional group. It called for further clarification about who can and cannot be part of this process. One anonymous respondent who supported the Bill stated that while registered general medical practitioners were the right people to facilitate end of life assistance, they would not be opposed to other categories of competent people being included with a specified amount of experience and/or a requisite qualification to perform this role. (Anonymous (S, 174))

**Provisions on age and connection with Scotland**

**Age**

Section 4(1)(a) stipulates that, along with the other eligibility criteria, that the person requesting assistance “is 16 years of age or over at the time of making the first formal
request”. Overall the view taken on this provision followed their overall view on the Bill itself. However, there were a number of discussion points.

**Opposed**

The majority making detailed comment were opposed to the proposal that someone aged 16 or over should be able to seek assistance to end their own lives. Discussion tended to concentrate in particular on the 16 to 18 age group. The key arguments against were:

- the age of 16 is too young to make such a decision (eg S McGettrick et al (O, 107), Pro-Life - All Party Parliamentary Group (O, 241) and EM Grant (S, 302)
- young people are not emotionally mature enough or have enough life experience in order to make the decision (eg L Cameron (O, 016), Dying Well (O, 016), Independent Association of Nurses in Palliative Care (O, 203), PJ Helms (O, 284), Church of Scotland et al (O, 297) and SPUC Scotland (O, 457)
- young people may be at risk of undue pressure being placed upon them (Dr J Leiper (O, 137), Scottish Council of Jewish Communities (O, 472)
- the law does not allow people to drive until they are 17, or smoke, drink alcohol and vote until they are 18, so they should not be allowed to take such a decision (eg B Mournian (O, 073), J Bryden (O, 308) A Bentley (O, 383) and RM Wardle (O, 444).

Some could understand why age 16 was chosen but felt the decision was such that it would be prudent and responsible to err on the side of caution, (eg Care Not Killing Scotland (O, 391). C Simpson (O, 141) believed that, theoretically, a person may not be mature enough to make such a decision until they were 25, and noted that Switzerland was moving to recognise that assisted suicide was inappropriate for the very young.

Prof’s Laurie and Mason (NP, 052) were amongst a number of respondents that noted Scots Law can and does intervene to protect children from harmful decisions. They considered there to be strong reasons for the provisions applying to those of 18 and over. Dignity in Dying (S, 398) said it preferred the age of 18 as the start of eligibility.

**Support**

Fewer people agreed with the provisions in the Bill as introduced. Anonymous (S, 174) believed that if people were considered old enough to marry and have the responsibility of a child, they must also be old enough to take decisions relating to their quality of life extending to ending their lives. M Branthwait (S, 150) agreed that age 16 seemed very young for a decision of this magnitude but accepted the need for a threshold age. Dr C Lunan (S 300) and Breast Cancer Care Scotland (NP, 388) also agreed with it.

There were respondents, though very few in number, who questioned or believed that provision should be made for those aged 12 to 16 if supported by a parent and guardian (eg E Duncann (S, 027) and Dr H Wynn (S, 402)). This would bring the legislation in line with legislation for organ donation.

**Additional structures**

Some of those who had no stated position on the Bill or who supported it felt there should be additional mechanisms put in place for the younger end of the eligibility scale. For example EXIT (S, 350) believed there should be a special system for those aged under 21, whilst I Smith (S, 088) wanted to see an additional mechanism to ensure those under the age of 35/40 received professional guidance to ensure all alternatives were explored before permission was granted.
Capacity

This was raised both in defining an appropriate age but also in questioning whether age was the correct test.

As regards defining an appropriate age, the Royal College of Psychiatrists (O, 286) noted that the Mental Health (Care and Treatment) (Scotland) Act 2003 requires NHS Boards to provide “age-appropriate” mental health services for those under 18. It contends that if the Bill was passed, then psychiatrists undertaking assessments in 16- and 17-year olds would need to be specifically trained in adolescent mental health. It therefore considered the eligibility age should be 18.

Other respondents reflected on whether chronological age was the correct test for establishing capacity. The Royal College of Physicians of Edinburgh (NP, 448) believed it would be important to ensure that psychiatric assessment of capacity confirmed the mental age for some patients. The Association for Children’s Palliative Care (O, 291) noted that assessment of mental capacity is increasingly moving away from an age-based ability to make assessments towards a capacity to make decisions. Prof’s Laurie and Mason (NP, 052), although being more comfortable with the age of 18, did note that any mechanism could reflect the concept of understanding as per the Age of Legal Capacity (S) Act 1991. Finally, West Dunbartonshire Council (NP, 100) questioned whether the children’s hearing system could determine eligibility/capability on a case by case basis. However, it added that irrespective of differing views the proper care and protection of children must be balanced by the right of the child to make certain decisions for themselves.

Connection to Scotland

Section 4(1)(b) of the Bill stipulates that, along with the other eligibility criteria, a person placing a request “has been registered with a medical practice in Scotland for a continuous period of at least 18 months immediately prior to making that request”. A small minority of people discussed this in detail, though again there were a number of points raised.

A number of respondents were happy with the provisions and felt they would be sufficient in preventing “suicide tourism” (eg Breast Cancer Care Scotland (NP, 388), Dr J Douglas (S, 026), Anonymous (S, 174) and Dignity in Dying (S, 398). A Watson (S, 381) felt 12 months would be sufficient. Prof R Duff et al (S, 441) queried why assistance should be denied to those wanting to come to Scotland to end their lives through the Bill, “unless the fear is that the Bill would have an even smaller chance of passing without that restriction”.

There were a number of respondents who were concerned that the provision could discriminate against those who moved to Scotland for perfectly legitimate reasons (eg West Dunbartonshire Council (NP, 100) and Royal Society of Edinburgh (NP, 449)), and those who are terminally ill or severely disabled who choose move to be closer to relatives, which is quite common (eg Dr H Wynne (S, 402), Friends at the End (S, 249) and the Royal College of Physicians of Edinburgh (S, 448)).

The majority of those who discussed this issue did not believe the provision was sufficient. A number of reasons were presented, including:

- there is no role in the Bill for a medical practitioner from that the practice that the patient must be registered with, which may lead to concerns regarding how well the doctor providing assistance will know the patient (eg Mental Welfare Commission for
Scotland (NP, 169), Dr K Grahame (O, 050), Christian Concern for our Nation and the Christian Legal Centre (O, 294)

- the type of practice is not defined in the Bill, meaning no requirement to be registered with a NHS practice and potential for a private practice to be established for the purpose of assisted dying (eg S McGettrick et al (O, 107), Free Church of Scotland (O, 146) and Dying Well (O, 030))
- may be an avenue to obtain registration through temporary residence (eg Pro-Life - All Party Parliamentary Group (O, 241), L Nunn (O, 280), Care Not Killing Scotland (O, 391)
- 18 months is not long enough to prevent “suicide tourism” (eg Church of Scotland et al (O, 297 and SPUC Scotland (O, 457))

Provisions on eligible medical conditions

Section 4(2) of the Bill states that eligibility would be based on:

a. the person has been diagnosed as terminally ill and finds life intolerable; or
b. is permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable.

Section 4(4) defines “terminally ill” as “if the person suffers from a progressive condition and if death within six months in consequence of that condition can reasonably be expected”.

The Explanatory Notes (para 21) explains that “intolerability” under both conditions has not been further defined as the test should be a subjective one determined by the person themselves, though notes they would be subject to a psychiatric assessment. The Explanatory Notes (para 22) also explain that the second condition will “encompass persons who have been the subject of a trauma as well as persons with progressive and irreversible conditions, provided the dependency and intolerability criteria are met”.

These provisions proved to be the most contentious within the submissions received. Concerns were raised on all sides of the debate, and these will be discussed in the following subsections. However, it should be noted that a number of those who were classed as supportive of the Bill were largely supportive of the medical categories as proposed (eg Cllr E Glass (S, 038), Anonymous (S, 174), British Humanist Society (S, 245), Friends at the End (S, 249) and Dr H Wynne (S, 403). There were a small number of respondents that believed the categories could be widened or added to take account of ‘living wills’ and ‘advanced statements’ (eg Prof Duff et al (S, 441)), for example for people with early stages of dementia who have capacity in order to do so (eg H Macfie (S, 354).

The categories in general

Some respondents considered that the scope of the conditions in legislation were too broad, with the concern that what was aiming to cover a small number of people who were finding life intolerable would in fact cover a range of physical conditions and often quite vulnerable people (eg Christian Concern for our Nation and the Christian Legal Centre (O, 294), CARE for Scotland (O, 390), Dr TRM Morgan (O, 408) and the Evangelical Alliance (O, 413). Dying in Dignity (S, 398) considered that assistance should only be available to those with a terminal illness who had capacity.

Others were concerned with achieving clarity over the position of certain conditions. For example, Age Scotland (NP, 379), whilst those with dementia were unlikely to meet the criteria to be able to seek assistance they felt this needed to be clarified, “given the
perception among some members of the public that the Bill would allow assisted suicide, or even euthanasia, for people with dementia”. In addition, Parkinson’s UK (NP, 471) considered that it is possible that people with advanced Parkinson’s could be included in both of the categories defined in the Bill, though on the other hand there are requirements which might rule them out. It noted how it can be difficult to predict what will happen because the condition affects individuals in different ways. It suggested that consideration be given to changing the definitions to reflect this, which would likely be shared with other progressive neurological conditions.

*The use of the word “intolerable”*

There was widespread dissatisfaction from across respondent groups to the lack of definition to “intolerable” in both condition categories. For many respondents there was a straightforward view that the term was too subjective with questions raised as to how it would actually be judged and measured (eg Dr Iain Bassington (S, 010), Dying Well (O, 030), Suslak T (NP, 136), Association of Chief Police Officers (NP, 386) and Care Not Killing Scotland (O, 391)). Other associated comments included:

- it requires criteria on which to judge it (eg Royal College of Psychiatrists (O, 286))
- will depend upon the life experiences and the perception of the assessor, therefore more than one person must be involved in this judgement (eg D Foster (S, 217))
- many people find life intolerable for some part of their illness. D Luke (O, 177) (who spoke of personal experience living with a long term condition), J Elliott (O, 204) and Association of Hospice and Palliative Care Chaplains (O, 106)
- depends on many unspecified factors eg psychological, emotional, physical and social, and as a result each individual’s state of mind will fluctuate over time (Free Church of Scotland (O, 146), Highland Hospice (O, 275) and Association for Children’s Palliative Care (O, 291))

In discussing this issue, some respondents referred to the findings of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, which was introduced by Lord Joffe. The Chair of the Committee, Lord MacKay of Clashfern (NP, 058) submitted a response to the Committee’s call for evidence, which referred to this issue. Lord Joffe proposed the term “unbearable suffering” in his Bill but the Select Committee considered after hearing evidence that more objectivity was required and instead suggested “unrelievable” or “intractable” suffering as a more satisfactory criterion, as long as it was associated with a suitable test. However, Prof’s Laurie and Mason (NP, 052) suggested that the concept of ‘unbearable suffering’ should replace ‘intolerability’ “on the grounds that something that is intolerable, cannot, by definition, be tolerated whereas ‘unbearable suffering’ more accurately reflects the subjective experience of the patient and his/her choice to end that suffering”. They also felt this took account of recent English case law. Other suggestions included:

- detailing what is “intolerable” and the actions that could be taken to relieve the situation. (Faculty of Education, Health and Social Sciences, University of the West of Scotland (S, 192))
- more explicit criterion may be “untreatable suffering” which requires an assessment of whether all reasonable medical measures to treat suffering, physical or psychological, have been considered (eg Dr B Cleminson (O, 299))
- criteria should be “unbearable and unrelievable” (EXIT (S, 350))
Permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable

Overall comments

The second medical condition listed in the Bill also came in for significant criticism on a number of levels. The major concern voiced by many respondents was the breadth of the provision and the large numbers of people that could feasibly be covered. The Free Church of Scotland (O, 146) provided a list of those it considered could be covered: “progressive neurological disorders, paralysis, severe heart or lung disease and many other disabilities, both congenital and acquired”. Similar points were made by Scottish Partnership for Palliative Care (NP, 259), Age Scotland (NP, 379), Care Not Killing Scotland (O, 391), as well as range of private individual and medical professional submissions. The British Psychological Society in Scotland (NP, 389) argued that the inclusion of the physically disabled “seems haphazard (in the Policy Memorandum they are not directly mentioned until paragraph 96) and there appears to be little thought about how those with a disability who are dying differ from those with a life-time of chronic physical disability”.

Other concerns raised concerning the provision included:

- could be interpreted as allowing some people to end their life for social, rather than health, reasons and that would be entirely wrong (eg West Dunbartonshire Council (NP, 100))
- the wide interpretation may leave the scope of legislation unclear which could leave persons seeking voluntary euthanasia/assisted suicide in an unsatisfactory position (Scottish Partnership for Palliative Care (NP, 259))
- would be possible to argue that “living independently” could mean “living in one’s own home without any support” (Age Scotland (NP, 379))
- the concept of physical incapacity and the related lack of ability to live independently do not reflect the complex dependence-independence relationship which is a normal facet of growing up and maturing (Association for Children's Palliative Care (O, 291))

There were a number of calls for this provision to be revised or considered further. Breast Cancer Care Scotland (NP, 388) was one of those who discussed a possible amendment. It argued that: “Someone who finds their circumstances change through some form of accident should have a minimum period of time to adjust to their condition and not be allowed to request end of life assistance through a period of extreme emotional turmoil and difficulty.”

Terminal illness

The definition of terminal illness with a prognosis of death within 6 months raised concern, particularly amongst the medical profession and palliative care groups. The key point made was that this is extremely difficult to predict particularly in non-cancer, non-malignant conditions.

Many respondents made this point or similar, including: Dr David Gray (O, 041), Dr David Jeffrey (O, 048), Dr John Walley (O, 096), Independent Association of Nurses in Palliative Care (O, 206) Scottish Partnership for Palliative Care (O, 259), St Columba’s Hospice (O, 288), Breast Cancer Care Scotland (NP, 388), Royal College of General Practitioners (NP, 446), Highland Hospice (O, 275) and CARE for Scotland (O, 390)
The issue of disability and the provisions

There was some concern raised particularly by those representing people with disabilities that the medical conditions stipulated in the Bill could have a discriminatory effect on those with disabilities. For example, Inclusion Scotland (O, 167) was concerned that the Bill could lead to a situation where most of those who would qualify for assistance would be people with disabilities, whilst the vast majority of those excluded from assistance would be people without disabilities: “That suggests that the lives and existence of one group are being treated as of less value than the other”. It also noted the reference in the Explanatory Notes (para 22) to “dependency”, and felt this condoned “the stereotype that disabled people’s lives are so valueless, tragic, burdensome and insufferable that they must want to die”. This was a point also taken up by Care Not Killing Scotland (O, 391).

The issue of dependency was raised, in particular, when considering the second medical condition which linked physical incapacity to being unable to live independently. Independent Living Scotland (O, 469) was particularly unhappy at this proposal as it felt it was completely contradictory to the efforts to promote independent living through initiatives undertaken by national and local government, which sees it as “support to empower disabled people to have choice, control, freedom and dignity”. It added:

“More worrying than this, is the implication that if an individual needs support to live their life in the way they choose, as others take for granted, they are considered “dependent”. If the individual then begins to “find life intolerable”, for any reason (not inconceivable if services and structures continue to view disabled people as “dependents” and so do not deliver on independent living) then they are eligible to be assisted to die. The inclusion of criteria based on the misconception of independence is of concern.”

Other concerns on similar points included:

- the concept of physical incapacity and the related lack of ability to live independently do not reflect the complex dependence-independence relationship which is a normal facet of growing up and maturing (Association for Children's Palliative Care (O, 291))
- there could be serious problems surrounding the interpretation of what amounts to ‘independent living’. Again, given the authority handed to doctors by this Bill, this is presumably open to interpretation which could be based on personal attitudes. ‘Independent living’ does not seem to be susceptible of objective analysis. Prof Sheila McLean (NP, 019)

Consent and verification process

This section considers the processes put in place (outside actual end of life assistance itself), which the Bill proposes as part of the safeguards for ensuring proper consent and verification.

Some of the issues that were discussed by respondents to this question have been covered in the section on ‘Requesting end of life assistance from a registered medical practitioner’ above, such as concerns over the specialisation of end of life services. It should also be noted that significant numbers of those who held strong views either in support or opposition to the Bill did not necessarily make detailed comment on these aspects of the Bill on the grounds that they either completely agreed or disagreed with the Bill and the principle behind it. Therefore most of the discussion concerns issues that were identified in different parts of the process by those from all sides.
General

Given the pivotal role of the designated medical practitioner throughout the process a number of general points were made considering this.

There was some debate concerning the fact that the Bill proposes that the same designated practitioner see the whole process through from beginning to end. Whilst welcomed by some, others felt this was quite onerous and could place pressure on resources, particularly given the time it would take to meet the various criteria and meet various time constraints that become evident throughout the process (eg RM Wardle, (O, 444). There were suggestions based round allowing the designated practitioner to co-opt another medical practitioner into the process as long as it had the agreement of the requesting person (eg Anonymous (S, 174)). However, others questioned the reason behind nominating a medical practitioner to undertake the process as ultimately medical considerations were only part of the process. Other suggestions were made, such as lawyers, social workers, panels of carefully selected and trained lay people (eg Prof Diff et al (S, 441), Royal Society of Edinburgh (NP, 449).

Some respondents noted that there is nothing in the Bill that stipulates the need for the designated practitioner to be someone with whom the person has been registered with or treated by. In these circumstances there was a concern that the doctor would not have the familiarity with the person’s medical condition, their psychological state and family background (eg W Lawrie (O, 460). However, on the other hand the objectivity of the designated practitioner was a crucial point for some who supported the Bill. EXIT (S, 350) felt this was crucial as it would be the only way a patient would feel assured that the request would be considered without prejudice, and, that they would examine palliative care options with the patient without prejudice, being open to the eventual wishes of the patient. Dr C McArthur (S, 062) felt that doctors who provided normal care for a patient who makes a request should not be permitted to be actively involved in ending that patients life, even if they wished to.

Finally, the Royal College of Physicians and Surgeons of Glasgow (O, 447) noted that whilst the Bill requires documentation at various stages of the process, it does not specify what is expected, which could be crucially important for legal protection of the doctor.

Need for two formal requests

Section 2 of the Bill proposes that end of life assistance may only be provided where two formal requests for such assistance have been made to a registered medical practitioner and those requests have been approved by that practitioner. There was little said about this particular section, though Prof’s Laurie and Mason (NP, 052) considered there should be reference to the experience of a medical practitioner and that they are holding a license to practise. The issue of experience is one that emerges throughout the process. Prof Sheila McLean (NP, 019) felt giving the registered medical practitioner the sole role of approving the requests could give excessive power to doctors, and may allow them to impose their own morality in deciding whether or not to allow the patient’s request. She suggested this could be overcome by including obligation to refer for a second opinion.

Overall, respondents tended to pass comment on the later sections of the Bill which stipulated the requirements for each of the first and second requests (see below).
Requirements relating to designated practitioners and psychiatrists

Section 5 of the Bill imposes constraints upon who can act as a designated practitioner or psychiatrist with regard to the processes set out in the Bill. Firstly, neither can be a relative of the requesting person (this is defined in the Bill). Secondly, neither can personally benefit, or have a relation that will benefit, from the requesting person’s estate, though this does not apply to any reasonable fees for work done in relation to the application or its assessment.

There were not many comments concerning this section specifically, though West Dunbartonshire Council (NP, 100) felt there should be a requirement on both the medical practitioner and the psychiatrist to state formally that they have no such links to the patient.

Requirements relating to the first formal request

Section 6 requires that the first formal request be in writing and signed by the requesting person as well as two witnesses. As well as witnessing the requesting person’s signature the witnesses must also certify, that to the best of their knowledge and belief, that:

- the requesting person understands the nature of the request
- is making the request voluntarily
- is not acting under any undue influence in making the request

Witnesses cannot knowingly be related to the requesting person, be a beneficiary of their estate or have another interest in the person’s death and cannot be the designated practitioner. There is also provision that for requesting persons living in care homes that an employee of that establishment must be one witness if practicable and that they know the person well.

A number of comments were made on these provisions from across respondent categories. Firstly, a number of respondents felt the stipulation that the request could prevent eligible people requesting end of life assistance because, although they have capacity, they do not have the physical ability to place it in writing due to their condition. It was felt provision should be made for such people to make a request (eg Association of Chief Police Officers in Scotland (NP, 386), Prof Sheila McLean (NP, 019), M Branthwaite (S, 150), Friends at the End (S, 249)).

There were also issues raised on the exclusion criteria for witnesses. Here there was a divergence of opinion. Some, for example the Free Church of Scotland (O, 146), felt close friends should also be excluded from being a witness on the grounds they may lack objectivity. However others, whilst perhaps acknowledging the reasons behind the exclusion criteria, were concerned that strangers who did not know the person well were far less likely to be able to determine whether a risk of internal or external undue influence existed (eg J Elliott (O, 204), D McElroy (O, 399 and SPUC Scotland (O, 457)). Indeed it was felt there was a contradiction with the provisions for witnesses from care homes who did need knowledge of the person (eg SPUC Scotland (O, 457). EXIT (S, 350) felt that at least one witness should know the person well and if that is not practicable there may need to be a review process put in place for such cases.

The provisions over care home witnesses also caused some comment. There were concerns that this potentially exposed care home residents to (albeit a minority of) unscrupulous staff and they may be pressured to request end of life assistance (eg Dying Well (S, 030), C Simpson (O, 141), Free Church of Scotland (O, 146), Age Scotland (NP, 379) and Parkinson’s UK (NP, 471). One suggestion put forward was that the designated
practitioner should provide an opinion as to whether or not it is practicable for an employee of the care home to act as one of the witnesses. (Anonymous (S, 174).

As regards witnesses in general, the Royal College of Physicians of Edinburgh (NP, 448) felt there needed to be clarity on how close and knowledgeable witnesses needed to be and on what basis they would be judged to have made a “reasonable” decision. St Andrew’s Hospice (O, 324) felt that witness statements needed to be subject to the “most rigorous of scrutiny”. There were also calls for any staff member from the same medical practice as the designated practitioner to be prohibited from acting as a witness (eg Anonymous (S, 174) and Royal College of Physicians of Edinburgh (NP, 448)).

Finally, the Scottish Disability Equality Forum (NP, 466) stated that some of its 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. A similar point was made by the Scottish Independent Advocacy Alliance (NP, 454).

Consideration of the first formal request by the designated practitioner

Section 7 of the Bill makes it clear that the designated practitioner cannot approve the first formal request unless certain requirements are satisfied. First they must meet with the requesting person and discuss with them:

- their medical condition that makes them eligible for assistance
- all feasible alternatives including palliative care and hospice care
- the consequences of approval together with the ability to revoke the request at any time, and
- the forms of the assistance that will be available

Secondly, the designated practitioner must be satisfied that the person:

- meets all other eligibility criteria
- is acting voluntarily and without undue influence
- has received a psychiatrist’s report under section 9 of the Bill (this report must include a statement from the psychiatrist that they are satisfied that the person is acting voluntarily and without undue influence)

Finally the designated practitioner, if they approve the request, must do so in writing which must also be signed and dated.

A number of issues were raised concerning this process, some of which are pertinent to the rest of the process involving the registered medical practitioner.

Firstly, a number of respondents questioned whether all doctors agreeing to participate (GP or hospital based) would have the necessary knowledge and experience to discuss end of life issues with patients, and confirm that eligibility criteria were met, particularly with regard to discussing all feasible alternatives (eg Royal College of Physicians of Edinburgh (NP, 448), Dr J Walley (O, 96), J Bryden (O, 308), Alzheimer Scotland (O, 462) and M Branthwaite (S, 150)). There were also questions raised as to how the doctor could be sure that the person was not under undue pressure and how were they to assess that person was acting “voluntarily” (eg A Mathers (O, 180), Pro-Life - All Party Parliamentary Group (O, 241), Catholic Bishops Conference of Scotland (O, 293) and Evangelical Alliance (O, 413), Scottish Council of Jewish Communities (O, 472)). Allied to this were
concerns that inexperienced and young medical doctors could be asked to facilitate the process (eg T Suslak (NP, 136)) and those that wished clarification on what these competency levels should be (eg Association of Hospice and Palliative Care Chaplains (NP, 106), Dr T R M Morgan (O, 408), J Utting (O, 420) and Highland Hospice (O, 275)).

Another key issue concerned the discussion of palliative care with the requesting person. For a number of respondents this was not sufficient, and there were calls for the person to first experience palliative care before making a request (eg Rev Dr Donald M MacDonald (O, 057), Independent Association of Nurses in Palliative Care (O, 203), Highland Hospice (O, 275) and Care Not Killing Scotland (O, 391)).

Monitoring of the process was also raised as an issue, with some concerned there was a lack of scrutiny and reporting mechanisms to ensure all the procedures were being followed (eg Dr JM Reid (O, 229), Anonymous (S, 174), Highland Hospice (O, 275), D Braine (O, 298) and the Catholic Bishops Conference of Scotland (O, 293)).

Following on from concerns that the Bill did not mention the feasible role of other health and social care professionals, a number of respondents noted that assessments in palliative care took place on a multidisciplinary basis involving a whole range of professionals including, doctors, palliative care specialists, nurses, pharmacists, social workers, psychologists, psychiatrists and spiritual care providers. Calls were made for this process to be acknowledged, but in addition to consider the role some of these may inevitably play in the process should the Bill be passed (eg Dr Jane Pinketon et al (O, 483), Scottish Partnership for Palliative Care (NP, 259) and (Association of Directors of Social Work (NP, 387)).

Finally, Dr C Lunan (S, 300) felt there needed to be an appeals process should a request be turned down.

Consideration of capacity etc by a Psychiatrist

Section 9 of the Bill provides for the psychiatric assessments required for the first and second formal requests. It requires that a psychiatrist must meet the requesting individual in person after the making of the requests, to discuss with them the following:

- the person’s medical condition that makes them eligible for assistance
- the availability of all other alternatives including palliative and hospice care
- the nature of the request and the revocability of the request; and,
- the person’s feelings and reasons for making the request.

Discussions will also have to cover what is required for the report to the designated practitioner, namely that the person has capacity to make the request; is doing so voluntarily; and is not under undue influence. In assessing capacity, all reasonable efforts must be made to communicate with the adult in an appropriate way before arriving at a decision eg the assistance of an independent interpreter who is familiar with the adult’s means of communication could be considered as well as any necessary equipment. A person is deemed as having capacity if they are not suffering from any mental disorder (as stipulated in the Mental Health (Care and Treatment) (Scotland) Act 2003), which might affect the decision to make such a request. In addition the person must be capable of communicating, understanding and remembering such decisions. Finally, there are provisions stating the same psychiatrist “need not “undertake the assessments for both formal requests, and that the report be in writing, addressed to the designated practitioner and is signed and dated by the psychiatrist.
As will be noted, many of the issues that the psychiatrist must discuss with the requesting person are the same as those by the designated practitioner, and as such many of the issues raised were similar in those cases. The following will relate only to those points specifically raised about the psychiatric assessments.

As regards psychiatrists themselves, a number of respondents called for a definition of a "psychiatrist", such as in terms of whether they are appropriately licensed and registered (eg Prof’s Laurie and Mason (NP, 052), PJ Helms (O, 284), I McOwan (S, 069) and Scottish Humanist Society (S, 187)). There was also some discussion as to whether all psychiatrists would have the right skills and experience to deal with all the matters stipulated in the Bill. This included particular concerns that whilst psychiatrists can competently diagnose, for example, major depression, the diagnosis and management of depressions in people who are seriously physically ill is more specialised. (eg Mental Welfare Commission for Scotland (NP, 169), Scottish Partnership for Palliative Care (NP, 259), Dr J Walley (O, 096), JF Utting (O, 420). The British Psychological Society (NP, 389) stated that it was satisfied that psychiatrists, psychologists and other specialist professionals have the skills to make the assessments outlined in the Bill with regards to capacity (eg British Psychological Society (NP, 389). Though there were those that argued for a more multidisciplinary approach to the assessments.

Lord MacKay of Clashfern (NP, 058) in discussing the scrutiny of provisions in Lord Joffe’s Bill, noted that the Select Committee was concerned that there should be a thorough psychiatric evaluation, involving other professionals – eg neuropsychologists or palliative care physicians – involved as necessary. This was in line with a number of respondents who called for a multidisciplinary approach involving health and social services. As an example the process in evaluating capacity under the Adults with Incapacity (Scotland) Act 2000 was often referenced. (West Dunbartonshire Council (O, 100), Dr D Maliepaard (NP, 367), British Psychological Society (NP, 389), Royal College of Physicians of Edinburgh (NP, 448), Parkinson’s UK (NP, 471) and Dr J Walley (O, 096)).

There was also some comment as to whether the assessment process in the Bill would be sufficient. A number of respondents noted that while severe mental disorder or blatant coercion may be readily detectable, a potentially common combination of factors affecting a requesting person (mild depression, mild cognitive impairment and an internalised perception that they are a burden to relatives) may be more difficult to identify without a much more thorough process (eg Scottish Partnership for Palliative Care (NP, 259), Royal College of Physicians of Edinburgh (NP, 448), J Elliot (O, 204), L Nunn (O, 280), CARE for Scotland (O, 390). As regards depression, in particular, there was a concern raised that the definition of mental disorder in the Bill may not cover depression and there were calls that there should be specific screening for this (eg S McGettrick (O, 107), Pro-Life - All Party Parliamentary Group (O, 241), St Andrew’s Hospice (O, 324), Care Not Killing Scotland (O, 391), SPUC Scotland (O, 457). Similar points were raised in regards to drug or alcohol dependency (eg Pro-Life - All Party Parliamentary Group (O, 241), CARE for Scotland (O, 390) and Dying Well (O, 030).

The appropriateness of the test of capacity in the Bill was also seen as problematic by some. Prof Sheila McLean (O, 019) noted that the mere presence of a mental illness does not necessarily (in law) mean that a person lacks competence. Whilst EXIT (S, 350) noted 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.
In addition, the lack of necessity in the Bill for separate psychiatrists to carry out the assessments for the first and second formal requests was also criticised, with some respondents feeling that given the nature of the request there should be (eg Dr David Jeffrey (O, 048), E Love (O, 131), Care Not Killing Scotland (O, 391), Dying Well (O, 030). However, on this point it should be noted that there was some comment that the need for two assessments and visits to a psychiatrist could be quite an onerous one (eg M Branthwaite (S, 150).

Other issues raised included:

- there needs to be a resolution mechanism should there be separate psychiatric reports for the first and second formal request which disagree (eg Prof’s Laurie and Mason (NP, 052), Dr David Jeffrey (O, 048)
- there is no requirement for the psychiatrist and the designated practitioner to agree on the course of action, which is unsafe and unfair on the designated practitioner. (S McGettrick et al (O, 107), Free Church of Scotland (O, 146) and Dr Harry Gray (O, 042)
- a concern that psychiatric and psychological resources are scarce and the affect this could have on the assessment process (eg Dr D Maliepaard (NP, 367), Dr M Gilmour (O, 041), Dr David Jeffrey (O, 048), G Vlaar (S, 095) Royal College of Psychiatrists (O, 286))
- agrees with provisions concerning communication but would like to see the involvement of a speech therapist (eg Parkinson’s UK (NP, 471)
- the report does not need to include the evidence which the psychiatrist has based their opinion on as regards the various criteria they have to take account of ( eg D Braine (O, 298) and Alzheimer’s Scotland (O, 462)

Requirements relating to second formal request

Section 8 of the Bill stipulates that the second formal request for assistance may not be made unless: a first formal request has been approved by the designated practitioner; the requesting person has been informed of the approval of the first formal request; and a period of not less than 15 and not more than 30 clear days have elapsed since the requesting person was informed. Failure to submit a second formal request within the 30 days period will have the effect of ending the process; where there is such a failure the Bill stipulates that the requesting person would require to go to the beginning of the process for a first formal request, should they wish to. There is also a requirement that the second formal request be addressed to the designated practitioner, who must be the same as that who undertook consideration of the first formal request.

Exactly the same requirements as in the making and consideration of the first formal request would apply in relation to the second formal request eg in relation to the form of the request, witnessing, the need for a psychiatrists report and the consideration of that request by the designated practitioner. However, the witnesses to the second request do not need to be the same as those to the first request.

Again many of the issues raised in relation to the first formal request are pertinent to this section, which will not be reiterated.

The key issue of discussion on this part of the Bill was the proposed 30 day timescale. For those opposed to the timescale, the basic problem was that the timescale was felt to be too short. A number of reasons for this were given:
would put extra pressure on vulnerable people and lead to them feeling unduly pressured (eg Free Church of Scotland (O, 146), Anonymous (O, 459), Leeza Mundaden, (O, 074)

insufficient waiting period to allow for any potentially therapeutic interventions (including treatment for depression) to be assessed, or for improvements in care and symptoms or coming to terms with an illness or condition (eg A Bentley (O, 383), Dr J Walley (O, 096), L Nunn (O, 280), Dr T Everett Julyan (O, 247)

too short a time for all necessary assessments (including psychiatric assessments) and considerations to be made (eg British Psychological Society in Scotland (NP, 389), Dr David Jeffrey (O, 048), CARE for Scotland (O, 390)

However, it should be noted that there were those supporting the Bill who were in agreement with the Policy Memorandum that that the person is making the request because they find their life intolerable and as such the process should not be unnecessarily prolonged.

Similarly in the discussion concerning psychiatrists, a number of respondents also wished to see consideration of the second formal request being undertaken by a different designated practitioner or suggested that a second opinion should be sought. (Free Church of Scotland (O, 146) and Dying Well (O, 030). The Royal College of Physicians and Surgeons of Glasgow (O, 477) considered this essential and also noted that doctors were neither qualified nor skilled in conducting the background searches which would be necessary to establish eligibility of all participating personnel. SPUC Scotland (O, 457) felt that because, potentially only one medical practitioner and one psychiatrist had to be involved in the two formal stages it was likely that on the second occasion both designated practitioner and psychiatrist would be conditioned to more readily accept a request. Dr C Lunan (S, 300) considered similar medico-legal scenarios, such as cremation, or termination of pregnancy require and felt that at this stage a second opinion should be the least that is sought, but suggested the final decision may be best made though a panel. On this point Dr Craig McArthur (S, 062) felt the final decision should be taken by a panel.

Agreement on assistance and requirements related to the actual provision of assistance

Section 10 of the Bill details the requirements that must be agreed between the requesting person and the designated practitioner, once the second formal request has been approved and before end of life assistance can be provided. They must agree:

- that end of life assistance is to be provided;
- who is to provide the end of life assistance;
- the place where that assistance to be provided; and
- the means by which that assistance is to be provided.

Further provision is made under section 11 stipulating that the end of life assistance cannot be undertaken by a relative of the requesting person, or someone with an interest in that person, and that place chosen for assistance must not be one where the public does not have access at the relevant time (this does not preclude it being a public place). The agreement must be put in writing, signed by both the requesting person and the designated practitioner, and dated. Finally provision is made for a cooling off period by preventing the agreement from applying for at least two clear days after it has been concluded, though under selection 11 of the Bill the agreement can only apply during a period of 28 days from the date the person was advised that the second formal request had been approved, after which the authorisation is no longer valid.
Section 11 is concerned with the requirements relating to the provision of assistance, and (in addition to those provisions discussed in relation to section 10) stipulates that the assistance must be provided so far as reasonably practicable in accordance with the agreement made under section 10; that the designated practitioner undertake another check to be satisfied that the requesting person is still acting without any undue influence and still wishes to proceed; and, that regardless of who administers the means to bring about the end of life, the designated practitioner is required to be present when end of life occurs.

Agreement on assistance
A number of points were made in relation to the agreement itself:

- no necessity for the designated practitioner and requester to meet and discuss the agreement (eg Scottish Partnership for Palliative Care (NP, 259) and (Anonymous (S, 174))
- consideration should be given to the agreement stating what action the registered practitioner (or others) are to take in the event of complications (e.g. failure to die, unexpected side effects) (eg Scottish Partnership for Palliative Care (NP, 259))
- other non-medical complications should also be considered (e.g. the non-availability at short notice of the designated practitioner due to sickness) (eg Scottish Partnership for Palliative Care (NP, 259))
- places no obligation on the designated medical practitioner and requesting person to involve the person nominated to undertake the final act of assistance in any of the advance discussions leading to the decision of method/place/time nor to oversee any of the legislative requirements relating to designated practitioners or psychiatrists (Royal College of Nursing (NP, 321)
- far from clear whether there is an expectation that normally the “designated practitioner” would be expected to take an active role in the act of assisted death in addition to being in attendance (Royal Society of Edinburgh (NP, 448)
- it is unclear as to whether the patient can choose the exact time that they want “assistance” (A Bentley, O, 383)

There were also some comments concerning the two day cooling off period. A number of respondents felt it was two short a period given the gravity of the decision (eg Free Church of Scotland (O, 146) and Christian Concern for our Nation and the Christian Legal Centre (O, 294). T Suslak (NP, 136) was concerned the time-window would be too short should any concerns be raised concerning the whole procedure or other late-onset factors. They suggested it should be extended to a minimum of seven days or a working week after the conclusion of formal proceedings. However, some respondents who supported the Bill questioned the need for the two days (eg I McOwan (S, 069), with the Humanist Society for Scotland (S, 187) considering that it was unnecessary given the other checks and balances.

The 28 day provision
Of those that responded in detail on concerning this provision there was a general feeling that 28 days was too short.

For some the issue was in connection with provisions in the Bill that should timescales not be met then the requesting person, should they still wish to, would have to start the process again. I McOwan (S, 069) felt it would be acceptable to leave the commitment open ended with a proviso that the request be simply reaffirmed within 12 moths of the
approval of the first request. Prof’s Laurie and Mason (NP, 052) felt there should be a provision to allow a further 28 days if needed. Prof Sheila McLean (NP, 019) felt there was no obvious rationale for the request’s validity to expire after 28 days, noting that in Oregon there was evidence to suggest that some people are comforted by knowledge they can end their life at time of their choosing and may in fact live longer than if forced to take medicine within specified time limit (Prof Sheila McLean (NP, 019).

However, for others the issue was connected with the possibility that putting such a short timescale on the process may in fact lead to the person feeling pressured to carry it through (eg M Branthwaite (S, 150), Parkinson’s UK (NP, 471) and Dignity in Dying (S, 398).

Who should undertake final assistance
In general, there were calls for greater clarity on who this should be.

The place of end of life assistance
A number of respondents felt this needed to be further clarified (eg Association of Hospice and Palliative Care Chaplains (O, 106) and CARE for Scotland (O, 390). The provision in the Bill led others to surmise as to where final assistance could take place. The Free Church of Scotland (O, 46) believed it could be NHS premises, but the Christian Legal Centre (O, 294) and MC McGinley (O, 430) queried whether that would be the case. Highland Hospice (O, 275) was concerned that palliative care premises whilst E Grant (O, 165) was concerned that should assistance be allowed in hospitals or care homes the many people may become reluctant to enter them. The Free Church of Scotland (O, 146) also raised the issue of who would regulate the premises that it did take place in, and mentioned people’s own homes in particular.

The Faculty of Education, Health and Social Sciences, University of the West of Scotland (S, 192) was concerned about the place where end of life assistance would be provided and the cost of/payment for assisted death:

“There is a risk that in order to provide this service for the people who might be interested that the service will be provided in a single unit supervised by a number of practitioners who may deal with all second requests. Many GP’s and many Psychiatrists may have sound ethical and moral reasons not to wish to be involved in what in effect is life ending treatment which may lead to a few medical professionals and their associated teams dealing with many of the cases that come forward. Would our NHS be in danger of creating its own NHS “Dignitas” clinic and is this desirable? What safeguards exist to prevent this?”

Presence of the designated practitioner
A number of issues were raised concerning this provision. Prof Sheila McLean (NP, 019) questioned the requirement on the basis that there may be reasons why the designated practitioner may be unable to be present, a point reiterated by Dr David Jeffrey (O, 048). Dignity in Dying was concerned that this would force the medical practitioner to be involved when they may not wish to be, adding that it didn’t allow the patient and family privacy at a sensitive time (S, 398).

Independent Association of Nurses in Palliative Care (O, 203) questioned it in relation to where a requesting person self-administers the medication, but called for more clarification as it considered that the provision suggests that the designated practitioner would be administering the assistance to die, a point reiterated by E Grant (O, 165). Clarity was
also sought by the Royal College of Physicians of Edinburgh (NP, 448) as it felt it was unclear whether “designated practitioner” was expected to supervise and intervene in the event of complications (eg unexpected side effects or failure to die). The British Humanist Association (S, 245) felt that this was exactly the reason the provision should exist, considering it an additional safeguard to ensure that the means of death is as humane, dignified and pain-free as possible.

The Association of Chief Police Officers in Scotland (NP, 386) felt the presence was necessary in situations where persons were unable to self-administer the means of end of life assistance in order for them to have the opportunity to be “notified” by the requesting person right up to the point where the method of ending life is put into irreversible process, as up to this point it can still theoretically be stopped. However, it recommended an independent second witness to be provided for to simplify any subsequent investigation.

**Means of assisting death**

The lack of clarity in the Bill as to the means of death was a significant issue for many respondents. The majority of those who discussed this issue looked for greater clarity on what the means would be (eg T Suslak (NP, 136), Association of Hospice and Palliative Care Chaplains (O, 106), Free Church of Scotland (146), Pro-Life - All Party Parliamentary Group (O, 241), Dr J M Reid (O, 229), Nurses’ Christian Fellowship of Scotland (O, 317) and Care Not Killing Scotland (O, 391).

Others were quite specific in the issues they raised:

- it is not clear from the Bill how it is intended to source any medicines that may be required to end life, which is currently governed by the Medicines Act 1968 and the Misuse of Drugs Act 1971 (as amended). Given these are reserved legislation there is a need to examine where precedence lies and if supplies for this purpose are permitted (Community Pharmacy Scotland (O, 114))
- there is a need to consider how the risk of complications and untoward events could be minimised during the actual provision of voluntary euthanasia/ assisted suicide (Scottish Partnership for Palliative Care (NP, 259)), and also as to what should happen if the means do not work (DJ Taylor (O, 183) and D Somerset (O, 218))
- whilst understanding why a definite method has not been stipulated, once this is coupled with the option of nominating a person who is not a regulated clinician to deliver the final act, there is concern that the Bill cannot adequately ensure that the clinical intervention chosen will be delivered by a suitably competent person (Royal College of Nursing Scotland (NP, 321))
- the Bill assumes that doctors would know what to do in providing the final assistance, which is not true. Neither does it stipulate who would provide appropriate education and training (St Columba's Hospice (O, 288))
- a lack of clarification may be problematic in the event of an inquiry (Association of Chief Police Officers in Scotland (NP, 386))
- although not endorsing voluntary euthanasia believe that this end-stage must be defined to ensure all participants in the process know what to deliver and expect, and to ensure it is applied with uniformity and can be audited (Dignity in Dying (S, 398))

**Further consideration of safeguards**

In general terms those that were supportive of the Bill or its principle considered that safeguards were appropriate and, indeed, a number of these felt they were maybe too cautious though they understood why. For those opposed to the Bill there was a widespread concern that the safeguards would not protect the most vulnerable from being
exploited or pressured, and that the whatever safeguards there were they would be easily circumvented by doctors or relatives that were determined to do so. In a significant number of cases there were never going to be adequate safeguards to deal with the Bill.

Many of these matters have been discussed above. However, there were two key matters that arose from respondents in addition to these – a lack of overall monitoring and safeguards for doctors and other health professionals.

**Overall monitoring**

The Explanatory Notes (para 104) discuss the likelihood that the Crown Office Procurator Fiscal Service would investigate any assisted death. However, for many respondents this was not sufficient, and many from across respondent groups and points of view criticised the Bill for not proposing proper reporting, monitoring and oversight processes (eg SPUC Scotland (O, 457), Faculty of Education, Health and Social Sciences, University of the West of Scotland (S, 192), Dr Craig McArthur (S, 062), Dignity in Dying (O, 398), Independent Association of Nurses in Palliative Care (O, 203) and Royal College of Physicians of Edinburgh (NP, 443).

The reliance on the Crown Office Procurator Fiscal Service to investigate was commented on by some. Dignity in Dying (O, 398) was concerned that the process outlined in the Explanatory Notes was specifically referenced in the Bill itself. The Royal College of Physicians and Surgeons of Glasgow (O, 447) considered that the requirement for the death to be reported to the Procurator Fiscal, together with the simple expectation that the inquiry would follow was insufficient. It felt that an inquiry should be mandatory if there was to be any meaningful scrutiny of the procedures. M Somerset (O, 431) felt that all cases should be reported to the Procurator Fiscal before the event, and the method of death clearly described. However, the Association of Chief Police Officers in Scotland (NP, 386) stated if the Bill was passed there would be an increase in the overall number of investigations carried out by the police as a result of additional enquiries into deaths where assistance had been provided. It noted this would be likely to be protracted and resource intensive. The Royal College of Psychiatrists considered that the Procurator Fiscal had insufficient powers of oversight where criminal offences had not been committed. As such this may be inadequate to prevent a psychiatrist working in this area unsupervised.

Other points raised included:

- no guidance is given regarding the requirements which would pertain to completion of death certificates or cremation papers (Royal College of Physicians and Surgeons of Glasgow (O, 447))
- it would be much better for a patient’s case to be scrutinized by a review panel prior to death (A Bentley (O, 383))
- the Bill should contain an express provision in respect of the certification of death resulting from end of life assistance (Royal Society of Edinburgh (NP, 449))
- queries whether the Bill should specify the standards of diligence expected in regard to the roles of practitioners, in order to provide clarity and reassurance to practitioners in the event of post mortem allegations, investigations by the Procurator Fiscal’s Office and possible prosecution (Scottish Partnership for Palliative Care (NP, 259))
- as the Bill contains no external check or regulation of the medical opinions there would need to be a new independent safeguarding body and such a function would have cost implications for the Bill (Mental Welfare Commission for Scotland (NP, 169))
Safeguards for doctors and other professionals

There was significant concern, particularly amongst those opposed to the Bill that whilst the Policy Memorandum (para 113) stated that no element of compulsion would be imposed on a registered medical practitioner to participate in any end of life assistance processes, this was not explicit. As a result there were a large number of calls for a specific conscience clause to be included in the Bill. Amongst other professions, particularly nursing and pharmacy, similar calls were made. Lord MacKay of Clashfern, (NP, 058) noted that the House of Lords Select Committee also considered this as part of its scrutiny of Lord Joffe’s Bill and recommended such a clause for doctors and any other health and social service staff that may find themselves involved in an end of life assistance process.

Specifically concerning doctors, there was concern that even where they objected to undertaking any actions under the Bill there they may have to refer patients on to doctors who were prepared to accept the role. A number of respondents considered the Policy Memorandum (para 114-115), which discussed the GMC guidance on personal beliefs and how this would link in with any objection amongst doctors to undertaking processes in the Bill:

“The GMC guidance is clear, however, and there would be a duty on registered medical practitioners who object to participating to make arrangements to see a registered medical practitioner who would be prepared to consider a request for end of life assistance.”

In its submission on the Bill, the GMC Scotland (NP, 468) clarified this slightly:

“..our guidance does not impose a duty on doctors to do this unless the patient is unable to make those arrangements him or herself.”

The GMC also noted that the same paragraph stated: “The GMC guidance states that registered medical practitioners should not share their personal view with the patient and should make them aware of all options”. GMC Scotland clarified this sentence as well saying:

“Doctors should, in fact, tell the patient (in advance where practical) if they don’t provide a particular procedure because of a conscientious objection. Doctors must, however, be careful to be respectful of the patient’s dignity and views, whatever their (the doctor’s) personal beliefs about the procedure in question.”

Other considerations

Many of the key arguments put forward by respondents are outlined in the sections above. However, there were a number of other issues raised that Members may wish to be aware of:

- a concern amongst many opposed to the Bill that it would deflect attention and resources away from palliative care, when the key focus should be enhancing provision across the country to ensure that those who need it get it. This is disputed by those who agree with the Bill or its principle, who argue that end of life assistance is and should be seen as completely separate from palliative care
- a view amongst a cross section of respondents that the numbers identified in the Policy Memorandum may be an underestimate on the grounds that it compares the Scottish population to what happens in Oregon, when the Bill proposes a system which is much broader
a view that certain cost implications identified in the Financial Memorandum may be an underestimate, particularly in terms of the resources that may be required in GP Practices and psychiatry, and the amount of training and education that will be required.

References were made, by both sides, to the international experiences or similar legislation.

It is intended that some of these will be discussed further in the forthcoming SPICe briefing.

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