

Briefing

House of Lords – Palliative Care in England and the Access to Palliative Care Bill

20 October 2015

Purpose of this briefing

To provide peers with more information about the End of Life Care Coalition's position on Baroness Finlay's Access to Palliative Bill in advance of the Bill's Second Reading on **Friday 23rd October**.

Introduction

The End of Life Care Coalition is a group of seven charities who are campaigning to ensure better access to and quality of care for people at the end of life.

Three million people will die over the course of this Parliament. Millions more will be bereaved. Yet there are significant variations in the quality of care that people experience.

Overview of the Access to Palliative Care Bill

The End of Life Care Coalition is supportive of the aims of the Access to Palliative Care Bill. Everybody who is dying should be able to access high quality palliative care in the place of their choice.

The Bill places a duty on Clinical Commissioning Groups (CCGs) to commission specialist palliative care services for people with palliative care needs:

- to support people at home, in hospital, in hospices and care homes;
- to make palliative and hospital services available every day of the week, with telephone advice from a qualified palliative care specialist available at all times (i.e. to bring care in line with the NICE quality standard);
- to ensure adequate staffing levels and a single point of contact available at all times for people with palliative care needs;
- to ensure appropriate information-sharing systems are in place.

The Bill also makes provisions in relation to:

- Requirements on health and social care providers to ensure professionals receive appropriate training and education in pain control, communication, the Mental Capacity Act and supporting families and carers;
- Participation in research to advance innovations in palliative care;
- Requirements of the Care Quality Commission to evaluate the provision of palliative care.

The case for improved access to palliative and end of life care

Palliative care has been shown to reduce symptom burden and increase the likelihood of dying at home,ⁱ and to reduce Emergency Department attendances in the last month of life.ⁱⁱ There is also good evidence that palliative care saves money overall.ⁱⁱⁱ

The provisions in the Bill address issues that impact on the quality and availability of care for people at the end of life. Not everyone who is dying gets the quality of care that they need:

- Each year **110,000 people in the UK who need palliative care miss out** ([London School of Economics, 2015](#)).
- Around **50% of people in the UK die in hospital**, despite this being the place where most people would least prefer to be and where the quality of care is rated substantially lower than care at home, in a hospice, or a care home ([National Survey of Bereaved People, 2013](#)).
- Just **21% of hospital trusts** in England are meeting the NICE guidelines of providing at least 9-5, seven day a week, face to face access to specialist palliative care. Just 2% of sites are providing face-to-face access on a 24/7 basis ([National Care of the Dying Audit of Hospitals, 2014](#))
- A lack of resources and education and training is already impacting on people's quality of life as they approach death. A survey by the RCN found **over half (58.5%) of nurses** said patients' wishes could not be fulfilled during the last six months of life. Reasons given included a lack of time, with some also citing a lack of training. About **half (49%)** said that they do not always have the chance to discuss with patients how they would like to be cared for during their final days ([Royal College of Nursing, 2014](#)).
- Just **10p out of every £100** of the UK's medical research budget is spent understanding how to improve care for people at the end of their lives; in contrast, the health service spends an estimated **15-20% of its total budget** in the last year of life.

The Parliamentary and Health Service Ombudsman's [Dying without Dignity](#) report provided a stark examples of the care failings that have occurred because palliative care is not readily available or not of sufficient quality. This included the example of a gentleman who suffered 14 attempts to insert a central line before he died because doctors did not realise his veins were collapsing and did not take the appropriate steps to provide subcutaneous pain relief. Without radical change, these kinds of care failings will keep happening and leave a lasting, detrimental impact on carers and families.

Next steps

Earlier this year the independent [Choice Review](#) made recommendations to the Government on how it could support more people to access high quality palliative care that meets their needs and preferences, including their place of their choice (usually their own home or usual place of residence).

The Choice Review's recommendations align with the provisions in the Access to Palliative Care Bill and include:

- A new right in the NHS constitution for everyone to have choice in end of life care and have their choices and preferences recorded in an individual care plan
- 24/7 access to palliative and end of life care in the community by 2019

- 100% coverage of electronic palliative care registers or similar systems by 2018
- Free and fast access to social care for people at the end of life

By implementing the Choice Review, the Government could make a start on achieving some of the objectives of the Access to Palliative Care Bill. This would require an initial investment from the Government of £130m (£30m for NHS services and £100m for social care).

The End of Life Care Coalition has strongly urged the Government to implement the recommendations of the Choice Review and make available £130m in additional funding during the next Comprehensive Spending Review.

We would be very grateful if you could raise these points during the Second Reading Debate of the Access to Palliative Care Bill.

For more information on this briefing or to arrange a meeting with the End of Life Care Coalition partners, please contact:

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ⁱ Gomes B, Calanzani N, Curiale V, et al: Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev 6:CD007760, 2013
<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007760.pub2/abstract;jsessionid=A874E3B6685101BE29A39D030D8CF35F.f03t02>

ⁱⁱ Henson LA, Gao W, Higginson IJ, et al: Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. J Clin Oncol 33:370-6, 2015
<http://jco.ascopubs.org/content/33/4/370.full.pdf+html>

ⁱⁱⁱ Smith S, Brick A, O'Hara S, et al: Evidence on the cost and cost-effectiveness of palliative care: a literature review. Palliat Med 28:130-50, 2014 <http://pmj.sagepub.com/content/28/2/130.full.pdf+html>