Written evidence on the Health and Care Bill submitted by Marie Curie (HCB02)

In this submission, Marie Curie makes the case for ensuring the needs of people at the end of life are at the centre of the Health and Care Bill. We also draw the Committee's attention to areas of the Bill requiring further exploration to ensure our health and care system delivers the best possible end of life experience.

Summary of key points:

- ***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.***
- ***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.***
- ***Patients' rights to make choices about their care could help deliver personalised care for everyone at the end of life, if individuals were guaranteed the right to be offered a conversation about their needs, wishes and preferences for the end of their life.***
- ***Powers to make regulations in relation to 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 such services in local commissioning.***
- ***Integration and collaboration have the potential to deliver more joined up health and care for people at the end of life, but only if the voices of people at the end of life and providers and professionals with relevant expertise are placed at the centre of Integrated Care Systems.***
- ***Assessing care and support needs after hospital discharge could help people realise individual choices about where to spend the end of life, but a new duty is needed to ensure each person's health and care needs are promptly and fully assessed in all settings, including care homes and private homes.***
- ***The requirement for the Secretary of State to publish every five years a report on the workforce needs of the health service in England is wholly inadequate given the scale of the challenges facing the palliative and end of life care workforce in both the health and social care sectors.***
- ***The Bill fails to bring forward proposals on reform of social care funding and 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.***

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

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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 School of 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).

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.

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

Areas of the Bill requiring further exploration

Below, we indicate key areas of the Bill requiring further exploration in order to realise its potential to ensure our health and care system meets the needs of people with a terminal illness and their carers.

These areas are listed in the order in which the relevant clauses appear on the face of the Bill, but we draw the Committee's attention in particular to our two priority areas for exploration - **Patient choice** and **Commissioning of palliative and end of life care services** on pages 6-9 of this submission.

Integration and collaboration

Part 1 provisions to support integration and collaboration have the potential to deliver more joined up health and care for people at the end of life, but only if the voices of people at the end of life and providers and professionals with relevant expertise are placed at the centre of Integrated Care Systems.

Without amendments to the Bill to guarantee this, there is a risk that Integrated Care Systems simply reproduce the poor track record of predecessor models of health and care on meeting the needs of people with terminal illness and their carers. For example, a recent study found that only half of Health and Wellbeing Strategies in England mentioned end of life care, only 4% prioritised it, and none cited evidence for effective interventions;[11]

We propose the following areas for exploration to ensure Integrated Care Systems result in plans, financial allocations and commissioned services that are focused on meeting the needs of people at the end of life in local populations:

Schedule 2 inserts a new Schedule 1B into the NHS Act which sets out further detail about Integrated Care Bodies (ICBs). The Schedule provides that the composition of the ICB will, at a minimum, consist of a chair, CEO, and at least 3 other members known as 'ordinary members'.

- We recommend adding a requirement for Integrated Care Bodies to include in their membership at least one member with expertise in palliative and end of life care.

Clause 19 of the Bill provides requirements for ICBs to involve the public (whether by consultation or otherwise) and patients in the commissioning process, which appear to be broadly similar to existing duties on Clinical Commissioning Groups (CCGs).

- We recommend adding a requirement for ICBs to involve people with a terminal illness and their carers in the commissioning process.

Clause 20 requires the establishment of an Integrated Care Partnership (ICP) to bring together health, social care, public health, and wider partners. The ICP membership will include as a minimum one member appointed by the ICB, one member appointed by each of the relevant local authorities, and any other members appointed by the ICP.

- We recommend requiring the inclusion of at least one member representing charity sector providers of palliative and end of life care (PEOLC), because these providers currently deliver most the of existing PEOLC service provision in England.

Clause 20 also requires the ICP prepare an 'integrated care strategy' to address the health, social care and public health needs of its system, building on the relevant joint strategic needs assessments. There is a requirement for local authorities and the ICB, in response to and with regard to the integrated care strategy, to create a joint local health and wellbeing strategy.

- We recommend a requirement to ensure the 'integrated care strategy' and the 'joint local health and wellbeing strategy' address the needs of people at the end of life.

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[11] Sleeman KE, Leniz J, Higginson IJ, Bristowe K. Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health care strategies. Palliat Med. 2018 Oct;32(9):1474-1486 (2018).

Workforce

Clause 33 places a duty on the Secretary of State to publish, at least once every five years, a report on the system in place for assessing and meeting the palliative and end of life care workforce needs in both the health and social care sector. This clause requires amendment to ensure workforce plans are fit for purpose.

Current recommendations for the number of palliative medicine specialists equate to only 0.8 workers (FTE) per population of 100,000 people in the UK, compared to 2.2 workers in Ireland and 1.5 in Australia. Recent changes to the GP contract have made it harder for GPs to develop a specialism in palliative and end of life care, yet they and district nurses are having to deliver more palliative and end of life care in the community. The nursing workforce is also facing significant challenges around recruitment and retention.[12]

The social care workforce is also under pressure. In 2019/20, the estimated staff turnover rate in the adult social care sector was 30.4%, equivalent to approximately 430,000 leavers over the year. It is estimated that 7.3% of the roles in adult social care were vacant, equal to approximately 112,000 vacancies at any one time. Around a quarter of the workforce (24%) and almost half (42%) of the domiciliary care workforce were on zero-hours contracts.[13]

Every health and social care worker is likely to be involved in caring for people experiencing dying, death or bereavement at some point in their career, but palliative and end of life care training is not currently a compulsory part of either initial training or continuing professional development for most workers. Barriers also exist for workers seeking to work flexibly across different settings, such as inconsistent requirements in areas such as safeguarding.

A report from the Secretary of State to Parliament on the healthcare workforce once every five years is insufficient for meeting these challenges. The Bill should introduce a statutory duty for a more regular independent assessment of health and social care workforce projections and a requirement on Government to respond to that assessment. It should also make end of life care a compulsory part of initial and ongoing training for all health and social care workers.

Clause 33 sets out a duty on the Secretary of State to publish, at least once every five years, a report on the system in place for assessing and meeting the workforce needs of the health service in England.

In line with recommendations from the Royal Colleges, King's Fund, Nuffield Foundation, and the Health Foundation, we recommend that this clause is amended to:

- Place a duty on Health Education England to publish annual, independently verified, projections of the future supply of the palliative and end of life health care workforce in England and how those projections compare to projected demand for healthcare

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[12] https://apmonline.org/wp-content/uploads/2019/08/palliative-medicine-workforce-report-2019-2.pdf

[13] https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx

workforce in England for a 15 year period consistent with the long-term projections of health care spending produced by the Office for Budget Responsibility (OBR).

- Place a duty on the Secretary of State for Health and Social Care to ensure that annual independently verified projections of the future supply of social care workforce in England are published, setting out how those projections compare to projected demand for social care workforce in England for a 15 year period, consistent with the long-term projections of adult social care spending produced by the OBR.
- Require the publication of the assumptions underpinning the projections for the workforce flows from and to the other UK countries; and immigration and out-migration of the registered professions in health care.
- Require the process for independent verification and a fixed annual date for publication to be published in advance.
- Ensure that the Independent verification of the projections meet the relevant standards set out in the National Statistics Authority's code for official statistics for collecting, preparing, analysing and publishing government statistics.

Marie Curie also recommends that the Bill is amended to:

- Require palliative and end of life care training as a compulsory part of initial training and continuing professional development for all health and social care workers, not just those in regulated professions, for example through inclusion on the General Practitioner and Nursing curriculums.

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 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[14] and reduced care costs[15]. One study suggests it can 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.[16]

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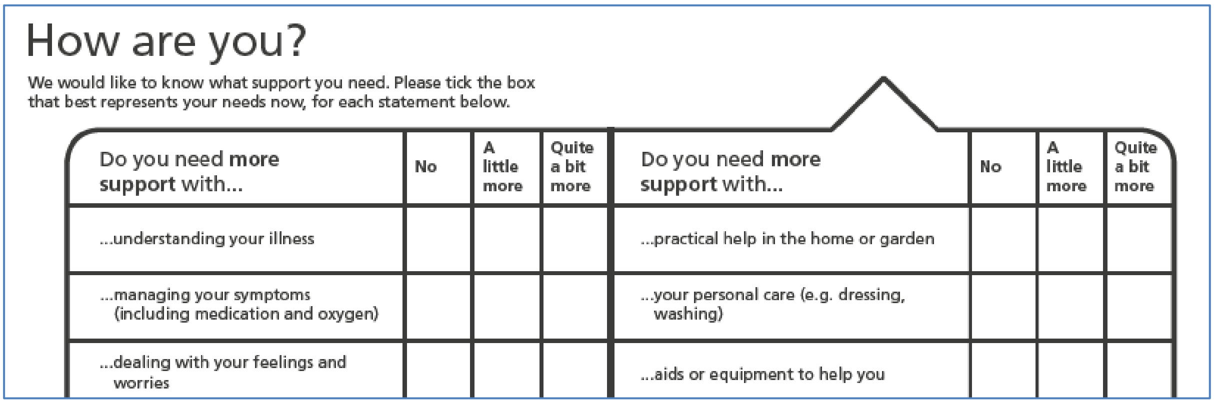
[14] Brinkman-Stoppelenburg, A, Rietjens, JAC, van der Heide, A. The effects of advance care planning on end-of-life care: A systematic review. Palliative Medicine; Sep 2014; vol. 28 (no. 8); p. 1000-1025 (2014).

[15] 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).

[16] 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).

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* prepared to receive such as 'Do Not Attempt Cardiopulmonary Resuscitation' orders.[17] 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 alternative approach 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.[18]



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[19].

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

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[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] 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/).

[19] RCGP. The Daffodil Standards.

to have sensitive and effective communication with patients, adapted to each individual and their situation[20].

Everyone nearing the end of their life should have the right to be offered a conversation about their needs, wishes and preferences – what matters most to them at the end of life. 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 (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.

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'.

Subsection 3 inserts new sections that: provide an enforcement mechanism for NHS England to enforce the patient choice requirements; require NHS England to publish guidance on how it intends to exercise its patient choice power and consult appropriate people before publishing or revising guidance; and require Secretary of State approval for guidance.

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 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 commissioning of services.

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[20] Healthcare Improvement Scotland. Anticipatory care planning.

Commissioning of palliative and end of life care services

Clause 68 enables the Secretary of State to make regulations in relation to the procurement of health care services in England and the procurement of health care services as part of mixed procurements e.g., with social care services.

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 are required to commission sufficient palliative care services to meet people's needs.

There are growing concerns about the financial sustainability of the end of life care sector and concerns about the sustainability of a fundraising model which relies so heavily on charitable giving.

Charitable hospices are the main providers of specialist palliative and end of life care in the UK, yet they currently receive only around 30% of their funding from government and NHS sources, and have to raise the rest through their own efforts including fundraising activities and charity shops.[21] Hospice income has been badly hit by the pandemic, and many charitable hospices will struggle to match the government's new offer of a 3% pay rise for NHS nurses.

Without a requirement to commission sufficient palliative care, many 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.

Clause 68 enables the Secretary of State to make regulations in relation to the procurement of health care services in England and the procurement of health care services as part of mixed procurements e.g. with social care services.

Marie Curie recommends amending this clause to introduce a requirement for relevant authorities to commission sufficient specialist and generalist palliative care services to meet the needs of all those who need this.

Hospital discharge and social care assessments

Clause 78 revokes the requirement for needs assessments to be carried out prior to a person's discharge from hospital, making permanent changes introduced during the pandemic to facilitate speedy discharge from hospital.

This clause could help ensure people can make real choices about place of care at the end of life, reducing the likelihood of them dying in hospital if they would prefer to spend their last few days and weeks at home. However, the proposals carry the risk of a person's needs not being assessed or delays in assessment of their needs once they have been discharged into the community.

Prior to the pandemic, just 7% of people expressed a preference for dying in hospital, yet that is where nearly half of all deaths took place.[22] One key reason why so many people were unable realise their preference for home as the place of care is that performance in fast-track continuing

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[21] Hospice UK. Hospice facts and figures.

[22] NatCen Social Research. British Social Attitudes Survey 30 https://www.bsa.natcen.ac.uk/media/38850/bsa_30_dying.pdf

healthcare has long been characterised by delays and failures to put packages in place, as well as a postcode lottery of variable performance in different parts of England.[23]

A second key reason why people are unable to realise their preference for home as the place of care is that they are unable to access the full range of care and support services they require in community settings, especially out-of-hours access to palliative and end of life care.

Finally, as outlined above, if conversations about a person's care preferences at the end of life do not take place, this may lead to more unplanned admissions as these interventions are correlated with lower hospital attendances and admissions.

Multiple, unplanned admissions to hospital are incredibly distressing for people nearing the end of life, and their families. Emergency admissions also have significant financial implications for the NHS. We estimate that the total cost of emergency admissions for people in the last 12 months of life exceeded £1.2bn in 2018-19.[24]
Discharge to assess proposals in clause 78 require improvement to ensure the needs of people discharged into the community are promptly and fully assessed.

Clause 78 revokes the requirement for needs assessments to be carried out prior to a person's discharge from hospital, making permanent changes introduced during the pandemic to facilitate speedy discharge from hospital.

We recommend a new duty to ensure each person's health and care needs are promptly and fully assessed in all settings, including private homes and care homes.

Social care for people at the end of life

Part 2 and Part 5 provisions on adult social care data, quality assurance of social care and financial assistance to social care providers have the potential to address some challenges in social care for people at the end of life, but

Social care is a vital form of support for people at the end of life who are living in care homes and private homes, especially those who live alone and rely heavily on paid care. Marie Curie welcomes proposals in the Bill to improve the quality of social care including: the new assurance framework for social care; the new duty for the Care Quality Commission to assess local authorities' delivery of their adult social care duties; and the new power for the Secretary of State to intervene where local authorities are failing to meet their duties.

The Bill fails to bring forward proposals on reform of social care funding and 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. Current estimates suggest that there is a gap of at least £6.1 billion between the funding councils have available for adult social care and future demand for these services up to 2030/31.[25]

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[23] Marie Curie, 'When time really matters: Fast track care at the end of life' (2018).

[24] Marie Curie, 'In and out of hospital: Emergency hospital admissions and A&E attendances in the last year of life in England' (2021).

[25] The Health Foundation 'Social Care Funding Gap' Idriss et al (2021).

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.

For further information on any of the issues covered in this briefing or Marie Curie's wider work in Parliament please email Ruth Driscoll via Parliament@mariecurie.org.uk

Friday 30th July 2021.