

Written evidence submitted by Hospice UK (ADY0411)

1. [About Hospice UK](#)

1.1. Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, by supporting our hospice members and by collaborating with other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do.

2. [About hospice care](#)

2.1. The adult and children's hospices across the UK collectively support 300,000 people with palliative and end of life needs each year, as well as thousands of families and carers. They are the main providers of specialist palliative care services in the health and care system. In addition, hospices provide bereavement support to 72,000 people in their communities, making the hospice sector the largest provider of bereavement support in the UK.

2.2. Hospice care aims to improve the quality of life and wellbeing of those with a terminal condition, and is delivered in many settings including people's own homes or in hospice inpatient units. Almost 90% of hospice care is provided in a patient's own home. Hospice care is provided by multi-disciplinary teams of staff and volunteers, working to meet the individual's clinical, physical, emotional, social and spiritual needs.

2.3. Our country's charitable hospices rely heavily on the support and generosity of the communities they serve, raising £1.5bn in charitable funds each year. On average, the state meets just 32% of the costs of adult hospice care in the UK, and just 17% of the costs of children's hospice provision, although there is also huge local variation in the levels of funding received. Together, hospices need to raise £2.8 million every day of the year to supplement the funding that they receive from the state.

3. [About this submission](#)

3.1. This submission has been informed by input from Hospice UK's member hospices. It reflects and is aligned with Hospice UK's position of having no collective view on the question of whether or not the law should be changed to permit assisted dying.

4. Hospice UK's position on Assisted Dying

- 4.1. The nurses, doctors, social workers, therapists, councillors, and trained volunteers working tirelessly in the UK's hospices for high-quality palliative care inevitably hold a wide range of individual views on assisted dying. This is why, as a membership body, Hospice UK takes a position of 'no collective view'.
- 4.2. But as advocates for high-quality end-of-life care, we believe everyone who is facing the end of their life has the right to the full facts and a clear understanding of all the available options and to access the best quality care and support possible.
- 4.3. The whole ethos of hospice and palliative care, as defined by the World Health Organization, is that it "intends neither to hasten nor postpone death"¹. This philosophy is a cornerstone of hospice care in the UK.
- 4.4. We believe that it is important that people are aware of their options and have access to high-quality palliative and end-of-life care. Hospice UK believes that there is an urgent need to improve access and availability of end-of-life care. Tackling this will require appropriate, sustainable funding and a plan to tackle the inequalities that prevent people from getting the care they need and deserve.

5. Response to the Inquiry questions

- 5.1. **To what extent do people in England and Wales have access to good palliative care? a) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?**

There are currently significant geographic and diagnostic inequalities in access to palliative and end of life care. Around one in four people are not getting the expert palliative and end of life care that they need. Without urgent action, this gap is likely to increase as a result of people living with, and dying with, increasingly complex needs; as a result of our ageing population; and the effect of later diagnosis due to the pandemic.

We commend the steps taken in the Health & Care Act 2022 to place a new duty on Integrated Care Boards in England to arrange the provision of palliative care services to meet population need². In implementing this new duty, it is vital that Integrated Care Boards establish a comprehensive picture of population need and current inequalities in access to palliative and end of life care support.

- 5.2. **What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?**

Others are better placed to provide evidence from the perspective of jurisdictions which permit a form of assisted dying/assisted suicide. We believe that there are a number of important lessons emerging from those experiences, including:

- The importance of facilitating and enabling open and honest conversations with people and their families about all of the palliative and end of life care options that are available to them
- The need for clarity and precision in the terminology that is used. In general terms, there are divergent views about what constitutes 'assisted dying', and a low level of awareness and understanding about end of life care more generally
- The importance of supporting staff wellbeing for those who might be participating in the delivery of assisted dying in any way
- The need to have support for people and staff to help them navigate access to services, which might include access to any form of assisted dying

¹ <https://www.who.int/europe/news-room/fact-sheets/item/palliative-care>

² Health & Care Act (2022) c.31. Available at <https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted> (Accessed 20 January 2023)

- The relatively low take up of assisted dying in jurisdictions that have permitted it in some form, relative to the total number of deaths (although it is important not to make generalisations about different approaches in different jurisdictions).

5.3. What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

A fundamental question in any consideration about a future potential change in the law relating to assisted dying is the question of how it might be delivered. To date, there has been inadequate consideration of the role that different staff, and services, might be asked to play, and the extent to which they will be free to conscientiously object to participation, if they wished to. It remains unclear whether such conscientious objection would apply only to individuals, or would also be extended to organisations and services who may wish to opt out of participation in such a system, and what effect this might have on a person's new right to access such a service.

There are also important questions relating to the risk of conflict with professional and regulatory requirements for physicians and others who might be asked, or expected, to participate in the implementation of such a policy.

5.4. What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying/assisted suicide services?

In the absence of a proposed scope of any potential change in the law, it is impossible to answer this question fully. It would be for Parliament to determine the scope of any potential change in the law.

There is, however, widespread confusion about the scope of a potential change in the law. For instance, a 2017 study from New Zealandⁱ found that 66% of respondents believed that assisted dying included 'turning off life support' while 52% of people believed that ceasing medical treatment was a form of assisted dying. Language around end-of-life decisions varies and often causes confusion about care and treatment decisions.

5.5. What protections could be put in place to protect people from coercion and how effective would these be?

Safeguarding potentially vulnerable people in a system in which assisted dying was, in some form, permitted, would be a key priority. Hospice UK does not believe that sufficient attention has yet been given to the safeguards that would be required, although it is impossible to consider the nature of those safeguards in the absence of a concrete proposal about the scope and reach of any potential change in the law.

It is also important to recognise that the question of establishing criteria for any potential change in the law is not the same thing as determining the safeguards that might be needed. Establishing safeguards are the mechanism by which the actions required to ensure that the eligibility criteria are adhered to, and that people are protected from avoidable harm.

Given that so few people access the care and support that they need at the end of life in the current system, Hospice UK believes that one important safeguard would be to establish a new legal right to palliative care. This is a position supported also by the recent report of the Scottish Medical Advisory Groupⁱⁱ. This would have the effect of helping to ensure that people are aware of, and are offered access to, the range of services and support to help them manage their end of life care needs. It could be supplemented by a legal right to an assessment of a person's palliative care needs, and would complement the new legal duty on Integrated Care Boards in England to arrange the provision of palliative care services to meet population need.

5.6. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/assisted suicide services?

It is vital that everyone with palliative and end of life care needs, and their families and carers, have access to information to help them make informed choices about their care and support. This includes helping to navigate people to appropriate care and support services.

There is evidence that people are not currently fully aware of where to obtain end of life care. A Hospice UK poll conducted in December 2021 found that nearly 6 in 10 respondents did not feel they had a good understanding of where they would go to receive end of life careⁱⁱⁱ.

In addition, there are widespread misperceptions about palliative care options which can lead people to make decisions based on information that may not be right for their specific circumstance.

If there was to be a future change in the law relating to assisted dying, it would be even more critical that people and families had much improved information on how to access the full range of palliative and end of life care services so that they could make informed choices about their options.

This would require clarity on which organisations and agencies might be authorised to deliver such a service, and which organisations, and/or individual professionals, would have the option of opting out. It would be the responsibility of the health care system to ensure that there was adequate provision of such a service to meet population need without creating, or exacerbating, existing inequalities in access to care and support.

Currently, people with palliative and end of life care needs must navigate a complex network of services, often without any coordination. Evidence shows that few people know where to turn to if they have palliative care needs^{iv}. Many hospices provide case management and coordination for people in their care to help reduce the burden of navigating across primary, secondary and tertiary care, social care, welfare benefits and family and carer support. Action to improve the coordination of care should be a key priority.

5.7. **What capabilities would a person need to be able to consent to assisted dying /assisted suicide?**

In supporting people to make any decisions about palliative and end of life care treatment and care, it is essential that people have the opportunity to express their own goals, wishes and preferences. This includes the person themselves, and those important to them, recognising that it is not uncommon for there to be conflict in those views.

Currently, people have an absolute right to refuse medical treatment and to make other decisions about their treatment and care, provided that they have the capacity to do so. If there was to be a change in the law to permit a form of assisted dying, establishing both capacity and the absence of coercion would be essential, and basic, building blocks.

5.8. What should the Government's role be in relation to the debate?

It is vital that the Government takes steps to increase access to, and availability of palliative and end of life care services and support.

Government also has a role in ensuring that people are aware of their options for care and support at the end of life. Too few people know what support is available, or how to access it. Government should work with the wider health and care system to raise the profile of end-of-life issues and to facilitate conversations with one another about choices and availability of care for people as they approach the end of life.

The step taken to introduce a new statutory duty on Integrated Care Boards in England to arrange the provision of palliative care services to meet population need is extremely welcome, but the fact remains that too many people are missing out on the care and support that they need. Resolving this will require investment in local services, including sustainable funding for the country's hospice sector, and a credible plan to tackle inequalities in palliative and end of life care support.

ⁱ <https://blogs.bmj.com/bmj/2021/09/08/assisted-dying-we-must-prioritise-research/> (accessed 20 January 2023)

ⁱⁱ <https://www.assisteddying.scot/wp-content/uploads/2022/12/Medical-Advisory-Group-Report.pdf> (accessed 20 January 2023)

ⁱⁱⁱ Opinion poll, commissioned by Hospice UK, December 2021

^{iv} Opinion poll, commissioned by Hospice UK, December 2021