ASSISTED DYING FOR TERMINALLY ILL ADULTS (SCOTLAND) BILL

FINANCIAL MEMORANDUM

INTRODUCTION

- 1. As required under Rule 9.3.2 of the Parliament's Standing Orders, this Financial Memorandum is published to accompany the Assisted Dying for Terminally Ill Adults (Scotland) Bill, introduced in the Scottish Parliament on 27 March 2024. It has been prepared by the Non-Government Bills Unit on behalf of Liam McArthur MSP, the member who introduced the Bill.
- 2. The following other accompanying documents are published separately:
 - statements on legislative competence by the Presiding Officer and Liam McArthur MSP (SP Bill 46–LC);
 - Explanatory Notes (SP Bill 46–EN);
 - a Policy Memorandum (SP Bill 46–PM);
 - a Delegated Powers Memorandum (SP Bill 46–DPM).

BACKGROUND

Policy objectives of the Bill

- 3. The aim of the Assisted Dying for Terminally Ill Adults (Scotland) Bill is to allow mentally competent terminally ill eligible adults in Scotland to voluntarily choose to be provided with assistance to end their lives. The Bill establishes a lawful process, delivered by health professionals, for terminally ill adults, if eligible, to access the provision of assistance.
- 4. The Member believes that an individual's personal autonomy to decide on their medical care, and how their life should end in situations of terminal illness, should be protected in law and that people in Scotland should have access to safe and compassionate assisted dying if they choose, rather than face the potential of a prolonged and painful death. He believes that the current de facto prohibition on such assistance is unjust, unacceptable and causes needless suffering for many dying people and their families across Scotland.
- 5. The Member believes that the current legal position is unacceptably unclear as there is currently no specific legislation in Scotland which makes assisted dying a criminal offence, yet it is also possible to be prosecuted for murder or culpable homicide for assisting the death of another person. The Bill improves legal clarity by making it lawful for a person to voluntarily access assisted dying if they meet the various criteria set out in the Bill and for health professionals to

SP Bill 46–FM 1 Session 6 (2024)

assist in that process, while continuing to ensure that assisting death outwith the provisions of the Bill remains unlawful.

6. The Member believes that the respect for personal autonomy should equally apply to health professionals (as is the case with some other medical procedures) and therefore that they should not have to participate in the provision of assistance if they conscientiously object to doing so. The Bill therefore provides that registered medical practitioners or other healthcare professionals should not be compelled to directly participate in assisted dying if they have a conscientious objection to doing so.

Operation and limited effect of the Bill

- 7. As explained fully in the Policy Memorandum, the Bill sets out (in section 15) a process for the provision of assistance to be provided to eligible terminally ill adults to end their lives. This involves (following a declaration and assessment process which has established that an adult is eligible and wishes to be provided with assistance to end their lives) an approved substance being provided to the terminally ill adult for them to administer themselves which will end their life.
- 8. The Bill allows Scottish Ministers to make regulations about what substances can be approved to be provided to, and used by, a terminally ill adult to enable them to legally and voluntarily end their life. 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. These are subject matters which are reserved to the UK Government under the Scotland Act 1998.
- 9. The Member acknowledges that, in order to achieve a truly comprehensive assisted dying scheme, something else would likely need to happen (this could be if for example certain regulated medicines or controlled drugs were to be brought within the executive competence of the Scottish Ministers, or by way of a transfer of legislative power through amendment of Schedule 5 (or Schedule 4) of the Scotland Act 1998. More detail on this is provided in the Policy Memorandum).

Estimated number of assisted deaths in Scotland

- 10. The underpinning methodology of this Memorandum is based on 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.
- 11. The estimated uptake in Scotland is based on an understanding of case numbers (both in terms of the numbers who begin the process and the number who have an assisted death) from two other jurisdictions: the state of Oregon in the United States of America, and the state of Victoria in Australia. These 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 (the model used in Victoria is not as similar as some other states in Australia, such as Queensland, but has been operating longer than assisted dying has in Queensland and so is used as a comparator due to the available data). Assisted dying has been legal in Oregon since 1998 and in Victoria since 2019. As

a result, a significant amount of information and data on assisted deaths is available from Oregon and Victoria and therefore provides a useful basis of comparison.

- 12. The latest data published in Oregon¹ shows that in the first year of assisted dying being available, 4.87 in every million of the overall population had an assisted death (16 people in year one). After the next five years these figures had risen to 8.98 in every million of the population (an average of 31 people over the five-year period). In the first 16 years that assisted dying was operating in Oregon, there were fewer than 100 deaths per year, an average of around 25 deaths per million of the population. Assisted dying has been operating for over 20 years in Oregon, and the data shows that uptake numbers have continued to grow, and over a 20-year period, an average of 25 people per million of the overall population had an assisted death. In the last five years (2018-2022) the numbers have increased, with an average of 54.9 deaths per million of population (an average of 233 per year, with a high of 278 recorded in 2022).
- 13. Victoria has been operating assisted dying since June 2019, so data is currently only available for the first three years.² In that period, there were 110 deaths in 2019, 176 in 2020 and 231 in 2021 (between 16 and 35 deaths per million of population).
- 14. It is reasonable to conclude from the data in Oregon and Victoria, 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. It is also reasonable to conclude from the data that the number of deaths in Scotland may range from between 5 deaths per million of population in the first year, increasing steadily to a potential 60 deaths per million after approximately twenty years.
- 15. A report³ published by the Medical Advisory Group (MAG)⁴ established by Liam McArthur used a different methodology to estimate the number of potential assisted deaths in Scotland. It used 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 applied those to the average total number of deaths in Scotland. This led the MAG report to state that it could be expected that there may be somewhere between 174-580 annual assisted deaths in Scotland. However, these figures are based on the most recent figures in the respective jurisdictions, and therefore do not take account of the pattern of deaths from assisted dying from when it first became legal. These figures therefore perhaps overestimate the number of deaths which can be anticipated in the first, and early, years. The MAG estimates also give a range based on a ceiling of 1% of total deaths from illness being assisted deaths, which is a higher number than in most comparable jurisdictions, and therefore also may overestimate the highest number of assisted deaths which may be expected in Scotland. However, in general, the MAG estimated figures overlap those estimated above, and are not significantly different from the

¹ Oregon Death with Dignity Act 2022 Data Summary. Published 8 March 2023. Available at: <u>DWDA 2022 Data Summary Report (oregon.gov)</u>.

² Report of operations July 2021 to June 2022. Published June 2022. Available at: <u>Voluntary Assisted Dying Review Board Report of Operations July 2021-June 22_FINAL.pdf</u> (safercare.vic.gov.au).

³ Assisted Dying for Terminally Ill Adults (Scotland) Bill, Medical Advisory Group Report. Published November 2022. Available at: Medical-Advisory-Group-Report.pdf (assisteddying.scot).

⁴ Liam MacArthur established a working group of senior healthcare practitioners to advise and inform him as part of the consultation process on his proposed bill. The subsequently established Medical Advisory Group (MAG) is chaired by Dr Sandesh Gulhane MSP.

estimates arrived at, particularly when the mid-point of the MAG range, which is 377 estimated deaths per year, once assisted dying has been operating and available for a number of years, is considered.

- 16. When considering this data from other jurisdictions, along with patterns/trends experienced, and taking account of the estimates in the MAG report, it is estimated for the purposes of this Memorandum (based on Scotland's current estimated population in 2023 being 5.45m people, estimated to rise to 5.53m in the next ten years, and its average number of deaths per year from illness being 58,000) 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.
- 17. The Member understands that in jurisdictions where assisted death is legal (including Oregon, other American states and states in Australia) 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.
- 18. In conclusion, it is estimated for the purposes of this Memorandum that over the first 20-year period of assisted dying being available in Scotland, the number of adults entering the process will range between 33 and 533 people per year, with the number likely to have an assisted death ranging between approximately 25 terminally ill adults, rising to 400 terminally ill adults.

Methodology

- 19. As noted above, this Memorandum has used data available from comparable assisted dying processes in other jurisdictions to estimate the likely number of terminally ill adults who may request assisted dying, and who may die as a result of taking an approved substance provided to them. This understanding of the estimated number of terminally ill adults who may be involved has provided a basis for some of the costings in this Memorandum, by allowing any estimated costs, where available to be scaled up realistically.
- 20. However, while assisted dying processes very similar to that provided for in Liam McArthur's Bill are lawful in many parts of the world, there is little detailed, meaningful data available on costs. Where cost information is available, because various countries have very

different systems of healthcare structure, provision, and funding, it is difficult to use such information to estimate potential costs in Scotland. There is also, to date, no form of lawful assisted dying provided for in the UK, or in any immediate more comparable jurisdictions, such as elsewhere in the British Isles.

COSTS ON THE SCOTTISH ADMINISTRATION

- 21. The majority of costs and savings associated with the Bill will fall on NHS health services in Scotland, including registered medical practitioners, registered nurses, hospitals, and Public Health Scotland.
- 22. Other costs which will fall on the Scottish Administration include: the preparation and publication of any guidance issued under the Bill; the preparation and publication of annual reports and a report following a review of the legislation after 5 years; general awareness raising activity; the development and laying of regulations required/allowed for by the Bill (including any consultation); and costs for the Crown Office and Procurator Fiscal Service, Scottish Court Tribunal Service, and Scottish Prison Service, as a result of offences created by the Bill.

Annual report and report on review of operation of Act

- 23. The Bill provides that the Scottish Ministers must prepare, publish and lay before Parliament an annual report on the lawful provision to terminally ill adults of assistance to end their own lives.
- 24. There is limited recent information available regarding the expenditure incurred by the Scottish Government in producing annual reports. However, one example can be found in the financial memorandum that accompanied the Child Poverty (Scotland) Act 2017.⁵ That Act requires Scottish Ministers to publish an annual report on progress made towards meeting child poverty targets and implementing the relevant delivery plan. The cost of doing so was estimated as £9,376 for staff time for each annual report and £2,000 for publication costs.
- 25. Based on the above estimates and adjusted for inflation, an amount of £14,312 has been estimated for each annual report required under the Bill.⁶ It is expected that these costs would be met by existing Scottish Government budgets.
- 26. In addition to an annual report, the Bill also requires Scottish Ministers to prepare, publish and lay before Parliament a report which reviews the operation of the Act. This review will take place 5 years after section 1 of the Bill has come into force.
- 27. The Child Poverty (Scotland) Act 2017 includes a requirement for Ministers to prepare and publish three delivery plans relating to progress towards child poverty targets. The Scottish

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⁵ Child Poverty (Scotland) Bill Financial Memorandum (parliament.scot).

⁶ Inflation costs throughout document estimated using SPICe calculator and adjusted for 2023-24 costs. <u>Real terms calculator – SPICe Spotlight | Solas air SPICe (spice-spotlight.scot).</u>

Government estimated a cost of £21,673 for staff time and £5,000 for staff costs for each delivery plan.

- 28. Although the circumstances and subject matter are different in the case of this Bill, it is reasonable to assume that the requirement to produce and publish a report would incur a similar cost 5 years after the Bill has come into force.
- 29. Based on the above estimates and adjusted for inflation an amount of £33,556 has been estimated for the report on the operation of the Act. It is expected that this cost would be met by existing Scottish Government budgets.

Guidance

- 30. The Bill provides for the Scottish Government to be able to prepare and publish guidance relating to the practical operation of the Bill following its enactment. In doing so, Scottish Ministers must consult with such persons as they consider appropriate.
- 31. One possible comparison can be found in the financial memorandum for the Female Genital Mutilation (Protection and Guidance) (Scotland) Bill, which estimated that the production of statutory and practitioner guidance, including consultation and community engagement would be £25,000. While the guidance required under this Bill is on a different subject-matter and is under different circumstances, the Member considers it reasonable to assume that the Scottish Administration would incur similar costs in producing and publishing statutory guidance. Allowing for inflation, £30,327 has therefore been estimated for the cost of producing guidance.
- 32. The Bill also provides that the guidance produced by the Government may include information about the lawful provision to terminally ill adults of assistance to end their own lives (including information to be provided to such adults and to the general public.) This could include, for example, providing online and paper-based information and education to the public about the change to the law and the assisted dying process in a variety of accessible formats (including online and paper based).
- 33. The Scottish Government publishes information relating to how much it spends on awareness raising campaigns to provide information to the public. The most recent available figures are for 2022-23,8 during which time the Scottish Government ran several campaigns. The amount spent on each topic varied greatly, and it is difficult to compare the figures as there is limited information about what each campaign involved. The Member anticipates that any such campaign would be relatively low compared to some awareness-raising costs incurred by the Scottish Government, as any work would be educational rather than promotional.
- 34. Taking a health-related awareness raising exercise in relation to cervical screening as an example, it is noted that the spend on that campaign in 2022-23 was £9,938. Using this figure as a comparison and allowing for 2023-24 costs an amount of £10,544 has been estimated for awareness raising costs. Taking another figure, £41,706 was spent on a campaign relating to

⁷ Female Genital Mutilation (Protection and Guidance) (Scotland) Bill Financial Memorandum (parliament.scot).

⁸ Marketing+spend+2022-23+publication+25+September+2023.xlsx (live.com).

breastfeeding and £46,359 on 'Ready Scotland'. Using these examples, a range of between £10,000 and £47,000 has therefore been estimated for awareness raising costs.

35. Based on this cost and the estimated £30,327 allowed for producing and publishing statutory guidance would mean that an estimated £40,327 and £77,327 has been estimated for guidance costs. While these costs have been attributed to the Scottish Administration, they may in practice fall on NHS Scotland.

Costs on the Crown Office and Procurator Fiscal Service and the Scottish Courts and Tribunals Service

- 36. 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 offence would be subject to either summary procedure (which may result in imprisonment for a term not exceeding 2 years or a fine not exceeding level 5 on the standard scale (currently £5,000), or both) or on indictment (which may result in imprisonment for a term not exceeding 14 years or a fine, or both). In addition, under section 25 of the Bill a new offence may be created by Scottish Ministers by regulations. The potential offence relates to circumstances in which disclosure of information related to the provision of assistance is prohibited, and where breach of such a prohibition would be an offence. Should the offence be created, it would be subject to summary procedure and a fine not exceeding level 5 on the standard scale.
- 37. The 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). The costs of court procedures likely to vary greatly depending on the complexity of the case in question. Scottish Government figures for 2016-17 provided the average costs of Sheriff Court (summary procedure) and Justice of the Peace Courts as follows:

Table 1 – Estimated Scottish courts costs

	Sheriff Court	Expressed	Justice of	Expressed	Average	Expressed
	(summary	as 2023/24	the Peace	as	cost	as
	procedure)	costs		2023/24		2023/244
				costs		costs
Prosecution	£444	£559	£444	£559	£444	£559
costs						
(COPFS)						
Court Costs	£440	£554	£243	£306	£341.50	£430
(SCTS)						
Total	£884	£1,113	£687	£865	£785.50	£989

38. The number of terminally ill adults who make a declaration to have an assisted death is expected to be relatively low (between 33 and 533) and it is anticipated that a very small proportion of people seeking an assisted death, if any, will be coerced into making a declaration. It is the member's understanding that there have been no prosecutions for such a crime in any of the jurisdictions where assisted dying is legally available, and a similar offence exists. It therefore may be the case that inclusion of this offence in the Bill will not result in any prosecutions and therefore

no costs will be incurred as a result. However, for the purposes of this memorandum, an example is set out of the potential costs. If, for example, the offence was carried out in 1% of all cases where someone is pursuing an assisted death there would be around 1 offence in year one, rising to 5 per year by year 20.

- 39. Based on the figures set out in table 1, and the estimated number of prosecutions, it is estimated that the costs incurred by the creation of a new offence under the Bill will be minimal ranging between £0 if there are no prosecutions, up to £989 if there was one prosecution, and to £4,945 if there were 5 prosecutions. Breaking the costs down, during the same timescale costs incurred by COPFS are estimated to be between £0 and £2795 and by SCTS are estimated to be between £0 and £2150.
- 40. Costs have not been estimated for the potential offence provided for under section 25 of the Bill as it is not known whether Ministers will choose to create the offence. However, if the offence is created it is expected that there may be no prosecutions, or that the number of prosecutions will be low and that similar costs as those outlined in paragraph 39 will be incurred.

Costs on Scottish Prison Service

- 41. Should there be convictions made under the offence created by the Bill (and evidence suggests there are unlikely to be), there may be a resultant cost on the Scottish Prison Service. However, it is difficult to estimate the cost that this would place on the Scottish Prison Service as for each offence varying factors would need to be taken into account, including whether the person was given a fine or a custodial sentence and, if a sentence was given, how long would it be for.
- 42. Given the very low numbers of offences estimated in paragraph 38, and the member's understanding that there have been no convictions for any such offences in any jurisdictions where assisted dying is legally available, the number of people, if any, who will potentially serve a prison sentence is estimated to be very low and therefore costs to the Scottish Prison Service, if any, are expected to be minimal.

Table 2 – Estimated Scottish Administration costs9

Item	Year 1 cost	Year 5 cost	Annual cost
Annual reporting	£14,312		£14,312
Report on operation		£33,556	
of the Act			
Guidance	£40,327 and		
	£77,327		
Crown Office and	£0 - 559		Dependent on uptake
Procurator Fiscal			of assisted dying and
Service			resultant
			offences/convictions

⁹ Costs in this table are best estimates and therefore should be considered as approximate figures.

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Scottish Courts and Tribunal Service	£0 - 430	Dependent on uptake of assisted dying and resultant offences/convictions.
Total	£54,639-£92,628	£14,312 plus costs dependent on uptake of assisted dying and resultant offences/convictions

COSTS ON THE NATIONAL HEALTH SERVICE SCOTLAND

- 43. The assisted dying process provided for by the Bill is one that is operated by health professionals and therefore costs are expected to fall on the National Health Service in Scotland. The Bill operates on the basis of registered medical practitioners (RMPs) being involved throughout the process (first declaration stage, first and second eligibility assessments, second declaration stage, and during, and after, the end-of-life process).
- 44. There will be administrative costs (a maximum of five forms to be issued and completed by the person seeking an assisted death and/or up to two RMPs; updating of medical records) and clinical costs (time spent by RMPs assessing eligibility; time spent by RMPs and any other health professionals in other parts of the process, including attending the assisted death and completing necessary data gathering and reporting).

Production and administration of forms

- 45. As noted above, when someone requests an assisted death, several forms will require to be completed, processed and added to the terminally ill adult's medical records. The details of the process are explained further in the Policy Memorandum.
- 46. Given that the content and layout of the forms are provided for in the Bill's schedules, it is not anticipated that there will be costs attached to determining the content of the forms. Costs are therefore expected to be generated by the printing and storing of the forms. While it will be for NHS Scotland to determine how to manage the production and distribution of such forms, it may be that they are saved on an online platform, which healthcare professionals can then access and print as and when they are required. Alternatively, a batch of forms could be printed and kept at each GP practice or health care premises, this could be done directly by NHS Scotland employees or through an existing outsourced printing contract. Procedures for storing the forms would be expected to be in line with existing NHS Scotland practices.
- 47. As noted earlier, the number of people entering the process of assisted dying following the Bill's enactment is expected to be relatively low. The number of forms that require to be produced, printed and stored are therefore expected to be minimal and funded by existing NHS Scotland budgets.

Translation and interpretation

- 48. There may be some additional costs associated with producing information in different languages and formats, including declaration forms and any leaflets produced to help people understand the assisted dying process. In addition, someone who is seeking an assisted death may require a translator to attend appointments related to this with them.
- 49. It should be noted that NHS Scotland is obligated under the Equality Act 2010 to ensure that all patients are communicated with in a way that they understand. NHS Scotland guidance states that:
 - "All service users whose first language is not English must not be disadvantaged in terms of access to and quality of healthcare received (Equality Act 2010). They have a legal right to effective communication in a form, language and manner that enables them to interact with and participate in their healthcare and understand any information provided." ¹⁰
- 50. It therefore follows that NHS Scotland will already have procedures and services in place to help patients who need translation and transcription services. NHS guidance lists several ways in which such support is provided, including the provision of face-to-face, telephone and video interpreters and written and audio interpretation. In addition, provision should be made where required to provide documents in accessible formats such as Makaton or easy read.
- 51. NHS guidance further states that the costs of such services should be met at an individual health board level and that "services should be monitored regularly to ensure that they are cost effective, high quality and achieve their intended impact."
- 52. It is therefore expected that any costs associated with providing interpretation or translation services, or in producing documents in accessible formats, in relation to the provision of assisted deaths will be met by individual health boards existing budgets. As previously demonstrated, only a very small proportion of Scotland's population is expected to access assisted dying following the Bill's enactment. The proportion of people who wish to access assisted dying and who also require transcription services is expected to be low, with, for example, the 2011 census stating that 94% of people aged over 3 and living in Scotland understood written and spoken English. As a result, the impact on the requirement on NHS Scotland to provide interpretation and translation services and documents in accessible formats is expected to be minimal.

Updating guidance

53. NHS Scotland guidance may need to be updated in order to account for the change to the law and the implications for NHS Scotland. This may involve updating existing material and/or producing new guidance that specifically deals with assisted dying. It is expected that NHS Scotland already have established processes for updating such documentation to reflect changes of legislation or other developments. It should also be noted that other jurisdictions who have legalised assisted death have produced guidance which could be used as a source of information to help establish similar guidance for Scotland. In addition, many documents may be in digital

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¹⁰ Interpreting, communication support and translation national policy (healthscotland.scot).

¹¹ Languages | Scotland's Census (scotlandscensus.gov.uk).

form only, meaning that no printing costs are incurred and that the main associated costs would be incurred by staff time required to develop the content of the guidance and update it accordingly. As such, the member considers it reasonable to assume that any additional costs can be absorbed within existing budgets.

Anticipated clinician hours

- 54. As set out in detail in the Policy Memorandum, the process for accessing assisted dying requires the involvement of registered medical practitioners (RMPs) and other healthcare professionals. This will include one RMP undertaking the role of co-ordinating doctor, signing the declaration forms and undertaking an assessment of the person seeking an assisted death. A further RMP will also play a role, including assessing the person seeking an assisted death. Further to this, a RMP or registered nurse, authorised by the RMP will attend on the day of the assisted death and provide the assistance, and other health professionals (registered medical practitioners, registered nurses and registered pharmacists) may also attend.
- 55. While the Bill sets out the parameters for the process to be followed prior to an assisted death taking place, it 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.
- 56. In addition, it is envisaged that many of the initial discussion with the RMP will take place at a regular GP appointment, albeit one which may last longer than the usual allotted time. Separate timeslots may also be required for the assessments to be carried out by both RMPs. It should be noted that the initial discussion does not have to take place at a GP practice and it may involve, for example, a home visit, a hospital appointment or an appointment at a hospice. Where the RMP has to travel to see the terminally ill adult, time may have to be spent in travelling to and from the appointment.
- 57. As noted above, it is difficult to quantify how much of an RMP's time would be taken up by participating in the process. A study in Queensland (where assisted dying is legal) recorded the average clinical time taken in participation in the lawful assisted dying process as being between 6 and 17 hours per case. The time taken was dependent on a range of complex factors including the patient's condition and geographic location. Based on those entering the assisted death process each year ranging from an estimated 33, with up to 553 entering the process by year 20, it could be estimated that in year one between 198 and 561 hours of total health professional time will be used. This would rise to between an estimated 3,318 and 9,401 hours per year by year 20.
- 58. While an attempt to estimate the cost of RMPs and other healthcare professional's time is made above, it is anticipated that the RMPs would undertake the role as part of their existing employment and thus that costs would be absorbed by existing budgets. However, for the purposes

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¹² Ref: Preliminary, unpublished results from qualitative interviews with nurses involved in voluntary assisted dying in Queensland: White, B., Ward, A. & Willmott L (2024) (Australian Centre for Health Law Research. Queensland University of Technology).

of this memorandum, efforts have been made to estimate the cost of the clinical hours that are anticipated to be involved in the provision of assistance to eligible terminally ill adults in Scotland.

- 59. As noted above, it is expected that the role of co-ordinating doctor will normally be undertaken by the terminally ill adult's GP or by another RMP in charge of their care. In addition, there will be at least one other RMP involved in each case where someone has an assisted death.
- 60. Figures from 2022-23 state that a GP in Scotland's basic salary is between £61,346 and £91,564 per year, while the pay range for other RMP ranges from £26,462 per year for a Foundation Doctor (year 1) to £116,313 for a consultant who has completed 19 years or more as a consultant. Given that the Bill allows for any RMP to be involved in an assisted death and does not limit involvement to RMPs of certain roles or grade other than that they are a fully registered medical practitioner. An average of the lowest and highest basic RMP salary (as set out above) has been used for the purposes of this memorandum. On that basis, £71,388 has been assigned as the yearly salary of an RMP.
- 61. For the purposes of this memorandum, 40 hours a week has been estimated as an RMP's basic contracted hours. ¹⁵ On that basis, and using the estimated average salary as set out in paragraph 58 –an RMPs average hourly rate of pay is estimated as £34.32.
- 62. If this figure is multiplied by the total amount of healthcare professionals time required per assisted death (as set out in paragraph 58), an estimate of between £6,795 and £19,254 would be spent on clinician time in year one, with the amount rising to between £113,874 and £322,642 in year 20.

Staff training

- 63. The Health and Care (Staffing) (Scotland) Act 2019¹⁶ places a duty on every Health Board in Scotland, as well as the Common Services Agency for the Scotlish Health Service, to ensure staff are suitably trained.
- 64. It is anticipated that training will have to be undertaken by RMPs, registered nurses and registered pharmacists who will be, or may be, involved in the assisted dying process. This could involve, for example, training for clinicians on the overall process (patient pathway, completion of forms etc.), accessing the eligibility of a person who wishes to have an assisted death, and on how to detect if someone is being coerced or unduly pressured. It should be noted, however, that some training may already be offered to NHS staff, for example training relating to consent and coercion. Such training may therefore require to be updated to account for assisted dying rather than newly developed.
- 65. Any training would have to be developed and delivered, either 'in-house' or by a person/organisation contracted by NHS Scotland to do so. The amount and type of training

¹³ The Complete Guide To NHS Pay For Doctors (bmj.com).

¹⁴ Section 4(5)(a) of the Bill provides for Scottish Ministers to specify in regulations the qualifications and experience required by RMPs involved in assisted deaths.

¹⁵ The Complete Guide To NHS Pay For Doctors (bmj.com).

¹⁶ Health and Care (Staffing) (Scotland) Act 2019 (legislation.gov.uk).

required will be for NHS Scotland to determine, although it is anticipated that this could involve an online training module, or in-person training for RMPs and other healthcare professionals, such as pharmacists, who may be involved in the assisted dying process.

- 66. As a comparison of the type of training that may be required, in Victoria, Australia, where assisted dying is legal, healthcare professionals undertake 8 training modules and a training assessment, which take around 6 to 8 hours in total to complete¹⁷. The training can either be completed online or as part of a group training day. The member considers it reasonable that a similar amount of training will be required by RMPs and other healthcare professionals who may be involved in the assisted dying process following the Bill's enactment.
- 67. A report published by the General Medical Council stated that there were 25,934 doctors on the medical register in Scotland in 2022, ¹⁸ with further data showing that there were 69,000 registered nurses in Scotland in March 2023 ¹⁹ and 5,285 registered pharmacists. ²⁰
- 68. One possible comparator can be found in the financial memorandum which accompanied the Human Tissue (Authorisation) (Scotland) Bill,²¹ which was introduced in 2018 and came into force in 2019. That Act introduced a soft opt out system of deceased organ and tissue donation for the purposes of transplantation. The financial memorandum estimated £163,000 costs for the development and delivery of training in year 1 and 2 following the Bill's implementation. This included a half-time project management/training and development post in the lead up to and for one year following implementation of the soft opt-out system. This memorandum therefore, uses the figure of £200,000 as an estimate for staff training (uprating the figure of £163,000 to allow for inflation).

Substance provided to end life

- 69. The Bill allows Scottish Ministers to make regulations about what substances can be approved to be provided to, and used by, a terminally ill adult to enable them to legally and voluntarily end their life.
- 70. On the day of an assisted death, (following all checks) the person seeking an assisted death will be provided by a healthcare practitioner with an approved substance. The Bill provides that the life ending substance must be self-administered.
- 71. Information provided to the Member by Community Pharmacy Scotland estimated that, as an example, one substance that may be used in such circumstances would cost an estimated £80 for each dose provided to a terminally ill adult to end their own life. On the basis of the estimate of 25 people having an assisted death in year one following the Bill's enactment, rising to 400 by

¹⁷ Voluntary assisted dying training for medical practitioners (health.vic.gov.au).

¹⁸ Scotland report 2022 (gmc-uk.org).

https://www.nmc.org.uk/globalassets/sitedocuments/data-reports/may-2023/0110d-annual-data-report-scotland-web.pdf.

²⁰ gphc-scotland-register-diversity-data-may-2022.docx (live.com).

²¹ Financial Memorandum Human Tissue (Authorisation) (Scotland) Bill (parliament.scot).

year 20 it can be estimated that the cost of the required substances would be around £2000 in year one, rising to £32,000 per year by year 20.

Data collection, reporting and review

- 72. The data collected on first and second declarations (and any cancellation of either of these), medical practitioner's statements, and final statements, will form part of a person's medical records and therefore be subject to the same management (including retention periods) as other personal health information held by the NHS in Scotland.
- The Bill requires Scottish Ministers to make regulations which provide for relevant data to 73. be provided to Public Health Scotland and requires Public Health Scotland to report annually to the Scottish Government, and for the Scottish Government to publish relevant statistics on an annual basis and lay a report before the Scottish Parliament.
- 74. It is expected that the costs incurred by Public Health Scotland in producing an annual report to the Scottish Government are expected to be minimal and covered by existing budgets.
- Table 3 below shows a summary of the potential costs to the health service in Scotland 75. which have been able to be estimated. As noted above, additional, minor, administrative costs will be incurred, including the production and administration associated with the various forms.

Table 3 – Estimated health service costs

Item	Year 1 and ongoing cost per annum ²² , ²³
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

²² Ongoing costs will be at least in part dependent on the number of terminally ill adults who wish to have an assisted death and inflation.

²³ The figures in table 3 are best estimates and therefore, particularly where ranges have not been included, should be considered as approximate figures.

COSTS ON LOCAL AUTHORITIES

- 76. The Bill does not impose any new obligations on local authorities and, as such, there are not expected to be any costs for local authorities.
- 77. Some terminally ill people who request an assisted death may receive care from local authority-run care homes or hospices. However, as the parts of the assisted dying process that will incur more significant costs (such as the assessment process and other costs incurred by registered medical practitioners) will not directly involve such organisations, it is anticipated that any costs incurred by local authority managed care homes and hospices as a result of an assisted death taking place on their premises will be minor.

COSTS ON OTHER PUBLIC BODIES

Regulatory and representative bodies

- 78. Following the Bill's implementation, it is anticipated that several bodies will update their guidance and codes of practice to account for the change to the law and its implications. It is expected that this will include, but will not be limited to regulatory bodies, such as the General Medical Council (GMC the independent regulator of doctors in the UK), the Nursing and Midwifery Council (NMC the regulator for nursing and midwifery professions in the UK), the Health and Care Professions Council (HCPC a regulator of health and care professions in the UK) and the General Pharmaceutical Council (GPhC the independent regulator for pharmacists, pharmacy technicians and pharmacy premises in Great Britain)and representative/membership bodies such as the British Medical Association (a trade union for Doctors in the UK) and the Royal College of Nursing (RCN a membership body for registered nurses, midwives, health care assistants and nursing students).
- 79. The member also expects that relevant regulatory bodies, such as the General Medical Council will ensure suitable training is provided for health professionals who will be involved in supporting the assisted dying process to ensure that they are familiar with the process set out in the Bill.
- 80. It is expected that these bodies already have established processes for updating such documentation and providing training to reflect changes of legislation or other developments. As such, it seems reasonable to assume that any additional costs can be absorbed within existing budgets.

COSTS ON BUSINESSES AND THIRD SECTOR ORGANISATIONS

Private and third sector care homes and hospices

81. Some terminally ill people who request an assisted death may receive care from private or third sector-run care homes or hospices. However, as the parts of the assisted dying process that will incur more significant costs (such as the assessment process and other costs incurred by registered medical practitioners) will not directly involve such organisations, it is anticipated that any costs incurred by private and third sector care homes and hospices as a result of an assisted death taking place on their premises will be minor.

Private sector healthcare providers

82. While it is expected that the majority of assisted deaths will be facilitated by NHS Scotland, there may be cases where terminally ill adults access the process through a private healthcare provider. This would incur some costs on the healthcare provider, for example in staff training and clinician hours. However, it is expected that any such costs would be covered by individual's paying for the process, either via insurance or directly.

Support and navigation services

83. It is noted that some other jurisdictions that have legalised a form of assisted dying have established (often via third sector initiative) support and navigation networks for those involved in the process (including health professionals, patients, and family and friends). While this is not provided for in the Bill, the Member anticipates that similar networks may be established in Scotland once the Bill has been passed and the Act is operational. As the networks are not part of the Bill, they have not been costed in this memorandum, but it is anticipated that costs would be absorbed by the organisations existing funding models.

COSTS ON INDIVIDUALS

84. It is not expected that the Bill will incur any costs on individuals other than an adult who chooses to access assisted dying via private healthcare arrangements. However, it is anticipated that the Bill will create potential savings for individuals (see section on savings).

Table 4 – Estimated overall costs²⁴

	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

SAVINGS

85. It is emphasised 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. 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.

²⁴ Other costs incurred on an ongoing will be dependent on the uptake of assisted dying and resultant offences/convictions.

86. Every person who has an assisted death will not require further care, and therefore no further costs will be incurred by health and care services. Estimating the cost of palliative care provision in Scotland is complex. Most people who die from an illness in Scotland die at home or in the community, with only around 10% of people dying in hospital. Most people who are terminally ill will receive palliative care. Palliative care in Scotland can be delivered by a wide range of healthcare professionals in a wide variety of settings including in third-sector hospices or care homes, in local authority or privately run care homes, in hospital or at home.

Palliative care

- 87. It is difficult to estimate the cost of palliative care, given that there is a lack of relevant data available and that, as noted above, people may access it in a variety of ways, all of which incur varying costs. Further to this, while most terminally ill people receive palliative care, it is difficult to determine when someone will need such care and for how long.
- 88. Figures from the British Medical Journal estimate that in 2017 52,148 people in Scotland died with palliative care needs. It also estimated that this figure would rise to 65,756 by 2040.
- 89. While specific data on the costs of palliative care in Scotland could not be found, figures on such costs in England estimate that the average cost of palliative care per day is £425 for hospital, £280 if the person is at home and £145 when the person is receiving community care.²⁶ Research by Nuffield Trust²⁷ looked at both social care and hospital care use in the last 12 months of life. The results are presented in table 5. As the report was from 2010, uprated figures to allow for inflation have been included.

Table 5 – Estimated end of life costs

	Number of people	Social care cost per user	Inpatient cost per user	Social care plus inpatient cost per user
Inpatient care only	8,085	-	£8,017	-
Uprated figure			£11,317	
Social care only	1,188	£16,921	-	-
Uprated figure		£23,885		
Both inpatient and social care	3,786	£7,791	£9,998	£17,790
Uprated figure		£10,998	£14,112	£25,112

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²⁵ https://publichealthscotland.scot/publications/percentage-of-end-of-life-spent-at-home-or-in-a-community-setting/percentage-of-end-of-life-spent-at-home-or-in-a-community-setting-financial-years-ending-31-march-2014-to-2023/.

²⁶ The Nuffield Trust Social care and hospital use at the end of life <u>social-care-hospital-use-summary-web-final.pdf</u> (<u>nuffieldtrust.org.uk</u>).

²⁷ The Nuffield Trust Social care and hospital use at the end of life <u>social-care-hospital-use-summary-web-final.pdf</u> (nuffieldtrust.org.uk).

- Further research by the Nuffield Trust from 2014²⁸ estimated cost of £10,000 for each death 90. of someone in hospice care. Adjusted for inflation to 2023/2024 costs, the estimated cost for each death in a hospice would be £13,117.
- In relation to Scotland specifically, a study²⁹ which looked at healthcare use in the last 12 91. months of life among people aged over 60 who died in Scotland between 2012 and 2017 found that the mean cost of secondary care in the last year of life was £10,134, with costs highest in the last few months of life. If this figure is updated for 2023/24 to allow for inflation the cost would be £12,749.
- 92. Someone who chooses to have an assisted death may also receive palliative care prior to their death. However, it is difficult to quantify for how long they would receive palliative care, by what means and at what financial cost.
- 93. Given the lack of available data, and the variations in types of end-of-life care and costs attached to such care, no estimate of potential savings is provided. It is considered 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. It is thought likely that a terminally ill adult who dies as a result of being provided with assistance to end their life would have a very short time left to live, and therefore that care would have continued for a matter of days or, at the most, weeks. It is therefore considered reasonable to conclude that the cost of the provision of assisted dying will, approximately, be negated by savings made by the discontinuation of care after death has occurred, albeit for an expected short period.

Existing organisations providing assisted deaths

- There are potential savings for eligible terminally ill adults who may seek assisted dying elsewhere, should it not be available in Scotland. DIGNITAS, a Swiss non-profit organisation providing physician-assisted suicide to members with terminal illness or severe physical or mental illness, states that in the last 23 years, 16 people have travelled from Scotland to DIGNITAS to access assisted dying.³⁰ The member also understands that organisations other than DIGNITAS provide an assisted death service, and that, as of May 2022, at least 25 Scots had travelled to Switzerland for an assisted death.
- It has been estimated that the cost of travelling to Dignitas and having an assisted death has 95. an average cost of £10,000.31 However, this does not appear to include the costs of flights or hotels and instead lists medical assessments, procedures, admin fees and funeral costs.³² Anecdotal evidence suggests that travel, hotel and other expenses may cost around £1,600³³ to £3,000.³⁴ Based on an average of those two examples and the £10,000 estimated on fees and other costs an

²⁹ Diernberger et al (2021).

²⁸ The Nuffield Trust, Exploring the cost of care at the end of life Headings Arial 14pt / 17 (nuffieldtrust.org.uk).

³⁰ https://www.assisteddying.scot/wp-content/uploads/2022/09/Response-13593-DIGNITAS-%E2%80%93-To-livewith-dignity-%E2%80%93-To-die-with-dignity- 181537153.pdf.

³¹ The fees to be paid - A user's guide to Swiss end-of-life centres (theswitzerlandalternative.com).

³² The fees to be paid - A user's guide to Swiss end-of-life centres (theswitzerlandalternative.com).

³³ My trip in 2022 - A user's guide to Swiss end-of-life centres (theswitzerlandalternative.com).

³⁴ It cost £13,000 to help my terminally-ill husband die on his own terms | Metro News.

estimated £12,300 has been attributed to having an assisted death at DIGNITAS or a similar organisation.

96. Should the 25 people who, it is understood, have travelled abroad to access assisted dying no longer choose to do so as a result of the Bill an overall saving to individuals of £307,500 would be made over a twenty plus year period.

CONCLUSION

- 97. Where costs are incurred, they are estimated to be relatively low. This is partly due to the expectation that a small number of terminally ill people will seek to have an assisted death and partly due to much of the infrastructure required to provide the service already being in place. For example, it is anticipated that those who are involved in the assisted dying process will be existing healthcare employees rather than there being a need to recruit new staff. In addition, 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.
- 98. There may also be some savings, for example in cases where palliative care is not, or is no longer, required as a result of someone choosing to have an assisted death. Where the costs incurred by the Bill are estimated to be relatively low, so too are any savings that may be made as a result of the Bill's enactment. On balance, it is concluded that the Bill is likely to be effectively cost neutral.

ASSISTED DYING FOR TERMINALLY ILL ADULTS (SCOTLAND) BILL

FINANCIAL MEMORANDUM

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