END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE

AGENDA

7th Meeting, 2010 (Session 3)

Tuesday 21 September 2010

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

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

    Paul Philip, Deputy Chief Executive, General Medical Council;

    Professor Tony Hazell, Chair, Nursing and Midwifery Council;

    and then from—

    Reverend Dr Donald MacDonald, Retired Professor of Practical Theology, Free Church of Scotland;

    Major Alan Dixon, Assistant to the Scotland Secretary, Salvation Army;

    Reverend Ian Galloway, Convener of Church and Society Council, Church of Scotland;

    Dr Bill Reid, Connexional Liaison Officer, Methodist Church in Scotland;

    Dr Salah Beltagui, Convener, Muslim Council of Scotland;

    Leah Granat, Public Affairs Officer, Scottish Council of Jewish Communities;

    John Bishop, Secretary, Humanist Society of Scotland.
The papers for this meeting are as follows—

**Agenda Item 1**

Submission from the General Medical Council Scotland  ELA/S3/10/7/1

Submission from the Nursing and Midwifery Council  ELA/S3/10/7/2

Submission from the Free Church of Scotland  ELA/S3/10/7/3

Joint Submission from the Church of Scotland, the Methodist Church in Scotland and the Salvation Army  ELA/S3/10/7/4

Submission from the Muslim Council of Scotland  ELA/S3/10/7/5

Submission from the Scottish Council of Jewish Communities  ELA/S3/10/7/6

Submission from the Humanist Society of Scotland  ELA/S3/10/7/7
Thank you for the opportunity to submit evidence on the End of Life Assistance (Scotland) Bill.

The General Medical Council licenses doctors to practise medicine in the UK under the provisions of the Medical Act 1983 (as amended). Our purpose is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.

In responding to the consultation we feel it is important to emphasise that we are a regulator, not a representative body: our role is not to represent the views or interests of doctors or patients. Our four main functions under the Medical Act are:

1. keeping up-to-date registers of qualified doctors
2. fostering good medical practice
3. promoting high standards of medical education and training
4. dealing firmly and fairly with doctors whose fitness to practise is in doubt.

One of the ways in which we foster good medical practice is by giving advice to the profession, primarily through our published guidance, on the standards of practice expected of them. We require doctors to observe the law (paragraph 13, Good Medical Practice 2006) and our guidance will always be consistent with the law. Consequently we have not developed policy or issued guidance on assisted suicide, since to have a ‘freestanding’ policy position on an issue which is currently illegal would undermine both the guidance and our authority to provide it.

To hold a policy position distinct from the legal position on an issue would also compromise our position in considering complaints and make our judicial process untenable. For example, if a doctor were convicted for assisting a suicide, it would be difficult for a panel to consider the doctor’s breach of the law if we, as the regulator, had expressed a view that we believed such an act was ethical or acceptable. Conversely, if the law were to change to allow assisted dying and we had previously expressed the view that it was morally or ethically unacceptable, we would either be unable to discipline such a doctor, or we would have to set ourselves above the will of Parliament.

We note the reference, on page 18 of the Policy Memorandum (paragraphs 114 and 115), to our guidance on Personal beliefs and medical practice (2008). On the whole it is an accurate reflection of our guidance. However, we are concerned that the final sentence of paragraph 115, taken out of context, could be misleading. The memorandum states that “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”. However, our guidance does not impose a duty on doctors to do this unless the patient is unable to make those arrangements him or herself.

At the beginning of paragraph 115 you say doctors “should not share their view”. 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.

Finally, we would suggest that any references to “registered medical practitioners” in this context (certainly in relation to the practitioner providing assistance, if not also to the psychiatrist) should be changed to “licensed and registered medical practitioners” since only those registered doctors who hold a licence to practise are entitled to prescribe medicines. We have noted references in the Bill itself in section 2 and in the Policy Memorandum at paragraphs 104, 106, 108-9, and 112 although there may be others.

Thank you once again for the opportunity to comment on the Bill and accompanying papers. I hope you find this response helpful in explaining our position.

Jane Malcolm  
Head of Scottish Affairs  
General Medical Council  
12 May 2010
Agenda Item 1  ELA/S3/10/7/2
21 September 2010

End of Life Assistance (Scotland) Bill

Nursing and Midwifery Council

Thank you for giving the Nursing and Midwifery Council (NMC) the opportunity to contribute to your consultation on the End of Life Assistance (Scotland) Bill. I am responding on behalf of Professor Dickon Weir-Hughes, the NMC’s Chief Executive and Registrar, who is away from the office at the current time. Please accept my apologies that our letter is coming to you after the closing date. Nevertheless, I hope that you will be able to consider our thoughts at this time.

The NMC is a statutory regulator within the United Kingdom and exists to safeguard the health and wellbeing of the public. We do this by maintaining a register of nurses and midwives, setting standards for education and practice, and giving guidance and advice to the two professions. We aim to inspire confidence by ensuring that the nurses and midwives on our register are fit to practise and by dealing swiftly and fairly with those who are not.

The NMC is not a representative body; we do not seek to reflect the views or interests of nurses, midwives or those in our care. We do, however, require those on our register to take account of current law, and the principles of good practice set out in The code: Standards of conduct, performance and ethics for nurses and midwives NMC 2008 (the code).

We recognise that the issue of end of life assistance is an extremely emotive one for healthcare professionals, patients and members of the public. Any move towards legislation in this direction would have a significant impact on nurses and their practice and their adherence to our code of practice. As a healthcare regulator operating across the four UK countries, you will also appreciate that any legislation of this nature affecting Scotland would have considerable implications for the NMC in its setting of UK-wide standards.

We would welcome the opportunity to contribute to the developing debate on the planned legislation and we look forward to hearing how we can bring the NMC’s perspective on the implications on this legislation to the attention of members of the Scottish Parliament.

We look forward to hearing from you.

Peter Pinto de Sa
Manager, Office of the Chair and Chief Executive
Nursing and Midwifery Council
14 May 2010
End of Life Assistance (Scotland) Bill

The Free Church of Scotland

Introductory Comments
The original Draft Bill was entitled “End of Life Choices (Scotland) Bill”. We responded to the consultation, opposing the Bill on principle as well as criticising its detailed provisions. In the Consultation Document and Draft Bill the emphasis was on individual autonomy and the right to choose “assisted dying”. The change in title reflects a change in emphasis to regulating the activity of some persons, including medical practitioners, who may assist in ending the life of a wide variety of persons who apply for such assistance. However, individual autonomy is still basic to the argument behind the Bill.

Many of our criticisms of the Draft Bill are still applicable. In particular we quote from paragraph 6 of our submission:

Individual autonomy. The foundation of the proposed Bill is clearly stated on page 2 [of the Consultation Document] to be “the principle of autonomy, that the person has the right to determine the quality of his or her own life and its value, unrestricted by the moral, cultural, religious, or personal beliefs of others”. This would appear to give the individual an absolute right to decide when his/her life has such a quality and value that it should be ended. This extreme individualism ignores the importance of the fact that we humans exist in relationships and in community. We come into the world as completely dependent creatures and we remain dependent on one another to a greater or lesser extent throughout our lives. As well as rights we have responsibilities and duties towards others. The care we exercise towards one another is part of what makes us fully human. We should also learn to receive care as well as give it. It should not be regarded as loss of dignity to be dependent on others. We have no right to demand that someone help to end our life. Deliberately taking a human life is so serious that only extremely grave reasons can be used to justify it, such as, for example, a just war, and even that concept has many problems. ending an innocent person’s life, even with the purpose of reducing the amount and length of suffering is not justified, especially when good palliative care is available. Our common humanity is best represented and supported by that kind of care and not by deliberately ending a life. We fear that this Bill, if it comes into force, would lessen people’s willingness to care sacrificially for those suffering from disabling, debilitating and terminal illnesses.

As detailed below, we find that the Bill as introduced into Parliament is seriously defective and should be summarily rejected. If, after considering the many trenchant criticisms that emerged in the extensive consultation, the drafters of the Bill could not present a more clearly defined and well-worked out document, this shows either that they are incompetent, or that the Bill is deliberately vaguely drafted, or that it is impossible to frame a satisfactory Bill on this subject.
Summary of criticisms

- We oppose the Bill on the basis of the principles of the sanctity of human life and the duty of care to the very end of our natural lives. This does not mean prolonging life unnecessarily by intrusive, futile and distressing treatment, but it excludes the deliberate ending of a human life, even with the motive of ending suffering.

- The Bill is poorly drafted and lacks clarity, being full of euphemisms. It fails to specify what exactly is meant by “end of life assistance”, what means of ending life are permitted and who is actually to administer the fatal dose or whatever means are used to end life. As pointed out below, it appears to include euthanasia as well as assisted suicide, although this is not specified.

- The categories eligible for “end of life assistance” under the Bill include a large number of people – not just the terminally ill (again poorly defined) but people with many different kinds of illnesses and disabilities who may “find life intolerable”. The inference is that ending life is a valid ‘treatment option’ in these conditions. This is demeaning and detrimental to the interests of persons with disabilities and chronic illnesses.

- The Bill gives medical practitioners and the National Health Service a key role in the process. We strenuously oppose this perversion of the roles of the doctor and the NHS from that of carer, healer and preserver of life to that of the destroyer of life, however well-intentioned this action may be.

- The decision to end life involves only the “requesting person” and the “designated practitioner”. The role of the psychiatrist is confined to judging capacity, whether the person is making the request voluntarily and whether the person is acting under any undue influence. This is too limited a role and there is no provision for a ‘second opinion’ or any review of the decision.

- The Bill is hopelessly optimistic that the “safeguards” provided will prevent abuse of this legislation. For example, the requirement that palliative care should be discussed with the requesting person is not sufficient (7.1). It should be specified that the person must experience palliative care before a request for “end of life assistance” can be considered, for reasons mentioned below.

- The Financial Memorandum (96-101) accompanying the Bill grossly underestimates the number of people who may avail themselves of the provisions of this legislation. Estimates are based on figures from Oregon (where reporting is voluntary and therefore not exact) rather than on figures from the Netherlands, which would be more realistic given the nature of the Bill, which appears to permit euthanasia as well as assisted suicide. The number of people applying for “end of life assistance” could very quickly run into hundreds and then even more as it becomes a routine procedure.
Because of this underestimate the framers of the Financial Memorandum (96-101) play down both the financial and time implications for Health Boards, GPs and Psychiatrists and the Crown Office Procurator Fiscal Service. They even make the suggestion that money may be saved by the Health Boards (97)! That, of course, is not the motive of the sponsor the Bill, but it could very quickly become a major factor in decision making.

Section by section critique

1. Title, introduction and section 1

- **End of life assistance** This phrase is in itself ambiguous. It could mean “assistance at the end of life”, which could just signify all the usual help and care, including palliative care, that people need as they approach death. It could also mean “assistance to end life”, which could encompass both euthanasia and assisted suicide. These latter are two well-known and well-defined terms which lack ambiguity, but are nowhere to be found in the Bill. However, the following definition is given in 1.2:

In this Act “end of life assistance” means assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress.

This definition is so vague that it actually hides the meaning which it is supposed to convey! In itself it could just mean palliative care. The phrase “to enable a person to die with dignity and a minimum of distress” is subjective and means different things to different people. The clue to the intended meaning is given in the opening sentence of the Bill. We are told that the purpose of the Bill is “to permit assistance to be given to persons who wish their lives to be ended; and for connected purposes”. The assistance is not limited to help to end one’s life oneself, but for one’s life to be ended – obviously by someone else if necessary. The inference is that this is the best (or the only) way to “die with dignity and a minimum of distress” – an inference we strongly dispute.

Furthermore the mention of “administration” as well as “provision” of “appropriate means” would confirm that euthanasia (the administration of fatal means to end someone’s life) as well as assisted suicide (the provision of means to end one’s own life) is permitted. In other words this Bill is a Netherlands-type, rather than an Oregon-type, Bill and encompasses euthanasia as well as assisted suicide.

- **Appropriate Means** Nowhere in the Bill are these means defined. There are many means of causing death. Do these “appropriate means” include administering a poison such as a large dose of barbiturate, an opiate, intravenous potassium chloride or a muscle relaxant, or the introduction of an air embolus into a vein, or suffocation with a pillow or plastic bag? Who is to judge what is “appropriate”? It
appears that it is down to an agreement between the “requesting person” and the “designated practitioner” (10.1.d). Again a large amount of subjectivity is apparent, leaving a wide degree of latitude in the choice of means. This naively assumes that people and practitioners will choose some kind of “dignified” and efficient means of ending life. What if the agreed means fails? Can another means be used without another agreement between the person and the practitioner? The hint is given in 11.1 that the end of life assistance must, “as far as reasonably practicable”, be provided in accordance with the agreement between the requesting person and the designated practitioner. This vagueness is inappropriate in a legislative instrument.

2. Need for two formal requests
It appears that the “designated practitioner” does not need to be the GP with whom the person is registered. This practitioner will not know the requesting person well and will obviously be predisposed to granting such a request, or he/she would not be involved at all. Since it is well known that the majority of doctors in Scotland are not in favour of euthanasia and assisted suicide, we can foresee the emergence of a “list” of doctors who are willing to be involved. Would the person’s registered practitioner have a duty to give that list to the person and also supply him/her with the requisite application form for a formal request? No such forms are mentioned, but it is easy to see such a bureaucratically framed procedure requiring them as the procedure becomes routine.

3. Revocability of request for assistance
This appears to be one of the “safeguards” which are supplied. However, it is not at all clear how effective this would be in practice. It is difficult to see how an “informal” notice could be given to the designated practitioner, even through a third party, if the requesting person was very ill and the designated practitioner not readily available. It could all too easily be ignored. There would have to be yet another form!

4. Eligibility requirements
- Why is the qualifying age not 18, the age of majority? Sixteen is too young.
- The 18 month registration requirement seems to be to guard against people from other countries coming to Scotland to take advantage of the law, but this could be circumvented in various ways – non-residents could register in advance with a private practice set up for this purpose. There is no stipulation in the Bill that registration must be with an NHS General Practice.
- The two categories of persons eligible are loosely defined. “Terminally ill” is defined as six months’ life expectancy, but this is notoriously difficult to predict accurately. “Permanently physically incapacitated to such an extent as not to be able to live independently” would include a very large number of people with, for example, progressive neurological disorders, paralysis, severe heart or lung disease and many other disabilities, both congenital and acquired. This widens the ambit of the Bill to people who are not terminally ill and is really an
affront to all persons with disabilities. “Finding life intolerable” is a very subjective judgement and depends on many unspecified factors – psychological, emotional, physical and social. This is unsatisfactory, as this state of mind may well fluctuate over time. Yet, as Explanatory Note 21 makes clear, the phrase is deliberately vague and not further defined in the Bill.

5. Requirements relating to designated practitioners and psychiatrists
Why are close friends of the requesting person not excluded from this category also? They too would lack objectivity.

Who is to judge whether the professed ignorance of “relationship, benefit or interest” is genuine?

There is no mention of a conscience clause for doctors and other health workers who do not wish to partake in “end of life assistance” on grounds of conscience. The unacceptable inference is that it is a doctor’s duty to consider a request for “end of life assistance” and refer the person to a doctor who has no objection to the procedure. This is confirmed in the accompanying Memorandum (113-115) which states that the existing GMC guidelines are sufficient to cover this situation. This is an unwarranted assumption, as this precise situation was not envisaged at the time the guidelines were drawn up. Indeed “end of life assistance” is such a radical departure from the accepted role of a medical practitioner that it cannot be regarded simply as a “certain procedure” or one of “all the options”.

A further cause for concern is that, at the moment, doctors are, quite rightly, not trained to kill patients. Is it envisaged that there would be specialist training in “End of Life Assistance Medicine” with its own qualifications and protocols?

6. Requirements relating to first formal request
The request is “for end of life assistance under this Act”. Given the vague wording of the proposed Act this is like signing a blank cheque! How can a witness, however knowledgeable and impartial, certify that the person “understands the nature of the request”? We cannot envisage anyone quizzing the requesting person in such circumstances. Those who would know the person’s state of mind best are, quite rightly, excluded from being witnesses. Close friends should also be excluded. We can envisage this requirement becoming a formality, like witnessing any other document that doesn’t have the life and death implications of this request.

The requirements relating to care home employees are unsatisfactory, as they are in a position to exercise influence on the requesting person. Again who is to judge whether professed ignorance of “relationship, benefit or interest” is genuine?

7. Consideration of first formal request by designated practitioner
The designated practitioner has to “physically meet” and “discuss” certain things with the requesting person but there is no requirement to examine the
person or medically assess his/her condition. Would the designated practitioner have full access to all records and to relatives and carers who might be able to assist his/her assessment? Despite the conditions to be met it is all too easy to envisage this approval becoming a perfunctory procedure.

Mere discussion of alternatives such as palliative care is not sufficient. Surely palliative care must be provided for and experienced by terminally ill people before a request for “end of life assistance” is considered. It is well known that experience of palliative care usually leads to the person withdrawing a request to have life ended.

Again, “forms of end of life assistance” are not specified. Are there no limits? This is unacceptable.

The psychiatrist has only to give a “positive” report and the designated practitioner appears to be able to approve the request. This assumes that every situation will be clear-cut. There appears to be no requirement for consultation and agreement between practitioner and psychiatrist, despite the accompanying Memorandum stating, “The designated practitioner will consider the request along with a psychiatrist …” (173). The burden of decision is on the designated practitioner alone, which is both unfair and unsafe.

8. Consideration relating to second formal request
The time-limits are far too short – a minimum of 15 and maximum of 30 days. These limits would put extra pressure on vulnerable people. The first limit should be at least doubled and the second at least trebled. Only a small minority of people have a steely determination which is unalterable. The second request should be processed by a different practitioner in order to provide a second opinion; otherwise it would become a routine endorsement of the first request.

9. Consideration of capacity etc. by psychiatrist
The role of the psychiatrist is fairly circumscribed and yet ought to require a full psychiatric assessment to make it meaningful. “Discussion” with the person is not enough on which to make such a momentous decision. For instance assessment of the possible presence of a depressive illness ought to be looked for specifically, and evidence of internal pressure as well as external pressure. Why should the effects of drugs or alcohol be specifically excluded just because they are not included under the rubric of “mental disorder” as defined in the Mental Health (Scotland) Act 2003? They could well be important factors in making such a request.

The psychiatrist for the second request should be a different one from the one who examined the person for the first request as a further safeguard.

10. Agreement on provision of assistance
Although the Bill specifies who may not provide “end of life assistance” it does not state positively who may do so. Can they be people who are not registered medical practitioners? Will the name of the person who administers
the means of causing death be recorded?

The place in which “end of life assistance” is provided is not clearly specified. Will it normally be an NHS clinic or hospital? The Financial Memorandum in the Explanatory Notes (96-101) would suggest that this is to be a new service provided by the NHS. The thought fills us with horror, especially as the Memorandum casually suggests that this could actually result in savings for Health Boards (the definite inference of paragraph 97).

If private ‘end of life assistance clinics’ spring up, are they to be registered, inspected and controlled or can anyone get into the business? Who will regulate “assisted deaths” at home?

The 2 day ‘cooling off period’ is far too short in such a serious matter.

11. Requirements relating to the actual provision of assistance
While there are some details about provision, there is nothing about the actual administration of the means of ending life, surely a glaring omission. This encourages suspicion that the Bill is intentionally vaguely worded in order to allow a wide variety of approaches. This is further confirmed by the Memorandum, paragraph 109, which states, “The means to be used and the method of delivery is [sic] not specified in the Bill.” The reasons given are unsatisfactory, largely centring on individual choice of the requesting person and the “expertise” of the designated practitioner.

Although the designated practitioner has to be present, there is no mention of who actually administers the fatal means to end life (11.6). This omission must be intentional, because the Explanatory Notes (79) say “regardless of who administers the means to bring about the end of life … the designated practitioner must be present when the end of life occurs.” The Bill treats this central and most serious part of the procedure with complete indifference. This omission underlines the grossly unsatisfactory nature of the Bill.

There is no mention in the Bill of the procedure following death. The Explanatory Notes (104) state, “It can be expected that COPFS will consider each case of assisted death and instruct investigation into the death.” In the case of suicide this would be so, but if the Bill includes euthanasia, this is not immediately apparent from current guidelines. This omission highlights the deliberate understatement of the radical departure the introduction of this legislation would signify.

Conclusion
While we maintain our opposition to the Bill on principle, we also strongly believe that because of the many defects highlighted above, this Bill should be rejected by the Scottish Parliament. If this Bill were to become law, it would have a detrimental effect on society’s respect for human life, would damage the doctor-patient relationship, would be difficult to administer without widespread abuse and would lead to a devaluing of the lives of people who are dependent on others because of disability or chronic illness. We urge Members of the Scottish Parliament to reject it. Instead we would encourage
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Parliament to continue the excellent work it is doing in promoting the availability of palliative care for all who need it.

Rev Dr Malcolm Maclean  
Convenor  
Communications Committee  
Free Church of Scotland  

3 May 2010
End of Life Assistance (Scotland) Bill
Church of Scotland, the Methodist Church in Scotland
and the Salvation Army

Introduction

This response to the Call for evidence on the above Bill has been prepared by the following Christian denominations:

The Methodist Church in Scotland: There are over 70 congregations and over 3 thousand Methodists in Scotland who are part of the Methodist Connection which has around 265 thousand members across the UK which is associated with 75 million Methodists around the world. Methodists are on a journey to follow in Jesus’ steps. By care about society and the wider world that we all live in and by engaging with politics and society, Methodists live out our calling to love and hope.

The Salvation Army: The Salvation Army has 82 Corps/centres in Scotland with approximately 4,500 members, and are part of the United Kingdom Territory with the Republic of Ireland. The Salvation Army is at work in 120 countries. The three-fold mission of the Salvation Army as detailed in its Mission statement is ‘Called to be disciples of Jesus Christ, the Salvation Army in the United Kingdom Territory with the Republic of Ireland exists to save souls, grow saints and serve suffering humanity.’

The Church of Scotland: The Church of Scotland has around 984 active ministers, 1,179 congregations, and its official membership at approximately 489,000 comprises about 10% of the population of Scotland. In the 2001 national census, 42% of Scots identified themselves as ‘Church of Scotland’ by religion. The Church of Scotland seeks to inspire the people of Scotland and beyond with the good news of Jesus Christ through enthusiastic, worshipping witnessing, nurturing and serving communities.

A number of people from each of these groups, many of them with professional expertise in areas relevant to this response, have contributed to the writing of this response.

This response includes two lines of argument:

First, it highlights arguments against assisted suicide in principle, and

Second, while not accepting the need to introduce such legislation, it highlights specific problems with the way this particular piece of legislation has been drafted.

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

The Churches fundamentally disagree with the proposed legislation, which represents much more than simply a tinkering with the law. Such legislation, breaching as it does the societal prohibition on the taking of human life, carries implications for attitudes to many aspects of health and social care, not simply for the determined few who are pushing for change.

The Churches reaffirm that an important aspect of their ministry is providing pastoral support to both individuals and communities, and particularly in
caring for the most vulnerable in society. On this matter we are clear that, while we are sympathetic towards the fears and desires of those who may be afraid of a painful death, what is proposed in this Bill is not the solution. Rather, there is a necessity to ensure that, as far as possible, all have access to good palliative care, which, in the widest sense, involves caring not just for the physical but also the emotional and spiritual needs of people coming towards the end of their lives.

**Autonomy:** 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.

**Dignity:** The term “dignity” is used loosely in the Bill, so that it is presented as an objective and clearly defined entity, embodied by assisted dying. Human dignity is a very complex but extremely important issue which cannot simply be reduced to the manner in which a person considers him or herself. It is also erroneous, and agenda-driven, to define dignity in care, and in dying, simply in terms of the availability of assisted dying. The issue of dignity in care and dying has been extensively explored in the medical literature. There is a necessity to accept that death is a natural process, and that not every death is a medical failure.

**What is a good death?** What is a dignified death? Arguably assisted dying as envisaged by this Bill is less dignified than the natural process because of the requirement to submit to a formal protocol, with numerous perfunctory consultations, scrutiny of one’s mental health (with possible significant cost, as access to NHS psychiatrists is not normally available within the timescales required by the Bill). All this is required under the legislation to take place within a short time frame and without the opportunity to discuss hesitation or distress lest that should be interpreted as a revocation, at a time when life is already deemed to be intolerable.

The modern world has seen changes to family life with increasing numbers of people living geographically apart from their relations. The ways in which care and support for the vulnerable are provided therefore also need to change. While this Bill may represent an attempt to address some of these issues, as a society we need to do better.

**Additional costs:** The Bill is clear that there are likely to be costs to the individual associated with seeking assisted suicide; it is therefore possible that such legislation would create a two tier system which would enable the wealthier to choose assisted suicide and leave the poor with the current arrangements. It would be more desirable to improve end of life care for all.

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

Our opposition to the Bill in principle notwithstanding, we believe it is entirely inappropriate that end of life assistance should be offered to a sixteen year old. It is not possible that a final and definitive judgement regarding the
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intolerability of their life might be made by a person who has not yet achieved maturity, particularly when it is entirely accepted within the terms of the Bill that such a perception is necessarily subjective.

We are also concerned that the residency requirement of only eighteen months creates the possibility that persons may move to Scotland and register with a medical practitioner in order to seek end of life assistance.

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

There is a fundamental difference between someone who is “terminally ill and finds life intolerable” and someone who is “permanently physically incapacitated to such an extent as not to be able to live life independently and finds life intolerable”. As there is no definition of “permanently physically incapacitated” and no definition of “live independently” there is ambiguity as to what is actually being legislated for and therefore it is difficult to comment on the categories of people who would qualify for end of life assistance under this Bill. There are strong arguments that could be made that no one is able to live independently; these are explored more fully in a subsequent question about safeguards.

There are many factors which may make life seem intolerable to a person. End of life assistance is not the best response to such a perception. The many factors, including the intense suffering of severe physical pain and perceived loss of dignity, can and should be addressed holistically.

The potential subjectivity and inaccuracy of a diagnosis of terminal illness is also not sufficiently recognised in the Bill. Indeed, some persons whose diagnosis is uncertain to at least to some degree would inevitably be allowed to proceed.

4. The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

We do not wish to respond to this question.

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

The safeguards in the Bill all relate to the individual who may seek assisted suicide, they do not relate to society. Human beings are essentially social; each of us is dependent on others for physical and spiritual survival and flourishing. It is impossible for a person to ask for assistance to end their life without that affecting their family and community. The safeguards included in this Bill focus only on the individual who may wish to end their life. Allowing legally assisted suicide would fundamentally affect the nature of the medical profession, it would fundamentally affect those who provide care for the sick and home help for the incapacitated, and it would fundamentally affect our society. The Bill does not, and to a large extent cannot, offer safeguards for the medical profession, for other care providers for example in residential care settings or home help and for society as a whole.

The value of human life is not determined by whether a person has the capacity to live unaided, nor need the quality of a life be diminished because a
person needs assistance, provided that the assistance provided is respectful, loving and appropriate to the needs of the recipient.

The Bill provides safeguards intended to check that the person “is not acting under any undue influence” when making the request. This is a subjective test as influence comes in many guises. The Bill makes explicit provision relating to people living in residential care, and in this environment the question of influence is especially complex. For example, if a resident of a care home seeks assistance to end their own life how this would affect other less able residents? It is not simply about the attitudes of staff or family members; it is about how a person experiences the expectations of those around them. It is not possible to provide a legal process which can check whether a vulnerable person, dependent on the care of others, is acting freely.

This legislation requires that members of the medical profession are active participants in the process of assisted suicide. It is agreed that there is a role for the medical profession to support people at the end of their lives; however, that role should not include the intentional ending of life. Requiring members of the medical profession to intentionally end life will fundamentally change the relationship between medical professionals and the society they serve. This is a point of principle that goes beyond the individual practitioner and the individual patient. While a conscience clause would enable individuals to opt out of participation in this process there would be practical problems in rural areas where alternative practitioners may not be available.

The following headings could be explored in more detail:

How society understands / communicates / discusses death, dying and bereavement.

Avoidance of inappropriately aggressive medical interventions as people near the end of their lives: the (sometimes implicit) view that every death is a medical failure needs to be challenged.

What about illnesses such as dementia in which there is minimal medical treatment / intervention but a high need for care, which may be expensive?

Rights of family members.

Care is spiritual as well as physical. There is a great fear of a painful death, which can be mitigated, although not always completely removed, by palliative care.

Protection of the weak and vulnerable, people who cannot argue against being led down a particular route.

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

The drafting of the Bill includes the possibility of euthanasia. We would urge that the possibility of euthanasia be explicitly prohibited.

Major Alan Dixon,
Assistant to The Scotland Secretary,
The Salvation Army
Rev. Ian Galloway,
Convener, Church and Society Council,
Church of Scotland

Dr. Bill Reid,
Connexional Liaison Officer,
Methodist Church in Scotland
16 September 2010
This submission is mainly concerned with refuting the principle of the Bill and thus does not deal with the proceedings. The statements below are views expressed by those consulted in the community, including faith leaders, medical persons are

**The Moral Principle and Sanctity of LIFE**

There are moral values for Muslims that do not change because they are grounded in teachings of God. The Islamic Laws are based on the protection of the life, faith, family, wealth and honour (dignity).

Life is the greatest gift from God and to tamper with it or interfere to end it is the most serious sin and an act of ingratitude against the creator. This applies whether it is the person’s own life or someone else’s life. God has given life and it is not for physicians, or others, to end a person’s life early.

Here are some quotations from Islamic Traditions:

- *Do not take a life, which God made sacred.*

- *If anyone kills a person it would be as if he killed the whole of humanity. Of course the exception is when law is applied by state for crimes or defending the state.*

- *God decides how long each of us will live. When their time comes they cannot delay it for a single hour nor can they bring it forward by a single hour.*

- *Do not put yourself in destructive situations.*

- *A person man who got a wound, and growing impatient (with its pain), he took a knife and cut his hand with it and the blood did not stop till he died. God said, 'My servant hurried to bring death upon himself so I will deny him my Paradise.*

**What about Suffering and Care:**

- The concept of a life not worthy of living does not exist in Islam.
- Suffering physically is not everything, spiritual suffering is the more serious, and is can only be relieved by strong faith in God and support from community around.
- The idea of life being intolerable, is not right when we believe that God does not burden a soul with a load that is beyond its ability and God is the only one who knows it.
- As a society it is our responsibility and duty to care for each other, especially the old, infirm, sick etc. It is a duty to lend care with love to
those of kin and neighbours. Care and high respect for parents in old age are strongly emphasised.

- This care is the real measure of the civilised human society. The opposite is to treat human beings as machines which is to be scraped when it does not function properly or as good as a new one.

- Believers accept physical suffering as part of life trials and a way to gain forgiveness for their bad deeds, however this does not mean to ask for suffering.

- It is also an opportunity for the carers to offer charitable deeds to bring them nearer to God.

- With spiritual care and physical care especially with the progress made in palliative care, together should make life tolerable.

- Spiritual care means all the love and emotional attachment given by the family and society at large by ensuring that as far as possible they suffer as little as possible without showing them that they are a burden on the society and even think of depriving them of life.

- This care will ensure the real dignity of death before and when it comes, without interference to end life.

- Assistance in any form to end life will destroy the relation between patient and medical staff, in addition to society as a whole.

- Majority of medical staff are opposed to physician assisted suicide on principle. Also, it is incompatible for those directly involved in the care of the dying to also be involved in assisted end of life.

- This Bill would have a detrimental effect on society’s respect for human life, would damage the doctor-patient relationship, would be difficult to administer without widespread abuse and would lead to a devaluing of the lives of people with disabilities and those in extreme old age.

Muslim Council of Scotland
End of Life Assistance (Scotland) Bill

Scottish Council of Jewish Communities

The Scottish Council of Jewish Communities welcomes the opportunity to comment on the End of Life (Scotland) Bill, and to express our grave concern at the proposals therein.

*Halachah* (Jewish Law) regards human life as being sacrosanct. Its value is absolute, not relative to a person’s age or health, and it is certainly not something that can be ended at will. The commandment of *Pikuach Nefesh* (saving life) is central to Jewish belief - the Talmud states that "one who saves a single life is regarded as if he had saved the whole world" and other religious obligations must (not "may") be set aside in order to do so.

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

The responsibilities of a medical practitioner should relate only to the preservation of life and the alleviation of pain and distress, not to a deliberate intention to terminate life. Furthermore, we do not agree that a person should have his or her life deliberately terminated, or death deliberately hastened.

The language employed in the Bill and associated documents minimises what is being proposed. The people it purports to want to assist are not even those relying on life support systems about whom there may be debate as to whether they are actually “alive”. It is about people who are indisputably alive. The correct word for facilitating the transition from life to death is “killing”, not “end of life assistance”, and any argument for legislating to permit it should be prepared to stand under that description. To do otherwise is to rely on a sophistical redefinition, not on the facts of the matter.

Judaism is unequivocally opposed to both euthanasia and suicide, and sets great store by genuine end of life assistance, namely the dedicated care given to patients in their final illness by members of the health care team. Jewish religious tradition gives clear guidance to those caring for terminally ill patients and for the patients themselves. Expressed simply, the principle is that it is forbidden to do anything that will hasten death. An eminent authority on Jewish law and ethics, Rabbi J.D. Bleich, has stated, in summarising the Jewish view on euthanasia: “Any positive act designed to hasten the death of the patient is equated with murder in Jewish law, even if the death is hastened only by a matter of moments. No matter how laudable the intentions of the person performing an act of mercy-killing may be, his deed constitutes an act of homicide.” (Judaism and Healing, Ktav Books, 1981).

However, whilst it is not permitted to shorten life neither is it permissible artificially to prolong the process of dying, and a patient has no obligation to accept burdensome treatment even when it might appear to be his or her best option. Furthermore, adequate pain relief supplied with the sole intention of
relieving pain and distress is permitted by Halachah even if there is the possibility that the patient's life may be shortened in consequence. Since this is a complex area, consultation with doctors and a competent religious authority may be required to establish what is necessary for each individual patient.

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

This presupposes physician-assisted suicide to be acceptable. We do not agree that this is the case.

We are particularly concerned that young adults could be put under pressure to request “end of life assistance” if, for example, they were aware that their family had moved to Scotland whilst they were still a child in order to facilitate such a request once the child was 16. The premise of the Bill is that a person under 16 is not competent to make such a request. However, 16 year-olds in this situation will effectively have made – or have had made for them – this decision whilst still under age, and may feel compelled to abide by it, the more especially if their siblings have had to move school, and parents change job, or become unemployed as a result.

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

This presupposes physician-assisted suicide to be acceptable. We do not agree that this is the case.

Experience shows that doctors are not always able to anticipate the course of an illness to predict accurately when death might occur. However, information about a patient's prognosis provided in the context of a request from a patient for assistance to terminate his or her life, may exert considerable psychological pressure, causing the patient to feel a burden on family and friends if he or she does not request an assisted premature death. We believe it to be intrinsically wrong that anyone should be placed in this position.

Furthermore, a person’s view of what is “intolerable” is liable to change according to factors other than his or her experience of illness or incapacitation. For example, it is not uncommon for a person who does not believe life worth living on one day, desperately to wish to live long enough to attend a wedding or see a grandchild when an engagement or pregnancy is revealed on the next. It is not tenable to rely on a criterion that is not only subjective, but which may be subject to complete reversal in response to factors that have no bearing on the extent of a person’s illness or level of incapacitation.
The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

This presupposes physician-assisted suicide to be acceptable. We do not agree that this is the case.

It is not, in our view, possible for either witnesses or “designated practitioner” to make a safe determination that an individual “is making the request voluntarily” since the person concerned may feel constrained to withhold information that would lead to a contrary determination. Moreover, being ‘voluntary’ does not preclude a request from having been made as a result of real or perceived pressure. We are concerned that some people may feel pressured to request assistance to end their life because they believe that otherwise they will be a financial burden to their family or to the NHS, but that this may not always be apparent. The simple presence on the statute book of a law legalising a form of euthanasia would in itself introduce an additional psychological pressure on patients. No-one should be forced into a position where they feel obliged to evaluate their life in such terms, and it is our view that this Bill will tend to devalue life and relegate it to being a commodity.

We are also extremely concerned by the requirement that both the designated practitioner and psychiatrist must discuss “all feasible alternatives to proceeding under this Act ...; [and] the forms of end of life assistance which may be provided”, and believe it to be entirely unacceptable that the deliberate ending of life should be regarded as one of a range of healthcare provisions.

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

This presupposes physician-assisted suicide to be acceptable. We do not agree that this is the case.

Despite assertions to the contrary in the Policy Memorandum, we do not believe that the proposed safeguards can be relied on to ensure that an individual does not feel under pressure to request “end of life assistance”. A decision to die can never be an unforced decision; in its nature, it relates to illness, concern about the impact that one is having on others, reflection on limited alternatives, and even on the perceived attitude of the health care team. If, for example, any of the witnesses, designated practitioner, or psychiatrist believes that, were they in the situation of the requesting person, they would find life intolerable, this view will undoubtedly be communicated, by tone and body language, if not in words, and will be an additional pressure on the person to proceed. The position of trust which they occupy in relation to a person requesting “end of life assistance”, would itself lend weight to their view, whether explicitly stated or only implied.

We are also concerned that the proposed lawful killing may become a cover for murder. The death of a burdensome relative may be welcome to some
people, and though the proposed safeguards might limit the scope for direct abuse, a considerable potential still exists for indirect abuse.

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

Almost everyone who is in the situation where assisted dying might be considered, in a regime where suicide is permitted, falls under some pressure to comply. If the Bill were to be enacted it would inevitably place a moral and emotional burden on those who are already suffering.

Judaism believes that all people, including the dying, should be invested with dignity, and that the dying should be treated with the greatest respect. It disagrees absolutely with the suggestion that a dignified death is one that is "assisted" to take place before its natural time, and is entirely opposed to the putative ethic on which the Bill is based. Indeed we would regard the basis of these proposals as entirely unethical, and, accordingly, cannot support the Bill to any degree.

Note: The Scottish Council of Jewish Communities (SCoJeC) is the representative body of all the Jewish communities in Scotland comprising Glasgow, Edinburgh, Aberdeen, and Dundee as well as the more loosely linked groups of the Jewish Network of Argyll and the Highlands, and of students studying in Scottish Universities and Colleges. SCoJeC is Scottish Charity SC029438, and its aims are to advance public understanding about the Jewish religion, culture and community. It works with others to promote good relations and understanding among community groups and to promote equality, and represents the Jewish community in Scotland to government and other statutory and official bodies on matters affecting the Jewish community.

In preparing this response we have consulted widely among members of the Scottish Jewish community.
End of Life Assistance (Scotland) Bill

The Humanist Society of Scotland

The Humanist Society of Scotland seeks to represent the increasing numbers in Scotland who choose to adopt a non-religious, but ethical life stance. Humanism is not a religion. The 2001 census showed that 1.4 million Scots (27.5%) choose to live their lives without religion; the Scottish Annual Household Survey of 2008 put that figure at 40%.

Secular Humanists think that:

- We can live good and worthwhile lives guided by reason and compassion, rather than religion or superstition
- This world and this life are all we have
- We should try to live full and happy lives ourselves and, as part of this, make it easier for other people to do the same
- All situations and people deserve to be judged on their merits by standards of reason and humanity
- Individuality and social co-operation are equally important.

The Humanist Society is active in many fields in its aim for a better secular world. At present, the Society's main efforts are in helping to bring about secular schooling and a secular Scottish state, and in the development of its increasingly popular range of humanist rites of passage, particularly humanist funeral ceremonies. The study of humanism is one of the options in the Higher Religious, Moral and Philosophical Studies (RMPS) curriculum.

In 2008, Glasgow University appointed its first ever Humanist Chaplain and the Society elected its first president, the novelist Christopher Brookmyre.

Membership of the Society has grown from 850 in 2005 to over 6,400 in 2010, an increase of over 750% in five years.

Distinguished Supporters of the Humanist Society of Scotland include

- Claire Rayner OBE
- Iain Banks
- Professor Richard Dawkins
- Stephen Fry
- Polly Toynbee
- Professor James Lovelock
- Iain McWhirter

The Bill

Addressing the questions set out by the Committee –

1. We DO agree that a person should be able to request end of life assistance from a registered medical practitioner under strictly controlled circumstances.
2. We **ARE SATISFIED** with the requirements for age and connection with Scotland as set out in the Bill – this is in recognition that the age of adulthood in Scotland is 16.

3. We **ARE SATISFIED** with the two categories of people who would qualify to be assisted under the terms of the Bill.

4. Regarding the “several stage consent and verification process”, We have reservations and would prefer to see some latitude in very specific circumstances. Please refer to the notes below.

5. We **DO consider** the level and nature of the safeguards as set out in the Bill to be appropriate and adequate.

6. **YES** – We do have other considerations not included in the above answers.

**Notes**

These notes need to be read in conjunction with the details of the Bill. Paragraph numbers are as per the Bill.

At 6(1)(b), 8(2)(c) & 10(2) – “must be in writing and signed”

**What if the ‘requesting person’ can neither write nor sign their name?**

We can envisage two sets of circumstances where this could arise –

1. Where someone is illiterate and can neither read nor write.
2. Where someone with a degenerative condition, such as Motor Neuron Disease, that has progressed to such a point that they can no longer write, nor sign their name.

Would it be acceptable (within the terms of the Bill) to have the request typed up and the ‘requesting person’ either makes their mark or indicates their assent in some other way?

**‘Advance Statement with regard to Future Medical Treatment’ [Adults with Incapacity (Scotland) Act 2000]**

In the case of any degenerative condition where the ‘requesting person’ is no longer able to communicate (such as Motor Neuron Disease) but has made a valid ‘Advance Statement’ and lodged a copy with their medical practitioner, could this document be taken into consideration and given the force of law? If someone has made their wishes clear in a formal way whilst they were able to communicate, it can not be right that they are then denied access to assistance because they have since lost the facility to communicate in the way envisaged in the Bill.

At 8(1)(c) & 11(2) – time scales

**What if the ‘requesting person’ wants to exercise the option – but not have it enacted just yet?**

The Bill sets out a finite time scale. The second request must be made between 15 and 30 days of the ‘requesting person’ being informed that the
first request has been approved [8(1)(c)] - and the end of life assistance must be provided within 28 days of the ‘requesting person’ being informed that the second request has been approved [11(2)].

This presents possible problems at the two extremes.
1. If the ‘requesting person’ accepts that they are likely to die in the short term and is suffering really severe pain, then the best part of 3 months could seem an awfully long time to have to wait. Accepting that the built in safeguards are necessary, is there any way to expedite this process?
2. If the ‘requesting person’ has a progressive degenerative condition and recognizes at an early stage the debilitating nature of their illness, they may want to set up the process whilst they are still capable of so doing but not want to envisage enactment within a maximum of about 4 months? They have dilemma – move too soon and they may have to let it lapse and start again – move too late and they may not be able to comply with stringent conditions of writing and signing the 2nd request!

For example in the case of Motor Neuron Disease, we know that the rate of progress is difficult to predict. There may be an average time span between diagnosis and conclusion but there is a wide variance between the shortest and the longest.

Why have such a limited maximum time scale? Surely 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. Although the act stipulates that the ‘requesting person’ has to be terminally ill and is therefore expected to die within 6 months, forecasting the outcome is not an exact science. The ‘requesting person’ could still revoke the request at any time.

At 10(3) – “expiry of at least two clear days”

Having got to point of agreement as per clause 10, why wait another two clear days?

With the checks and balances already built in, and with ample opportunity to revoke the request, why impose another 2 day delay? If someone is in extreme distress and has battled through the process, they may be desperate to have it over and done with. This strikes me as an imposition too far!

At 7(2)(d) and subsequently – reference is made to “a psychiatrist”

Does the Bill adequately define the term ‘psychiatrist’?

This is not defined in Clause 12 Interpretations. I suggest that this should refer back to qualifications and/or registration in a similar vein as applies to the ‘registered medical practitioner’.
Conclusion

The Humanist Society of Scotland fully support this proposed legislation on the grounds that –

- It is permissive in that it would enable people who qualify to seek help, should they choose to do so. No one is obligated to do anything against their own judgment.
- It respects the dignity and autonomy of the individual competent adult.
- It presents a humane solution to what can be a very painful and distressing situation.
- It has reasonable and appropriate safeguards to ensure the request is the settled will of the ‘requesting person’ and that it has not been made as the result of pressure from any source whatsoever.

We sincerely hope that Scotland will, once again, lead the way with a piece of enlightened legislation.

John Bishop
Secretary
Humanist Society of Scotland
6 May 2010