End of Life Assistance (Scotland) Bill

Francis Edwards

I wish to register my deep concern regarding what I consider to be a most dangerous development in end of life outcomes as proposed in the Bill put forward by Margot McDonald MSP.

With regard to the specific questions, which you have asked to be addressed, my responses are as follows:

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

If by end of life assistance, you mean that a person can request that their doctor provide them with the means to kill themselves or that the medical practitioner actually, physically, assist in the process of a person killing themselves, then my answer is a clear no.

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

I am very dissatisfied with this and that Scotland appears to be “leading the way” in the UK in this process. It seems that you can chose to take your life in Scotland, before you can have a drink in a pub. There has to be something wrong here. I also feel that a bright 15 year old may well be able to challenge this in the European court of human rights.

Age is not the only determinant of the capacity of a young person to make decisions.

I recognise that the age of 16 reflects the age of majority and that in general law functions, age determined definitions are used but believes that an age related decree in relation to decision making does not take into account the capacity of the young person to make decisions.

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

In view of my reply to question one, clearly my reply to this question must be no. No - defining the categories in the way suggested by the proposed Bill is not possible in practice.

The inclusion of a terminal illness as a qualifying condition requires clinicians to be able to provide an accurate prognosis in an uncertain speciality. This is especially problematic in the case of young people with non-malignant conditions.
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. The degree of incapacity related to a reliance on others does not necessarily purely reflect a physical dependence, but includes varying degrees of emotional, psychosocial and even financial dependency.

Intolerability is a subjective measure and is therefore variable for individuals and is unsuitable as a criterion for determining best interests. Many individuals have borderline capacity, which will lead to such decisions/judgements being made by others on their behalf. If a person, and particularly a child, does not have capacity then someone else (and ultimately the court) has to determine best interests. In English law, following Mr Justice Wall's comments in the Charlotte Wyatt case, a determination of intolerability by proxy now plays a much less important role in the determination of best interests than it used to. The question is "intolerable to who?" It is almost impossible not to make some kind of substituted judgement when the patient cannot express what is intolerable to him or herself. When considering assisted dying, having two doctors making two assessments will be no safeguard if the criteria applied to those with reduced capacity are inappropriate. The later GMC v Burke judgement also discarded it as a legal concept for adults, although ACT recognises that there still is an ethical concept of unbearable.

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?

As for question one, No.

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

This is one of the particularly disturbing aspects since the terms of the safeguards are particularly vague. The proposed measures do not adequately protect children under the age of 18yrs.

The safeguards are unlikely to prevent the vulnerable who seek to end their life because they feel a burden to others, or who cannot see a reasonable alternative. There is little recognition of the need for independent advocates to protect the vulnerable individual.

The inclusion of young people from the age of 16 and the psychiatric assessment should ensure that developmentally appropriate considerations are included - currently young people in Scotland would be assessed by adolescent mental health services. It is imperative that any assessments do not merely exclude significant psychopathology, but also is carried out by practitioners who have the expertise to assess full capacity. Assessment of mental capacity is increasingly moving away from an age-based ability to make assessments towards a capacity to make decisions. There is a need to
balance age-specific and decision specific issues and for consideration given to ensuring the level of the competency test is set higher for complex and very serious tasks.

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

As a professional who works with dying children long serving clinician, who has not infrequently come in contact with vulnerable individuals who might reasonably be expected to come within the remit of the Bill. I can only reiterate my observation of the overwhelming sense of desire by terminally ill patients and their families to offer good palliative care rather than be considered for voluntary euthanasia. Even at times of severe pain or distress, which I know good palliative care can address.

The difficulty in end-of-life care lies elsewhere. More than anything, I have often been struck by the fact that, despite great compassion conveyed by many of the health care professionals to individuals experiencing this end-of-life distress, there has been a lack of high quality palliative care services and support for the severely ill and dying.

It seems illogical to me to fill this gap in palliative care simply by hastening the demise of the affected individual by shortening the process of dying. Where is the evidence that dying during the process of assisted suicide is any better /less painful / more dignified than that dying by natural causes?

Apart from the many additional risks to the elderly and infirm population that this Bill would bring, from first principles the thesis that each individual has the right to choose when to terminate their life is an extremely dangerous premise to allow to be established. Given the extreme variations in mood, mentality, perception, suggestibility and other factors.

What is needed, as I have stated above, is better end-of-life care, and our communities and the NHS should work towards providing this for all members of our society. This would remove the need for such a Bill. Care and support at the right time is the key here.

Together with colleagues and professionals in the Grampian Region, as a member of a group called ‘Better End-of-life Care –Grampian’, I am registering my strong objections to this Bill from first principles based on the flawed logic that what is being proposed is better than what we already have. However, the Bill has highlighted the deficiencies in palliative care and I would urge you as MSPs to seek ways to improve this aspect of health care rather than support the abject proposal of simply hastening life’s end.

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