End of Life Assistance (Scotland) Bill

ACT

About ACT

ACT is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited or life-threatened child or young person and their family. ACT supports a children’s palliative care professional and family membership across the UK and provides a national helpline and information service.

ACT produces a range of publications and resources, including care pathways for life-limited or life-threatened children and young people, and publishes the International Journal for Children’s Palliative Care.

ACT takes a lead on lobbying and campaigning for sustainable children’s palliative care services and plays a key role in ensuring that the needs of all affected children and their families are heard.

This response was developed by ACT’s Ethics Committee. In addition, ACT’s 1000 members were consulted via the charity’s website and respondents were in agreement with the responses contained within this document.

ACT considers that the questions which are relevant to our sphere of interest (children and young people’s palliative care) relate to age and capacity and require a response from us and these are:

1. Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?
2. Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?
3. Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

Response

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

No - ACT believes that age is not the only determinant of the capacity of a young person to make decisions.

ACT recognises 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.
The inclusion of young people from the age of 16 and the psychiatric assessment should ensure that developmentally appropriate considerations are included. 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 and who are able to recognise the impact of the speed of emotional development in late adolescence and the rapid swings in emotion on decision making. Currently young people in Scotland would be assessed by adolescent mental health services, who will have the skills to assess age-related issues, but may not have the knowledge to assess capacity in relation to the decisions relating to assisted suicide.

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 to be given to ensuring that the level of the competency test is set higher for complex and very serious tasks.

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

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 whom?" 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 ‘unbearable’ is still an ethical concept

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

No. The proposed measures do not adequately protect children under the age of 18yrs.

The safeguards are unlikely to protect 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.

Other points

ACT welcomes the national strategy for palliative and end of life care (Living and Dying Well, Oct 2008) and believes that the Government should actively promote excellence in palliative care and adequately fund palliative and end of life care.

ACT believes that all babies, children and young people should have access to choice in their place of care and their place of death and that they should be provided with the support necessary to achieve a “good” life and a “good” death\(^1\). A good death not only benefits the ill child or young person, but also their loved ones and carers.

ACT considers the title of the Bill ‘End of Life Assistance’ to be inappropriate as there is a lack of clarity in what End of Life Assistance means. The process reflected within the documentation would be more accurately described as euthanasia and assisted suicide and the implications of both processes should be described within the Bill.

The Bill fails to recognise the involvement of other professionals in the proposed process – and merely focuses on the role of doctors, and not on the roles of nurses, carers and pharmacists who could all be involved in the role of assistant. There is no provision for practitioners who would choose to opt

\(^1\) “As a society, we fight shy of pondering on death, yet inherent in each of us is a deep desire, both for oneself and for those we love, for a ‘good’ death. It would be absurd to try to describe that concept more fully beyond saying that everyone in this case knows what it means: not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love [her] most.” – Mr Justice Hedley, High Court Ruling on the Charlotte Wyatt case, 7 October 2004

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out of this process and the Bill does not provide adequate legal protection for practitioners who choose to engage around the final act of assistance.

ACT is concerned that these proposals will bring about differences in treatment for those aged 16-18 between England and Scotland.

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