

ACCESS TO PALLIATIVE CARE BILL [HL]

EXPLANATORY NOTES

What these notes do

These Explanatory Notes relate to the Access to Palliative Care Bill [HL] as introduced in the House of Lords on 5 July 2017 (HL Bill 33).

- These Explanatory Notes have been prepared by Baroness Finlay of Llandaff, the Peer in charge of the Bill, in order to assist the reader of the Bill and to help inform debate on it. They do not form part of the Bill and have not been endorsed by Parliament.
- These Explanatory Notes explain what each part of the Bill will mean in practice; provide background information on the development of policy; and provide additional information on how the Bill will affect existing legislation in this area.
- These Explanatory Notes might best be read alongside the Bill. They are not, and are not intended to be, a comprehensive description of the Bill.

Contents

| | |
|--|----------|
| Overview of the Bill | 2 |
| Policy and legal background | 2 |
| Territorial extent | 3 |
| Commentary on provisions of the Bill | 3 |
| Clause 1: Palliative care support | 3 |
| Clause 2: Duty to produce a strategy on the provision of palliative care support | 3 |
| Clause 3: Interpretation | 3 |
| Clause 4: Extent, commencement and short title | 3 |
| Commencement | 3 |
| Financial implications of the Bill | 4 |

Overview of the Bill

- 1 This Bill creates a duty for Clinical Commissioning Groups (CCGs) based in England to ensure that persons in their area with palliative care needs have access to palliative care services. Individual CCGs are also required to prepare and publish a strategy about how they will meet this obligation.

Policy and legal background

- 2 According to the Office of National Statistics, 495,309 people died in England in 2015, a figure which it expects to increase with the population size and age.
- 3 Palliative care means care which is delivered to seek to improve the quality of life of persons with life-limiting illness or approaching the end of life, through the prevention and relief of suffering by means of early identification, assessment, treatment and management of pain and other problems whether physical, psychological, social or spiritual. Palliative care differs from curative strategies in focusing primarily on the consequences of a disease rather than its cause or specific cure. Palliative care is intended to complement oncological or other disease-focused treatments and not substitute for or replace them.
- 4 Research published in *Palliative Care* concludes that around three quarters of people will require some form of palliative care during their last illness.¹ Analysis published in *BMC Medicine* in May 2017 suggests that demand for palliative care across England and Wales will rise by 40% by 2040.²
- 5 In February 2017, the Marie Curie charity and *Nursing Standard* published a report concluding that two thirds of nurses do not have time to offer a high level of care for dying people.³ An analysis by Hospice UK, published in May 2016, identified that 27% of CCGs did not have a strategy to address end of life care in their area.⁴
- 6 The Health and Social Care Act 2012 gives authority over the commissioning of palliative care in England to CCGs. They have a duty to commission health services (implicitly including palliative care) based on the assessed needs of their local population.
- 7 In Wales, the principle of seven-day working by clinical nurse specialists has been in place since the Palliative Care Planning Group Report (2008)⁵ chaired by Viv Sugar was implemented.
- 8 By requiring a published assessment of need and criteria for need to be met, the Bill aims to provide transparency between different CCGs, facilitating the sharing of best practices and allowing variable outcomes to be analysed.

¹ Murtagh FEM, Bausewein C, Verne J, Groeneveld EI., 'How many people need palliative care? A study developing and comparing methods for population-based estimates'. *Palliative Medicine*, 2014, vol 28(1), pp 49–58
<https://journals.sagepub.com/doi/pdf/10.1177/0269216313489367>

² S.N Etkind et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', *BMC Medicine*, 18 May 2017, vol 15 (102)
<https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

³ Marie Curie, '[Nursing Standard - Marie Curie Survey Findings](#)', 22 February 2017

⁴ Hospice UK, 'A low priority? How local health and care plans overlook the needs of dying people', 21 May 2016, p 3
<https://www.hospiceuk.org/policy-advocacy/briefings-consultations?page=4>

⁵ All Wales Palliative Care Planning Group, '[Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services](#)', June 2008.

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- 9 The Bill has been shortened compared to previous versions of this Bill. It now makes provision for individual CCGs to establish local strategies for palliative care, helping ensure local autonomy. This is in accordance with the principle of local autonomy established in the Health and Social Care Act 2012.

Territorial extent

- 10 This Bill will apply to England only. This is because health policy is devolved to the Scottish Parliament, the Welsh Assembly and the Northern Ireland Assembly.

Commentary on provisions of the Bill

Clause 1: Palliative care support

- 11 Clause 1 creates a legal obligation for CCGs to ensure that persons in their area with palliative care needs have access to certain health services relating to palliative care, including but not limited to –
- a. Access to pain and symptom management;
 - b. Psychological support for themselves and their relatives; and
 - c. Information regarding their condition and palliative care.

Clause 2: Duty to produce a strategy on the provision of palliative care support

- 12 Clause 2 creates a duty on individual CCGs to prepare and publish a strategy on how to provide palliative care as required by Clause 1.
- 13 Each strategy must include, but is not limited to, the following –
- a. An estimation of the expected palliative care needs of adults and children in their area;
 - b. How these palliative care needs will be met;
 - c. Under what circumstances specialist palliative care needs will be provided by the CCG and how;
 - d. The methods of data collecting and reporting.
- 14 Each strategy must be published no later than nine months after the commencement of this Bill and they must be updated and published at intervals not exceeding three years.

Clause 3: Interpretation

- 15 This clause sets out how terms used in the Bill are to be interpreted.

Clause 4: Extent, commencement and short title

- 16 This clause is self-explanatory.

Commencement

- 17 Clause 4(2) states that the Bill will come into force on the day it receives Royal Assent.

Financial implications of the Bill

- 18 A review of Choice in End of Life Care, commissioned by the Department of Health, reported in 2015 with an estimate that the provision of choice in end of life care would cost £130 million. However, savings have been identified by other research. A literature review, published in *Palliative Medicine* in 2014, concluded that palliative care is “most frequently found to be less costly relative to comparator groups”.⁶

⁶ Samantha Smith et al, ‘Evidence on the cost and cost effectiveness of palliative care: A literature review’, *Palliative Medicine*, 2014, vol 28(2), pp130–150
<https://journals.sagepub.com/doi/pdf/10.1177/0269216313493466>

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