

## Health and Care Bill

### Consideration of Lords Amendments, House of Commons, 30 March 2022

#### A briefing for MPs from Together for Short Lives on the amendments relating to children's palliative care

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##### About us

1. Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill babies, children and young people, and to build a strong and sustainable children's palliative care sector. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers.

##### About this briefing

2. This briefing sets out our position on the proposed amendments to the Health and Care Bill which directly relate to palliative care for babies, children and young people.
3. This includes the government's amendment 12, which would "***specifically require integrated care boards (ICBs) to commission services or facilities for palliative care, including specialist palliative care, as they consider appropriate for meeting the reasonable requirements of the people for whom they have responsibility.***"
4. Alongside our palliative care partner charities Marie Curie, Hospice UK, Sue Ryder and the Alzheimer's Society, we ask MPs to support this amendment. It is very welcome and is a significant step forward for children's palliative care. This briefing provides additional information for MPs on why action is needed to help bring about equitable access to palliative care for children and their families.
5. With our partners, we ask that the minister provides further clarification and assurance on how ICBs will implement the requirement to ensure that children and adults can benefit from this important amendment. We explain this in more detail in this briefing.
6. This briefing also sets out our position on amendment 90 entitled 'Dispute Resolution in Children's Palliative Care'. The amendment seeks to ensure that parents and doctors will be able to engage in effective mediation if they disagree about the best interests of a child. We also set out our position on the government's own amendment on this issue, which would remove amendment 90 but place a duty on the health and social care secretary to carry out a review into the causes of disputes between parents and professionals – and publish a report within one year.
7. We support the amendments tabled by the government relating to the health and wellbeing of children and young people.
8. We would be grateful if MPs could make the points we raise in this briefing when the corresponding amendments are debated.

**Our support for the government's amendment 12 to Clause 16, which would specifically require integrated care boards (ICBs) to commission palliative care.**

9. We very much welcome the government's decision to table this amendment.
10. Alongside our palliative care partner charities Marie Curie, Hospice UK, Sue Ryder and the Alzheimer's society, we ask that the minister provides further clarification and assurances about how the duty will be implemented by ICBs. We are keen to make sure that it leads to seriously ill children and young people in England – and their families – being able to access the palliative care they need, when and where they need, regardless of where they live.
11. We request that MPs ask the following questions of the minister when this amendment is debated:
  1. **Can the minister confirm that while the wording of the amendment requires ICBs to commission palliative care 'where appropriate', it is his intention that all ICBs should deem it appropriate and therefore all of them should commission palliative care services, including for seriously ill children and their families?**
  2. **Can the minister confirm that the government will provide statutory guidance to supplement its amendment and to support ICBs to interpret their responsibilities, including for children, and when will this be available?**
  3. **Can the minister set out the government's expectations regarding the nature of the palliative care services that ICBs will be required to commission?**
  4. **Will the minister confirm that it is the government's intention to communicate with all ICBs that they should fulfil the requirements within its amendment? If so, how do they intend to do this to ensure that palliative care for children is effectively commissioned?**
  5. **What action will the minister take to make sure that ICBs have the financial resources to fulfil the new duty?**
  6. **What action will the minister take to make sure that there are enough professionals with the skills and experience needed to provide the palliative care for children that ICBs will have a duty to commission?**
12. The UK Government, NHS England and NHS Improvement (NHSE/I) and the National Institute for Health and Care Excellence (NICE) have published a number of clear policies which provide an imperative for providing palliative care to terminally ill children and their families. These are clear that:
  - children and young people with a life-limiting condition and their parents or carers should have the opportunity to develop an advance care plan
  - children with a life-limiting condition should have a named professional who leads and coordinates their care
  - children with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it

- children with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team
  - parents or carers of children approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death
  - children approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.
13. Worryingly, however, the extent to which terminally ill children and their families can access services which achieve these standards is very patchy and depends on where they live. Of particular concern is children and families' access to end of life care at home, 24 hours a day, seven days a week, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training).
  14. There is also inconsistency between what is commissioned and what is provided. In some areas, standards are being met without commissioned service specifications being in place. It is likely that the costs of some clinical children's palliative care services – particularly some specialist services provided by NHS acute trusts – are being absorbed by the NHS trusts themselves or funded from charitable sources without being fully reimbursed by CCGs.
  15. Where it is available, children's end of life care at home is provided by children's nurses as part of NHS community children's nursing (CCN) teams, hospice at home teams, hospital outreach teams or a combination. Nurse consultants, clinical nurse specialists and/or children and young people's oncology outreach and symptom care nurse specialists (CYPOONS) have the skills and experience to manage a range of symptoms, including prescribing where needed. In many cases, the medical support provided by consultant paediatricians, including those who have completed special interest (SPIN) training in paediatric palliative care, is sufficient to manage these symptoms.
  16. However, it is important that nurses and paediatricians providing children's end of life care in family homes in every part of England have access to advice from GRID-trained specialist paediatric palliative medicine consultants. This should be organised using a hub and spoke network model in each region. They have the skills and experience to meet the most complex palliative care needs, either directly or remotely through advice provided to other paediatricians. This is the level of care is set out in guidance and quality standards published by NICE.
  17. The lack of access to 24/7 community children's nursing and/or GRID-trained specialist paediatric palliative medicine consultants that we have found means that too many terminally ill children and their families do not have choice and control over how, when and where they receive palliative care. Too many are unable to access end of life care at home if that is what they choose. This is a serious health inequality. When families wish to be cared for at home – and it is in the best interests of the child to be there – keeping them in hospital because of a failure to invest in community-based children's palliative care represents an ineffective use of NHS resources.

18. A recent study of a project in the East Midlands<sup>1</sup> to implement a system of identifying children who need palliative care early and providing them with personalised care planning has found:

- hospital admissions, bed days and costs for children in the last 12 months of life were reduced and advance care planning increased
- staff reported increased confidence and satisfaction when providing end of life care
- having paediatricians with expertise in paediatric palliative care (PPC) in each district general hospital working together with the specialist PPC team in the tertiary children's hospital, can support coordination and quality improvement of services for children with palliative and end of life care needs across a regional network with improved care and choice for children and families
- the lack of resilient community nursing teams with the ability to reliably provide a 24/7 face-to-face on call service for children's end-of-life care at home reduces patient choice at end-of-life.

19. In 2018, the APPG for Children Who Need Palliative Care inquiry report, 'End of Life Care: Strengthening Choice'<sup>2</sup>, highlighted five areas of particular concern, where many children and their families had limited access to:

- children's palliative care out of hours and at weekends
- short breaks for respite
- age-appropriate palliative care and smooth transitions to adult services
- specialist children's palliative care teams led by specialist paediatric palliative medicine consultants
- advance care planning.

20. The APPG asked the government to make the following commitments to make sure:

- Seriously ill children approaching the end of their lives and being cared for at home will have 24-hour access to both children's nurses skilled in providing palliative care and advice from a consultant in paediatric palliative medicine.
- Seriously ill children and their families will be involved in developing an advance care plan.
- Seriously ill children and their families will have a named medical specialist who leads and coordinates their care.

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<sup>1</sup> Wolff T, Dorsett C, Connolly A, et al. Chameleon project: a children's end-of-life care quality improvement project. *BMJ Open Quality* 2021;10:e001520. doi: 10.1136/bmjopen-2021-001520. Available to download from: <https://bmjopenquality.bmj.com/content/10/4/e001520>

<sup>2</sup> All-Party Parliamentary Group for Children Who Need Palliative Care. 2018. End of life care: strengthening choice. Available from: [https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol\\_Res\\_181019\\_APPG\\_Children\\_Who\\_Need\\_Palliative\\_Care\\_inquiry\\_report.pdf](https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_181019_APPG_Children_Who_Need_Palliative_Care_inquiry_report.pdf)

- Seriously ill children and their families will be given information about emotional and psychological support, including how to access it.
- Seriously ill children and their families will be cared for by a multidisciplinary team that includes members of a specialist children's palliative care team.
- Seriously ill children and their families will be able to access regular short breaks for respite at home, in a children's hospice or in another setting that meets their needs.
- Parents or carers of seriously ill children approaching the end of their lives will be offered support for grief and loss when their child is nearing the end of their life and after their death.
- Seriously ill young people will be able to access age-appropriate palliative care and smooth transitions to adult services.
- Seriously ill children will receive palliative care services in hospitals, homes and hospices which is planned, funded and provided by managed clinical networks (MCNs).

21. Together for Short Lives is delighted to have had the opportunity to work with NHS England and NHS Improvement (NHSE/I) to produce a new service specification for children's palliative care. This clearly sets out the services that commissioners should plan and fund in every local area. We believe that amending Clause 16 of the bill would help to make sure that the standard of palliative care set out in the specification is available to seriously ill children in all parts of England.

22. Together for Short Lives asks that the government now makes sure that ICBs have the resources they need to meet this duty. It is also vital that hospital teams, community services and children's hospices, provided by the NHS and voluntary sector, are given access to the finance and the workforce they need to deliver high standard of palliative care that seriously ill children and their families should expect.

### **Our position on amendment 90 entitled 'Dispute Resolution in Children's Palliative Care'.**

23. Together for Short Lives believes that this amendment could help to make sure that parents of seriously ill children and the professionals and services caring for them resolve conflicts about what is in a child's best interests by mediation and not in court. It is important that parents and professionals are supported as much as possible to reach consensus about a child's best interests, with access to independent mediation if needed.

24. Ahead of its return to the Commons, the government has tabled an amendment to remove the Lords dispute resolution amendment from the bill. However, it has tabled its own amendment, which would place a duty on the health and social care secretary to carry out a review into the causes of disputes between parents and professionals, which would report within one year.

25. The Lords amendment could help to make sure that parents of seriously ill children and the professionals and services caring for them resolve conflicts about what is in a child's best interests by mediation and not in court. While the government's amendment would prevent this from becoming a legal duty, Together for Short Lives would welcome a review into these disputes which are distressing for both parents and professionals.

26. However, **we request that MPs ask ministers during the debate to describe to parliament what the terms of reference would be. Please also ask if the review will involve young people, parents, professionals, children’s palliative care services and Together for Short Lives.** As a principle, it is important that parents and professionals are supported as much as possible to reach consensus about a child’s best interests, with access to independent mediation if needed.”

#### **Other amendments relating to the health and wellbeing of children and young people**

27. We support the amendments tabled by the government relating to the health and wellbeing of children and young people, specifically those numbered:

- 22, which requires the joint forward plan for an ICB to set out any steps that the ICB proposes to take to address the particular needs of children or young persons under the age of 25
- 83, which inserts a new clause requiring the Secretary of State to publish and lay before Parliament a report describing the government’s policy in relation to information-sharing by or with authorities with health and social care functions, for purposes relating to children’s health or social care or the safeguarding or promotion of the welfare of children.

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## Appendix: further information

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### The current policy framework affecting children with life-limiting conditions, their families and the professionals and services who care for them

1. We welcome the clear policy imperative for children's palliative care set out in:
  - the government's end of life care choice commitment<sup>3</sup>: this applies to people of all ages, and states that whether a dying person is being cared for at home, in a hospital, a care home or in a hospice, they have the right to expect that their pain will be managed actively at all times, whether at day or at night
  - the National Institute for Health and Care Excellence (NICE) guideline<sup>4</sup> and quality standard on end of life care for children<sup>5</sup>
  - the NHS Long Term Plan<sup>6</sup>, which on paragraph 3.41 states that children's palliative and end of life care is an important priority for the NHS
  - the Ambitions for Palliative and End of Life Care Framework<sup>7</sup>
  - NHSE/I's Palliative and End of Life Care Delivery Plan<sup>8</sup>.
2. Together for Short Lives supports NHSE/I's palliative and end of life care programme. The programme has the potential to realise the Long Term Plan commitment improve the extent to which children and families can access palliative care when and where they need it. The programme aims to:
  - improve access, so that people are offered and able to access the palliative care services they need in a timely manner
  - improve quality, so that palliative care is safe, personalised and high quality
  - improve sustainability, so that palliative care is sustainably commissioned, funded and delivered.
3. The programme has already worked with Together for Short Lives and others to produce the following helpful resources:
  - a service specification for children's palliative care
  - a palliative care commissioning and investment framework
  - palliative care contracting guidance and methodologies.

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<sup>3</sup> Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOUsfj>

<sup>4</sup> The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

<sup>5</sup> The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: <http://bit.ly/2M6BHx3>

<sup>6</sup> NHS Long Term Plan. 2019. Available to download from: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

<sup>7</sup> Ambitions for Palliative and End of Life Care. 2020. Available to download from: <https://bit.ly/3CVIeH5>

<sup>8</sup> FutureNHS. 2021. NHSE/I consultation on universal principles for advance care planning. Available to download from: [https://future.nhs.uk/EOLC\\_Practitioners/view?objectId=113057285](https://future.nhs.uk/EOLC_Practitioners/view?objectId=113057285)

4. These are available for commissioners and providers to download and use from the FutureNHS Platform<sup>9</sup>.
5. We believe that NHSE/I's work to develop regional palliative care strategic clinical networks (SCNs) also provides an important opportunity to improve the way in which England-wide guidelines, standards and best practice examples are shared with integrated care systems (ICSs).

### **What are life-limiting and life-threatening conditions? How do they affect children and young people?**

6. Life-limiting conditions are those for which there is no reasonable hope of cure and from which people are expected to die. Life-threatening conditions or episodes are those for which curative treatment may be feasible but can fail. People with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.
7. Life-limiting and life-threatening conditions in children and young people can be defined by the following four categories:
  - I. Life-threatening conditions for which curative treatment may be feasible but can fail – such as cancer or congenital heart disease.
  - II. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well – such as Duchenne muscular dystrophy.
  - III. Progressive conditions without curative treatment options, such as Batten disease.
  - IV. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

### **How many children and young people with life-limiting conditions are there?**

8. Fraser et al<sup>10</sup> highlight the prevalence of life-limiting conditions in children and young people for every local authority district in England. Overall, Fraser et al estimated that more than 86,625 in children (0–19 years) in England in 2017/2018 were living with a life-limiting or life-threatening condition.
9. There was some evidence in these data that this increase in prevalence was driven by both an increase in recording of these diagnoses and an increase in survival in this population. The former may reflect a change in coding practice rather than a true increase in incidence.
10. The prevalence of life-limiting conditions (LLCs) was highest in the under one-year age group at 226.5 per 10,000 in 2017/18.

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<sup>9</sup> [https://future.nhs.uk/EOLC\\_Practitioners/grouphome](https://future.nhs.uk/EOLC_Practitioners/grouphome)

<sup>10</sup> Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>



11. The prevalence of LLCs was highest for congenital abnormalities which by 2017/18 was 27.2 per 10,000 more than twice the next most prevalent group, neurological disorders (10.8 per 10,000).
12. The prevalence of LLCs was significantly higher among boys (72.5 per 10,000 vs girls 60.0 per 10,000 (2017/18) although there was no difference in the rise in prevalence between sexes over time.
13. Prevalence of LLC are highest amongst children of Pakistani origin (103.9 per 10,000) and lowest among children of Chinese origin (32.0 per 10,000) in 2017/18.
14. More children than expected with a LLC lived in areas of higher deprivation (13% most deprived versus 8% in least deprived). The deprivation categories were population weighted therefore you would expect approximately 10% of children to have a LLC in each category.