House of Commons Health and Social Care Committee: Assisted Dying / Assisted Suicide

Government's Response to the Second Report of Session 2023-24

(29 February 2024)

INTRODUCTION

This is the Government's formal response to the recommendations made by the Health and Social Care Committee in its report *Second Report – Assisted Dying/Assisted Suicide,* published on 29 February 2024.

Assisted dying/assisted suicide (AD/AS) is a controversial subject, and the purpose of the report was to serve as a basis for further discussion and debate in future Parliaments. The long-held position of successive UK governments is that any change to the law of England and Wales in this area is a matter for Parliament and an issue of conscience for individual parliamentarians rather than one for government policy. It would be for the UK Parliament to develop a specific proposal on AD/AS reform, not the Government, because this is a matter of conscience.

Therefore, much of the report focussed, quite rightly, on palliative and end-of-life care provision and with that in mind this response will primarily focus on that too.

The Department has already introduced a number of significant changes to improve the provision of palliative and end-of-life care in England in recent years, which we have highlighted in response to the individual recommendations. Additionally, the UK has been considered an international leader in palliative and end-of-life care for a number of years and, in a recent *Cross-Country Comparison of Expert Assessments of the Quality of Death and Dying,* the UK was ranked no. 1 of 81 countries for high-quality end-of-life care. However, with an increasing ageing population and a growing number of people living and dying with multiple long-term conditions, there is more work to be done.

The Government welcomes the Committee's report, and we are grateful to everyone who contributed their time and expertise to the inquiry. The Committee took evidence from a wide range of organisations and individuals, from the UK and overseas, with an interest in palliative and end-of-life care, and from those with views or expertise specifically on AD/AS. The culmination of this work provides a comprehensive and up-to-date body of evidence on this difficult, sensitive, and emotive subject. The report is not intended to provide a resolution, but it will be a significant and useful resource for future parliamentarians.

RECOMMENDATIONS

We have carefully considered all the recommendations in the report and have provided a response to each in turn below.

Recommendation 1

The UK Government must consider how to respond to another jurisdiction in the UK, or the Crown Dependencies, legislating to allow AD/AS, and how it may impact jurisdictions which do not allow it. Following the recommendation by the Jersey Citizens' Assembly, it looks increasingly likely that at least one jurisdiction among the UK and Crown Dependencies will allow AD/AS in the near future and Ministers should be actively involved in discussions on how to approach the divergence in legislation. (Paragraph 68)

Response

The criminal law is a devolved matter in Scotland and Northern Ireland. The Crown Dependencies are not part of the UK, but are self-governing dependencies of the Crown, with their own health services, legislatures and courts of law. The UK Government works closely with the devolved administrations and the Crown Dependencies on a wide range of matters, and we will discuss with them the practical implications for England and Wales of legislation introduced to allow AD/AS and any constitutional issues that such legislation may present. Should any AD/AS legislation be enacted, we would expect the implementation period to allow time for such discussions whilst the necessary regulatory measures are put in place.

Recommendation 2

The UK has long been a world leader in palliative and end of life care, but access to and provision of palliative and end of life care is patchy. The Government must ensure universal coverage of palliative and end of life services, including hospice care at home. It is important that everyone is able to choose what type of support they need at the end of their life, and that their advanced care plan is honoured where possible. (Paragraph 278)

Response

While the NHS has always been required to commission appropriate palliative and end-of-life care services to meet the reasonable needs of local populations, palliative care services were added to the list of services an integrated care board (ICB) must commission, promoting a more consistent national approach and supporting commissioners in prioritising palliative and end-of-life care.

To support ICBs in this duty, NHS England has published statutory guidance and service specifications. Further work is ongoing to support ICBs in this legal duty, including:

- From April 2024, NHS England is including palliative and end-of-life care in the list of topics for its regular performance discussions between national and regional leads.
- NHS England has commissioned the development of an all-age palliative and end of life care dashboard, which brings together relevant local data in one place. The dashboard helps commissioners understand the palliative and end-of-life care needs of those in their local population, enabling ICBs to put plans in place to address and track the improvement of health disparities.

Regarding the recommendation to ensure universal coverage of hospice care at home, due to the way the hospice movement organically grew, hospice locations were largely not planned with a view to providing even access across the country or to prioritise areas of greatest need based on demographics. Therefore, there are disparities in access to hospice services, especially for those living in rural or socio-economically deprived areas.

While the majority of palliative and end-of-life care is provided by NHS staff and services, we recognise the vital part that voluntary sector organisations, including hospices, play in providing support to people at end of life and their families. Most hospices are charitable, independent organisations who receive some statutory funding for providing NHS services.

We are working hard to encourage the use of advance care plans (ACPs). We recognise that high-quality palliative and end of life care should include the opportunity for individuals to discuss their wishes and preferences so that these can be taken fully into account in the provision of their future care, also known as advance care planning, a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care. It is important that ACPs are respected, and that individuals' preferences are honoured as far as possible.

NHS England published Universal Principals for Advance Care Planning in March 2022 to provide a consistent national approach to advance care planning. In addition, there is a specific document to support health and care providers supporting advance care planning for those with dementia: NHS England » My future wishes: Advance Care Planning (ACP) for people with dementia in all care settings

Resources available to support healthcare professionals in engaging people in advance care planning includes guidelines and a quality statement from the National Institute for Health and Care Excellence (NICE), and a specific module within the End-of-life Care for All e-learning training programme hosted by Health Education England (now part of NHS England). Advice is also available on NHS.UK at the following link: End-of-life Care For All (e-ELCA) - elearning for healthcare (e-lfh.org.uk)

As part of the *Major Conditions Strategy: Case for change and strategic framework*, published in 2023, we recognised that personalised care and empowering patients and service users is particularly important as people near the end of their lives. Advanced care planning, when done well, can allow people to feel they have had the opportunity to plan for their future care.

Recommendation 3

We understand that the flexible nature of the current funding model for hospices is valued by some hospice leaders, and rather than suggesting that the Government funds 100% of hospice operations, we call on the Government to commit to an uplift of funding to guarantee that support will be provided to any hospices which require funding assistance. (Paragraph 280)

Response

Most hospices are charitable, independent organisations which receive some statutory funding for providing NHS services. The amount of funding hospices receive is dependent on many factors, including what other statutory services are available within the ICB footprint. Charitable hospices are autonomous organisations that provide a range of services which go beyond that which statutory services are legally required to provide. Consequently, the funding arrangements reflect this.

Due to the way the hospice movement organically grew, hospice locations were largely not planned with geographic or demographic purposes as a driving force. Therefore, there are disparities with access to hospice services, especially for those living in rural or socio-economically deprived areas. However, the majority of palliative and end of life care is provided by NHS staff and services, commissioned to meet the needs of their local population.

At a national level, as part of the NHS COVID response, c. £356 million was provided to hospices to secure and increase additional NHS capacity, enable hospital discharge and ensure they can continue delivering quality care to those who need it.

In addition, from December 2021 to March 2022, NHS England made grant funding available to purchase the establishment of 24/7 and Single Point of Contact specialist palliative care support and advice services. This was done at pace with 73 successful bids and totalling over £4 million of funding.

At a national level, NHS England has supported palliative and end-of-life care for children and young people through the Children and Young People’s Hospice Grant, providing approximately £15 million in 2020/21, £17 million in 2021/22, £21 million in 2022/23, and rising to £25 million in 2023/24.

Furthermore, as part of the NHS Long Term Plan, up to £2 million in 2020/21, up to £3 million in 2021/22 and up to £5 million in 2022/23 of matched funding has been made available to commissioners who increase their overall level of investment in local children’s palliative and end of life care services, rising to up to £7 million in 2023/24.

Last year, NHS England confirmed that it will be renewing the funding for 2024/25, once again allocating £25 million funding for children’s hospices using the same prevalence-based allocation approach as in 2022/23 and 2023/24. This prevalence-based approach ensures funding matches local need. Funding will be distributed via ICBs in line with NHS devolution.

Recommendation 4

There is a pressing need to understand how to better provide mental health support, and guidance, for people who are living with a terminal diagnosis. We therefore recommend that the Government commission such research and report back to Parliament. (Paragraph 307)

Response

The Department, through the National Institute for Health and Care Research, is investing £3 million in a new Palliative and End of Life Care Policy Research Unit. This will help build the evidence base on all-age palliative and end-of-life care to inform policymaking in this vital area.

Adults can access NHS Talking Therapies services, which provide evidence-based psychological therapies for people with common mental health conditions, including anxiety disorders and depression, implementing the National Institute for Health and Care Excellence (NICE) guidelines. NHS Talking Therapies can be accessed via a number of routes, including self-referral, through a GP or via other services. The implementation of long-term condition pathways in NHS Talking Therapies has been identified as a priority to support integration of mental health and physical health services for people with co-morbid long-term conditions, such as cancer, which can include palliative and end of life care.

Recommendation 5

The Government must establish a national strategy for death literacy and support following a terminal diagnosis. This strategy will help healthcare professionals to better support someone and their loved ones, from the moment of a terminal diagnosis. (Paragraph 308)

Response

We do not plan to establish a national strategy for death literacy. However, the Government's inclusion of palliative and end of life care in wider strategies will continue to drive the conversation and reduce the taboos associated with death and dying. For example, inclusion in the forthcoming Major Conditions Strategy, the new Visiting Legislation, DWP's Special Rules for End-of-Life changes and the Chief Medical Officer for England's recent report on healthy ageing.

In addition, there is a comprehensive suite of free training on palliative and end of life care available (e-ELCA) for health and care professionals.

As stated in the report, the Palliative and End of Life Care Policy Research Unit will focus on how best policy-makers can respond to a range of issues across palliative and end of life care, including key issues that emerged during the pandemic such as quality of care and disparities in access to services in different settings. It will also include research into understanding the barriers to discussing palliative and end of life care and the wider role of society in supporting people who are dying and those important to them.

The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) is a partnership between DHSC, NHS England, the UK Health Security Agency and sector representatives. This partnership works together to: drive transformation of health and care systems; promote equality; address health disparities; and help people, families and communities to achieve and maintain wellbeing. The HW Alliance has previously commissioned a number of projects investigating disparities in accessing palliative and end of life care. These include cross-cutting considerations at the end of life, digital inclusion, and barriers for those likely to be in the last year of life without a life-limiting diagnosis.

Palliative and End of Life Care Strategic Clinical Networks are in place in every NHS England region, supporting the delivery of personalised high-quality palliative and end of life care for all, irrespective of age, area, condition or setting. Led by a core team, the networks combine the experience of clinicians, service commissioners and patients to improve the delivery of care to patients across primary, secondary and tertiary settings, including social care and the voluntary sector.

In addition, there is a wealth of national guidance for commissioners and healthcare professionals, including:

- NHS England has published statutory guidance and services specifications to support commissioners with palliative and end of life care provision.
- NHS England's Children's palliative and end of life care service specification.
- NHS England's guidance on addressing palliative and end of life care needs for people living with heart failure.

- Care Quality Commission’s (CQC) guidance on Planning for the Future.
- The Universal Principles of Advance Care Planning.
- National Institute of Clinical Excellence (NICE) Quality Standards on Adult end of life care
- National Institute of Clinical Excellence (NICE) Quality Standards on Children’s end of life care.