End of Life Assistance (Scotland) Bill

Breast Cancer Care

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

Breast Cancer Care does not have a formal position on whether end of life assistance should be legalised. However, as a charity that seeks to advocate for the best service provision and support for women who are living with a secondary breast cancer diagnosis, we feel our response should comment on the robustness of the proposal if there were public and parliamentary support to make the Bill law.

Although there are no official data (as yet) on how many women with a primary diagnosis will develop a metastasized form of the disease, the English government has estimated that around half of all women with primary breast cancer go on to develop terminal cancer. Despite this diagnosis, many women live with the disease for many years and palliative care as well as a slowly-expanding course of treatment options means that many women lead a higher quality of life for longer – the average life expectancy for women with a secondary diagnosis is 18-36 months. If this Bill did become law in Scotland, it would potentially be relevant to this group of eligible patients in the latter stages of their lives.

This Bill also provides a good opportunity to argue for better funding to improve palliative care services, which can have a crucial role to play in peoples’ decisions about their options towards end-of-life. Hospice and palliative care services to support people living with a terminal illness and their families are currently under funded. In order for a person to make the best end-of-life choices for them, the Scottish Government should increase the availability and quality of palliative care, not least because good pain relief can substantially affect a person’s quality of life in their dying stages, making it less likely that assisted death will be sought.

End of life assistance must not be confused with a legal and vital use of pain control and other medication to relieve suffering. Regulated use of pain relief is essential to relieve the suffering of those in severe pain at the end of life. Used correctly, strong pain killers relieve pain without hastening death. People should be made increasingly aware of the availability of pain relief services and clinics.

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2 Audit Scotland report, Review of palliative care services in Scotland (2008) stated that access to good palliative care in Scotland needs to improve and it must be more consistently provided. The availability of specialist care varies significantly across Scotland.
We would express concern if this legislation was to dilute or damage the practice and provision of palliative care, which benefits many thousands of people in Scotland every year.

As the Bill aims to give people more choice in how they die, it needs to be accompanied with a renewed emphasis on allowing people to die in their place of choice. The figures for people dying at home, where they would have preferred this, are woefully low\(^3\) and more funding should be available to ensure this can happen.

Another vital element that needs to be promoted is increased funding for support and information services (including financial advice, information about peoples’ own conditions and prognosis, state entitlements, family support etc.) Improving such support can make a big difference in how people view their condition and options and this needs to be at an excellent level so that people can make the most informed choice about whether they choose to apply for an assisted death.

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

Breast Cancer Care is satisfied with the recommendations for age and connection to Scotland. The latter is an effective measure in curbing the kind of ‘suicide tourism’ that currently takes place when people travel to Switzerland to end their own lives.

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

Breast Cancer Care is satisfied with the categories of people eligible for end of life assistance. ‘Terminal’ as defined by having less than six months to live is a specific and helpful definition that prohibits people with a general ‘advanced’ cancer diagnosis, many of whom can live much longer than six months, particularly in the typical case of a secondary breast cancer diagnosis, where the average life expectancy is 18-36 months.\(^4\)

Some further clarification may be required in the criteria of point 4 (2) b. Is there a minimum period of time for which the person in question has experienced permanent physical incapacity and finds life intolerable? The rationale being that someone who finds their circumstances change through some form of accident should have a minimum period of time to adjust to their condition and not be allowed to request end of life assistance through a period of extreme emotional turmoil and difficulty. A psychiatric assessment may

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\(^3\) About half of the 75,000 people who died from cancer between 2003 and 2007 died in NHS acute-care hospitals, the place people say they would least like to be, while only one in four died at home according to *The Place of Death from Cancer* report, issued by NHS Scotland (2009)

deem the person to be of sound mind to make this decision but a minimum time stipulation may be helpful to protect people from making hasty decisions.

**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?**

Breast Cancer Care is satisfied that the process as outlined in the Bill is robust and protects vulnerable people from being forced, coerced or pressured into a decision.

We would add that a clear distinction should be made between palliative care practitioners exploring the emotions being experienced by the patient and their end-of-life choices with the request under the Act for assistance in ending life.

For some medical conditions that are deemed terminal, particularly non-malignant conditions, it is difficult to predict whether death is likely to occur within six months. How would a request for assisted death be viewed in this context?

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

We are glad to see the Bill includes the point that the decision to die through assisted means is revocable right up until the moment of ‘assistance’ and that any notice to terminate the arrangement, no matter how informal, will prevent it from going ahead. We believe that this, and the various time delays throughout the process, will give patients enough time and opportunity to change their minds as they approach death, which is crucial due to the psychological effects of approaching death. During the metastatic phase of cancer the patient’s views, feelings and wishes may change, which is more likely to be influenced by their timely access to psychological support, symptom management and treatment choices. Patients who wish to get assistance to die because of distressing physical symptoms may change their minds when these symptoms are addressed through appropriate palliative care.

The stipulations to have witnesses who are unrelated to the patient and will not knowingly gain from that person’s estate, as well as the psychological assessments after the two formal requests have been made should guard against the potential risk that vulnerable people might feel they should choose the option of assisted suicide, rather than being a ‘burden’ to their family or society or a drain on the healthcare system.
Do you have any other considerations on the Bill not included in answers to the above questions?

The bill is not clear on the protection and/or legal obligation on healthcare professionals who may be requested to assist and have conscientious objections to carrying out or assessing requests.

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Breast Cancer Care
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