

Legislative Consent Memorandum for the Terminally Ill Adults (End of Life) Bill

Health and Social Care Scrutiny: Supplementary Evidence

July 2025

1. Introduction

Marie Curie retains a neutral position on assisted dying. We neither campaign for nor against a change in the law. We were pleased to submit written evidence to the Health and Social Care Committee as part of its scrutiny of the Legislative Consent Memorandum for the Terminally Ill Adults (End of Life Bill (the Bill)).

Since submitting our initial evidence, the Bill has been through report stage and passed third reading in the House of Commons. Amendments tabled at this stage have given rise to further considerations the committee may wish to explore. This supplementary evidence sets out these considerations, which relate to Clauses 47 and 50 of the Bill.

These clauses make a link between evaluation of palliative and end of life care and the effective implementation of the Act. In this context, we believe there are questions about the appropriateness and effectiveness of the clauses as drafted, given that palliative and end of life care in Wales is wholly devolved.

2. Clause 47 – Reporting on the implementation of the Act

2.1. This Clause has the purpose of requiring the Secretary of State to review the implementation of the Act within 12 months of the Bill becoming law. Reviews of the implementation of the Act would then be required at six monthly intervals.

2.2. The first report under this Clause requires the Secretary of State to set out plans for implementing the Act. Of particular relevance is that this first report must:

- set out an assessment of the state of health services to persons with palliative and end of life care needs and the implications of this Act on those services.
- include an assessment of the availability, quality and distribution of appropriate health services to persons with palliative and end of life care needs, including - pain and symptom management; psychological support for those persons and their families; information about palliative care and how to access it.

3. Clause 50 – Review of the Act

3.1. This Clause has the purpose of requiring the Secretary of State to review the Act five years after the Bill has become law. Akin to the first review under Clause 47, this review must:

- include an assessment of the availability, quality and distribution of appropriate health services to persons with palliative and end of life care needs, including - pain and symptom management; psychological support for those persons and their families; information about palliative care and how to access it.

3.2. Furthermore, this five year review is also required to include:

- any concerns with the operation of this Act which have been raised;
- the Secretary of State's response to any such concerns, including any recommendations for changes to codes of practice, guidance or any enactment (including this Act).

4. Appropriateness

4.1. We think the appropriateness of requiring the UK Secretary of State to evaluate the delivery and sufficiency of palliative and end of life care may need to be explored.

4.2. Our concern is that without the Welsh Ministers themselves being explicitly responsible for the required review of palliative and end of life care in Wales, the reports may not present an accurate picture of delivery in Wales. It would also be quite unusual for a UK Minister, and Parliament, to lead such a formal review of a devolved service, with no clear role for the Welsh Ministers.

4.3. Furthermore, since the Welsh Ministers will be granted some powers over the establishment of an assisted dying service, that service may well look different in Wales to England. This could also raise questions

about the appropriateness of the UK Secretary of State being solely responsible for reviewing the implementation of the Act in Wales.

5. Effectiveness

- 5.1. Since these reports are to be drafted and responded to by the Secretary of State and laid only before Westminster and not the Senedd, it may be worth considering whether these clauses will have the desired effect in Wales. This is because neither the Secretary of State nor Westminster are responsible for palliative and end of life care in Wales.
- 5.2. This is particularly the case with Clause 50, which at point **e** requires the Secretary of State to respond to any concerns raised in the five year report, and include any *recommendations for changes to codes of practice, guidance or any enactment (including this Act)*.
- 5.3. As the Secretary of State cannot (and should not) directly change or direct the delivery of palliative and end of life care in Wales, any recommendations related to devolved public services or response to the reports would currently have no effect in Wales.
- 5.4. Additionally, MSs, who are elected to scrutinise the delivery of health services in Wales, have no clear role in scrutinising any reports and evaluation of palliative and end of life care, since reports under the Bill are only required to be laid before Parliament.
- 5.5. As the legislation links evaluation of palliative and end of life care with the effective implementation of the Act, if these reports do not include input from the Welsh Ministers nor scrutiny by MSs, our concern is that there will no direct means through which any issues raised within the required evaluations (in relation to devolved services) can be addressed. It would be for the Welsh Ministers and Senedd to implement any changes to palliative and end of life care in Wales or to aspects of any assisted dying services in Wales that have been created via regulations.

6. Conclusion

As outlined in our initial evidence to the Committee, we believe that it's imperative that accountability for palliative and end of life care in Wales remains clear.

We believe that Clauses 47 and 50 as drafted should be considered within this context.

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