End of Life Assistance (Scotland) Bill

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About the Scottish Partnership for Palliative Care (SPPC)

The Scottish Partnership for Palliative Care (SPPC) is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 15 of Scotland’s voluntary hospices, 18 major national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at www.palliativecarescotland.org.uk. Through a collaborative approach, the Partnership supports and contributes at national level to the development and strategic direction of palliative care in Scotland and the promotion of 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.

SPPC Position Statement on Legalisation in Principle

The SPPC is not able to adopt a position on the principle of whether or not physician assisted suicide and voluntary euthanasia 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 health boards) are institutionally unable to hold a position.

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

Any possible damage to the practice and provision of palliative care. Palliative care benefits thousands of people in Scotland each year.

The protection of vulnerable people. All people are potentially vulnerable, depending on events and circumstance.

The content of this submission is guided by these twin considerations. The submission aims to support the deliberation of MSPs both by providing relevant factual information and also by directing the attention of MSPs to questions of practical relevance to these twin considerations. MSPs are also encouraged to examine the report and recommendations of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill.

About Palliative Care

Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin 'palliatius' (covered or hidden with a cloak) and is used to mean 'relieving without curing'.

Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about
care in the last months, days and hours of a person’s life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement. The World Health Organisation (WHO) 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;
- integrates neither to hasten or postpone death;
- 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. It may be part of the work of a range of health and social care practitioners including GPs, care assistants and hospital staff.

There is a common misconception that the use of opioid medicines to control pain in palliative care 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.
The views, feelings and wishes of patients change over time and may alter frequently during the course of an illness. Patients who wish to get assistance to die because of distressing physical symptoms often change their minds when these symptoms are addressed through appropriate palliative care.

Living and Dying Well (2008) is the Scottish Government’s ambitious action plan for palliative and end of life care. The plan describes how palliative care will increasingly be available to patients and families regardless of their diagnosis, prognosis or place of care. Work is progressing across Scotland to improve the identification and assessment of people with palliative care needs, and to better meet those needs identified. Audit Scotland’s Review of Palliative Care Services in Scotland (2008) suggests that over 40,000 people in Scotland each year could benefit from palliative care.

ISSUES FOR PARTICULAR CONSIDERATION BY MSPs
(numbers quoted refer to sections and sub-sections of the Bill)

Terminology and the Practice of Palliative Care (1 & 2)

MSPs are asked to consider whether the Bill’s use of the term “end of life assistance” with the associated definition (1.2) could create serious difficulties for the practice of palliative care. As drafted the definition of “end of life assistance” would cover euthanasia and assisted suicide. The definition would also include existing routine practice in palliative care.

As the Bill is currently drafted it is unclear whether the practitioners providing palliative care (for example pain killers, or psychosocial support – both assistance at the end of life) could only do so under the terms of (2) i.e. following two formal requests.

MSPs are also asked to consider whether this terminology in the Bill could also hamper communications between patients, healthcare staff and families. It is fundamental in palliative care that practitioners explore the needs and wishes of patients as the end of life approaches, aiming to assist them to die with dignity and a minimum of distress. Practitioners may also seek to surface in discussion a patient’s feelings of hopelessness in order to be able to explore the causes of those feelings and hence plan care to meet the patient’s needs. This process may involve exploring with the patient whether they are having suicidal thoughts. It would be easy, given the imprecise terminology used by the Bill, for patients involved in such exploration to believe that a practitioner was suggesting euthanasia or suicide when this was not the case (and for them to reach the potentially devastating conclusion that their doctor did not believe their life was worth continuing). These terminological imprecisions could also impact on discussions between patients and their families and friends. The complex, sensitive and nuanced communications which are at the heart of caring for people towards the end of their life risk being compromised when terms such as “assistance”, “distress” and “dignity” become clouded with double meaning. There is potential for informed decision-making by patients to be made more difficult.
Alternative and more clearly defined and understood terms such “euthanasia” and “assisted suicide” are available.

MSPs are asked to consider whether assisted suicide and euthanasia are equivalent in all regards and if not whether a single legislative framework which does not distinguish between them is likely to represent an optimal arrangement.

MSPs are invited to consider whether systems and processes to provide assisted suicide/voluntary euthanasia in which the medical profession are less centrally involved might reduce potential damage to the practice and provision of palliative care.

**Eligibility Requirements**

MSPs are asked to consider whether in (4.2.a) the criterion “incapacitated to such an extent as not to be able to live independently” is imprecisely worded such that it is capable of multiple and widely varying interpretations. MSPs are invited to consider whether this leaves the scope of the proposed legislation unclear. Lack of sufficient clarity could leave both doctors and persons seeking voluntary euthanasia/assisted suicide in unsatisfactory positions.

(4.4) For many medical conditions, particularly non-malignant conditions, it is difficult to predict whether death is likely to occur within six months.

**Consent and Verification Process**

**Duty on designated practitioner and psychiatrist to discuss hospice care and palliative care (7.1.a, 9.2.b)**

MSPs are asked to consider whether the Bill is sufficiently clear as to what this discussion should entail:– are the designated practitioner and the psychiatrist assessing the palliative care needs of the individual or describing such services and their potential benefits? Either way, MSPs are invited to consider whether the Bill should make provision that the designated practitioner and psychiatrist be sufficiently qualified, knowledgeable and experienced to undertake the envisaged discussions.

**Issues Related to the Assessments (7 & 9)**

The multiple assessments contained in the Bill are to be welcomed. However, designated practitioners and psychiatrists will potentially face challenges. Severe mental disorder or blatant coercion may be readily detectable, but a potentially common combination of factors affecting a requesting person (mild depression, mild cognitive impairment and an internalised perception that they are a burden to relatives) may be much more difficult to identify. MSPs are encouraged to consider how safeguards in respect of this and other groups could be strengthened.

The Bill does not require the assessing designated practitioner to have any prior knowledge of the requesting person or their social and family
circumstance. The psychiatrists conducting the assessments may meet the requesting person only once.

It is not clear why the psychiatrist but not the designated practitioner is required to discuss “the requesting person’s reasons for, and feelings with regard to, the decision to seek end of life assistance” (9.2.e). It would seem that any designated practitioner assessing a request should be required to explore these issues directly with the requesting person.

**Cooling Off Periods and Deadlines**

MSPs are asked to consider whether the cooling off periods, deadlines and revocation arrangements contained in the Bill could create an undesirable dynamic in which a vulnerable person feels impelled to proceed. Having spent their own time and money (and the time of multiple witnesses and practitioners) in respect of four assessments the requesting person will have a relatively short period in which to act (or face having to go through the whole process again). The willingness of patients to discuss with practitioners any doubts about proceeding with the process may be inhibited by (3.1) which says that any notice “however informal” that the patient doesn’t wish to proceed will revoke the initial request. In Oregon, where there are no such deadlines, many patients who are granted suicide assistance (through the prescription of medication) choose ultimately not to take the medication, though they retain access to it.

**Agreement on Provision of Assistance (10)**

The Bill does not require that the written agreement on the details of the provision of voluntary euthanasia/assisted suicide is based on a meeting or discussion between the requesting person and the designated practitioner.

MSPs are asked to consider whether it would be prudent for the Bill to stipulate that the agreement should state what action the registered practitioner (or others) are to take in the event of medical complications (e.g. failure to die, unexpected side effects). Other non-medical complications should also be considered (e.g. the non-availability at short notice of the designated practitioner due to sickness).

**Requirements Relating to the Actual Provision of Assistance (11)**

MSPs should consider how the risk of complications and untoward events could be minimised during the actual provision of voluntary euthanasia/assisted suicide given that: the Bill places no restrictions on the range of methods which may be used to carry out the voluntary euthanasia/assisted suicide. The Bill makes no requirement about the competence of the individual providing voluntary euthanasia/assisted suicide. Medical personnel do not have training or experience in voluntary euthanasia/assisted suicide. The Bill would sanction members of the public to undertake medical procedures for which they have had no training and would appear to sanction members of the public to undertake any act which would result in the death of the patient, so long as that act is contained in the agreement between the designated practitioner and the requesting person.
Clarity Regarding the Roles and Responsibilities of Practitioners

MSPs are asked to consider whether the Bill provides sufficient clarity about roles in order to protect practitioners involved. The Bill outlines the role and responsibility of the “designated practitioner” and the assessing psychiatrist only. However, both specialist and general palliative care (in fact most health and social care) are provided by teams and so the Bill may impact on/involve a much wider group of professionals which could include nurses, pharmacists, healthcare assistants, social workers, care workers, psychologists etc. all of whom might be expected to have contact with the patient requesting euthanasia or assisted suicide. What are the roles and responsibilities of the members of this team? For example, if the requesting person says to his Macmillan nurse that he is “no longer so sure about receiving assistance” does this count as giving notice of revocation (3.1)? Should the designated practitioner have a legal duty to inform other members of the care team at the outset that a patient has made a request for euthanasia/assisted suicide so that they can be alert for revocation or to signs of undue influence, incapacity or mental disorder? How will issues of conscientious objection be handled in this team setting? The Bill is silent on all issues concerning conscientious objection.

MSPs are asked to consider whether the Bill should specify the standards of diligence expected in regard to the roles of practitioners, in order to provide clarity and reassurance to practitioners in the event of post mortem allegations, investigations by the Procurator Fiscal’s Office and possible prosecution. For example, in satisfying themselves that a patient is not acting under any undue influence should the designated practitioner proactively investigate relevant family dynamics and social background? Should criminal record checks be required? Should the financial circumstances of patients and families (including provisions in Wills) be identified? If a designated practitioner does not feel qualified to make these financial/forensic assessments should the Bill impose a duty on him/her to take further expert advice?

Recording, Reporting and Monitoring Arrangements

The Bill does not describe arrangements for reporting on and monitoring the provision of voluntary euthanasia/assisted suicide, although it is understood that the Procurator Fiscal’s Office would have the power to investigate. A more robust reporting regime, based on appropriately formal documentation of the whole process, which generates a clear data set, could allow for monitoring, scrutiny, audit, regulation and research into a highly controversial, contested and potentially evolving area of public policy. MSPs are invited to consider this.

Conflicts of Interest

MSPs are asked to consider whether in the event of a registered practitioner specialising in the provision of voluntary euthanasia/assisted suicide through private practice it may become difficult to interpret (5.2.b). Such a practitioner may be charging “reasonable fees”, but since his or her income could be
wholly or largely dependent on providing voluntary euthanasia/assisted suicide there could be a perceived conflict of interest.

**Oral Evidence**

As the umbrella organisation representing the major organisations involved in palliative care in Scotland the SPPC would welcome an opportunity to participate in future oral evidence sessions of the Committee.

**Background to Internal Consultation on this Evidence**

The membership of the SPPC was consulted on the content of this submission. 30% of nominated member representatives responded to the consultation. Of these responses 93% supported the submission.

References to support the evidential assertions in this submission are available on request to the SPPC.

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