Marie Curie

Assisted Dying Bill Scotland

Marie Curie Scotland responses to the Scottish Parliament Committees' Stage One Calls for Views

16 August 2024

Introduction

Marie Curie Scotland has responded to two Calls for Views from Scottish Parliament Committees for Stage One of their scrutiny of the Assisted Dying Bill:

1. The Health, Social Care and Sport Committee Call for Views on the Bill
2. The Finance and Public Administration Committee Call for Views on the Bill's Financial Memorandum

Notes:

- These responses were submitted on 'Citizen Space'.
- The response to the Health, Social Care and Sport Committee was subject to a 2000 character limit for answers to all but the final question.
- Further information: Amy Dalrymple, Associate Director, Policy and Public Affairs Scotland - amy.dalrymple@mariecurie.org.uk or policyscotland@mariecurie.org.uk

1. Marie Curie Scotland Response to Scottish Parliament Health, Social Care and Sport Committee Call for Views

2.1. About your organisation

1. Marie Curie is the largest third sector provider of palliative care for adults in Scotland, supporting over 8,000 terminally ill people in 2022-23. Marie Curie delivers expert support and advice through its two Hospices in Glasgow and Edinburgh, and Hospice Care at Home Service across almost all Local Authorities.

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2. Marie Curie's Information and Support services can be used by anyone affected by dying, death and bereavement for practical and clinical information, and emotional support. In Scotland 2022-23, our Information and Support services were used over 100,000 times.
3. Marie Curie's Companion at Home tackles social isolation and loneliness, and can continue for up to three months after a patient has died to ensure families and carers still receive the support they need.
4. Marie Curie is the biggest charitable funder of palliative care research in the UK. We are a campaigning and social justice organisation with a mission to close the gap in end of life care.

2.2. Question 1 – Overarching question

The purpose of the Assisted Dying for Terminally Ill Adults (Scotland) Bill is to introduce a lawful form of assisted dying for people over the age of 16 with a terminal illness.

1.2.1. *Which of the following best reflects your views on the Bill?*

- *Fully support*
- *Partially support*
- ***Neutral/Don't know***
- *Partially oppose*
- *Strongly oppose*

Comments:

1. This is an important debate; there are compelling arguments both for and against a change in the law.
2. This Bill must be judged in the context of how people die now.
3. Marie Curie has a neutral position on whether assisted dying should be legalised, but we're far from neutral on the critical need to improve palliative care so that no one suffers because they can't get the care they need.
4. International evidence suggests that if assisted dying was legalised, a small minority of us would choose this path. But 90% of us will need palliative care in our last months, weeks and days of life, including people who subsequently opt for Assisted Dying. It's a pressing need that will affect the vast majority of the population.
5. Too many people can't get the care they need now. People are dying in emergency departments following unnecessary admission to hospital. For thousands of people in Scotland, a terminal diagnosis means being pushed into poverty, with people from ethnically minoritised groups and those who become terminally ill in working age disproportionately affected. People without family or friends around them face dying alone.
6. These problems will only grow in coming years unless we act now. By 2040 up to 10,000 more people will need palliative and end of life care each year in Scotland.

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It's why we need a Right to Palliative Care in Scotland, and why MSPs must make sure they understand the full context and implications of their decisions about this Assisted Dying Bill.

7. The crisis in our health and social care system cannot and must not be a reason for introducing assisted dying. The idea of people choosing an assisted death because they are unable to access the care they need at the end of life should be intolerable to all of us. MSPs must decide if it is irresponsible to introduce assisted dying without also having a realistic plan for ensuring that everyone has access to the best possible palliative and social care at the end of life.

1.2.2. *Which of the following factors are most important to you when considering the issue of assisted dying?*

- *Impact on healthcare professionals and the doctor/patient relationship*
- *Personal autonomy*
- *Personal dignity*
- *Reducing suffering*
- *Risk of coercion of vulnerable people*
- *Risk of devaluing lives of vulnerable groups*
- *Sanctity of life*
- *Risk of eligibility being broadened and safeguards reduced over time*
- ***Other, please specify***

Other:

1. Assisted Dying is one part of the debate on how we all experience end of life, including the 90% of dying people who need palliative care. MSPs must consider all of these and further relevant issues.

Comments:

1. It is important that each member of this committee, and each MSP, consider all these issues, and the many others which would affect assisted dying were it to be made legal. Throughout this response, we highlight some of those, but it is incumbent on every MSP to consider thoroughly the implications for their decisions about this proposed legislation as a whole, each detail within it, and also what is not included that it will be relevant to its effect.
2. This legislation will feel important to many people at the end of life, those who are making future care plans, and their loved ones. It will have implications across our health and social care system, and MSPs will want to satisfy themselves that they have identified and explored what these are, for people using health and social care services, for staff, and for resourcing, commissioning, decision making and governance.
3. In reflecting on the question of how we enable people to have their own choices at the end of life respected, it is important that MSPs consider the nature of

autonomy. It could be argued that a dying person may not be able to make a "free" choice for an assisted death if they are constrained by inadequate access to health and social care services.

4. Given this, Marie Curie is clear that the Scottish Government must act urgently so we aren't neglecting to address the needs of every dying person, and supporting those caring for them, regardless of the ongoing assisted dying debate. This means effective, accountable delivery of the forthcoming national strategy for palliative and end of life care, improving funding to end the postcode lottery in access, and improving financial support for dying people to end the indignity of poverty at the end of life.

2.3. Question 2 – Eligibility

The Bill proposes that assisted dying would be available only to terminally ill adults.

The Bill defines someone as 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'.

An adult is defined as someone aged 16 or over. To be eligible a person would also need to have been resident in Scotland for at least 12 months and be registered with a GP practice.

1.3.1. *Eligibility – Terminal illness*

Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?

- *No-one should be eligible for assisted dying*
- *Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness should be narrower than in the Bill*
- *Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness in the Bill is about right*
- *Assisted dying should be available only to people who are terminally ill, but the definition of terminal illness should be broader than in the Bill*
- *Assisted dying should be available to people who are terminally ill, and to people in some other categories.*
- ***Other – please provide further detail***

If you have further comments, please provide these.

Other:

1. Marie Curie has a neutral position on these options. Below are set out important issues that MSPs could explore to inform their decision about the question.

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Comments:

1. MSPs should consider whether this definition of terminal illness is sufficiently clear to enable the public, and the medical professionals whose role it would be under this legislation to determine eligibility, to understand whether a person does or does not fall within the scope of this Bill.
2. This definition was developed to ensure accelerated access to social security support for everyone who needs it; it is based on clinical judgement and is deliberately inclusive and flexible. MSPs must consider whether such an aim is appropriate in the context of Assisted Dying legislation. MSPs will wish to consider whether a more tightly drawn definition of a 'terminally ill adult' might be developed and used for this Bill.
3. Issues that MSPs must consider about the definition of terminal illness include:

- What is meant by 'premature' death in this definition? Premature death can be caused by circumstances such as homelessness, mental illness or being in prison.
- This definition is designed to include people with a terminal illness diagnosis who will have many months – in some cases years – to live, and those for whom their prognosis is uncertain. It is important to be clear about the intent of this Bill, and whether MSPs would wish it to include those people.
- If MSPs would wish to limit the application of this Bill to people with only a short amount of time left to live – however long they may determine that to be – they must be cognisant that prognosis is difficult and inexact, even for the most expert, experienced healthcare professionals, and predictions made to patients and their families are regularly proved wrong; patients' conditions in many cases improve for a period of time, or in other cases they may deteriorate more quickly than was able to be predicted.

1.3.2. *Eligibility – minimum age*

Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?

- *No-one should be eligible for assisted dying.*
- *The minimum age should be lower than 16*
- *The minimum age should be 16*
- *The minimum age should be 18*
- *The minimum age should be higher than 18*
- ***Other – please provide further detail***

If you have further comments, please provide these

Other:

1. Marie Curie has a neutral position on these options. Below are set out important issues that MSPs could explore to inform their decision about the question.

Comments:

1. Scotland's residents are entitled to vote in Scottish Parliament and local authority elections and to consent to medical treatment from the age of 16. There are a number of other areas where 'adulthood' does not commence until a person is older, including in the justice system where it is 18, 21 or 26, depending on the circumstances. Transition to adult health and social care services can happen from the age of 16 but there is no fixed age, and any decision should be taken on a case-by-case basis in collaboration with the young person and appropriate care and support professionals. Scotland's longstanding whole system 'GIRFEC' framework applies until a person is 18.
2. MSPs must consider how they balance the Bill's stated intention to provide equal access to the option of an assisted death, with the considerations about young people's decision making that have informed the age boundaries for youth justice, GIRFEC and other recent policy and legislation affecting young people, including the incorporation into Scots law of the UN Convention on the Rights of the Child.

2.4. Question 3 – The Assisted Dying procedure and procedural safeguards

The Bill describes the procedure which would be in place for those wishing to have an assisted death.
It sets out various procedural safeguards, including:

- *examination by two doctors*
- *test of capacity*
- *test of non-coercion*
- *two-stage process with period for reflection*

Which of the following most closely matches your opinion on the Assisted Dying procedure and the procedural safeguards set out in the Bill?

- *I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle*
- *The procedure should be strengthened to protect against abuse*
- *The procedure strikes an appropriate balance*
- *The procedure should be simplified to minimise delay and distress to those seeking an assisted death*
- ***Other – please provide further detail***

If you have further comments, please provide these.

Other:

1. Marie Curie has a neutral position on these options. Below are set out important issues that MSPs should explore to inform their decision about the question.

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Comments:

1. We see that the Bill seeks to erect robust safeguards. MSPs should explore the effects of those safeguards, including to ensure that they aren't discriminatory against individuals by protected characteristics, socio economic status or other characteristics.
2. MSPs must consider the implications of the exclusion of people with a mental illness. A large proportion of the adult population has a mental illness diagnosis at some point, but that diagnosis may now have no impact on a person's decision making including about whether they wish to seek an assisted death in the event of a terminal illness diagnosis.
3. MSPs will wish to consider the situation of people with a dementia diagnosis if this bill passes. WHO ICD-11 classes dementia as a "mental, behavioural or neurodevelopmental disorder" but it is a terminal illness and many people with dementia have capacity for medical decision making.
4. MSPs should assure themselves that none of the proposed safeguards deter help seeking including support and treatment which manages symptoms enough so that that someone may not want an assisted death. For example, someone may benefit from mental health support but the diagnosis would make them ineligible for assisted dying. Or there can be medication which sufficiently eases a person's symptoms but affects their capacity. Can MSPs ensure that the eligibility criteria and safeguards minimise distress and that there is equity of access to Assisted Dying, which does not conflict with access to palliative care.
5. MSPs must explore the Bill's definition of 'coercion' which is limited to an individual coercing another person. There is no safeguard in the Bill against a person seeking an assisted death due to suffering that could be alleviated if they had the health and social care support they need.
6. MSPs must consider how they can ensure that any safeguards are not changed or lost over time without adequate oversight or scrutiny including from the Scottish Parliament.

2.5. Question 4 – Method of dying

The Bill authorises a medical practitioner or authorised health professional to provide an eligible adult who meets certain conditions with a substance with which the adult can end their own life.

Which of the following most closely matches your opinion on this aspect of the Bill?

- *It should remain unlawful to supply people with a substance for the purpose of ending their own life.*
- *It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill*
- *It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill, and it should also be possible for someone else to administer the substance to the adult, where the adult is unable to self-administer.*
- ***Other – please provide further detail***

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If you have further comments, please provide these.

Other:

1. Marie Curie has a neutral position on these options. Below are set out important issues that MSPs should explore to inform their decision about the question.

Comments:

1. MSPs should consider how the Bill or subsequent regulations defines "self-administration" of the approved substance to cause an assisted death. Is there any level of assistance that another person, whether a clinical professional or not, my provide to the terminally ill person – noting that the intent of the Bill is to enable assisted death for people whose illness is already advanced? Could self-administration be via a non-oral route, such as a feeding tube, which is mechanical help? How this is defined has implications for how accessible the option of assisted dying is for people with different terminal illnesses, especially when they are at an advanced stage.
2. MSPs should also consider whether they wish to address a gap in the process described in Section 15 of the Bill. This section addresses both the situation where the terminally ill person takes the approved substance and dies, and the situation where they decide not to take the approved substance. However, no process is indicated if the terminally ill person decides to take the approved substance, but they do not die. This may or may not be due to failure to ingest or absorb the full prescribed dosage of the approved substance. Such a scenario could result in pain and distress for the terminally ill person, and uncertainty for the clinician present about the course of action they must take to minimise the patient's pain and distress.
3. MSPs should also consider whether they are content that no timescale is specified in the Bill within which the person must take the substance to cause their death, and the resource implications for that given that it is set out that an authorised health professional must remain with the person until they decide not to take it, or until they die.

2.6. Question 5 - Health professionals

The Bill requires the direct involvement of medical practitioners and authorised health professionals in the assisted dying process. It includes a provision allowing individuals to opt out as a matter of conscience.

Which of the following most closely matches your opinion on how the Bill may affect the medical profession? Tick all that apply.

- *Medical professionals should not be involved in assisted dying, as their duty is to preserve life, not end it.*
- *The Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out.*

- *Assisting people to have a "good death" should be recognised as a legitimate role for medical professionals*
- *Legalising assisted dying risks undermining the doctor-patient relationship*
- ***Other – please provide further detail***

If you have further comments, please provide these.

Other:

1. The options don't fully describe the important issues about the impact on the medical profession.
2. The third option is ambiguously worded; this must be recognised in the analysis of responses.

Comments:

1. The third option here is ambiguously worded. "Assisting a good death" is a legitimate and important existing role of medical professionals, and other health and social care professionals, especially through the provision of palliative care and support for people at the end of their lives. Were Assisted Dying to be legalised, it would remain only a small part of the huge range of ways in which medical professionals and many others assist people with terminal illnesses at the end of their lives.
2. A 'good' death means having the right care, support and systems in place, so a person feels protected and safe, and carers and loved ones understand what support is available. It's different for everyone, as it depends on what matters most to each person.
3. It means the right pain and symptom management and medical care to help a person live as well as they can, in line with their wishes. It means emotional and spiritual care to help a person feel safe and supported. It means ensuring they have enough money not to have to worry about the basics like putting food on the table or turning on the heating. And it means a smooth and joined-up experience of the health and social care system, so the person and those close to them can focus on the important things at the hardest of times.
4. It is important to be careful and clear about wording as we navigate the debate around assisted dying. We must not conflate the important existing role medical practitioners have in supporting someone to have a good death, and the potential role in assisting someone to end their own life.
5. MSPs must be clear that they have a shared understanding of terms that can be interpreted in different ways.

2.7. Question 6 - Death certification

If a person underwent an assisted death, the Bill would require their underlying terminal illness to be recorded as the cause of death on their death certificate, rather than the substance that they took to end their life.

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Which of the following most closely matches your opinion on recording the cause of death?

- *I do not support this approach because it is important that the cause of death information is recorded accurately*
- *I support this approach because this will help to avoid potential stigma associated with assisted death*
- ***Other – please provide further detail***

If you have further comments, please provide these.

Other:

1. These options do not reflect the important issues that MSPs should explore to inform their decision about this question; some of these are set out below.

Comments:

1. Marie Curie shares the view of bodies such as Healthcare Improvement Scotland that accurate death certification is important and necessary. Accurate, detailed death certification provides important data showing who dies from what causes, and where, enabling better direction of resources, knowledge for families and loved ones that is important to the grieving process, and an official source of truth which may be required for legal or contractual processes such as insurance or employer benefits.
2. We are therefore of the firm view that if assisted dying is legalised, death certification in the event of an assisted death must record **both** the mode of dying – that the death was assisted – **and** the underlying terminal diagnosis as well as any other underlying factors that would be included according to the current guidance from the Chief Medical Officer on death certification. Scotland has been making steady progress for many years in improving the accuracy of death certification, and the proposal in the Bill to not record the actual method of dying in the event of an assisted death, is a retrograde step.
3. Marie Curie rejects the suggestion in the answer options that recording that the method of dying was an assisted death, will create stigma. Indeed, we are of the entirely opposite view, that creating a statutory process that includes hiding this information, will in itself create stigma around an assisted death.

2.8. Question 7 – Reporting and review requirements

The Bill proposes that data on first and second declarations, and cancellations, will be recorded and form part of the person's medical record.
It also proposes that Public Health Scotland should collect data on; requests for assisted dying, how many people requesting assisted dying were eligible, how many were refused and why, how many did not proceed and why, and how many assisted deaths took place.

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Public Health Scotland would have to report on this anonymised data annually and a report would be laid before the Scottish Parliament.
The Scottish Government must review the operation of the legislation within five years and lay a report before the Scottish Parliament within six months of the end of the review period.
Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?

- *The reporting and review requirements should be extended to increase transparency*
- *The reporting and review requirements set out in the Bill are broadly appropriate*
- *The reporting and review requirements seem excessive and would place an undue burden on frontline services*
- *Other – please provide further detail*

If you have further comments, please provide these.

Other:

1. Marie Curie has a neutral position on these options. Below are set out important issues that MSPs should explore to inform their decision about the question.

Comments:

1. Marie Curie supports robust reporting and review requirements in health and social care to drive improvement, effectiveness and efficiency, support research and identification of research needs, provide public transparency, and enable proper accountability for quality, equitable service provision and fulfilment of responsible bodies' obligations. All these serve to benefit both the public and the institution on which they rely for health and care.
2. Such robust reporting and review is not possible without the proper information about services, the context in which services are delivered, and the circumstances and experiences of the people who are, and who are not accessing those services. The provision of this information requires the collection, collation and analysis of quality, comprehensive data. This would need to include data about which professionals are providing services related to assisted dying, any impact on workload, and the costs of service provision, with links to how assisted dying would be commissioned and regulated.

2.9. Question 8 – Any other comments on the Bill

Do you have any other comments in relation to the Bill?

1. There are several questions that have not been raised in this call for views which it is vital that MSPs consider when coming to their conclusions about this Bill.

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Ensuring equity, diversity and inclusion in Assisted Dying

2. It is important that MSPs consider, if this Bill is passed, how to ensure equality of access to assisted dying for those who choose it among the diverse populations in Scotland's communities.
3. People with protected characteristics are most likely to experience poverty throughout their lives, and the more protected characteristics a person has the more risk they bear(i). This increased risk persists to – and is magnified by – reaching the end of life. Terminal illness does not cause these inequalities, but exacerbates their impact.
4. Deprivation, geography, gender, religion, ethnicity, sexuality, learning disability, diagnosis and age are all biological and social determinants that can have an impact on whether someone gets the care and support they need at the end of life, as they impact access to health and social care services throughout the life course. MSPs will be well aware of longstanding and growing workforce pressures across health and social care impacting service availability and accessibility.
5. Marie Curie has made the case consistently to MSPs(ii) that inequities must be addressed within our health and care systems; if assisted dying is legalised it is important that access to it too is determined only by the eligibility criteria, not by where someone lives, their economic circumstances, their language or communication needs, or the trust they have in service providers.

Place of death

6. Place of care and death is a complex concept which has different connotations and implications for each person. It is one of the most common indicators used to measure quality of end-of-life experience, including whether a person's care wishes were met relating to where they wanted to receive palliative support, and to die.
7. The choice someone has about where they are cared for and where they die is often constrained by the health and care staffing and facilities available, or other circumstances.
8. Urban health and social care infrastructure and funding models are often transferred ineffectively to rural and island areas, deepening existing inequity for these communities. As a result, rural and island communities in particular often have choice about care and support at the end of life removed, with many determined by resources which are available not necessarily what an individual needs.
9. The concept of 'home' must be considered in the context of locality- at a Marie Curie stakeholder roundtable on the end of life experiences of rural and island communities, one participant shared their experience of a parent's end of life, where 'home' meant place of origin and returning to one of the Scottish isles. This was their wish, with no specific preference for which care setting support was delivered in.
10. 'Home' may also, for some, not be a safe place. This is particularly prevalent in deprived urban areas which experience higher crime rates(iii). Andy, a participant of the Dying in the Margins, had no choice but to spend his final weeks at Marie Curie Hospice Glasgow, as his flat had been broken into and it was not fit for purpose. Andy's preference was to die in his flat, which he considered home, but as

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clinicians have a duty of care to patients, a joint decision was made he would receive palliative support at the hospice(iv).

11. If assisted dying is legalised, these current issues about where people die will be applicable to that choice too; would each person who wishes and assisted death have the same amount of choice about where that happens?

Older people

12. MSPs must consider whether the intent of Bill is fulfilled by the content of the Bill. One group not covered by the Bill is the population of older adults who experience increasing frailty, and whose prognostication would indicate deterioration in the coming months to short number of years. The challenge of capacity in this group is made more difficult due to fluctuating cognitive function related to ageing exacerbated by any acute event such as an infection. MSPs must make sure that the Bill is clear about the inclusion or exclusion of people in this group.

13. We are aware that this population also do not, too often, get the palliative care they need. Research has shown older people have more unmet pain, and are less able to access and receive palliative care if they don't have a clear terminal diagnosis, because frailty is associated with the normal process of dying(v). We urge MSPs to consider the needs of people who are in pain, sometimes distressingly so, who are near death; this Bill may not help them, but a better understanding and resourcing of palliative care in social and primary care is needed to meet their needs.

Access to palliative care and support for wider needs

14. In our answers to the Committee's questions, we have referred several times to the importance of the context in which this legislation would be implemented. Marie Curie cannot emphasise strongly enough how vital it is that everyone who needs it has access to the care and support they need at the end of their lives, wherever in Scotland they live, whatever their circumstances. This includes health and social care, but also housing and financial security, and support for loved ones and those in a caring role.

15. Too many people in Scotland do not get the care and support they need at the end of life, because their needs are not recognised, and our health and care systems' resource is not structured or adequate to respond to those needs. MSPs must make sure they understand the inequities that impact someone's experience of dying and death, and consider what are the implications for how someone might make a choice whether or not to seek an assisted death.

Learning from where assisted dying already happens

16. MSPs should inform themselves as fully as possible about how Assisted Dying operates in other countries where it is legal, especially those where the structures and processes are similar to those proposed in this Bill – though also to learn from others what changes might strengthen this Bill, if it progresses.

17. These comparisons should include not only the operation of the relevant Assisted Dying legislation, but also the systems supporting the whole dying population – including the majority, who do not have an assisted death – and those around

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them who have a caring role, whether professional or unpaid. This should include gauging any changes to access to and funding for palliative care capacity and education. When assessing palliative care provision, MSPs should bear in mind that most palliative care is not provided by specialist palliative care services that have the term in their title, but by generalist services such as general practice or district nursing, in care homes, or in hospital wards and emergency departments.

Proposed legislation elsewhere in the UK

18. MSPs will want to note the similarities to and differences from the legislation proposed in the UK Parliament, both to take any learnings that might improve the Bill being considered here, and to be aware of any implications for Scotland and legislation in Scotland. Hey differences in the proposed legislation in the UK Parliament include

19. In the Bill proposed in the UK Parliament, the involvement of the High Court, which would determine eligibility(vi).

20. In the Bill proposed in the UK Parliament, the eligibility criteria include length of prognosis – proposed six months(vii).

21. In the Bill proposed in the UK Parliament there is an explicit provision that a doctor involved in the assisted dying process may not receive any benefit from their involvement(viii).

22. In the Bill proposed in the UK Parliament the minimum time for reflection is six days(ix), not the 48 hours allowed for in this Bill.

23. In the Bill proposed in the UK Parliament there is explicit provision that *"In deciding whether to countersign a declaration under subsection (4), the attending doctor and the independent doctor must be satisfied that the person making it has been fully informed of the palliative, hospice and other care which is available to that person"*(x).

24. In the Bill proposed in the UK Parliament it is stated explicitly that someone can be assisted to self-administer the lethal substance, including by a 'medical device'(xi).

25. In the Bill proposed in the UK Parliament all of the associated regulations created by the Bill are proposed to be subject to affirmative parliamentary approval.

26. In the Bill proposed in the UK Parliament, death certification must state that a death was an assisted death(xii).

Interaction with other relevant legislation

27. MSPs should assure themselves, and seek advice if they need to, about how the Bill would interact with the operation of other legislation, both reserved and devolved, and what amendments might be necessary to other legislation to resolve any conflicts or ambiguities. This might include – but not be limited to – the Mental Health (Scotland) Act 2003, the Adult Support and Protection (Scotland) Act 2007, the Equalities Act 2010, the Human Rights Act 1998, the Adults with Incapacity (Scotland) Act 2000, the Public Bodies (Joint Working) (Scotland) Act 2014 and the National Health Service (Scotland) Act 1978.

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Marie Curie research and briefings

28. Marie Curie has published briefings and reports on many of the issues we refer to in this response, and we are very happy to provide these to the committee and discuss their implications with committee members as they consider these issues deeply and thoughtfully to inform the Parliament's decision making about this Bill.

References

Below are relevant references for information included in answers to previous questions:

Question 1:

i. Finucane AM, Bone AE, Etkind S, *et al*; How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery; *BMJ Open* 2021;11:e041317. doi: 10.1136/bmjopen-2020-041317 How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery | BMJ Open (accessed 8 August 2024)

Question 3:

i. World Health Organisation International Classification of Diseases 11th Revision - ICD-11 for Mortality and Morbidity Statistics (who.int) (accessed 27 July 2024)

Question 6:

i. Healthcare Improvement Scotland's comments on death certification - https://blog.healthcareimprovementscotland.org/2023/10/10/learning-from-the-experiences-of-each-year-helps-the-death-certification-review-service-continue-to-make-improvements-in-providing-the-most-accurate-and-comprehensive-information-for-loved-ones/ (accessed 27 July 2024)
ii. Chief Medical Officer's guidance on death certification - https://www.sad.scot.nhs.uk/media/16841/cmo-final-version-sghd-cmo-2022-33-update-on-guidance-for-docs-completing-mccdplususe-of-abbrevs-210922.pdf and https://www.publications.scot.nhs.uk/files/cmo-2018-11.pdf (accessed 27 July 2024)

Question 8:

i. The Inequality of Poverty: Sara Davies and David Collings, University of Bristol: https://fairbydesign.com/wpcontent/uploads/2021/02/The-Inequality-of-Poverty-Full-Report.pdf
ii. Eg https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/scotland-briefings/marie-curie-scotland-response-to-the-health-and-social-care-committee-inquiry-fv.pdf; https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/marie-curie-response-inquiry-into-health-inequalities-.pdf; https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/scotland-briefings/marie-curie-msp-briefing-for-parliamentary-members-business-debate-on-dying-in-the-margins-161123.pdf (accessed 15 August 2024)

iii. Why do inequality and deprivation produce high crime rates and low trust? Benoit de Courson and Daniel Nettle, 2021, Scientific Reports: https://www.nature.com/articles/s41598-020-80897-8
iv. Dying in the Margins: https://www.gla.ac.uk/media/Media_1020538_smxx.pdf (accessed 15 August 2024)
v. Marie Curie: Enough for Everyone, Challenging inequities in palliative care https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/challenging-inequities-in-palliativecare.pdf
vi. Assisted Dying for Terminally Ill Adults Bill (HL) Section 1 Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)
vii. Assisted Dying for Terminally Ill Adults Bill (HL) Section 2 subsection (1) Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)
viii. Assisted Dying for Terminally Ill Adults Bill (HL) Section 3 subsection (3) Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)
ix. Assisted Dying for Terminally Ill Adults Bill (HL) Section 4 subsection (3) Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)
x. Assisted Dying for Terminally Ill Adults Bill (HL) Section 3 subsection (6) Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)
xi. Assisted Dying for Terminally Ill Adults Bill (HL) Section 4 subsection (4) Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)
xii. Assisted Dying for Terminally Ill Adults Bill (HL) Section 7 subsection (2) Assisted Dying for Terminally Ill Adults Bill [HL] (parliament.uk) (accessed 8 August 2024)

2. Marie Curie Scotland response to Scottish Parliament Finance and Public Administration Committee Call for Views on the Financial Memorandum

2.1. About your Organisation

1. Marie Curie is the largest third sector provider of palliative care for adults in Scotland, supporting over 8,000 terminally ill people in 2022-23. Marie Curie delivers expert support and advice through its two Hospices in Glasgow and Edinburgh, and Hospice Care at Home Service across almost all Local Authorities.
2. Marie Curie's Information and Support services can be used by anyone affected by dying, death and bereavement for practical and clinical information, and emotional support. In Scotland 2022-23, our Information and Support services were used over 100,000 times.
3. Marie Curie's Companion at Home tackles social isolation and loneliness, and can continue for up to three months after a patient has died to ensure families and carers still receive the support they need.

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4. Marie Curie is the biggest charitable funder of palliative care research in the UK. We are a campaigning and social justice organisation with a mission to close the gap in end of life care.

2.2 Question 1 - Did you take part in any consultation exercise preceding the Bill and, if so, did you comment on the financial assumptions made?

1. Marie Curie Scotland participated in the consultation on the Proposal for a Member's Bill which preceded this Bill. The response is published on Marie Curie's website https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/scotland-consultations/marie-curie-response-to-assisted-dying-2021-fv.pdf .
2. Our response commented on the evidence about palliative care investment that the consultation suggested might follow the legalisation of assisted dying.
3. Our response also commented on the evidence cited in that consultation to describe a limit to the efficacy of palliative care, and highlighted the lack of robust evidence about unmet need for palliative care in Scotland, and quality of palliative care in Scotland.
4. All these areas are relevant to the financial assumptions made about assisted dying.

2.3 Question 2 - If applicable, do you believe your comments on the financial assumptions have been accurately reflected in the FM?

1. The Financial Memorandum acknowledges that it is difficult to estimate the cost of palliative care given the lack of relevant data available and the complexities and variation in access and provision.
2. Existing research does tell us that by 2040 up to 10,000 more people will need palliative and end of life care each year. This growing demand comes as the cost of living with a terminal illness is increasing and the costs of delivering palliative care are also rising rapidly1.
3. Marie Curie research describes this projected future need in more detail, concluding that over 60,000 people will die with palliative care needs by 2040, with over 85s accounting for 45% of all deaths. People dying with multi-morbidities (more than one terminal condition) will have increased by over 80% in the next 20 years1. And by 2040, nearly two-thirds of all deaths in Scotland will take place in care homes, people's own homes or hospices. This represents a significant, continuing increase in demand for community-based palliative services including social care, for terminally ill people, which will also become more complex over time2.
4. MSPs must make sure that they are using all the evidence available gain the necessary understanding of how people in Scotland die now, to inform their

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decisions about whether assisted dying should be legalised and if it is, what the impacts of that would be on individuals near death and/or with a terminal illness, their families and those who care for them, the professionals with involvement in their care and treatment, and the systems within which that care takes place.

5. Marie Curie agrees with the Financial Memorandum that better data is needed to predict palliative care need at local population level, which needs adequate data gathering and data linkages between relevant organisations. However, the true picture of palliative care need would only become apparent if health and social care practitioners were not disincentivised from properly assessing someone's palliative care needs by the knowledge that the resources to meet those needs may well not be available; we know that too many people in Scotland die without the care and support they need at the end of life.

2.4 Question 3 - Did you have sufficient time to contribute to the consultation exercise?

1. A longer consultation period would have enabled more detailed analysis of the available evidence and the gaps in that evidence that would need to be filled to ensure that MSPs have all the information they need to make properly informed, robust assessment of the impact of this Bill if it were to pass.
2. It is incumbent on MSPs to assure themselves that they have each assessed all the evidence available about the impact of legalising assisted dying, and that if that happens, the Bill as passed is rigorous, amended where necessary to ensure that the law is clear, fair, and safe.

2.5 Question 4 - If the Bill has any financial implications for you or your organisation, do you believe that they have been accurately reflected in the FM? If not, please provide details.

1. It is not clear to Marie Curie why the Financial Memorandum states that third sector run care homes and hospices will incur only 'minor' costs if Assisted Dying were to be legalised. Marie Curie and other hospices may be involved with a patient's care at any point in the last year of a person's life – whether in the hospice building or a patient's own home - and care homes for longer.
2. For Marie Curie, therefore, it is likely that our organisation's staff may well be involved in the initial conversations with any patient wishing to explore the option of an assisted death. If the staff member has not conscientiously objected to involvement, our medical staff may well be one of the doctors participating in the proposed declaration process. And our clinical staff may well be the practitioner present with the dying person as they self-administer the approved substance, present until they die.
3. The above activities would all require Marie Curie to incur costs training a wide range of staff and volunteers who work with patients and their families to be able to be clear and compassionate when discussion assisted dying. Further, there will be a

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cost to using clinical resource to provide assisted dying according to the proposed process, making that resource at that point unavailable for palliative care.

2.6 Question 5 - Do you consider that the estimated costs and savings set out in the FM are reasonable and accurate?

1. It is important to re-state here Marie Curie's position of neutrality on the issue of assisted dying; we campaign neither for nor against a change in the law. However, if MSPs do decide to change the law they should do so with a full understanding of all the impacts of that decision.
2. Our answer to Question Four above describes under-estimates of the financial implications for Marie Curie if assisted dying were to be legalised.
3. MSPs must make sure that they use the best available evidence to scrutinise the assumptions made throughout this Financial Memorandum.

2.7 If applicable, are you content that your organisation can meet any financial costs that it might incur as a result of the Bill? If not, how do you think these costs should be met?

1. There has been a chronic underfunding of palliative care for decades, despite dying, death and bereavement being a universal experience. This has resulted in significant unmet palliative care need and services which are under acute pressure from increased demand, with decreasing resources to meet it.
2. The hospice sector as a collective in Scotland is operating at a £16m deficit3, which is not sustainable in the short, medium or longer term meaning people will continue to miss out on some or all of the palliative support they need.
3. We strongly believe that palliative care services commissioned through Integration Authorities, particularly those delivered by the third and independent sectors should be sustainably funded. Funding models should be outcomes focused and based on population needs, with a view to long term commitments that allow for innovation and change. Such funding models are vital to support third sector organisations commissioned to deliver services that meet the needs of terminally ill people including community-based palliative care services and hospices.
4. Marie Curie's current funding arrangement see commissioned income cover less than 40% of our costs, meaning charitable fundraised income supports the delivery of the palliative care we provide to dying people, their families and carers.
5. It is not stated in the Bill or its accompanying documents how assisted dying would be commissioned if it is legalised, although there is reference to the role of GPs and psychiatrists. Would delivery of assisted dying be organised as a separate service within NHS provision, or somehow absorbed into existing services? Would Marie Curie and other providers be expected to make assisted dying available to eligible patients who request it, and to be part of that process? If so, would it be funded in line with arrangements for our existing commissioned services, as described above, or would there be a separate arrangement for full cost recovery?

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6. Without clarity on the above questions, it is not possible to calculate the full financial impact of legalisation of assisted dying on Marie Curie.

2.8 Does the FM accurately reflect the margins of uncertainty associated with the Bill's estimated costs and with the timescales over which they would be expected to arise?

1. Many aspects of spending on the last year of life are unknown, including care from family and carers, social services, community nursing and core general practice. In NHS Highland for example, of the spend that is known, the amount spent on people in the last year of life has remained much the same over the period 2017-18 to 2019-20, with £44 million being spent in 2019/20- 71% (£31 million) of that £44 million is spent on emergency admissions4.
2. MSPs will also note that accurate information is not available for all the costs that are relevant to this Bill, and may wish to make recommendations for further research.

Amy Dalrymple
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