Finance and Public Administration Committee 36th Meeting 2024 (Session 6) Tuesday 17 December 2024

Assisted Dying for Terminally III Adults (Scotland) Bill – Financial Memorandum

Purpose

- The Committee is invited to take evidence in relation to the Financial Memorandum (FM) for the Assisted Dying for Terminally III Adults (Scotland) Bill, from the Member in charge of the Bill, Liam McArthur MSP, and Scottish Parliament officials—
 - Nick Hawthorne, Senior Clerk, Non-Government Bills Unit, and
 - Liz Anderson, Assistant Clerk, Non-Government Bills Unit.
- 2. This evidence session will provide an opportunity to review the potential costs associated with the measures introduced by the Bill, as set out in the FM, and to explore the issues raised by stakeholders in written evidence to the Committee.

Background

- 3. The <u>Assisted Dying for Terminally III Adults (Scotland) Bill</u> is a Member's Bill introduced by Liam McArthur MSP on 27 March 2024. The aim of the Bill is to allow mentally competent terminally ill eligible adults in Scotland to voluntarily choose to be provided with assistance by health professionals to end their lives. According to the <u>Policy Memorandum</u>, to be eligible to be provided with assistance to end their life, a person must—
 - be terminally ill (have an advanced and progressive disease, illness or condition which they cannot recover from, and which is expected to cause their premature death),
 - be aged 16 or over,
 - have been resident in Scotland for at least 12 months and be registered with a GP practice in Scotland, and
 - have sufficient capacity to make and understand the decision.
- 4. The Bill includes a number of safeguards "to ensure the process is proportionately and appropriately safe and requires data to be collected and reported to inform knowledge, understanding and any future decision-making"¹.
- 5. According to provisions in the Bill, two doctors would be required to assess a person as being eligible to be provided with assistance to end their own life. Both doctors would also need to be satisfied that a person is acting voluntarily, without being coerced or pressured. If confirmed as eligible, a terminally ill adult could

¹ Policy Memorandum accessible (parliament.scot)

lawfully be provided with an approved substance by a health professional. They could choose to administer this substance to themselves to end their life. Assisting death outside of what is set out in the Bill would remain unlawful.

- 6. The Policy Memorandum states that "no-one is required by or under the Bill to play an active participative role in the assisted dying process if they have a conscientious objection to doing so. Those participating will also be exempt from criminal or civil liability for carrying out activities authorised in the Bill in line with the Bill's provisions."
- 7. According to the Bill as introduced, it will be for the Scottish Government to make regulations about which substances/drugs are approved for use for assisted dying purposes. The Policy Memorandum explains that "Section 22 of the Bill ("Limitations on effect of Act") puts it beyond doubt that the Scottish Ministers can approve such substances by way of regulations only if they are not regulated by or under the Misuse of Drugs Act 1971 or the Medicines Act 1968 or, if they are so regulated, their use for the purposes of assisted death has been approved under those Acts".
- 8. The Bill also requires the Scottish Government to report annually on the provision of assisted dying and states that a detailed review of the legislation must take place five years after it comes into force.
- 9. The Policy Memorandum provides an overview of assisted dying/suicide and euthanasia legislation around the world, noting that "Liam McArthur's Bill has most in common with the legislation and process in Oregon, other American States, Australia, and New Zealand, where legislation follows the model of self-administered assisted dying for the terminally ill with strict safeguards, rather than, for example, the legislation in the Benelux² countries, which leans more towards euthanasia, and where access extends beyond those who are terminally ill."
- 10. A SPICe briefing on the Bill has been published and is available on the Scottish Parliament's <u>website</u>.
- 11. The Health, Social Care and Sport (HSCS) Committee is the lead committee for Stage 1 consideration of the Bill. The HSCS Committee ran two calls for views between 7 June and 16 August 2024 – "a short call for views for people who wished to express general opinions about the Bill as a whole [and] a detailed call for views for people, groups, bodies, or organisations who wished to comment on specific aspects of the Bill". The lead Committee received 13,821 responses to the short call for views and 7,236 responses to the detailed call for views. A summary and analysis of the responses received are available on the Bill webpage. The lead Committee took evidence on the Bill at meetings in November and will continue its scrutiny in early 2025.

²Netherlands, Belgium and Luxembourg

12. The Scottish Government submitted a <u>Memorandum</u> to the lead Committee, stating that the "Scottish Government will be maintaining a neutral position on the Bill at this Stage".

Financial Memorandum

13. Rule 9.3 of Standing Orders states in relation to Financial Memorandums that-

"2.A Bill must on introduction be accompanied by a Financial Memorandum which sets out best estimates of the costs, savings, and changes to revenues to which the provisions of the Bill would give rise, and an indication of the margins of uncertainty in such estimates. The Financial Memorandum must also include best estimates of the timescales over which such costs, savings, and changes to revenues would be expected to arise. The Financial Memorandum must distinguish separately such costs, savings, and changes to revenues that would fall upon—

- the Scottish Administration;
- local authorities; and
- other bodies, individuals and businesses.
- 14. The <u>Financial Memorandum</u> (FM) for the Bill provides an estimation of the likely number of terminally ill adults in Scotland who would make a declaration to be voluntarily provided with assistance to end their life, and the number of assisted deaths likely to take place, based on case numbers in two other jurisdictions: the state of Oregon in the United States of America, and the state of Victoria in Australia.
- 15. The FM explains that the jurisdictions "were primarily chosen to inform estimated statistics for Scotland due to the amount of data on assisted deaths that they have collated and published. In addition, the assisted death model in Oregon is very similar to that being proposed in Scotland". Data from Oregon shows that in the first year of assisted dying being available³, 4.87 in every million of the overall population had an assisted death (16 people in year one), rising to 8.98 in every million of the population after the following 5 years. Uptake has continued to rise since, reaching 54.9 deaths per million of the population in the most recent five-year period for which data is available (2018-2022). Based on this data, the FM states that "the number of assisted deaths in Scotland is likely to be low in the first years of operation, and then likely to rise as awareness and understanding of the process increases". Therefore, the FM estimates that—
 - "in year one, approximately 25 people are likely to have an assisted death;
 - by year three, 50-100 people are likely to have an assisted death each year; and
 - after 20 years of assisted dying being available up to 400 people can be expected to have an assisted death per year."

³ Assisted dying has been legal in Oregon since 1998.

FPA/S6/24/36/2

- 16. The FM states that evidence from jurisdictions where assisted dying is legal (including Oregon, other American states and states in Australia) suggests that "approximately two-thirds of those who enter the process go on to have an assisted death (in other words, there were approximately a further 33% of people who entered the process, who did not have an assisted death). Applying this to Scotland, it would mean that:
 - in year one, approximately 33 people are likely to enter the process. However, not all of those people will have an assisted death. Of the 33 people who enter the process, it is estimated that 25 will go on to have an assisted death and 8 will not;
 - by year three, 67-134 people are likely to enter the process, with 50-100 of those people going on to have an assisted death each year;
 - after 20 years of assisted dying being available up to 533 people can be expected to enter the process, with up to 400 people going on to have an assisted death each year".
- 17. The FM notes that a report published by the Medical Advisory Group (MAG) established by Liam McArthur used a different methodology to estimate the number of potential assisted deaths in Scotland, using the percentage of deaths from assisted dying compared to the number of the total average annual deaths in areas that have a similar form of assisted dying in place (Oregon, California and Victoria) and applying those to the average total number of deaths in Scotland. The MAG report concluded that it could be expected that there may be somewhere between 174-580 annual assisted deaths in Scotland. However, the FM considers that these figures "perhaps overestimate the number of deaths which can be anticipated in the first, and early, years", as they are based on the most recent figures in the respective jurisdictions, not taking into account the pattern of deaths from assisted dying from when it first became legal.
- 18. The Member in charge of the Bill expects the majority of costs associated with the Bill, as set out in the FM to fall on NHS health services, including registered medical practitioners (RMPs), registered nurses, hospitals, and Public Health Scotland. These are estimated in Table 3 of the FM, reproduced below:

Item	Year 1 and ongoing cost per annum	
Anticipated clinician hours	£6,795 rising to £19,254	
Staff training	approximately £200,000	
Substance provided to end life	£2,000 rising to £32,000	
Total	£208,795 rising to £251,254	

19. As explained in the FM, "the Bill does not prescribe how long each appointment should take, nor does it preclude more appointments from taking place than are strictly necessary under the Bill's provisions. Further to this, the Bill does not set out which job role the RMP should hold. However, it is expected that the co-ordinating doctor will normally be the person seeking an assisted death's GP or other RMP in charge of their care". The FM estimates that in year one between 198 and 561 hours of total health professional time will be used, rising to between

an estimated 3,318 and 9,401 hours per year by year 20. Based on an average of the lowest and highest basic RMP salary, amounting to \pounds 71,388, and a 40 hour week as an RMP's basic contracted hours, the FM estimates between \pounds 6,795 and \pounds 19,254 would be spent on clinician time in year one, with the amount rising to between \pounds 113,874 and \pounds 322,642 in year 20.

- 20. The Bill makes it an offence "to coerce or unduly pressure a terminally ill adult into making a first or second declaration that they wish to have an assisted death". The FM states that process of prosecuting someone for offences created by the Bill would incur costs on the Crown Office and Procurator Fiscal Service (COPFS) and the Scottish Courts and Tribunal Service (SCTS), which are likely to vary greatly depending on the complexity of the case in question.
- 21. The FM further anticipates other costs to fall on the Scottish Government (£54,639 - £92,628 for producing relevant guidance in year 1 and £14,312 annual cost for reporting) and on regulatory bodies for training and guidance. The Bill, as introduced, includes provision for a review of the legislation after 5 years which, it is estimated, would incur additional costs on the Scottish Administration amounting to £33,556.
- 22. The Bill does not impose any new obligations on local authorities and therefore the FM assumes no costs for local authorities.

Table 4	Year 1 and ongoing costs per annum	Additional Year 5 cost
Scottish Administration	£54,639- £92,628 plus £14,312 per annum	£33,556
NHS Scotland	£208,795 rising to £251,254	N/A
Total	£277,746 - £358,194	£33,556

23. Estimated overall costs are presented in Table 4 of the FM, reproduced below:

- 24. The FM emphasises that "while providing assisted dying as an option may lead to some cost savings in specific instances, this is not a policy aim of the Bill" and that "any savings are likely to be as a result of care no longer being required for a person who has decided to have an assisted death, and a person who may have previously chosen to end their life abroad, at a facility such as DIGNITAS, no longer doing so, due to assisted dying being lawfully available in Scotland". The FM does not provide an estimate of potential savings, due to lack of available data and variations in existing types of end-of-life care and costs. Instead, the FM considers "that the Bill will be broadly cost neutral, as it will involve a process (with administrative and clinical elements) for a small number of people, with terminally ill adults who die as a result of being provided with assistance to end their life not continuing with care they would likely have been receiving up to that point".
- 25. In their <u>Memorandum</u> to the lead Committee, the Scottish Government raises concerns in relation to the FM, stating that "the unit costs of staff time have been

underestimated, as this is costed using unrealistically low salaries and without on-costs, which are a key element of staff costs" and "the cost of staff time for training has been omitted [...] As such, it is our view that the costs associated with the Bill could be substantially higher than estimated in the Financial Memorandum".

- 26. The Member in charge wrote to the Committee in relation to the FM on <u>17 June</u> <u>2024</u>, providing revised figures, which separate year 1 costs from ongoing costs. According to the letter, year 1 costs are estimated to be "between £263,434 and £313,882, and ongoing costs rising year on year from between £23,107 and £35,566 in year 2, to between £160,186 and £368,954 in year 20". The letter also notes that "the general conclusion of the Financial Memorandum – that the Bill will be approximately cost-neutral – is unchanged".
- 27. The Committee received a further letter from the Member on <u>14 October</u>, which provides revised costings for the Bill, in relation to clinician hours and potential ongoing cost of prosecutions. The letter states that "the net effect of these revisions is that [...] estimated overall costs of the Bill, shows year 20 estimates as being between £156,067 and £362,230."
- 28. The Presiding Officer has indicated that a financial resolution under Rule 9.12 of the Parliament's Standing Orders is not required for the Bill.

Written submissions on the FM

- 29. The Finance and Public Administration Committee ran a call for views on the FM from 10 June to 16 August 2024 and received 22 responses, which are available on <u>Citizen Space</u>.
- 30. While some of the submissions agree with the costings in the FM, including Humanist Society Scotland and NHS Fife, who note that "NHS Scotland and relevant regulatory and representative organisations already have systems and structures in place to provide updated training and guidance when changes to medical procedures occur", other submissions point to potential underestimates and raise questions in relation to the most appropriate jurisdictions to use for comparison purposes.
- 31. The Royal Pharmaceutical Society Scotland states that the assumption, in the FM, that the cost of each dose provided to a terminally ill adult to end their own life would be £80 "is likely to be a huge underestimate of the actual cost for each dose, once all the costs of procurement, storage, facilitation, disposal etc. are considered". The Society also considers the number of people who would choose to access the service is likely to have been underestimated and offers the example of Queensland as reference, "where voluntary assisted dying legislation is in place, circa 300 people had an assisted death in the first 6 months. This is for a population which is very similar in size to Scotland."
- 32. Several other submissions offer comparisons with other jurisdictions. Living and Dying Well highlight that "there are greater cultural and medical system similarities between Australia and Scotland than there are with the US states".

Their submission notes that "Canada is also culturally and medically more similar to Scotland than the US. Their experience reveals that (adjusting for population) a wide interpretation of the law, which is possible as the Bill is currently written, would mean Scotland could expect 170-180 deaths in year 1, rising to 780-790 in year 3, 1330-1350 by year 5 and continuing to rise steeply". It further states that "it is inappropriate to look only at Oregon and Victoria for data, given the Scottish Bill as it currently stands is more expansive than either of these laws in several aspects". Claud Regnard, responding to the Committee in an individual capacity, suggests that "modern adopters [of assisted dying] see rapid rises in the numbers of assisted deaths". Similar issues are raised by the Anscombe Bioethics Centre. Their submission also highlights that "unlike USA, Australia and New Zealand, the proposed Bill in Scotland does not define terminal illness in relation to prognosis of 6 or of 12 months. It is much more similar to the requirement that exists in Canada between 2016 and 2021, that death be 'reasonably foreseeable'".

- 33. Hospice UK identify staff training and welfare support as areas where costs may have been underestimated and warn about a potential negative impact on the overall budget available for palliative care. Concerns in relation to palliative care resources, including the ability of hospices to raise charitable funds, were also raised by Marie Curie Scotland and the Scottish Partnership for Palliative Care, both of whom argued for further data and research on the potential impact of the Bill.
- 34. Hospice UK also note that "based on the eligibility criteria proposed in the Bill the vast majority of adults supported by hospices would be eligible to request assisted dying". Their submission states that "there appear to be assumptions made that any change in legislation would have minimal impact on normal processes, but that is not the view of the majority of hospice staff we have spoken with". Marie Curie Scotland explain that it is likely that their staff may be involved in the process, which would incur costs for the organisation.
- 35. The Royal College of Nursing also highlight that the FM "is largely silent on the resourcing implications for nursing, despite the Bill establishing a key role for registered nurses in the process" and argues for a dedicated assisted dying service to be established. In addition, Children's Hospices Across Scotland suggest that "hospices should have to opt-in to taking any part in facilitating assisted deaths and should be precluded from any civil or criminal liability should they not do so".
- 36. Submissions from Care Not Killing, the Society for the Protection of Unborn Children, the Anscombe Bioethics Centre and Cerebral Palsy Scotland raise concerns about "whether cost savings and lack of health and social care resources will become a significant motivation for the provision of assistance to end patients' lives"⁴. The Society for the Protection of Unborn warns that "financial pressures on the NHS could lead to the promotion of assisted suicide as the preferred option for those seen as a drain on health resources" and states that "the conclusion that the Bill is likely to be effectively cost-neutral appears to

⁴ Care Not Killing submission

underestimate the magnitude of the cultural shift that the introduction of assisted suicide has had in other jurisdictions". The Anscombe Bioethics Centre identifies further potential savings in relation to the costs of pensions, welfare (including disability benefits), and social care, in addition to savings on healthcare, and highlights that "individual choice will also be shaped directly or indirectly by these financial pressures". Cerebral Palsy Scotland raises similar concerns, warning that such savings risk "dehumanising patients by treating the end of their lives as an economic and medical benefit to others".

37. Other issues raised in submissions to the Committee's call for views include-

- the amount of clinical time involved (the Bill proposes that a professional is required to be there at the time when the substance is ingested, and to remain present until death has occurred),
- the potential need for additional staff for assessments, documentation, arranging independent doctors, liaising with legal authority,
- costs for setting up the place of death,
- costs for setting protocols to deal with complications,
- costs of indemnity,
- pharmacy costs,
- counselling of staff struggling with involvement, and
- costs for replacing staff who take time off due to the stress of involvement.

Next steps

38. Following consideration of the evidence received, the Committee will consider any next steps it wishes to take in relation to the FM.

Committee Clerking Team December 2024