Amendments to the Assisted Dying for Terminally Ill Adults (Scotland) Bill

SPPC's Approach

Following discussion at SPPC's Council SPPC is seeking changes to the Bill by encouraging and supporting MSPs to submit relevant amendments and/or by supporting relevant amendments developed by other organisations.

The changes we hope to see reflect the points SPPC has previously raised with the Parliament in written and oral evidence. SPPC amendments focus on:-

1. Strengthening safeguards for vulnerable people (as well as specific groups this means potentially anyone towards the end of life).
2. Protecting and promoting the practice and provision of palliative care.

In formulating possible changes SPPC's primary concern has been the safety of individuals. The resource implications of particular amendments has not shaped SPPC's approach to the Bill.

About this Document

Actual amendments to legislation often involve quite complex legal language, and a large number of amendments to different parts of a Bill may be necessary for even a simple change to be incorporated. In this paper we have used accessible language and kept cross referencing to the Bill to a minimum so that stakeholders can understand the intent of the changes SPPC is seeking.

However, on the SPPC website you can see the actual amendments lodged which will be considered by the Health, Social Care and Sport Committee. These were drafted by the legislative team at the Scottish parliament based on a version of this paper and subsequent meetings with SPPC and Bob Doris MSP.

Please note that one of the amendments (SP 130) lodged was ruled as ineligible by the Chair of the Committee and so won't be debated. It was an amendment requiring that a person's palliative care needs be met prior to proceeding with the AD process.

Areas for Amendment

1. Strengthen safeguards against coercion

The need for amendment

- As currently drafted the Bill leaves the potentially difficult assessment and judgement about whether any individual seeking AD is being coerced to the coordinating registered medical practitioner, and 2nd medical practitioner. A narrow purely medical-based process isn't the strongest safeguard.
- Whilst the Bill isn't the place for detailed guidance it should specify the basic approach and diligence required concerning the assessment of coercion by a registered medical practitioner approving a request for AD. This is currently lacking.
- The conception of coercion (and conversely voluntary choice) used in the Bill is narrow (narrower than that used in General Medical Council guidance which is referenced in the Bill's Policy Memorandum).

Proposed changes

These changes will mostly affect Sections 6 and 7 of the Bill which relate to assessment.

1. For all requests for AD the coordinating medical practitioner must seek, receive and review a statement from the relevant Local Authority regarding any pre-existing and identified vulnerabilities. [This can be done by a Local Authority check on risk registers. Local authorities have relevant legal duties (Adult Support and Protection Act 2007) to keep records of adults who have been identified as vulnerable or "at risk of harm". Social workers are key in discharging these duties and bring relevant practical expertise around coercion].
2. Where a pre-existing vulnerability is identified by the Local Authority the coordinating registered medical practitioner must refer the requesting individual for a social work assessment.
3. Notwithstanding 1) and 2) if the coordinating registered medical practitioner has any doubts or concerns as to whether the requesting individual is acting freely they must refer the requesting individual for a social work assessment.
4. Not withstanding 1), 2) and 3) the person making the request for AD must be informed that they are entitled to request a social work assessment (and informed as to the potential benefits of such an assessment).
5. Insert a clause in Section 29 (the section which states how various terms in the Bill are to be interpreted) which clarifies the meaning of "coercion" for the purposes of the Bill. In the Bill "coercion" should be interpreted as meaning undue pressure by: individuals; from a person's beliefs about themselves; from

society's expectations; from the health and social care system; from the state. [this would make the Bill more consistent with the Policy Memorandum which references existing GMC guidance on identifying coercion and which uses a broad conception of coercion].

6. In addition in Section 29 insert a clause that "acting voluntarily" (a formulation used by the Bill in places as an alternative to the absence of coercion) means the absence of coercion as defined above.

2. Enable Access to Palliative Care as a Safeguard

The need for amendment

Currently if a person with a terminal illness presents to a health care professional with thoughts about ending their life then good/best/normal practice would expect the professional to refer the person for a specialist palliative care assessment. Under the Bill there is no requirement to make such a referral. There is no requirement to find out whether the person requesting AD has received or is receiving palliative care. There is no requirement to assess whether the person has unmet palliative care needs. Even where unmet palliative care needs are identified and form part of a person's reasons for seeking an assisted death there is no requirement to seek to address those needs. The assessment described in the Bill has no requirement to elicit the person's reasons for seeking an assisted death.

Proposed Changes

These changes will mostly affect Sections 6 and 7 of the Bill which relate to assessment.

1. Require that the assessment must include the exploration and documentation of the reasons for seeking an assisted death given by the person making a request.
2. Where a person requests AD the coordinating medical practitioner must refer them for an assessment of their palliative care needs by an appropriate specialist.
3. Where a person requesting AD has recently had their palliative care needs assessed by an appropriate specialist the coordinating medical practitioner must receive and review a report of that assessment.
4. Any assessment under 2) or 3) must be holistic and include social needs.
5. Where an assessment has taken place under 2) or 3) the person must be provided with palliative care in line with their assessed needs. [This amendment was ruled inadmissible by the Convenor of the committee and so was not lodged and will not be considered]

3. Strengthening the duties of the Coordinating Medical Practitioner (CMP)

The need for amendment

In various instances the Bill gives the CMP too much discretion as to whether or not to do something. For example:

- the CMP **"**must.. **in so far as they consider it appropriate"** tell the requesting person's GP about their request.
- Where the CMP has doubts about whether the person has a terminal illness they **may** refer them to a specialist to secure an expert opinion.
- Where the CMP has doubts about whether the person has capacity they **may** refer them to a specialist to secure an expert opinion.

Proposed changes

In Section 6 where these issues are dealt change "**may**" to "**must**", and remove "**in so far as they consider it appropriate**".

4. Ensure Adequate Documentation of Assessment and Evidence Used to Support Decision-making

The need for amendment

The Bill contains a number of forms (described as "schedules") for recording different stages of the AD process. Currently these forms are inadequate to support the reporting/analysis required of Public Health Scotland (PHS) by the Bill. There is also no requirement to document the evidence gained in the assessment process and used to inform the decision on AD eligibility.

Reasons for Seeking AD

Understanding people's reasoning and motivation is vital to understanding how the Bill is operating in practice, yet the Bill fails to establish a process to gather and report on this issue.

Clause 24 sets out the data which PHS must provide to ministers in relation to AD. 24 (2) c iii says that data should be provided on "the reasons given by persons as to why they did not go on to make a second declaration, be provided with an approved substance or, as the case may be, to use the substance,"

However, the Bill contains no requirements for these reasons to be discussed with the medical practitioner as part of the assessment. There is no place for recording this information on any of the declaration forms published as part of the Bill. It is therefore unclear how PHS will report on this since there is no process for creating a data source.

The same is true for the provision of data in respect of 24 (2) e "the reasons given by persons wishing to be lawfully provided with assistance to end their own lives." There is nothing in the Bill which requires the collection and recording of data on this topic so it can't be reported on (see proposed amendment in section 2) of this paper).

Documentation of Evidence which underpins the decision of the Coordinating Medical Practitioner

The Bill currently requires no documentation of the evidence elicited and used to inform the decision of the Coordinating Medical Practitioner. This might include reference to reports from specialists and/or discussions with the person requesting AD.

Proposed Changes

1. Amend Schedule 2 to include a space for recording the reasons for seeking an assisted death ascertained by the Coordinating Medical Practitioner and Independent Registered Practitioner.
2. In Section 6 insert a requirement for the Coordinating Medical Practitioner to produce a report documenting the evidence elicited during the assessment process and used to inform the decision reached.
3. In Section 7 insert a requirement that this report should contain a statement by the Coordinating Medical Practitioner explaining why they are, or are not, satisfied that the AD process should proceed.
4. In Schedule 3 insert a clause requiring the Coordinating Medical Practitioner to confirm that a report (meeting the requirements described above) has been produced.

5. Definition of Terminal Illness

The need for amendment

The Bill says:

> *"For the purposes of this Act, a person is terminally ill if they have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death."*

However, the intention of the Bill, as stated in the accompanying Policy Memorandum, is that eligibility for AD should be restricted to people who are *"close to death"*. It is not clear that the definition in the Bill will restrict eligibility to people who are close to death.

Proposed changes

1. Qualify the definition above by adding an additional clause to Section 3 (Eligibility) 3 (1) d to the effect that a person is only eligible to be lawfully provided with assistance to end their own life if they have an expected prognosis of 6 months or less.

Obviously SPPC is aware of the evidence which shows the difficulty of accurately predicting when someone has 6 months or less to live, and so the revised definition would be imperfect in practice (as the current definition is also imperfect). The intention of the amendment is to reduce the population of people who might potentially be deemed eligible, and to bring the definition closer to the stated intention of the Bill.

6. Protracted or failed assisted dying

The need for amendment

The Bill currently says nothing concerning any duties placed upon health and social care practitioners if, following the planned ingestion of an approved substance provided to end their life, the person doesn't die within a reasonable timeframe. Such a scenario raises many complex and difficult questions of a legal, ethical and practical nature. For example: if the person is unconscious should they be killed by administration of further lethal substance [euthanised]? Should/could such a step be taken without consent? What should be the approach if the person doesn't have capacity? What information should be given about such scenarios to people requesting AD? Complex questions like this are best dealt with through detailed guidance rather than on the face of the Bill, but the requirement for guidance should be in the Bill.

Proposed changes

1. Insert into the Bill (in Section 15 - Provision of Assistance) a requirement for Ministers to consult and develop guidance for the management situations where following the planned ingestion of an approved substance provided to end their life, the person doesn't die within a reasonable timeframe.

7. Regulation and Scrutiny

The need for amendment

The Bill currently contains no requirements that the provision of assisted dying should be subject to any system of regulation and scrutiny, nor is there any process for the raising of concerns about any aspect of the provision of assisted dying.

Proposed changes

Insert the following as new clauses in the section on *General and Final Provisions* (starts on p10 of Bill) or somewhere else if advised:

Regulation and patient safety

(1) Before commencement of the Act, Scottish Ministers must by regulations make provision for the proper regulatory and oversight arrangements to ensure the safety and welfare of all persons in connection with functions under this Act.

(2) In making regulations under subsection (1), Scottish Ministers must consult such persons as they consider appropriate.

(3) Regulations under subsection (1) may in particular make provision about:
   (a) the types of setting or premises where functions under this Act may be lawfully or may not lawfully be carried out
   (b) the functions of Healthcare Improvement Scotland and Social Care and Social Work Improvement Scotland.

(4) Regulations under subsection (1) must include arrangements relating to the raising of concerns about any aspect of the provision of AD.