

Press release *For immediate use*

Baroness Finlay's Access to Palliative Care Bill has its Second Reading in the House of Lords on Friday June 14th.

The Bill would end the post-code lottery in palliative care

The Access to Palliative Care Bill, which was introduced to the House of Lords in July 2017, will be debated in the House of Lords on Friday 14th June 2019. Palliative care is an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness and this Private Member's Bill seeks to address the current wide geographical variations in the availability of this care in England, by legislating to require that all clinical commissioning groups (CCGs) ensure that high quality, specialist palliative care services are available to those who need them. The Bill aims to improve care for terminally ill children and adults.

This is an urgent healthcare issue, with recent projections that palliative care needs will rise by 42% in the next 25 years¹. Indeed, as growing numbers of British people live with a chronic diseases near the end of their life and, as the range of such illnesses widens, palliative care becomes more complex and requires more specialisation. Furthermore, the quality and availability of specialist palliative care services across England varies greatly, which adds to the challenge of ensuring that every patient receives the high-quality palliative care they need.

It will provide the legislative framework required to ensure that recent government initiatives, such as the Ambitions commitments, are met. The Ambitions provide 6 commitments: that each person is seen as an individual, gets fair access to care, has coordinated care and their comfort and wellbeing are maximised, with all staff prepared to care and each community prepared to help. It enables realisation of the NHS Long Term Plan, which states that 'With patients, families, local authorities and our voluntary sector partners at both national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care'.

This Bill will pave the way to addressing the current failures in care planning and access to out-of-hours services, documented over recent years, to ensure that patients with specialist palliative care needs have access to appropriate support to improve their quality of life in the face of life-limiting progressive illness as death approaches.

It is true that many people do receive high quality end of life care in England and Wales. For example, in the National Survey of Bereaved People in England (2013), 53% of those who died at home, 51% of those who died in a care home, 59% of those who died in a hospice and 33% of those that died in hospital received 'outstanding' or 'excellent' overall care during their last three months of life. A further 28% who died at home, 33% who died in a care home, 26% who died in a hospice and 36% who died in a hospital experienced care that was at least 'good'.¹ However, there remain significant gaps in the provision of specialist palliative care across all settings and these can and should be improved to ensure that those who are in their last few months of life enjoy the care they deserve. Indeed, as Marie Curie's report (2015)² demonstrated, some people who would benefit from palliative care do not receive any at all, either from specialist palliative care professionals or generalists. There are an estimated 118,000 people a year in England who would benefit from palliative care but are not

¹ ONS (2013b) National survey of bereaved people (VOICES), 2012.

² Dixon J, King D, Matosevic T, Clark M and Knapp M: Equity in the Provision of Palliative Care in the UK: Review of Evidence Personal Social Services Research Unit, London School of Economics and Political Science (2015)

currently receiving it. The Dying Matters coalition have also reported a lack of open communication, from clinicians, with patients and their families.

Specialist palliative care provide an important resource to educate generalists in all settings (other specialists and GPs) and to provide advice on management of complex problems. At present much palliative care is provided in the third sector, but Hospice UK have identified an ever-widening gap, with 73% of hospices reporting their statutory funding has been cut or frozen and 28% cutting services. Better integrated planning at a local level could ensure the best use is made of all resources available, with staff working across boundaries to drive up standards of care everywhere.

Fiscal benefits

Apart from a clinical perspective, insofar as it empowers palliative care clinicians to prioritise the provision of the person-centred and compassionate care to improve the quality of life for patients, it also has significant economic benefits. Not only could this Bill reduce the number of unnecessary and expensive hospital admissions but, as research by the Cicely Saunders Institute has shown, the timely provision of palliative care can improve quality of life at no extra cost.

Ubiquitous need

Everyone will be born and everyone will die. In the UK today, it would be totally unacceptable not to provide maternity services, including ensuring provision for those with complex needs to be able to access timely specialist intervention as needed around birth. The models of services vary because of demography and geography.

Yet we still have people dying with complex needs with no specialist service available in their area and inadequate support and training of some generalist services. This Bill will ensure fair access related to need, whatever the age of the patient.

Further Background information

Palliative care aims to ensure the best possible quality of life for people in advanced illness and at end of life, and for their families, by actively managing pain and other symptoms and providing psychological, social and spiritual support. Palliative care may be delivered by specially trained, multi-disciplinary specialists teams whose focus is on caring for those with complex needs and their families, and supporting other care providers. These generalist providers include GPs, district nurses, hospital doctors and nurses, allied health professionals, care home staff, social care staff, social workers, chaplains and others, who have not received accredited training in palliative care but routinely care for people with advanced illness or at end of life.

For more information please go to:

<https://www.kcl.ac.uk/cicelysaunders>

<https://www.dyingmatters.org/overview/resources>

Or contact:

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ⁱ Etkind S, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, and Murtagh FEM. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Medicine, 2017.