



## **Access to Palliative Care and Treatment of Children Bill [HL] HL Bill 13 of 2019–21**

On 7 February 2020, the second reading of the [Access to Palliative Care and Treatment of Children Bill \[HL\]](#) is scheduled to take place in the House of Lords.

### **Summary**

The Access to Palliative Care and Treatment of Children [HL] is a private member's bill introduced by Baroness Finlay of Llandaff (Crossbench). The bill would place a legislative duty on the Secretary of State to ensure that the National Health Service (NHS) clinical services commissioners in England arrange palliative care services, where necessary and appropriate, for the adults and children whom they have responsibility for. It would entitle hospices that provide palliative care services to access pharmaceutical services on the same basis as any other service commissioned by a clinical commissioning group. The bill would also introduce a mediation requirement, with limited exceptions, before an application could be made to the High Court to approve the giving or withdrawal of medical treatment to a child.

Commenting on previous versions of her bill, Baroness Finlay has referred to the disparity between end-of-life care provision and other healthcare services. She has also spoken of the need to introduce a mediation requirement for where conflict over the treatment of children was in prospect. The Government has previously advised that decisions about configuration of services and approach to meeting local demands was for clinicians, commissioners, providers and patients. On taking legal action in best interest cases, the Government has said that it does not issue guidance on this area as each case must be considered on its own unique circumstances by those involved.

NHS England set out its plans to personalise and improve end-of-life care in the NHS Long Term Plan published in January 2019. In August 2019, the Prime Minister Boris Johnson announced that £25 million would be provided to hospice and palliative care services. This investment's purpose was to help keep facilities open and "improve" the quality of end-of-life care.

On 29 October 2019, the Government also stated it would work with patients, families, local authorities and voluntary sector partners to ensure equity of access to general and specialist palliative care throughout England.

Claire Brader | 29 January 2020

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## Background

The Access to Palliative Care and Treatment of Children [HL] Bill ('the bill') covers two distinct areas. The first half relates to adult and children's access to palliative care services in England. The second half would provide a requirement for mediation to take place, in most circumstances, before making an application to the High Court to approve the giving or withdrawal of medical treatment for a child.

In previous sessions, Baroness Finlay of Llandaff introduced different versions of her bill.<sup>1</sup> These bills contained varying degrees of scope for the access to palliative care services. In addition, they did not seek to provide a legislative requirement of mediation during a dispute over the treatment of children. The 2006–07 and 2015–16 versions completed their stages in the House of Lords before falling in the House of Commons. The 2016–17 version of the bill, meanwhile, did not progress beyond first reading. The 2017–19 version completed its second reading in the House of Lords, before falling following the prorogation of parliament.

## What the Bill Does

### Access to Palliative Care Services

Clause 1 applies to England only. It would require the Secretary of State to ensure that NHS clinical services commissioners ('commissioners') in England arrange the following services, as they consider necessary and appropriate, for all persons they have responsibility for. The services are:

- access to specialist palliative care in hospital, in the community and in places of usual residence;
- facilities for the care of patients with life-limiting and life-ending conditions;
- general and specialist palliative care services consistent with the duty to reducing inequalities (as specified in section 1C of the National Health Service Act 2006).

Additionally, clause 1 would entitle hospices that provide palliative care services in England to access pharmaceutical services on the same basis as any other service that is commissioned by a clinical commissioning group (CCG). Commissioners would be required to ensure clinicians providing palliative care have access to specialist advice at all times. For adults and children predicted to require specialist palliative care and hospice care, commissioners would be required to include the provision of these services in any strategic plans they produce.

## Background

Speaking during the second reading debate on the bill she introduced in the 2017–19 session, Baroness Finlay discussed the disparity between end-of-life care and other healthcare services.<sup>2</sup>

<sup>1</sup> UK Parliament, '[Palliative Care Bill \[HL\] 2006–07](#)', accessed 20 January 2020; '[Access to Palliative Care Bill \[HL\] 2015–16](#)', accessed 20 January 2020; '[Access to Palliative Care Bill \[HL\] 2016–17](#)', accessed 20 January 2020; and '[Access to Palliative Care Bill \[HL\] 2017–19](#)', accessed 20 January 2020.

<sup>2</sup> [HL Hansard, 14 June 2019, col 613.](#)

She stated:

No one would countenance having areas in England with no maternity services, or only rudimentary midwifery without access to NHS obstetric care in the event of a complication, so why do we leave end-of-life care in some areas to services provided only through the voluntary sector, supported by fundraising and donations?<sup>3</sup>

Baroness Finlay explained how the bill would allow fair access to coordinated care and require CCGs to publish a strategy on the expected needs of adults and children in its area, with consideration of how such needs would be provided.<sup>4</sup>

In the same debate, Lord Browne of Ladyton (Labour) commended the 2017–19 bill, citing it as an “elegant solution to a problem” that “should be embraced”.<sup>5</sup> Baroness Barran, the then Government Whip, acknowledged that more needed to be done to reduce variation in end-of-life care for both adults and children.<sup>6</sup> However, she advised that the Government believed decisions about the configuration of services and approach to meeting local demands was for clinicians, commissioners, providers and patients. She highlighted that no other area of clinical care was mandated in primary legislation, and therefore argued that such an approach could “set an unhelpful precedent [...]”.<sup>7</sup>

### **Mediation for Disputes Surrounding Treatment of Children**

Clause 2 is entitled ‘Treatment of children with a life-limiting illnesses’. However, the body of the clause does not refer to life-limiting illnesses but instead refers to “the giving or withdrawal of any form of medical treatment for a child”.

The clause will apply to England and Wales.<sup>8</sup> It concerns mediation in instances where a health service body considers making a High Court application to seek approval for the giving or withdrawing of any form of medical treatment for a child. A “health service body” is defined in the bill as “any service functioning as part of or on behalf of the National Health Service”. It would require a health service body to undergo mediation with anyone with parental responsibility for a child, or someone who is recognised as having an interest in the welfare of the child, before it could make an application to the High Court. The mediation would need to be unsuccessful in reaching a substantial agreement before an application could be made.

The clause sets out exceptions. One exception would be where the health service body satisfied the court that there is substantial urgency and it would be in the best interests of the child to proceed without mediation. A second exception would be where the health service body could satisfy the court that, despite having made all reasonable attempts to undertake mediation, it had not been possible due to actions or omissions of those with parental responsibility or interest in the welfare of

<sup>3</sup> [HL Hansard, 14 June 2019, col 613–14.](#)

<sup>4</sup> *ibid.*, cols 615–616.

<sup>5</sup> *ibid.*, cols 624–626.

<sup>6</sup> *ibid.*, cols 639–641.

<sup>7</sup> *ibid.*

<sup>8</sup> As confirmed in explanatory notes provided by the bill’s sponsor, Baroness Finlay.

the child. When determining an application, clause 2 would allow the court to assume that any medical treatment proposals put forward by any person holding parental responsibility for the child are in the child's best interests. However, this would not require a doctor or health service body to provide specific medical treatment to a child where they had previously refused, on reasonable grounds, to provide it.

## **Background**

Currently, a health service body can make an application to the High Court under the Children Act 1989, or under the inherent jurisdiction of the High Court, seeking an order to approve the giving or withdrawal of medical treatment for a child. Several high-profile cases, including those of Charlie Gard and Alife Evans, saw the withdrawal of life support treatment, contrary to the parents' wishes, following a ruling from the High Court.<sup>9</sup>

During the second reading debate of the 2017–19 bill, Baroness Jolly (Liberal Democrat) confirmed her intention to table an amendment that would require the secretary of state to introduce measures to improve access to mediation where “conflict was in prospect”.<sup>10</sup> In response, Baroness Finlay advised that she believed the bill would be an “appropriate place” to put the requirement for access to mediation.<sup>11</sup>

The Government has provided its views on legal action in best interest cases. This was in response to a written question submitted by Eddie Hughes (Conservative MP for Walsall North) in October 2019.<sup>12</sup> Mr Hughes asked if the Government would review guidance issued to NHS trusts on taking legal action in the best interests of patients. The Government confirmed it did not issue such guidance, with Minister for Care, Caroline Dinenage, advising that:

Medical ethics committees and mediation services are often involved in such cases, but each case will be different and must be considered on its own unique circumstances by those who are involved—the national health services, clinicians, parents and patients.<sup>13</sup>

## **Interpretation and Territorial Extent**

Clause 3 would provide the interpretation of terms within the Act.

Clause 4 would provide for the bill's territorial extent. The bill extends to England and Wales only.

The clause would also provide for the commencement and short title.

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<sup>9</sup> Rachel Schraer, [‘Tafida Raqeeb: Who Decides the Care of Sick Children?’](#), BBC News, 3 October 2019.

<sup>10</sup> [HL Hansard, 14 June 2019, cols 640–642.](#)

<sup>11</sup> *ibid.*, cols 643–644.

<sup>12</sup> House of Commons, [Written Question: ‘NHS Trusts: Civil Proceedings’](#), 17 October 2019, 1774.

<sup>13</sup> *ibid.*

## Recent End-of-Life Care Policy Developments

### *NHS Long Term Plan*

The NHS Long Term Plan ('the plan'), published in January 2019 by NHS England, sets out the 10-year plan and service model to "future-proof" the NHS.<sup>14</sup> One aspect of the plan focuses on individuals getting "more control over their own health and more personalised care when they need it".<sup>15</sup> Amongst other things, the NHS stated that it will personalise care to improve end-of-life care. Through the roll-out of training to help staff identify and support relevant patients, the NHS stated that it will introduce "personalised care planning" for those identified to be in their last year of life.<sup>16</sup>

The plan also reflects on the care given to children and young people with cancer. The NHS describes children's palliative and end-of-life care as an "important priority".<sup>17</sup> It states that local NHS funding has not kept pace with growth in clinical care costs or inflation. NHS England plans to increase its contribution by match-funding with CCGs that commit to increase their investment in local children's palliative and end-of-life care, including children's hospices.<sup>18</sup> The plan states that this would more than double the NHS support, from £11 million up to a combined total of £25 million a year by 2023–24.<sup>19</sup>

### *Government Update*

In August 2019, the Prime Minister Boris Johnson announced that £25 million would be provided to hospice and palliative care services.<sup>20</sup> This investment's purpose was described as helping to keep facilities open and "improve" the quality of end-of-life care. The funding also aims to support the sector in "relieving workforce pressures" as well as implementing new services. For example, respite and specialist community teams.<sup>21</sup>

Tracey Bleakley, chief executive of national hospice and palliative care charity Hospice UK, welcomed the funding.<sup>22</sup> Ms Bleakley described it as "an important first step to help protect the vital care provided by charitable hospices".

### *Recent Parliamentary Activity*

On 29 October 2019, Fiona Bruce (Conservative MP for Congleton) asked the Government what steps were being taken to ensure the equity of access to general and specialist palliative care

<sup>14</sup> National Health Service, [The NHS Long Term Plan](#), January 2019.

<sup>15</sup> *ibid*, p 25, para 1.42.

<sup>16</sup> *ibid*.

<sup>17</sup> *ibid*, p 54, para 3.41.

<sup>18</sup> *ibid*.

<sup>19</sup> *ibid*.

<sup>20</sup> Prime Minister's Office, [Prime Minister Announces £25 Million Cash Boost for Hospices to Secure Their Future](#), 20 August 2019.

<sup>21</sup> *ibid*.

<sup>22</sup> Hospice UK, [Hospice UK Welcomes Financial Support from the Government for Charitable Hospices](#), 20 August 2019.

throughout England.<sup>23</sup> In response, Caroline Dinenage, Minister for Care, confirmed the Government’s commitment in this area and advised:

NHS England has produced a number of resources for commissioners, service providers and health, care and support staff focused on ensuring equality in end-of-life care. More recently, the publication of the NHS Long Term Plan [...] make[s] clear that the NHS wants to put health inequalities at the core of the personalised care agenda. As outlined in the NHS Long Term Plan, this will be achieved by working with patients, families, local authorities and our voluntary sector partners both nationally and locally to roll out training to help staff identify and support relevant patients and to introduce proactive and personalised care planning for everyone identified as being in their last year of life.<sup>24</sup>

On 15 January 2020, Baroness Walmsley (Liberal Democrat) cited “particular shortages” of nurses in certain specialities such as children’s palliative care and asked the Government how it planned to make improvements in these areas.<sup>25</sup> Baroness Blackwood of North Oxford, Parliamentary Under Secretary for the Department of Health and Social Care, responded:

The noble Baroness is quite right that we want to target recruitment towards the areas with the greatest shortages. That is one of the reasons why, when we announced the new non-repayable funding, we also announced a top-up for targeted specialties struggling to recruit. It is also why we have announced the availability of placements which can enable nurses to develop experience in specific specialties, which make it easier to recruit and retain those nurses in very rewarding and sometimes hard to recruit specialties.<sup>26</sup>

Following up on this point, Baroness Thornton (Labour) sought further confirmation, asking whether the Government intended to follow the Welsh and Scottish parliaments and introduce “safe nursing staffing legislation”.<sup>27</sup> Baroness Blackwood confirmed that the Government was considering proposals on staff safety and legislation.<sup>28</sup>

### Further Reading:

- House of Lords Library, [Access to Palliative Care Bill \[HL\] 2017–19: Briefing for Lords Stages](#), 5 June 2019
- Department of Health and Social Care, [Hospice and Palliative Care Funding Allocations: 2019 to 2020](#), 29 October 2019
- House of Commons Briefing, [‘NHS Funding Bill 2019–20’](#), 17 January 2020

<sup>23</sup> House of Commons, [‘Written Question: Palliative Care’](#), 29 October 2019, 7118.

<sup>24</sup> *ibid.*

<sup>25</sup> [HL Hansard, 15 January 2020, cols 697–698.](#)

<sup>26</sup> *ibid.*, col 698.

<sup>27</sup> *ibid.*, cols 698–699

<sup>28</sup> *ibid.*