

Written evidence submitted by Sue Ryder (ADY0256)

About Sue Ryder

Sue Ryder supports people through the most difficult times of their lives. For almost 70 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can.

We take the time to understand what's important to people and give them choice and control over their care. This might be providing care for someone at the end of their life, in our hospices or at home. Or helping someone manage their grief when they've lost a loved one. Or providing specialist care, rehabilitation or support to someone with a neurological condition.

We want to provide more care for more people when it really matters. We see a future where our palliative and neurological care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

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?

- Research shows that access to appropriate palliative care is not adequate.
 - Just under 50% of all people dying in England receive palliative care, yet estimates suggest up to 90% may have palliative care needs.¹
 - Over a quarter of people (27%) who had a loved one die without access to specialist end-of-life care felt they could have had a better death elsewhere.²
- Unless action is taken, access to palliative care is likely to worsen in the future. Sue Ryder projects that demand for palliative care services will rise from 245,000 people in 2021/22 to 379,000 in 2030/31.³
- We also know that some population groups are more likely to experience inequalities of access and standards of care.
 - A 2022 evidence review published in the British Medical Journal found there are *'persistent inequalities in hospice care provision: patients without cancer, the oldest old, ethnic minorities and those living in rural or deprived areas are under-represented in hospice populations.'*⁴
 - Additionally, a 2021 Hospice UK report stated that *'Inequalities of access and standards of care are particularly felt by those who have already encountered unfairness and discrimination throughout their lives.'*⁵

¹ Sue Ryder (2021). Modelling demand and costs for palliative care services in England.

https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf

² Sue Ryder polling (2022).

³ Sue Ryder (2021). Modelling demand and costs for palliative care services in England.

https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf

⁴ Tobin J, Rogers A, Winterburn I, *et al* (2022). Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/12/2/142>

⁵ Hospice UK (2021). Equality in hospice and end of life care: challenges and change. <https://hukstage-new->

- Inequalities in access and care standards are partly due to the fact that the health system is not set up to properly understand palliative and end-of-life care (PEoLC) population health needs. Monitoring, including demographic monitoring, is not suitably carried out. This leads to limited information on gaps in provision and inequalities in access to care, meaning that the right services to address inequalities are often not commissioned.
- To address this a national core data set should be developed, specifying the PEoLC data that Integrated Care Systems (ICSs), services and providers must collect and report. This would enable better planning of services to meet local needs, facilitate greater integration and support both providers and central bodies to compare data and better understand the national picture.
- Diversity data is key to an ICS understanding its PEoLC population health needs and in turn, meeting its statutory duty regarding the commissioning of palliative care services. However, collation of diversity data is currently inconsistent across different providers and it is not always done well. Diversity data must therefore be central to the development of a national core data set.
- Inadequate funding is also causing the lack of access to high quality palliative care across the whole population. Currently, the Government provides around a third (37%) of the funding that hospice services need and Sue Ryder, like the rest of the sector, must rely on fundraising activities and voluntary donations to cover the remaining costs. **The Government must provide adequate and sustainable funding to the hospice sector to ensure everyone can access high quality palliative care.**
- The Health and Care Act 2022 introduced a statutory duty for Integrated Care Boards (ICBs) to commission palliative care services that meet their population's needs. This is a step we very much welcome and hope will help to improve access to palliative care across England. However, we have yet to see the impact of this duty as ICBs were only formally established in July and their five-year forward plans are not due for publication until April 2023. We must see plans for how ICBs intend to meet the duty within their strategies and forward plans and regulators must hold ICBs to account to ensure they are meeting this duty.
- Improving access to palliative care would not negate all given arguments for assisted dying, as some may still want to have an assisted death even with access to the best possible palliative care. However, fair and equal access to high quality palliative care is essential if assisted dying was legalised as it would help to ensure that an assisted death has not been chosen because a person is not aware of, or cannot access, good palliative care.

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

- We should learn about the role of and impact on the palliative care sector in countries where assisted dying has been legalised. In particular, where there has been a recognition of the need to improve palliative care provision and how funding has been targeted as a result.

- For example, in 2022 the New South Wales (NSW) Government pledged an extra \$743 million in funding for palliative care over five years. This was announced a month after the passing of the state's voluntary assisted dying law. This funding was promised by NSW premier Dominic Perrottet in a debate on assisted dying.⁶ We should learn from this and ensure that conversations on assisted dying include recognition of the need to increase palliative care funding.
- A 2018 report⁷ found that in jurisdictions (*Oregon (USA); Washington State (USA); the Netherlands; Belgium; Canada; and Quebec Province, Canada*) where assisted dying is legal, the palliative care sector is usually further advanced following legalisation.
- It is important to note that the palliative care sector in the UK has been historically underfunded and so requires significant urgent investment. Waiting until assisted dying is potentially legalised to make improvements is not enough, this investment must be prioritised.
- Further research should be carried out to better understand what can be learnt from countries where assisted dying is legalised. This should include looking at the role (if any) of the palliative care sector.

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

- Sue Ryder believes that all individuals facing challenges associated with life-threatening illnesses should have access to the care they need in order to live the lives they choose. We recognise that assisted dying is a complex subject and we are sensitive to both sides of the debate.
- If assisted dying were to be legalised, all physicians must have the choice as to whether they assist someone to end their life. Physicians may have personal objections to assisted dying, which may include moral objections or feeling that it is not in keeping with their role. These views should be respected.
- A physician who does not wish to assist someone to end their life must have a duty to refer the patient to an alternative physician who does not personally object to this.
- Extensive consideration needs to be given to the setting in which assisted dying would happen. This should include learning from countries where assisted dying has already been legalised. These considerations must also include the voices of those working in existing services where assisted dying may take place.

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

⁶ The Guardian (2022). Dominic Perrottet says NSW palliative care boost will rectify his past mistakes. <https://www.theguardian.com/australia-news/2022/jun/09/dominic-perrottet-says-nsw-palliative-care-boost-will-rectify-his-past-mistakes> [last accessed 13.01.23]

⁷ Aspex Consulting (2018). Experience internationally of the legalisation of assisted dying on the palliative care sector. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

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

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?

- In order for people to be able to make informed choices around assisted dying there needs to be increased awareness of palliative care. Poor awareness of the care available creates a risk that people may choose assisted dying due to a perceived lack of other options.
- Research has found that awareness around palliative care is low. An evidence review published in the British Medical Journal in 2021 found that more than half of the patients did not have any information about palliative care or hospice care.⁸ Patients had limited information about pastoral care, social care and bereavement care. Patients' awareness about individuals or centres providing palliative care or hospice care was also limited.
- A 2021 study on public knowledge, attitudes and perceptions towards palliative care found that there are a range of knowledge gaps and misconceptions. It also found that a reluctance to have taboo conversations around death and dying may deter people from accessing integrated palliative care services earlier on.⁹
- Information, advice and guidance around planning for end-of-life needs to be improved. All staff providing face-to-face palliative care should be aware of and appropriately trained on human rights at the end of life, including rights around assisted dying. This will help to ensure that patients know all of their options around palliative care and assisted dying and are able to make well informed decisions.
- Planning for the future will also help people to make an informed decision about whether to access assisted dying. Our research has found that significant numbers have not made a plan for end-of-life and death:
 - Almost half of people in the UK did not know that everyone has a choice of where they die (44%).¹⁰
 - Over four fifths of people have not planned where they would want to die (83%).¹¹
 - Almost nine out of ten people in the UK have not written an advance care plan (86%).¹²
 - Three fifths of people have not spoken to their loved ones about their end-of-life wishes (60%).¹³

⁸ Masoud B, Imane B, Naiire S (2021). Patient awareness of palliative care: systematic review. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/early/2021/10/10/bmjspcare-2021-003072>

⁹ McIlfatrick, S., Slater, P., Beck, E. et al (2021). Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. *BMC Palliat Care*. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-021-00730-5>

¹⁰ Sue Ryder polling (2022).

¹¹ Sue Ryder polling (2022).

¹² Sue Ryder polling (2022).

¹³ Sue Ryder polling (2022).

- Better access to advance care planning is also needed. Improvements are even more vital if assisted dying were to be legalised.
- Having an advance care plan means that people can think about and set out how they want their care to be, and where they want to be cared for. It is an essential first step in any system in ensuring patients understand the options they may have. The quality of people's experiences is greatly impacted by having the time and information they need to talk about what care and support they want.
- **Sue Ryder supports the [CQC's principles](#) on Advance Care Planning, as well as those that are set out by the Ambitions Partnership.**¹⁴ There is a need for a **consistent national approach to advance care planning** so that patients are supported well to have these discussions and in their decision making.

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

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

- The Government must ensure that the voices of anyone who may be affected by this are included. This includes: patients, patient's families, a wide range of healthcare professionals, the PEoLC sector and other relevant healthcare-related third sector organisations.

¹⁴ Universal Principles for Advance Care Planning (2022). <https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf>