End of Life Assistance (Scotland) Bill

Suselle Boffey

Why assistance to live is more important than assistance to die

Perhaps I should introduce myself to give some background context to my position statement. Yes, I am a Christian and therefore have a personal belief in the sanctity of life in all its forms. However, I believe other factors fundamentally inform my position and it is these I wish to lay before you.

Professionally, I have worked as a social worker for 30 years. This has given me a broad experience of many situations where individuals experience disorder and extreme difficulty in their lives, and I have been alongside them as they struggle with illness, desperation and life changing decisions. For the second half of my working life, my field of expertise was in the area of independent living and I and my colleagues were committed to achieving creative ways of enabling disabled people to live well with sufficient support.

I am also a disabled person; I have lived with a progressive and life limiting impairment all my life, and increasingly have required medical intervention in order to survive. I have been privileged to receive high-quality medical care and social support, and currently give thanks daily for my powered wheelchair, my ventilator and associated equipment, and my social funding which enables me to employ my team of personal assistants. These I believe are my human rights in order to live equally with my contemporaries in this society; the fact that I cannot so much as blow my nose without assistance is irrelevant. In fact, I have been enabled to live an abundant and satisfying life to date, working full time and travelling across the world.

I am only too aware that many others facing similar circumstances do not experience the same levels of provision and confidence in our medical and social care structures. We all know that we live in a society where postcode lotteries all too often dictate the manner and extent to which our human rights are met. An appreciation of this unjust geographical patchwork is fundamental to our understanding of how life can and should be lived and how death can and should be encountered.

Such postcode lotteries and huge variations in attitudes to the whole area of quality of life can sometimes lead to frightening consequences. My friend and colleague Baroness Jane Campbell -- of whom many of you will know -- is an active and hard-working member of the House of Lords who has campaigned vigorously against assisted suicide and has worked tirelessly to change the terms and wording of the guidance produced by Westminster in order to protect the rights of disabled people. We share the same physical impairment; however, she has encountered horrifyingly different attitudes from medical professionals in her times of respiratory crisis. She has written and spoken of her experience at such times of having doctors approach her and state their presumption that she would not wish to be resuscitated if her
condition deteriorated. Imagine her fear and utter vulnerability, and imagine the anguish which this provoked in her husband and led him to produce Jane’s graduation photograph and evidence of her busy and fulfilling life in order to convince these doctors that their assumptions were ill founded to say the least.

This is not an isolated incident. Many disabled people can relate similar stories; some have even discovered Do Not Resuscitate written on their medical records with no prior consultation with themselves or their families. Current regulations should prevent this from happening, but does it? Has our society progressed to the extent that disabled people are truly seen as equals and thus are no longer subject to outdated attitudes and assumptions? I think not, and I think that doctors and other professionals are not exempt from the stereotypical attitudes and assumptions prevalent in our society.

My fundamental opposition to the legalising of assisted dying can therefore be summarised in 3 reasoned arguments, as follows:

1. Doctors and other professionals cannot be permitted to allow their assimilated stereotypical views and personal assumptions to influence their decisions about treatment and quality of life. Regulations and guidance statements may go some way to minimise this risk, but if the law on suicide and assisted suicide is changed then the opportunity remains for such attitudes to persist. If however the law remains robust, professionals will rightly be challenged to seek creative solutions to assist people to live comfortably and well up to the point of death.

2. Public monies must be prioritised to enable all citizens to live equally before any attention may be given to assisting them to die. The right to independent living must therefore be enshrined in law, with adequate and consistent resourcing to allow this to be effective across the nation. This will have a dual effect of securing the safety and well-being of ill and disabled people as well as forcing local authority services to be fully and creatively responsive to their needs. Similarly, palliative care services must be equally well resourced such that no individual need fear the pain of the dying process.

3. Ultimately, if the law were to change in order to enable life to be ended prematurely, this would in many cases allow subtle pressure to enter the lives of disabled people and those facing progressive illnesses. While the vast majority of families would not think of assisting premature death for their own ends, it is dangerously possible for the ill or disabled person to see themselves as a burden and gradually to seek ways of alleviating this perceived burden by means of assisted suicide.

It is for these reasons that I passionately oppose any change to the law. I have every sympathy for those facing painful and terminal illnesses, but I believe that high quality palliative care can and should be available to all in
our first world country. With good models of palliative and social care, and well publicised information about such resources, no individual citizen should be exposed to fear about the end of life or indeed about the quality of life when living with life limiting conditions. Further, the laws of this country must not permit judgements to be made about quality of life when in reality this is usually a matter of poor medical and social care provision.

This is not simply a matter of compassion. This is fundamentally an issue of equality and human rights. We all have a duty to communicate this to our elected representatives.

**Conclusion and Recommendations**

Further to my arguments above, I deeply hope that our Parliament will seriously consider implementing the following alternatives:

1. Firm guidance/instruction to Health Authorities to provide comprehensive and top quality palliative care services, with clear monitoring to ensure unquestionable consistency across Scotland.

2. Firm guidance/instruction to Local Authorities to provide comprehensive and top quality social care services and Direct Payments, with clear monitoring to ensure unquestionable consistency across Scotland.

3. The funding of high quality information services which will provide and promote information about 1 and 2 above to all citizens and inhabitants of Scotland, and which will encourage all people to maximize their rights to top quality services.

4. Rapid progress of current and future legislation enshrining rights to (fully resourced) Independent Living and to full equality for all Scottish people, disabled and non-disabled alike.

5. Promotion of equality thinking in all medical teaching and debate, with particular emphasis on the reduction of stereotypes and on the absolute priority of including the patient in all decision-making.

In conclusion, I would like to thank the Committee for this opportunity to give written evidence and to express my willingness to be called to give oral evidence, should the Committee find this helpful.

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