End of Life Assistance (Scotland) Bill

Scottish Branch of The Association of Hospice and Palliative Care Chaplains

The following response to the End of Life Assistance (Scotland) Bill is from the Scottish Branch of the Association of Hospice and Palliative Care Chaplains. The text offers a series of considered reflections which are intended to inform the debate and describe the lived reality of working closely with patients, families and healthcare professionals in an end of life context. The association is keen to emphasise the complexity of end of life care, which means that from a philosophical, theological, ethical and social perspective there is sure to be a range of perspectives.

A fundamental concern about the Bill is that it is trying to formulate a protocol for death and dying. The association doubts that managing death can be within a protocol. Dying is too complex and sometimes ‘not tidy’. The text finishes with some specific responses to certain aspects of the Bill.

Suffering, dying and death

- The issue lying behind the End of Life Assistance (Scotland) Bill is how society and individuals within that society face suffering, dying and death.
- Living with suffering is hard. There is a strong tradition within palliative care of embracing the tensions and finding a way to cope with ‘the intolerable’.
- The NHS Living and Dying Well (2008) and NHS Shaping Bereavement Care (2010, in press) are clear that there are very few conversations taking place in society about death and dying.
- The association is keen that some energy and effort is put into educating Scottish Society about the meaning and purpose of life.
- It is good and essential that conversations take place; and Margo MacDonald raises pertinent and worthwhile questions. Indeed if society were to turn a blind eye to the despair of certain individuals there would be no conversation and society would lose an opportunity to show compassion and to learn.
- The association considers that suffering, dying and death are an integral part of living and life. Paradoxically it is by living with and working through the crisis of illness and the challenges of suffering that humanity actually becomes more compassionate and mature. There are many situations where working through suffering and tragedy enhances individuals and strengthens communities.
- The association would advocate that Scottish society should have the courage to wrestle with existential issues about the meaning and purpose of live rather than enact a Bill which would validate despair. The preference is for society to discover a hope and resilience that can rise above suffering.
• People live and die within the framework of a story. Suffering and intolerable despair is always contextual. The Bill gives no recognition to the human process. People’s emotional, psychological and spiritual well-being change from day to day, and in end of life care from hour to hour.
• The nature and tone of the Bill may deny society, individuals and their families to experience this wilderness experience, and in turn may deny healing at a deeper level.

**Palliative Care**
• The association is very aware of the challenges involved in supporting individuals as they make their last journey towards death. There are times when individuals endure terminal agitation, anxiety and depression however again and again good palliative care, as defined by the Scottish Partnership for Palliative care, brings transformation and healing to the crisis of dying and death.
• High quality end of life care already exists within Scotland. The association is encouraged by the Scottish Government’s action plan for palliative and end of life care, Living and Dying Well (2008).
• However the experience of the association is that this high quality care is not available to all and would support the increased allocation of resources into palliative and end of life care.
• If there are times when quality end of life care does not occur this should motivate the health service to invest more resources in palliative care and projects such as Living and Dying Well.
• There is a serious concern that enacting this bill will at least seriously undermine and even destroy the current practice of palliative care in Scotland.

**The Bill**
• The Bill does not offer a framework for what it means to die with dignity, or heightened dignity.
• Death and dying is complex and dynamic and sometimes messy. There is no right kind of death or good death (Sandman, 2005). There is no protocol that can be applied to those facing their own death. It is very difficult for a Bill to encompass the range of lived experiences described and by doing so is in danger of making the exception the norm.
• There is a lack of evidence that the proposed legislation is actually needed in our society. The association is worried that in the Policy Memorandum the support for the Bill comes primarily from polls in the street. These opinions are far removed from those conversations engaged in daily by hospice chaplains. Again and again the individual who in their homes ask to be shot, or to be given a blue pill, if illness comes their way; in the reality and context of end of life care strived to hold onto life firmly.
• The Bill seems to allow both assisted suicide and euthanasia – and should be specific on these matters if this is what is being legislated
for. Indeed the title could be misleading because Scottish society already allows people to die with dignity; and this Bill’s focus is to legislate for the intentional ending of life.

• If the Bill is accepted it will change the relationship of trust between patient, family and the institution; it will change the relationship with the doctor; and the nature of end of life discussions with the chaplain will be altered irrevocably.

• The Bill seems to be addressed to a minority of people who are burdened with the very subjective experience of ‘intolerable despair’. But written in such a way that the scope extends to a vast number within society.

• There is a danger that the Bill will prejudice the safeguards of the majority for the sake of an articulate minority.

• The autonomy of an individual needs negotiating with the best interests of a community. The association is convinced that the nature of the decisions within the Bill, which value ‘autonomy’ are bound to have huge impact on wider family, community and society. None of which are considered in the Bill or the guidance.

• No Bill should be supported without a conversation at all levels of society.

• However, there is hesitation about accepting the proposed Bill because if accepted the legislation would ‘validate despair’; the way society faces difficult situations of suffering and distress would be radically and irrevocably changed. There would be no way of going back no matter what legislative safeguards. The Bill does not specify the means by which life is terminated. The Bill is legalising the intentional ending of life. This is unworkable within a society which extensively embraces the principles and ethos of palliative care.

• The norm of society should be based on the concept of ‘Life is sacred’; End of life assistance should always be the exception. Legislation should preserve the norm.

• Whose need is being served by the End of Life Assistance (Scotland) Bill? The patient, or the carer, or society? What is ethically clear is that no individual can make choices and decisions that have no bearing on either their immediate family or wider on society as a whole. Decisions to end one’s life affect all of society. It certainly should not be left up to the medical profession to make ethical decisions which affect society as a whole.

• Bereavement outcomes may be negatively affected by End of Life Assistance

• How can one define or describe a life which has become ‘intolerable’? Often it is the fear rather than the actuality that drives the desire for assisted dying, and people often change their minds.

• The Bill implies that there are situations in which society allows people to die without dignity. The Bill does not substantiate these claims.

• Dignity is a multi-factorial concept and virtually impossible to define. Dignity is more than assisted dying. Suffering is a huge moral and existential issue but even so is only one dimension of dignity. The Bill
does not offer a framework for what it means to die with dignity, or heightened dignity.

- The bill is silent about post-mortem inquiry/investigation. Reporting of recent cases implies that 'helping' relatives shouldn't be prosecuted. The association expects the state to investigate the death of a citizen.
- The association wonders what the impact of being participants in end of life assistance will have on individuals and society. Will healthcare professionals become hardened against taking life?
- The association worries that if adopted the Bill will be driven by economics.
- The association has serious concerns for anyone's vulnerability, who is facing end of life decisions.

Specific Issues

1. Applicability:
Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?
We have grave concern over the vulnerability of a 16 year old in being able to make such a decision. They are at a very difficult stage in their life and just learning the realities of decision making. It is wrong to give them the scope to end their lives.
Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?
The two categories are far too wide and embrace many people who may be considered seriously ill or disabled

2. Capability:
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?
There are grave concerns that individuals can know their own minds beyond doubt. Experience in end of life care shows that people change their views right up to their last breathe.
The association is worried that in a context of end of life care where over 50% of people suffer from depression or adjustment disorders that a healthcare professional can discern who is competent to make such significant decisions.
Waiting period between requests should be longer.
How competent are medical personnel to “explain” hospice/palliative care? Might it be necessary to experience it in order to understand it?

3. Attending physician responsibilities:
Do you agree a person should be able to request end of life assistance from a registered medical practitioner?
Very concerned that a doctor can discern the state of mind of these patients; nor judge the external influences which may bear on them from society; culture; families and themselves which all shape one's values and beliefs.
The designation “terminally ill” is subjective, imprecise and therefore inappropriate for legislation such as this. Prognoses (e.g. “six months”, as here indicated) are notoriously unreliable. There is no provision for any consideration of mood as a factor in prompting people to contemplate euthanasia. Recent research from Oregon reveals that as many as one in six people who commit suicide with the help of their doctors is suffering from treatable but undetected depression.

What are the practicalities of the Bill if doctors have conscious objections – is this incorporated into the Bill? The majority of clinicians involved with end of life care are against this Bill; the resistance to the Bill is even greater when one considers that decisions may be made by people who are not near the end of their lives.

How will society decide which clinicians are competent and skilled enough to make such decisions; communication with the terminally ill requires training and experience. The Bill could threaten the trust which exists between patients and their medical team.

4. Safeguards:
Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?
The association is very concerned about the rigour of the safeguards. Would the proponents of the bill care to indicate:
- Where precisely end of life assistance might be administered?
- Who precisely might administer it?
- How precisely the means might be provided? - All with due consideration of the conscientious rights, whether of professionals, of family members, or of friends/associates.

5. Other considerations
The Bill does not explore the impact of ‘end of life assistance’ on individuals; families, carers, and society as a whole.

The Bill’s memorandum is presented in emotive language; implying that those who do not support the Bill are showing no mercy.

Support for the Bill comes from a few opinion polls: the reality of working with people at the end of their life shows that the experience of living with the end of life issues is very different from abstract discussion when death and dying is distant.

The Bill does not detail the appropriate means by which ‘end of life assistance’ is implemented. How can one legislate for something which is not specified?

There is too much ambiguity and too little thought given to the impact of the Bill on society as a whole.
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