Marie Curie Parliamentary briefing

The Health & Care Bill: Committee Stage

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.

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

To help achieve this, we propose two changes to the Bill as currently drafted:

- There should be a requirement for palliative and end of life care services to be commissioned in every part of England.
- Everyone should have a legal right to be offered a conversation about what matters most to them at the end of their life.

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 to make 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 people 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 conditions.[1] The number of people dying with a need for palliative care is projected to increase by up to 42% by 2040.[2]

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 palliative care, only around 50% of people who die actually receive it.[3]

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 disabilities[4], those who are homeless[5] or in prison[6], BAME groups[7] including Gypsies and Travellers[8], and LGBTQ+ people[9].

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 hospital.[10] 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.

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[1] 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).

[2] 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 Medicine2018 – Feb; 32(2): 329-336

[3] 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.

[4] 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.

[5] 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).

[6] 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).

[7] 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).

[8] 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).

[9] 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).

[10] Investing in quality. The King's Fund (2019).

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.*

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 people 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 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 comprehensive and fully costed.
- 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 reform of social care funding. 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 prioritising two amendments that we feel have the most potential to improve health and care for people at the end of life.

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

The Bill gives Integrated Care Boards duties to commission hospital and other health services for those persons for whom they are responsible. ***Marie Curie strongly believes that a duty for Integrated Care Boards to commission palliative 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 palliative care needs, only around 50% of people who die receive palliative care.

The challenge of providing sufficient palliative and end of life care is only going to 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.

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.

At the same time, the nature of care needed is also changing – with an increasing proportion of people dying at home or in a care home – putting more pressure on the cost of social care provision at the end of life.

The charitable sector plays a critical role in delivering palliative and end of life care – however, the uncertainty of its funding model and reliance on charitable donations 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.

If the government does not commit to reforming how the hospice 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 palliative and end of life care providers 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 care would recognise that care for people at the end of their lives is a core part of the health and care system. Marie Curie believes that there should be a fundamental right to access to palliative care services for everyone who needs it. However, this right can only be met if relevant authorities have a duty to commission sufficient palliative care services to meet people's needs.

About the proposed amendment

The Bill gives Integrated Care Boards 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.

Marie Curie recommends amending the Bill to introduce a requirement for Integrated Care Boards to arrange for the provision of palliative care services as follows:

- *In every setting including private homes, care homes, hospitals, hospices and other community settings;*
- *Including hospice beds when required, including on an urgent basis;*
- *Making specialist and generalist palliative care available every day of the week;*
- *Ensuring the right 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 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.*

Amendment Two - Patient choice

The Bill includes provisions on patients' rights to make choices about their care, and has 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 right for every individual to be offered conversations about their holistic needs, wishes and preferences for the end of their life.***

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 wishes[11] and reduced care costs[12]. 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.[13]

Experience during the Covid-19 pandemic has highlighted problems with advance care planning conversations. Often such conversations do not take place, or when they do, they are hurried and focused narrowly on medical needs or offered to cohorts of the population rather than based on a clinician's judgment. They tend to concentrate on place of death and what treatment a person is *not*

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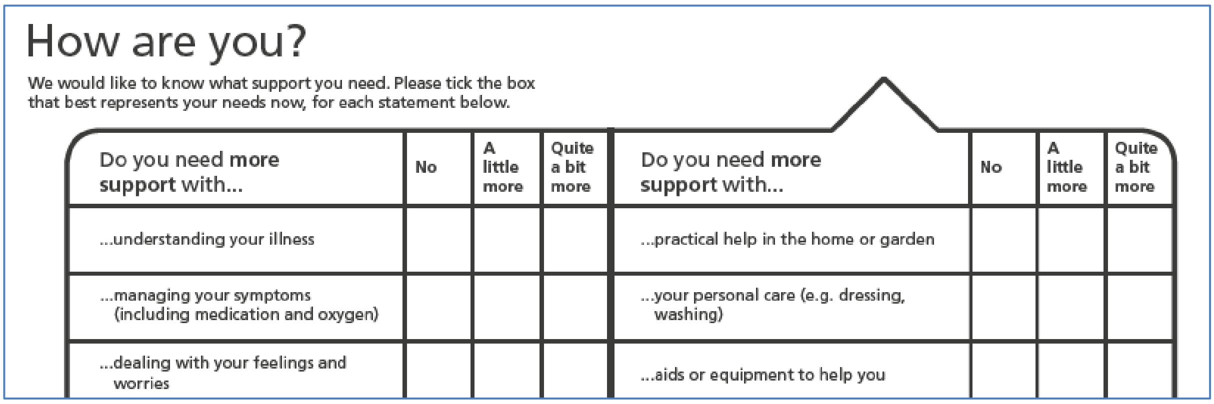
[11] Brinkman-Stoppelenburg, A, Rietjens, JAC, van der Heide, A. The effects of advance care planning on end-of-life care: A systematic review. Palliative Medicine; Sep 2014; vol. 28 (no. 8); p. 1000-1025 (2014).

[12] Klingler C, in der Schmitten 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).

[13] 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).

prepared to receive such as ‘Do Not Attempt Cardiopulmonary Resuscitation’ orders.[14] While these wishes are important, knowing what treatment people do not want towards the end of life is insufficient for ensuring personalised care.

The Support Needs Approach for Patients (SNAP) is one example of an approach to conversations about end of life preferences which seeks to enable person-centred care for adults with chronic or progressive conditions. SNAP helps people identify and express their support needs, and then discuss them with their health care professional. The SNAP Tool is short and simple to use. It helps people identify and express their support needs to a professional, acting as a prompt to help start a needs-led conversation about their unmet support needs. The SNAP Tool uses a simple question and tick box format to ask people to show the full range of their support needs. The content of the SNAP Tool is evidence-based and has been validated in a population of adult patients with chronic progressive disease.[15]



How are you?

We would like to know what support you need. Please tick the box that best represents your needs now, for each statement below.

Do you need more support with...	No	A little more	Quite a bit more	Do you need more support with...	No	A little more	Quite a bit more
...understanding your illness				...practical help in the home or garden			
...managing your symptoms (including medication and oxygen)				...your personal care (e.g. dressing, washing)			
...dealing with your feelings and worries				...aids or equipment to help you			

The Daffodil Standards, developed in partnership by Marie Curie and the Royal College of General Practitioners, are another example of how clinicians can deliver quality care to people approaching the end of life, and their families. The Daffodil Standards are a blend of quality statements, evidence-based tools, reflective learning exercises and quality improvement steps aimed at General Practitioners (GPs) to help them improve care for patients; Standard 5 covers assessing the unique needs of each patient and providing personalised care planning. The Daffodil Standards support quality improvement across GPs and care homes to enable consistency of care to all that need it and are recognised by the CQC in England as a robust framework that evidence the quality of care[16].

The RED-MAP tool developed by the University of Edinburgh is also designed to facilitate meaningful conversations between health and care professionals and individuals, their families or their legal proxies about their care choices, goals and preferences. The tool is designed to support professionals to have sensitive and effective communication with patients, adapted to each individual and their situation[17].

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.

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[14] 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

[15] The SNAP Tool is copyrighted. A licence is required for organisations using the tool (free to NHS and not-for-profit organisations; licence requests via the licence page on the SNAP website: https://thesnap.org.uk/).

[16] RCGP. The Daffodil Standards.

[17] Healthcare Improvement Scotland. Anticipatory care planning.

This conversation should cover 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. The person's individual needs, wishes preferences should be recorded, reviewed and updated when appropriate, as well as being shared with and acted upon by all health and care professionals involved in caring for them.

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 must have regard to the preferences stated through such conversations in making decisions about the commissioning of services.

About the proposed amendment

The Bill 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:

**The Bill is amended to introduce a new right for everyone with a diagnosis of terminal illness to be offered a conversation about 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.*

For further information or discussion on any of the issues covered in this briefing, please do not hesitate to contact Marie Curie's Policy & Public Affairs team at parliament@mariecurie.org.uk

Marie Curie is the leader in end of life experience in the UK. We work hard to provide a better life for people living with a terminal illness and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives. Our free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

We are the largest charitable funder of palliative and end of life care research in the UK and campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.