# Parliamentary briefing on the Health and Care Bill
## Clause 16: A vital amendment 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 specialist palliative care, prevent future crises and help ensure that nobody misses out on the care and support they and their families need during life limiting illness, 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 are calling for Clause 16 of the Bill to be amended to add a requirement for specialist palliative care services to be commissioned in every part of England. Baroness Finlay of Llandaff has tabled an amendment to this effect for consideration during the Bill's Committee Stage in the House of Lords.**

A similar amendment was debated during the Bill's passage through the House of Commons. While we appreciate assurances from the Government in respect of the importance of palliative care during the Commons debates, the Bill as currently drafted is insufficient for ensuring palliative care services are commissioned in every part of England.

***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 during their final illness and around death, both now and in the future.***
- ***Clause 16 of the Bill provides Integrated Care Boards with duties to commission hospital and other health services including specific services such as maternity, dental and ophthalmic services; however, the clause fails to mention specialist palliative care.***
- ***Of the 23 ICS Boards that have published their strategies ahead of the implementation of the Bill, just six have identified palliative care as a priority area and only three have identified measures of success relating to palliative care, such as reduced hospital admission.***
- ***76% of bereaved carers said their loved one did not get all the care and support they needed towards the end of life and 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 palliative care need is projected to increase by up to 42% by 2040.***
- ***Too many people already miss out on the care and support they need towards and 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 any palliative care.***
- ***A duty for Integrated Care Boards to commission specialist palliative care services could help to ensure the needs of people facing the end of life are met, and to address the current neglect of such services in local commissioning.***

# Rationale for amending Clause 16

## Why palliative care matters

The United Kingdom is at a critical moment for improving palliative care. As a result of our ageing population, in twenty years' time there will be 100,000 more people[1] dying each year in the UK – demand for palliative care will increase rapidly, with the number of people dying with a need for palliative care projected to increase by up to 42%.

Everyone deserves the best possible experience during their final illness and at end of life, 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 have a need for some specialist or generalist palliative care, only around 50% of people who die actually receive it.

Research by Marie Curie and others indicates that certain groups face particular barriers in access to palliative care, including people who are living in poverty, alone, or with dementia – as well as people with learning disabilities, those who are homeless or in prison, BAME groups and LGBTQ+ people.

The Covid-19 pandemic has been a stress-test for whether our health and care system is meeting the needs of people dying in all settings, with a significant rise in the number of deaths occurring in people's homes and care homes. A recent Marie Curie survey of carers of people who died at home during pandemic found that 76% felt their loved one did not get all the care and support they needed.

## Current commitments are not enough

Clause 16 of the Bill provides Integrated Care Boards with duties to commission hospital and other health services for those persons for whom they are responsible. Several specific services are highlighted in Clause 16, with a duty for commissioners to ensure they are provided, such as maternity, dental and ophthalmic services; however, the clause fails to mention specialist palliative care as currently drafted.

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, too many people already miss out on palliative care at the end of their lives; 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 any level of palliative care.

During debate of a similar amendment at the Commons Committee stage of the Bill, the Minister of State for Health, Edward Argar MP, indicated that the Government's view is that wording in Clause 16 requiring ICS Boards to provide "after-care" would encompass palliative care services.

However, palliative care services should not be understood as 'after-care' that occurs only once other options have been exhausted. These services are often provided in parallel to other treatments and services; defining palliative care as 'after-care' sends the wrong message – that it is a last resort when other options have been exhausted, when it is often too late for palliative care to be of full benefit.

In addition, despite a version of the language in Clause 16, including "after-care," having been in place since at least the 2012 Act, many Clinical Commissioning Groups (the responsible body under the 2012 Act) do not currently commission sufficient specialist palliative care.

Similarly, of the 23 ICS Boards that have published their strategies ahead of the implementation of the Health & Care Bill, just six have identified palliative care as a priority area and only three have identified measures of success relating to palliative care, such as reduced hospital admissions[2]. This is concerning, as ICS strategies set out the future direction for the ICS, and which areas of care will be prioritised.

We therefore continue to believe that there is a case to amend Clause 16 to provide Integrated Care Boards with a duty to commission palliative care.

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

[2] Research from academics at the Cicely Saunders Institute, King's College London.

### The benefits of improving palliative care availability

Improving the availability of specialist palliative care services will have a number of benefits to people at the end of life, including increased compliance with people's end of life wishes and reduced care costs. Ensuring proper palliative care is available to people nearing the end of life has been shown to also reduce pressure on NHS services, including by reducing hospital bed days for people at the end of life and reducing unplanned hospital admissions.

Reducing unplanned and potentially avoidable 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 £1.2bn[3].

By 2030, one in five people in the UK will be aged over 65 and the number of people receiving palliative care services is projected to increase from 47% of all deaths to 66% over the next decade. 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 – which will lead to growing pressure on primary care, social care and communities.

In this context, there are growing concerns about the sustainability of the palliative care sector and its funding model. Approximately two-thirds of expenditure on palliative care services comes from charitable fundraising and one-third from the NHS and other statutory sources; improving the availability of commissioned services will provide the sector with financial stability, supporting it to plan for the future.

## About the proposed amendment

Clause 16 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 and young children.

***We recommend amending this clause to introduce a requirement for integrated care boards to arrange for the provision of specialist palliative care services.***

These commissioned services should include:

- Providing support in every setting including private homes, care homes, hospitals, hospices and other community settings;
- Including hospice and other palliative care beds when required, including admission on an urgent basis;
- Making specialist palliative care advice 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 specialist 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.
- Supporting advance care planning development in all services to ensure patients are able to have open conversations about their needs and concerns.

A similar amendment was discussed in the Commons Committee stage (see above) but was not pressed to a vote.

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