

# ACCESS TO PALLIATIVE CARE AND TREATMENT OF CHILDREN BILL [HL]

## EXPLANATORY NOTES

### What these notes do

These Explanatory Notes relate to the Access to Palliative Care and Treatment of Children Bill [HL] as introduced in the House of Lords on 9 January 2020 (HL Bill 13).

- These Explanatory Notes have been prepared by Baroness Finlay of Llandaff 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.

## Table of Contents

Subject	Page of these Notes
<b>Overview of the Bill</b>	<b>2</b>
<b>Policy and legal background</b>	<b>2</b>
Access to Palliative Care	2
Treatment of Children	3
<b>Territorial extent and application</b>	<b>4</b>
<b>Commentary on provisions of Bill</b>	<b>5</b>
Clause 1: Palliative care and support	5
Clause 2: Treatment of children with a life limiting condition	5
Clause 3: Interpretation	5
Clause 4: Extent, commencement and short title	5
<b>Commencement</b>	<b>6</b>
<b>Financial implications of the Bill</b>	<b>6</b>

## Overview of the Bill

- 1 This Bill addresses two issues. The first clause addresses variations in the level of palliative care provision in England for adults approaching the end of life. The second clause addresses situations where there is a dispute between clinicians and those with parental responsibility for a child with a life-threatening condition.
- 2 This Bill provides for the Secretary of State to ensure that NHS clinical services commissioners arrange that persons in their area with palliative care needs have access to specialist and generalist palliative care services. Part of this provision enables hospices, where patients receive care free at the point of delivery, to be able to access pharmaceutical services on the same basis as other NHS providers.
- 3 Additionally, where there is dispute between parents and clinicians over treatment in the best interests of a seriously ill child, the Bill requires health service bodies to attempt resolution through independent mediation prior to applying to the High Court. The requirement to offer mediation would not apply where a decision had to be made with urgency for the child's interests.

## Policy and legal background

### Access to Palliative Care

- 4 According to the Office for National Statistics, 492,859 deaths were registered in England in 2019, a figure which is expected to rise as the population increases. Almost one third of these were deaths of people under 75.<sup>1</sup> Across all ages, many patients die of acute chronic co-morbidities, for example dying from heart disease with chronic kidney disease, meaning they died of an acute episode with an underlying severe life-limiting condition.<sup>2</sup>
- 5 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 aspects of care.
- 6 Research published in Palliative Care concludes that around three quarters of people will require some form of palliative care during their last illness.<sup>3</sup> Analysis published in BMC Medicine in May 2017 suggests that demand for palliative care across England and Wales will rise by 40% by 2040.<sup>4</sup>

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<sup>1</sup> Office for National Statistics. Weekly provisional figures on death registered in England and Wales 2019.

<sup>2</sup> Kerr M, Matthews B, Medcalf JF, O'Donoghue D. End-of-life care for people with chronic kidney disease: cause of death, place of death and hospital costs. *Nephrol Dial Transplant*. 2017 Sep 1;32(9):1504-1509. doi: 10.1093/ndt/gfw098.

<sup>3</sup> Murtagh FEM, Bausewein C, Verne J, Groeneveld EL, '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>

<sup>4</sup> 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>

- 7 Around 110,000 people in the UK who need palliative care die without receiving it, many of whom will have a terminal illness other than cancer.<sup>5</sup>
- 8 In a study at two London hospitals over half (56.8%) of the locally domiciled patients aged 65 years or over who died in the emergency department in 2006-07 had diagnoses suggesting palliative care needs, with two thirds (38) of these patients having clear symptoms or psychosocial needs in the preceding months but only 8 being known to any palliative care service.
- 9 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.<sup>6</sup> Yet Marie Curie has estimated that the costs for community care at the end of life is £145 per day compared with £425 for specialist in patient care. 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.<sup>7</sup>
- 10 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.
- 11 In response to a freedom of information request, CCGs reported very wide variations in commissioning of services, with allocated budgets ranging from £51.83 to £2329.19 per patient per annum.<sup>8</sup> Almost one third (32%) were not commissioning any education in palliative care for healthcare professionals. At that time, 83% reported commissioning 7-day specialist palliative care services for patients in their own homes.
- 12 There is not consist provision for pharmacy services to hospices in England. Unnecessary hospital admissions may be avoided if hospices could access the necessary medication, manage complex drug regimes and use drugs off license under pharmacist guidance, as would be available in an NHS hospital.
- 13 The Bill has been shortened compared to versions of this Bill introduced in previous sessions. It ensures local autonomy, as established in the Health and Social Care Act 2012.

## Treatment of Children

- 14 There have been several publicised cases where parents, faced with a child with a life-limiting prognosis, have disagreed with the clinicians providing care to such an extent that they have instigated court action over proposed treatment decisions. In other cases, the NHS provider has sought a court order to override refusal of consent from those with parental responsibility or to prevent an action such as transfer of the child's care to another provider. Such legal action has several detrimental effects including exacerbating failure of communication between clinicians and those with parental responsibility, taking clinicians' time and effort away from others for whom they also have a duty of care, incurring expense to both parents and the NHS, undermining overall trust in services through press coverage, and distracting

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<sup>5</sup> Dixon J, King D, Matosevic T, et al. 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, April 2015\_ <https://www.pssru.ac.uk/pub/4962.pdf>

<sup>6</sup> Marie Curie, '[Nursing Standard - Marie Curie Survey Findings](#)', 22 February 2017

<sup>7</sup> Hospice UK, 'A low priority? How local health and care plans overlook the needs of dying people', 21 May 2016, p3 <https://www.hospiceuk.org/policy-advocacy/briefings-consultations?page=4>

<sup>8</sup> Lancaster H, Finlay IG, Downman M, Dumas J. The commissioning of specialist palliative care services in England. *BMJ Supportive & Palliative Care*. 2018; 8(1): 93-101 [ doi:10.1136/bmjspcare-2016-001119]

from ensuring the holistic wellbeing needs of the child are met as gently and peacefully as possible.

- 15 Cases such as that of Charlie Gard have illustrated problems with the current dispute resolution approaches and the emotional harm and stress it causes to parents and clinical staff alike. The cases have also demonstrated the long-term damaging effects of such court proceedings.
- 16 The Bill seeks to ensure that before an NHS provider applies to the High Court under the Children Act 1989 for an order to withdraw or give a medical treatment, independent mediation must have been offered by the provider in an attempt to resolve differences of opinion as to what is in the best interests of the child.
- 17 Mediation must be voluntarily entered into and either party can refuse to engage with such discussions.
- 18 If the child's condition is so serious that lifesaving interventions are urgently required, or attempts at independent mediation have failed, the case may proceed to court.
- 19 Clause 2 reinforces the socio-medical norm that those holding parental responsibility are seeking to act in the best interests of the child. The High Court of England and Wales will be able to prevent a proposed action where it is not in the best interests of the child, i.e. where it is clearly established that the proposed action or medication would cause significant harm to the child.

## **Territorial extent and application**

- 20 This Bill extends to England and Wales only. Clauses 1 and 2 apply to England and only clause 2 applies to Wales because although Health Care is a devolved competence (clause 1), issues of Justice are not devolved (clause 2).

# Commentary on provisions of Bill

## Clause 1: Palliative care and support

- 21 Clause 1(1) provides that the Secretary of State must ensure that an NHS clinical services commissioner arranges for persons in their area with palliative care needs to have access to general health services relating to palliative care and can access specialist palliative care when needed, including:
  - a. Access to specialist palliative care input and advice must be available to patients, whether in hospital, in the community or in their usual place of residence;
  - b. Facilities for those with life limiting and life-ending conditions;
  - c. General and specialist palliative care services consistent with Section 1C of the National Health Service Act 2006, which created a duty to reduce inequalities. This would address the absence of services in some areas.
- 22 Subsection (2) provides for hospices to be treated as if their services were commissioned by a CCG for the purposes of a hospice purchasing their own medication. This addresses the existing situation in which hospices are unable to access the pharmaceutical services that would be available if the patient being treated was in an NHS provider unit or in the community.
- 23 Subsection (3) requires an NHS clinical services commissioner to ensure that patients with palliative care needs can access appropriate health services including specialist palliative care services, and that at all times generalist clinical providers can access advice from specialist palliative care, because complex urgent problems can arise at any time in or out of hours.
- 24 Subsection (4) requires NHS clinical services commissioners to include the provision of specialist palliative care and hospice care in any strategic plan to meet the needs of the population for whom services are being commissioned.

## Clause 2: Treatment of children with a life limiting condition

- 25 Subsection (1) defines the limits of this clause.
- 26 Subsection (2) requires the provision of mediation when disputes arise prior to proceeding to the High Court of England and Wales and that process has been unsuccessful.
- 27 Subsection (3) defines exceptions to the requirement for attempting mediation.
- 28 Subsection (4) provides that the court shall assume, unless the contrary is clearly established, that any medical treatment proposals put forward by any person holding parental responsibility for the child are in the child's best interests.
- 29 Subsection (5) provides that no doctor or health service body can be required to provide a medical intervention which there are reasonable grounds to refuse.
- 30 Part 6 excludes retrospective actions.

## Clause 3: Interpretation

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

## Clause 4: Extent, commencement and short title

- 32 This clause is self-explanatory.

## Commencement

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

## Financial implications of the Bill

- 34 Different research studies and literature reviews have repeatedly concluded that palliative care is “most frequently found to be less costly relative to comparator groups”.<sup>9</sup> In addition, better care decreases the risk of costly complaints and the long-term outcomes in the bereaved are better when care had been good.
- 35 Efforts to avoid court cases in determining treatment of seriously ill children will reduce legal expenses. It may also reduce NHS costs incurred in the long-term support of bereaved parents, whose grief is compounded by their experience of the legal dispute.

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<sup>9</sup> 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

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