

Briefing for MSPs on amendments to the Assisted Dying for Terminally Ill Adults (Scotland) Bill

HEADLINE

SPPC has very significant concerns about the Bill as it currently stands. We have worked closely with Bob Doris MSP (Convenor of the Cross Party Group on Palliative Care) to develop amendments related to some of these concerns. The particular issues are listed below together with the numbers of relevant amendments (proposed by Bob Doris unless otherwise noted). We have also highlighted relevant amendments proposed by other MSPs, developed variously with the support of Marie Curie, CHAS, Hospice UK, and the Association of Palliative Care Social Workers/Scottish Association of Social Work/Social Work Scotland.

Who We Are

SPPC is a partnership of more than 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, Scottish Ambulance Service, IJBs, local authorities, Scottish Care, the hospices, other Third Sector organisations and a range of professional associations¹. SPPC works closely with Scottish Government to facilitate engagement with the sector and to inform and support implementation of policy.

Our Position on Assisted Dying

SPPC does not adopt a position in principle either in support or in opposition to a change in the law. However, we have very actively engaged with all stages of this Bill, seeking to inform and question. Our input is based on the vast experience and unique perspectives of our members who work every day providing care and support for people approaching the end of life. We have focused on the need to protect vulnerable people, and on protecting the practice and provision of palliative care. We believe it is important to acknowledge openly that there may be trade-offs between different factors should the Bill become law. For example, maximising personal autonomy for some may increase the risk of coercion of other vulnerable people, since procedural safeguards are seldom fully effective.

¹ This briefing represents the corporate view of SPPC, but may not reflect the exact position of each and every member organisation across all issues.

KEY ISSUES

Definition of Terminal Illness

The definition in the Bill is very vague and imprecise and would allow people who may have many years to live to seek an assisted death, contrary to the stated policy intent of the Bill. **Amendments 162, 317, 323** together with **amendment 2** (Daniel Johnson) would limit eligibility to people who can reasonably be expected to die in the next 6 months. **Amendment 262** would require the production of guidance for practitioners applying this eligibility criterion.

Coercion and Indirect Pressures

We know that all sorts of factors may affect a person's ability to decide freely to seek an assisted death. For example, feeling a burden, financial pressures, or a major failure of services can exert indirect pressures. Currently the Bill doesn't consider such indirect pressures, focusing exclusively on coercion as something done *by another person*. **Amendments 27, 160** and **33** require an assessing doctor to enquire about and take account of indirect pressures and whether they are unduly limiting someone's ability to choose freely. **Amendment 54** requires guidance to be produced to support practitioners in this task. **Amendments 24,25,35,36,41,76,80, 82** and **84** all simply adjust the phrase "coerced or pressured by any other person" throughout the Bill, deleting "by any other person" to reflect that not all pressures arise from other people.

The role of social work - To protect the interests of vulnerable people Scotland has, over time, developed an established body of law and practice (with key duties held by Local Authorities). Coercion, undue influence, financial abuse and domestic abuse are every day concerns not theoretical risks. The Bill currently seeks to operate outwith that existing legal framework, leaving identification to medical practitioners (for whom this is not a core skillset). **Amendment 171** (Fulton MacGregor) requires the medical practitioners to consult with Local Authorities as to whether the person seeking AD is known to them as someone with vulnerabilities and to engage multidisciplinary expertise including social work in the assessment process where appropriate.

Assessment

Palliative Care - People with a life shortening condition who express a wish to shorten their life because of distressing physical or psychological symptoms (including common fears) often change their minds and go on to enjoy valuable time when these symptoms are explored, understood and addressed through appropriate palliative care. It is not reasonable or safe to assume that someone presenting to their GP to seek AD has already received appropriate palliative care. In fact a wish to hasten death is often an indication of a lack of appropriate palliative care. **Amendment 23** requires that the AD assessment ascertains whether appropriate palliative care has been offered or

provided to the person. **Amendment 165** requires that where that care has not been adequate, they must be referred to a palliative care specialist. **Amendment 166** requires that a person whose reasons for seeking AD are that they have uncontrolled symptoms or fears of such symptoms must also be referred to a palliative care specialist. **Amendment 167** ensures that if the person chooses not to have such an assessment, refusal in itself would not make them ineligible for AD (their autonomy is respected). **Amendment 168** allows the doctor making the AD assessment to take into account, if they wish, a refusal attend a palliative care assessment.

Young People Under 25 - Young adults under 25 can face unique challenges when diagnosed with a life shortening condition. These include: serious, fluctuating and unpredictable conditions; reduced cognitive maturity and greater risk of coercion; communication differences; heightened safeguarding needs; reliance on family/carers for daily living. Assessments for AD for this group therefore require specialist training, multidisciplinary input/support, and consistent national safeguards. Taken together **amendments 145, 146, 164, 274** (Jackie Baillie) and **147, 169, 170, 300, 301** (Miles Briggs) strengthen assessment, safeguarding and support for young people under 25 in the Bill.

Protracted or Incomplete Dying

International experience of assisted dying shows that occasionally people do not die as expected having taken the lethal substance. **Amendment 44** would require SG to produce regulations on how such situations should be managed.

Medical Practitioner's Report

Amendment 37 requires the medical practitioner to produce a report describing the evidence gathered to inform the AD assessment and the reasons for the judgment they reached. Neither are currently required, yet both are essential to understanding the operation of the Act should it become law, and also to provide a basis for investigating and responding to any concerns raised.

Code of Practice on interaction with palliative care services

Amendments 258, 129, 132 (Jackie Ballie) strengthen the Code of Practice designed to protect palliative care services from any adverse impacts of AD.

Review of Operation of the Act

We believe it is essential to include adequate mechanisms by which society can monitor the impacts, effectiveness and safety of the Act, should it become law. Given the complexity and nature of the issues involved, it is crucial that we have built in ways of understanding how the Act is working in practice. The following amendments relate to this:

Amendment 117 adds several important items to the list of issues to be included in five year the review of the Act: the operation and effectiveness of safeguards; compliance with and documentation of assessment requirements; provision of public information; and the availability of data for monitoring. These are all issues which have arisen in other jurisdictions). **Amendment 118** (Jackie Baillie) ensures that the review considers how the Code of Practice has supported palliative care services. **Amendment 299** (Miles Briggs) requires consideration of the availability/quality of palliative care services available, information about accessing palliative care, impacts of the Act on palliative care services, and actions Ministers intend to take as a result of the review.

Data for Oversight and Understanding

Amendment 278 requires periodic **detailed case reviews** of a representative sample of cases so that qualitative evidence is available about the operation of the Act (in addition to the limited basic statistics proposed currently).

Amendments 59, 60, 61, 62, 63, 64, 281, 282, 285, 286 identify important **data items** without which it will not be possible to adequately monitor and understand the operation of the act. For example **amendment 281** requires identification of the number of assisted deaths involving each practitioner, enabling the flagging of practitioners with unusually high rates. **Amendment 283** requires the time elapsed from AD sign-off to the date of death, allowing insights into accuracy of prognosis. **Amendment 60** would ensure reporting of the reasons why any applications for AD are rejected. **Amendment 286** requires the reporting of the numbers of people seeking AD and assessed as having or not having been offered or provided appropriate palliative care. **Amendment 288** (Miles Briggs) requires regular reporting on the availability of appropriate health and social care services available to those people making a first declaration (i.e. seeking AD).

Amendments 83, 83A (Brian Whittle) require the Co-ordinating Medical Practitioner to declare they are satisfied that the person seeking AD has been offered or provided with social care and palliative care appropriate to their terminal illness, recording this in the Second Declaration.

Raising and dealing with concerns

Amendment 55 requires SG to produce guidance on how concerns about an AD can be raised and dealt with.

Language and public confusion

Amendment 267 stipulates that any guidance produced under the Act should avoid public confusion caused by conflating assisted dying with palliative care, end of life care or care around dying (this has been an issue in other jurisdictions).

Concerns about reserved matters to be removed from the Bill: non-participation and training

We are concerned about the removal from the Bill of provisions to ensure health care staff can choose not to participate in AD, and to be protected from detriment if they do so. Similarly, provisions to specify the experience, qualification and training required of health professionals carrying out duties under the Act are fundamental, but we understand are also reserved matters and so to be removed. At the time of writing there is no identified process to develop and add such provisions which guarantees transparency and stakeholder participation.

A final note about palliative care

Whatever the outcome of the vote on the AD Bill the vast majority of people in Scotland will continue to depend on the provision of palliative care to enable them to live as well as possible with a life shortening condition, and to die comfortably and with dignity. All sides of the AD debate agree on this. Whilst there is a new SG palliative care strategy, there is no new resource to address long-identified deficiencies (beyond welcome support to sustain existing hospice services). SPPC asks that the next Parliament uses its time and influence to drive tangible improvement in palliative care, including a right to palliative care built on national standards.

More Information

The Bill raises complex and nuanced issues which are difficult to explore fully in a short briefing. For more detailed information and analysis please see our [evidence submitted](#) to the Health Social Care and Sport Committee earlier in the process. Or contact Mark@palliativecarescotland.org.uk or 07733884427

Mark Hazelwood
CEO
Scottish Partnership for Palliative Care