



Parliamentary briefing on the Health and Care Bill Report stage: Two vital amendments on palliative and end of life care

The Health and Care Bill is a unique and welcome opportunity for our health and care system to learn lessons from the Covid-19 pandemic, prepare for a future of growing demand for palliative and end of life care, prevent future crises and help ensure that nobody misses out on the care and support they need at the end of their life, both now and in the future.

However, as it stands, the Bill makes no direct reference to improving care and support for people living with a terminal illness. As the UK's leading end of life care charities, we believe that it is critically important that the Bill makes a positive difference for adults and children living with a terminal illness and their carers.

To help achieve this, we propose two amendments to the Bill:

- The first adds to the Bill a requirement for palliative and end of life care services to be commissioned in every part of England.
- The second adds to the Bill a legal right for everyone to be offered a conversation about what matters most to them at the end of their life.

These amendments were debated during the Committee stage of the Bill. While we appreciate assurances from the Government in respect of these issues given during the debate, we continue to want to see a clearer commitment from Government on these issues than is currently present in the Bill as drafted.

Ahead of the Bill's introduction in the House of Lords we would like to see these issues raised again at the Bill's Report stage. ***We are not asking for the amendments to be pushed to a vote in the Report stage debate.***

Summary of key points:

- ***The Health and Care Bill is a unique opportunity to help ensure that nobody misses out on the care and support they need at the end of their life both now and in the future.***
- ***76% of bereaved carers said their loved one did not get all the care and support they needed at the end of life when dying at home during the Covid-19 pandemic.***
- ***As a result of our ageing population, in twenty years' time there will be 100,000 more people dying each year in the UK.***
- ***The number of people dying with a need for palliative care is projected to increase by up to 42% by 2040.***
- ***Enhancing the role of patients in making choices about their care – including through the right to be offered a conversation about their needs, wishes and preferences for the end of their life - could help deliver personalised care for everyone at the end of life.***
- ***A duty for Integrated Care Boards to commission palliative and end of life care services could help to ensure the needs of people at the end of life are met, and to address the current neglect of such services in local commissioning.***

Why palliative and end of life care matters

The United Kingdom is at a critical moment for improving palliative and end of life care. As a result of our ageing population, in twenty years' time there will be 100,000 more people¹ dying each year in the UK – more than the total number of people who have died in the year since the Covid-19 pandemic began.

Demand for palliative and end of life care is set to increase rapidly, as our population ages and more people live for longer with multiple and complex conditions² The number of people dying with a need for palliative care is projected to increase by up to 42% by 2040³.

Everyone deserves the best possible end of life experience, but the reality for far too many people falls far short of what we all hope for and should be able to expect. Estimates suggest that while as many as 90% of people who die in the UK may need specialist or generalist palliative care, only around 50% of people who die actually receive it⁴.

Current policy commitments are not enough

A range of national policies, including *Our Commitment to you for end of life care*, the Ambitions Framework for palliative and end of life care, and National Institute for Health and Care Excellence (NICE) guidelines 31, 61 and 143 have set out the standards that should be met for people who need palliative and end of life care.

However, these standards are insufficient for ensuring our health and care system meets the needs of everyone at the end of life. [Research by Marie Curie](#) and others indicates that certain groups face significant barriers in access to palliative and end of life care including people who are living in poverty, alone, or with dementia – as well as people with learning disabilities⁵, those who are homeless⁶ or in prison⁷, BAME groups⁸ including Gypsies and Travellers⁹, and LGBTQ+ people¹⁰.

Most people express a preference for home over hospital as the place of care at the end of their life and over the past decade, fewer people have been dying in hospital¹¹. The Covid-19 pandemic has increased the number of deaths taking place in care homes and private homes, and been a stress-test for whether our health and care system is meeting end of life care standards in the community.

A recent Marie Curie [survey of carers of people who died at home during pandemic](#) found that:

- 76% said their loved one did not get all the care and support they needed
- 64% said they did not get the care and support they needed with pain management
- 61% said they did not get the care and support they needed with personal care; and
- 65% said they did not get the care and support they needed out-of-hours.

¹ The term 'people' here and throughout this briefing refers to babies, children, young people and adults.

² Etkind, SN, Bone, AE, Gomes, B *et al.* How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 15, 102 (2017).

³ Bone *et al.* What is the impact of population ageing on the future provision of end of life care? Population based projections of place of death. *Palliative Medicine* 2018 – Feb; 32(2): 329-336.

⁴ Von Petersdorff C, Patrignani P, Landzaat W. Modelling demand and costs for palliative care services in England: A final report for Sue Ryder. London Economics 2021.

⁵ Tuffrey-Wijne I *et al.* People with learning disabilities who have cancer: an ethnographic study. *British Journal of General Practice* 2009; 59 (564): 503-509.

⁶ Shulman C *et al.* End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine* Vol 32, Issue 1 (2018).

⁷ Turner, M, & Peacock, M. Palliative Care in UK Prisons: Practical and Emotional Challenges for Staff and Fellow Prisoners. *Journal of Correctional Health Care*, 23(1), 56–65 (2017).

⁸ Evans N *et al.* Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy. *BMC Health Serv Res* 11, 141 (2011).

⁹ Dixon KC, Ferris R, Kuhn I, *et al.* Gypsy, Traveller and Roma experiences, views and needs in palliative and end of life care: a systematic literature review and narrative synthesis. *BMJ Supportive & Palliative Care* (2021).

¹⁰ Almack, K *et al.* Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual older people. *Sociology* 44(5): 908–924 (2010).

¹¹ Investing in quality. The King's Fund (2019).

The potential of the Health and Care Bill

The Health and Care Bill has the potential to achieve a step change in end of life experience by helping to unlock the potential of our health and care system to meet the needs of babies, children, young people and adults with a terminal illness and their carers.

- Provisions to support **integration and collaboration** could help deliver more joined up health and care for people at the end of life, provided people at the end of life have their voices heard in Integrated Care Systems.
- Clauses on **patients' right to make choices about their care** could help to realise personalised care and support for everyone at the end of life, if everyone had the right to be offered conversations about what matters most to them at the end of life.
- Powers to make **regulations on procurement** could mandate the commissioning of palliative and end of life care services to ensure the needs of people at the end of life are met, and to address the current neglect of these services in local commissioning.
- The clause on **hospital discharge and social care assessments** could help prevent people dying in hospital when they would prefer to be at home, if steps were taken to ensure their care and support needs are fully assessed and met in the community.
- The requirement for the Secretary of State to **report on the workforce needs of the health service in England** could help meet challenges facing the palliative and end of life care workforce if capacity and demand projections were a comprehensive and fully costed plan.
- Provisions on **adult social care data, quality assurance and financial assistance** to providers will address some challenges in social care for people at the end of life, but the Bill fails to bring forward proposals on comprehensive reform of social care. The Government has stated that it plans to do so later this year. For people at the end of life, the urgency of doing so cannot be over-emphasised.

Two vital amendments on palliative and end of life care

The Health and Care Bill is a wide-ranging piece of legislation that could be amended in a number of different ways to maximise its potential for people at the end of life. We propose making two amendments to the Bill which would help to ensure it works to improve health and care for people at the end of life.

Amendment One: Commissioning of palliative and end of life care services

Clause 15 of the Bill provides Integrated Care Boards with duties to commission hospital and other health services for those persons for whom they are responsible. ***We strongly believe that a duty for Integrated Care Boards to commission palliative and end of life care services should be included in this section.***

Too many people already miss out on the care and support they need at the end of life – particularly those from disadvantaged groups. Estimates suggest that while as many as 90% of people who die may have hospice and palliative care needs, only around 50% of people who die receive palliative care.

Healthcare spending is already concentrated towards the last years of life¹², and the challenges of providing sufficient palliative and end of life care will only grow as the UK's population continues to age. By 2030, one in five people in the UK will be aged over 65 and the number of people receiving these services is projected to increase from 47% of all deaths to 66% over the next decade. The number of children in England with life-limiting or life-threatening conditions increased from 32,975 in 2001/2002 to 86,625 in 2017/2018, and is projected to grow.

In this context, there are growing concerns about the financial sustainability of the palliative and end of life care sector and concerns about the sustainability of a fundraising model which relies so heavily on charitable giving.

¹² Lee T and Stoye G (2019). Variation in end-of-life hospital spending in England: Evidence from linked survey and administrative data. Institute for Fiscal Studies.

At the same time, the nature of care need is also changing – with an increasing proportion of people dying at home or in a care home – meaning there is a need to invest more in social care, primary care and communities to meet the unmet needs of people at the end of life and their carers.

The charitable sector plays a critical role in delivering palliative and end of life care – however, the uncertainty of its funding model undermines the ability of the sector to plan for the future and secure financial stability in the context of increasing need. Approximately two-thirds of the expenditure on hospice and palliative and end of life care services comes from charitable fundraising and one-third from the NHS and other statutory sources.

There is also an urgent need to improve funding for both generalist and specialist palliative care in the wider primary care sector to plan for a future of growing palliative care need, address gaps in the workforce and enable the system to plan for and prevent future crises.

If government does not commit to reforming how the hospice, primary care and wider sector is supported in future:

- People will not be able to receive the personalised palliative and end of life care that the NHS has committed to in the Long Term Plan
- The government will not meet its end of life care choice commitment
- People who need palliative and end of life care will experience too many unnecessary unplanned, emergency admissions to hospital; this will have a negative impact on their quality of life and incur unnecessary and growing costs for the taxpayer; it could also hinder the NHS's ability to meet the needs of the growing numbers of people waiting for planned care, delayed as a result of the pandemic
- Many providers of hospice and community palliative and end of life care will be unable to meet demand over the next decade, and there is a serious risk that the sector could collapse under the weight of the growing needs of the population and financial instability.

A duty for Integrated Care Boards to provide palliative and end of life care, based on projections of future local demand and capacity, would recognise that care for people at the end of their lives is a core part of the health and care system.

We believe that there should be a fundamental right to access to palliative and end of life care and support services for everyone who needs it. However, this right can only be met if relevant authorities have a duty to commission sufficient palliative and end of life care services to meet people's needs.

About the proposed amendment

Clause 15 of the Bill provides Integrated Care Boards with duties to commission hospital and other health services for those persons for whom they are responsible.

It includes duties to provide dental services, nursing and ambulance services, and services or facilities for the care of pregnant women, women who are breastfeeding and young children.

We recommend amending this clause to introduce a requirement for integrated care boards to arrange for the provision of palliative and end of life care services as follows:

- *In every setting including private homes, care homes, hospitals, hospices and other community settings;*
- *Including hospice and other palliative care beds when required, including on an urgent basis;*
- *Making specialist and generalist palliative care available on a 24/7 basis;*
- *Ensuring the right, skilled workforce, equipment and medication is available to deliver this care;*
- *Providing support by telephone from qualified healthcare professionals;*
- *Ensuring a point of contact is available for people with palliative and end of life care needs if their usual source of support is not accessible; and*
- *Ensuring systems are in place to share information about the person's needs with all professionals involved in their care, provided they give consent for this.*

During debate of this amendment at the Committee stage of the bill, the Minister of State for Health, Edward Argar MP, responded that:

[MPs were] *absolutely right to highlight the amazing work being done by hospices ... in providing end of life and palliative care*. However, he then went on to state that the duty on Integrated Care Boards to arrange services does not apply if NHS England has a duty to arrange for their provision, arguing that some services are best commissioned nationally such as specialised services.

Pushed to give assurances that palliative care services were indeed the responsibility of ICS Boards to provide “care” and “after-care”, the Minister replied that *‘My understanding is that palliative care services and similar, as she has alluded to, would be captured ... it would encompass the services to which she has alluded.’*

While it is positive that the Government highlighted the work of hospices and the importance of palliative and end of life care, we are not satisfied that the definition of after-care services in the Bill can reliably be interpreted as requiring ICS Boards to commission palliative and end of life care services and continue to believe that it is necessary for these services to be specifically required through this amendment.

The amendment was not pressed to a vote in Committee.

Amendment Two - Patient choice

Clauses 67 and Schedule 11 relate to patients’ rights to make choices about their care and have the potential to help realise personalised care and support for everyone at the end of life, regardless of background or social characteristics.

Putting people’s individual preferences at the heart of the care and support they receive is critical to improving end of life experience for all. ***Achieving this would require a responsibility for health and social care commissioners to make provision for any individual nearing the end of their life to be offered conversations about their holistic needs, wishes and preferences.***

Discussion and recording of choices about future medical treatments at the end of life is known as Advance Care Planning. Studies suggest that advance care planning has a number of benefits including increased compliance with people’s end of life wishes¹³ and reduced care costs¹⁴. One study suggests it could reduce hospital bed days for people approaching the end of their lives by around half and reduce unplanned admissions by as much as two-fifths.¹⁵ Reducing unplanned hospital admissions would not only be less distressing for patients and their families, but would also reduce pressure on NHS hospitals – with around 5.5 million bed days among people in the last year of life in England, we estimate that the total cost of these admissions is more than £1.2bn¹⁶.

Experience during the COVID-19 pandemic has improved awareness of advance care planning conversations. However, there are risks that such conversations do not take place, or when they do, that they are hurried and focused narrowly on medical needs, offered to cohorts of the population rather than based on a clinician’s judgment, or that the quality of conversations and documentation is poor. They tend to concentrate on place of death and what treatment a person is *not* prepared to receive such as ‘Do Not Attempt Cardiopulmonary Resuscitation’ orders.¹⁷ While these wishes are important, focusing on what treatment people do not want towards the end of life is insufficient for ensuring personalised care.

Tools such as the [Support Needs Approach for Patients \(SNAP\)](#) approach¹⁸, the [Daffodil Standards](#) developed by Marie Curie and the Royal College of General Practitioners¹⁹ and the [RED-MAP tool](#) developed by the University of

¹³ Brinkman-Stoppelenburg, A, Rietjens, JAC, van der Heide, A. The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*; Sep 2014; vol. 28 (no. 8); p. 1000-1025 (2014).

¹⁴ Klingler C, in der Schmitzen J, Marckmann G. Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. *Palliative Medicine* 2016;30(5):423-433 (2016).

¹⁵ Baker A et al. Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation. *British Journal of General Practice* 2012; 62 (595): e113-e120 (2012).

¹⁶ Based on NICE estimate of care in an acute bed costing on average £222 per day.

¹⁷ Care Quality Commission. ‘Decisions about living and dying well during Covid-19’. (2021)

<https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19>

¹⁸ Gardener AC, Ewing G, Deaton C, Farquhar M (2021). Understanding how the Support Needs Approach for Patients (SNAP) enables identification, expression, and discussion of patient support needs: a qualitative study. *Chronic Illness*.

¹⁹ RCGP. [The Daffodil Standards](#).

Edinburgh²⁰ facilitate more meaningful and person-centred conversations between health and care professionals and individuals, their families or their legal proxies about their care choices, goals and preferences at the end of life.

Everyone nearing the end of their life should have the right to be offered a holistic conversation about their needs, wishes and preferences – what matters most to them at the end of life. ***The responsibility for delivering this should be placed on commissioners of health services, in order to ensure that the approach taken responds to the local context, and the needs of their local community.***

This conversation should be centred around and involve the person and those important to them, covering all aspects of a person’s care and support needs, wishes and preferences; and it should be conducted in accordance with best practice as set out in the [What Matters Most Charter](#) and [ReSPECT process](#). This should be recorded, reviewed, and updated when appropriate, and shared with and acted upon by all health and care professionals involved in caring for them. If the person, and everybody involved in their care, are clear on the plan, this is more likely to result their choices being met in an emergency.

It is also critical that such conversations are used in order to provide people with services which can help to ensure these needs are met. For this reason, we recommend that relevant authorities (as set out on clause 68 of the Bill) must have regard to the preferences stated through such conversations in making decisions about the commissioning of services.

About the proposed amendment

Clause 67 updates rules around patient choice, making it mandatory for NHS England and Integrated Care Boards to allow patients to make choices about their care. The existing power to issue regulations under this section is changed from a ‘may’ to a ‘must’.

We recommend that:

**Clause 67 is amended to introduce a new right for everyone with a diagnosis of terminal illness to be offered a conversation about ‘what matters most to them’ including, their holistic needs, wishes and preferences for the end of their life – including addressing support for their mental and physical health and wellbeing, financial and practical support, and support for their social relationships, and that,*

**Where that individual lacks capacity for such a conversation, this is offered to another relevant person, and that,*

**A “relevant authority” as defined in clause 68 of the Bill must have regard to the needs and preferences recorded in such conversations in making decisions about the procurement of services.*

During debate of this amendment at the Committee stage of the bill, the Minister of State for Health, Edward Argar MP, responded that:

“It is of course incredibly important that anyone at the end of their life, whether or not they have been diagnosed with a terminal illness, has the opportunity to discuss their needs, wishes and preferences for their future care, so that they can be fully taken into account” and referenced recent government initiatives related to this.

While we appreciate the support from the Government for the principles of ACP and its recognition of the importance of patient choice at the end of life, we continue to believe that non-statutory initiatives to promote ACP have been insufficient to ensure that patients at the end of life are involved in decisions about their care or that such discussions are in line with best practice. We continue to believe that there is a case to amend the Bill to require these conversations through this amendment.

The amendment was not pressed to a vote in Committee.

For more information on the issues covered in this briefing, please contact parliament@mariecurie.org.uk

²⁰ Healthcare Improvement Scotland. [Anticipatory care planning](#).