

Submission by the Scottish Partnership for Palliative Care to the Health & Sport Committee - Assisted Suicide (Scotland) Bill

This submission starts by setting out some background information before moving on to address the specific questions posed by the Committee. A fully referenced version is available.

About the Scottish Partnership for Palliative Care (SPPC)

SPPC is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership is detailed at www.palliativecarescotland.org.uk. The Partnership contributes at national level to the development and strategic direction of palliative care in Scotland and to service improvement at local level. The Partnership's aims are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis.

About Palliative Care

The World Health Organisation defines palliative care thus:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

Specialist palliative care focuses on people with complex palliative care needs (e.g. complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g. consultants in palliative medicine and clinical nurse specialists in palliative care). *General* palliative care forms part of the routine care of patients and support for carers. This may be part of the work of a range of health and social care practitioners including GPs, district nurses, care assistants and hospital staff. 1 in 3

patients in hospital are in their last year of life and 54% of Scots die in hospital.

Over 40,000 people in Scotland each year could benefit from palliative care.

Most people with palliative and end of life care needs are aged 65+. However some babies, children and young people also have palliative and end of life care needs.

There is a common misconception that the use of opioid medicines to control pain shortens life in dying patients. In appropriate doses the opioid medicines (e.g. morphine) do not shorten life. There is no robust evidence to support the assertion that medical staff use opioid medicines to shorten deliberately the life of patients.

Society-wide approaches to better death, dying and bereavement

Whilst death, dying and bereavement are inevitable, it is possible to reduce the harm/trauma associated with these experiences. How people experience death, dying and bereavement is only in part dependent on health and social care services. Other factors include access to adequate legal and financial planning, supportive workplace practices and the extent to which people are able to get support from family, friends and the wider community. There are many ways in which people can exercise choice and control towards the end of their lives. For example people can make a Will, a Power of Attorney, an Advance Directive, and an Advance Care Plan in discussion with their GP. However, levels of awareness and uptake of these opportunities are low. This is mainly because Scottish society is not open about death, dying and bereavement. These issues are seldom discussed. This lack of openness makes it more difficult for people to achieve the death that they may have wished for. SPPC has established Good Life, Good Death, Good Grief www.goodlifedeathgrief.org.uk – an alliance promoting more openness about these issues in Scotland.

1. Do you agree with the general purpose of the Bill to make it permissible, in the circumstances provided for, to assist another to commit suicide?

SPPC is not able to adopt a position on the principle of whether or not assisted suicide should be legalised. This is because the topic raises issues of a moral, personal and ethical nature upon which many of our member organisations (for example our member NHS Boards) are institutionally unable to hold a position.

However, SPPC holds the view that in contemplating legislating in this area MSPs should give careful regard to:-

- Any possible impact on the practice and provision of palliative care.
- The protection of vulnerable people. All people are potentially vulnerable, depending on events and circumstances, especially towards the end of life.

The content of this submission is guided by these twin considerations. The submission aims to support the deliberation of MSPs by providing relevant factual information and also by directing the attention of MSPs to questions of practical relevance to these twin considerations.

2. Do you have any views on how the provisions in this Bill compare with those from the previous End of Life Assistance (Scotland) Bill?

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3. The Bill precludes any criminal and civil liability for those providing assistance, providing the processes and requirements set out in the Bill have been adhered to. Do you wish to make any comment on this?

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4. The Bill outlines a three stage declaration and request process that would be required to be followed by an individual seeking assisted suicide. Do you have any comment on the process being proposed?

Assessment

The Bill should provide guidance to healthcare professionals on the standards of diligence required when assessing eligibility. Consideration should also be given to whether assessing clinicians require particular skills/expertise/knowledge beyond those universally required of all medical practitioners.

The Bill does not require the assessing practitioner to have any prior knowledge of the requesting person or their social and family circumstance. Assessment may be more difficult in these circumstances. Four separate practitioners may be involved in assessment and this reduces the time and continuity which tends to underpin therapeutic relationships.

Timescales

It would be possible to move through the entire process set out in the Bill in around 24 days. MSPs are asked to consider this timescale in the context of the experience of many practitioners (including specialists in palliative care) that the views, feelings and wishes of patients change over time and may alter frequently during the course of an illness. Patients who have a desire for an early death or who express a wish to get assistance to commit suicide because of distressing physical or psychological symptoms often change their minds when these symptoms are addressed through appropriate palliative care. It is recognised that palliative care cannot *always* successfully address *all* symptoms.

The Bill does not articulate a requirement that alternatives to assisted suicide are adequately explored and it seems likely as a result that some people will commit suicide who would otherwise have gone on to experience a further period of life which they would have valued. The timescales in the Bill make adequate exploration of alternatives difficult. The existence of assisted suicide as an option may make it harder to engage patients in discussion about alternative options.

MSPs should consider whether the cooling off periods, deadlines and revocation arrangements contained in the Bill could create an undesirable dynamic in which some vulnerable individuals might feel impelled to proceed.

Some people will have an enduring wish for suicide and such individuals have a need and a right to be respected, affirmed and valued, regardless of the legality or otherwise of assisted suicide.

Appeal

The Bill should be clear whether patients requesting assistance should have a right of appeal should they be deemed ineligible (and also be clear on any action required of assessors identifying undue influence).

5. Do you have any comment on the provisions requiring that the person seeking assisted suicide must have a terminal or life-shortening illness, or a progressive condition which is either terminal or life-shortening?

The experience of practitioners (including specialists in palliative care) is that it is difficult to predict accurately when a particular person may die. Prognostication is more difficult in some conditions and for some individuals than others. Prognostication is particularly difficult in the case of young people and adolescents with non-malignant disease.

The terms “terminal or life-shortening illness” and “progressive condition” are insufficiently precise to form part of clear eligibility criteria. Since the Bill (and accompanying documents) defines neither “terminal” or “life-shortening” it is unclear what the intended difference between these terms is.

The Bill therefore grants assessing doctors a high degree of discretion regarding eligibility. How these various terms are interpreted will impact on the numbers of people who are eligible. If the terms are not clear then the Scottish public and healthcare professionals will be left not knowing who is eligible and inconsistency is likely to arise.

It may be more meaningful to speak of an individual reaching “a terminal phase of their illness” based on a combination of their diagnosis or diagnoses and whether their illness is in an advanced stage. However, the term “advanced stage” does not itself have a clear definition unless linked to specified levels of need and/or predicted life expectancy.

The Bill should be clear about the level of experience/expertise it deems necessary to determine whether the requesting person meets the criteria in the Bill. For example would a neurologist be required to determine whether a specific person’s MS was “progressive”, “terminal” or “life-shortening” or would it be adequate for a general practitioner to make this determination?

It is very common for older people to have several chronic and progressive conditions concurrently. The Bill may need to reflect this in the definitions used within the eligibility criteria.

Life Unacceptable

A more objective criterion could be “unrelievably unacceptable” – in this circumstance a third party would assess whether a full range of measures which might normally be expected to relieve feelings of unacceptability (care, support, treatment) had been undertaken. The assessment would be about the adequacy of the relief measures rather than the individual’s feeling about their life.

Whether a person “sees no prospect of improvement in [their] quality of life” is in part a function of their knowledge of potentially beneficial options available. Public knowledge and awareness of the benefits of palliative care (both specialist and that provided by other practitioners) is typically low. People (especially with non-malignant disease) are typically not referred, or referred very late, to specialist palliative care.

The phrasing of 9(2)(c) means that the endorsing doctor isn’t required to ascertain whether the applicant is informed about, or has had access to, options to improve quality of life.

6. Are you satisfied with the eligibility requirements as regards age, capacity, and connection with Scotland as set out in the Bill?

Capacity

A potentially very common combination of factors affecting older requesting persons (mild depression, mild cognitive impairment, multiple morbidities and an internalised perception that they are a burden to relatives or others) may be difficult to identify. The criteria should be clear as to whether such a person is eligible.

In young people the age of legal mental capacity to give consent should not be assumed to be the same as the age at which an individual achieves the cognitive and emotional ability to make a particular decision. The criteria should be clear whether a 16 year old with capacity, pre-existing mental health problems and/or impulsive behaviours and/or self-harm behaviours is eligible.

If persons of the type cited in the previous 2 paragraphs should not be eligible then any legislation should contain adequate provisions for the identification and exclusion of such individuals.

It is difficult to predict when and how fast any individual may experience deterioration of capacity.

7. Do you have any comment on the roles of medical practitioners and pharmacists as provided for in the Bill?

See above (various).

The Bill is not clear as to who will prescribe/dispense any lethal medication or about the role of non-medical prescribers.

8. Do you have any comment on the means by which a person would be permitted to end his/her life under the Bill?

Any legislation should give consideration to dealing with medical complications arising during the assisted suicide. The role of clinical professionals called to intervene in such a circumstance (e.g. unsuccessful attempts) need to be made clear. What is the duty of care owed in such circumstances?

9. Do you have any comment on the role of licensed facilitators as provided for in the Bill?

It is easy to envisage complex scenarios being precipitated by the proximity of death and loss at the scheduled time of suicide e.g. sudden uncertainties, conflicts between family members, belated allegations of undue influence. Facilitators would need to be equipped to cope with such circumstances.

Any legislation should ensure robust vetting, regulation and adequate training for facilitators.

10. Do you have any comment on the role of the police as provided for in the Bill?

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11. Do you have any comment to make about the Bill not already covered in your answers to the questions above?

A robust reporting regime would allow for monitoring, scrutiny, audit, regulation and research into a highly controversial, contested and potentially evolving area of public policy.

Background to Internal Consultation on this Submission

The membership of SPPC was consulted on the content of this submission. 30% of nominated member representatives responded to the consultation. Of these responses 89% supported the submission.

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