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hbHealth Bill: call for evidence

Written evidence from Together for Short Lives

Executive Summary

- The Health Bill creates opportunities to improve care for seriously ill children, but only if ministers strengthen accountability, commissioning and patient voice.
- Children's palliative care remains too uneven, with major variation in access, funding and commissioning across England.
- We support key reforms, including stronger powers for the Secretary of State, a Modern Service Framework for palliative and end of life care, and a Single Patient Record.
- The government should explicitly include babies, children and young people in its palliative care goals and retain strong local authority involvement in ICBs.
- Ministers should review whether children's palliative care is better commissioned nationally or regionally, backed by sustainable funding, clear performance measures and stronger oversight.

About Together for Short Lives

1. Together for Short Lives is the leading UK-wide charity for children living with serious illness, their families and the services that provide them with palliative care.
2. **Together we support** families to live their lives, through the ups and downs, offering practical, emotional and financial help.
3. **Together we unite** our sector by prioritising and sharing crucial research, leading guidance and standards, connecting professionals and raising vital funds for children's hospice and palliative care services.
4. **Together we campaign** to make sure that children with serious illness and their families get the care and support they need, when and where they need it.

The extent to which families of children living with serious illness will benefit from the changes made by the bill – and the impact of the bill on the children's palliative care sector

5. We believe that the bill sets out real opportunities for families of children with serious illness, but also significant risks.

The powers of the Secretary of State

6. We support the new general powers that the Secretary of State would have to direct an integrated care board (ICB) to carry out its functions that would be broader than powers NHSE currently has to direct an ICB to carry out its functions if an ICB is failing.

7. The bill would also introduce new powers for the Secretary of State to make regulations imposing duties on ICBs in relation to waiting times, patient choice, and appeals concerning commissioned NHS services.

8. The measures would require ICBs to protect and promote patient choice rights and enable the Secretary of State to investigate and enforce compliance where ICBs fail to meet these obligations.

9. In England, ICBs have a legal duty[1] to commission palliative care for children, young people and adults that it considers necessary.

10. Yet across England and the wider UK, there is huge variance in the extent to which palliative and end of life care for seriously ill children and young people is being formally planned, funded and provided in ways that meet national and regional standards.

11. 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).

12. Despite some improvements, freedom of information (FOI) requests published in March 2025 have revealed that less than a fifth (19%) of ICBs currently commission these services on a formal basis.

13. Meanwhile, over a third (33%) are still failing to meet this established national standard.[2]

14. There is ongoing regional variation in local NHS funding for children's hospices, with NHS Shropshire, Telford and Wrekin Integrated Care Board (ICB) spending an average of £407 on children's hospice care per child or young person with serious illness in 2025/26, while NHS Northamptonshire ICB spent just £32.

15. As a result, many families feel abandoned by a complex system which should support them to provide care once their child is diagnosed.

16. The extent to which families caring for seriously ill children face variable and inequitable access to palliative and end of life care has also been highlighted by both the

[1] **Health and Care Act 2022, s3(1) NHS Act 2006 (as amended)**. Available at: https://www.legislation.gov.uk/ukpga/2022/31/data.pdf
[2] **Together for Short Lives.** (2025). Built to Last? The state of children's palliative care in 2025. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/the-state-of-childrens-palliative-care-in-2025/.

Commission on Palliative and End of Life Care,[3] and the Health and Social Care Committee's Expert Panel.

17. In its report, the Commission states that inequitable provision is particularly marked for children and cites research showing that preferences are sometimes not achieved for adolescents because the available services, including out of hours care, are not available.[4]

18. Meanwhile, the independent evaluation by the Health and Social Care Committee's Expert Panel emphasised the impact of fragmented commissioning, unstable funding and workforce shortages on families' access to services.[5]

19. In line with these publications, we believe that workforce shortages, funding shortfalls and inconsistencies in commissioning, leadership and accountability are key barriers preventing end of life care and wider symptom management for children with life-limiting conditions and their families from being sustainably planned, funded and provided.

20. While the government's decision to allocate up to £80 million in ringfenced NHS funding for children's hospices in England over the next three years is very welcome, many challenges remain.

21. Further commitments are therefore needed in the upcoming modern service framework for palliative and end of life care, which the government is currently developing, to fully implement its 10-Year Health Plan for seriously ill children and young people.

22. We have welcomed the recent ministerial update (4 June 2026) setting out the government's plans for improving access to high quality palliative care for babies, children, young people and adults in England.

23. We are urging ministers to go further by setting out a sustainable funding and workforce model for children's palliative care and by explicitly including babies, children and young people in the government's palliative care goal.

24. In its interim report on the work it is doing to develop a palliative and end of life care modern service framework (MSF), the government sets out its goal for palliative care services across England.

25. It also signals several areas in which will act, including how its approach to holding local NHS bodies to account for planning, funding and providing palliative care will change.

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[3] **Commission on Palliative and End of Life Care.** (2025). Palliative and End of Life Care: Opportunities for England. Available at: https://palliativecarecommission.uk/reports.
[4] **Odejide OO, Cernik C, Uno H, et al.** (2025). Preferred and Actual Location of Death in Adolescents and Young Adults With Cancer. Available at: https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2829188.
[5] **House of Commons Health and Social Care Committee.** (2025). Expert Panel: Evaluation of Palliative care in England. Available at: https://publications.parliament.uk/pa/cm5901/cmselect/cmhealth/632/report.html.

26. We support the decision to include performance and accountability metrics for children's services, and thank ministers and officials for meaningfully engaging Together for Short Lives and other representatives of the children's palliative and end of life care sector in the process so far.

27. We are pleased to see NHS England's decision to specifically ask health and care systems to assess the palliative care and end of life care needs of their local populations – and to strategically commission the services they could benefit from.

28. Every child deserves many moments of happiness together with their loved ones. But for many families who need palliative care, the system is falling short, leaving parents and siblings feeling isolated and alone, and children missing out on life-changing support."

29. In a system where families of children with serious illness are often overlooked, the final MSF should explicitly state that every baby, child, young person and adult who needs palliative or end of life care will have equitable access to high-quality support shaped by what matters to them, their families and carers.

Single patent record

30. More broadly, we welcome the proposal for a Single Patient Record: many children with serious illness are living with severe medical complexity and rely on a wide range of professionals and services across health, social care, education and other parts of the state.

31. Too many need to repeat their story a number of times when they engage with the health system, and too often professionals are unable to access vital information about a child and their family when they need.

32. We agree with the Patients Assocation[6] that, to be successful, it should be designed with patients, needs to work for people who find digital technology difficult, and that patients must stay in control of their own information.

33. We call on the government to set out a clear timetable for how this will be extended to children with serious illness and their families.

Abolition of Healthwatch England

34. We share concerns Healthwatch England being disbanded: it is currently the only body in England with a statutory duty to listen to patients and ensure that their experiences shape how services are run.

35. We call on the government to clarify how an independent patient voice can be maintained at an England-wide level once its functions have been brought into the

[6] **The Patients Assocation.** (2026). The Patients Association responds to the NHS Modernisation Bill announced in the King's Speech. Available online at: https://www.patients-association.org.uk/news/the-patients-association-responds-to-the-nhs-modernisation-bill-announced-in-the-kings-speech

Department of Health and Social Care – and how, locally, patient voice will be maintained within ICBs and local authorities.

Local authority representation on ICBs

36. We join the House of Commons Health and Social Care Committee in their concern at the government's proposal to remove local authority representation from ICBs[7]; children with serious illness rely on services which are often a blend of health and social care to meet their complex needs, such as short breaks for respite.

37. Social care plays a crucial role in enhancing their quality of life: services such as practical support and assistance with accessing suitable education help children and their families make the most of the moments they have together.

38. Despite NHS bodies and local authorities having a legal duty to commission jointly for disabled children and young people, the extent to which this happens in reality is patchy and inconsistent.

39. We join the House of Commons Health and Social Care Committee in recommending that the statutory requirement for ICBs to have at least one member jointly nominated by local authorities be retained.

40. Many children with serious illness have a special educational need or disability, with complex needs that need to be met for them to access education. We agree with the Health and Social Care Committee that, as the Health Bill makes provision about the duties of ICBs, it provides an ideal vehicle to provide a level playing field between education bodies and ICBs, so that ICBs are also under a legal obligation to comply with recommendations from SEND Tribunals.

The extent to which the bill allocates responsibility for highly specialised services at the right level

41. Specialist palliative care services for children and young adults are included in the list of agreed specialised services for delegation to ICBs published by NHS England in December 2024[8].

42. Specialist children's palliative care includes that provided consultant-led teams: these may include:

    - SPIN or GRID-trained paediatricians
    - advanced nurse practitioners

[7] **House of Commons Health and Social Care Select Committee**. (2026). Health Bill 2026–27: First Report of Session 2026–27. Available to download from: https://publications.parliament.uk/pa/cm5902/cmselect/cmhealth/219/report.html

[8] **NHS England**. (2024). Annex a - list of agreed specialised services for delegation. Available to download from: https://www.england.nhs.uk/wp-content/uploads/2024/12/Annex-a-list-of-agreed-specialised-services-for-delegation-agenda-item-8.pdf

- specialist medical and nursing teams
- multidisciplinary specialists managing complex symptoms and ethical decision-making, and including paediatric psychological medicine and community mental health services where appropriate.

43. Core children's palliative care services, which we would expect to be commissioned by ICBs, include targeted, skilled support in various settings delivered by:

- community children's nursing teams
- acute hospital staff
- children's hospices
- community child development services (community paediatrics)
- occupational therapy
- speech and language therapy
- physiotherapy
- dietetics
- wheelchair services.

44. Given the persistent variation in access, funding and commissioning set out above, we are concerned about giving ICBs further responsibility for children's palliative care without stronger regional or national coordination.

45. In many cases, this emphasises the vital role that managed clinical networks play in coordinating services and enhancing quality of care for families.

46. On the basis of the low volumes and highly complex needs of children with serious illness – and the fact that children's palliative care is often organised and provided by regional services, including tertiary children's hospitals and children's hospices – we recognise that it is challenging for individual ICBs to prioritise commissioning children's palliative care.

47. In recognition of these systemic challenges, the government has committed to developing a Modern Service Framework (MSF) for all-age palliative and end of life care.

48. Aligned with the ambitions of the 10-Year Health Plan, ministers intend to use the MSF to consider contracting and commissioning arrangements as part of the broader shift towards strategic commissioning and address the unwarranted variation in access and quality of care.

49. For the MSF to be a success, we believe that the government must ensure that the distinct needs of children and young people with life-threatening or life-shortening conditions, or with severe medical complexity and their families, are fully recognised and not overshadowed by an all-age approach.

50. Specifically, the framework must also commit to targeted action addresses the inconsistencies in commissioning and secures a sustainable future for paediatric palliative care managed clinical networks.

51. We therefore call on the government to take the following actions:

    - The Department of Health and Social Care (DHSC) considers a model in which specialist paediatric palliative care, as defined in the specialist tier of NHSE's children's palliative care service specification[9], is commissioned at a regional or national level to reduce variation and improve accountability.

    - The government establishes clear accountability and assurance mechanisms to underpin the MSF, including what happens if ICBs do not meet expectations.

    - The Secretary of State for Health and Social Care mandates the Care Quality Commission (CQC) to assess the extent to which ICBs are commissioning children's palliative care in line with national quality standards.

    - DHSC links commissioning responsibilities of ICBs to guaranteed funding streams, preventing unfunded mandates and improving service sustainability.

    - The government provides ringfenced funding, that increases in line with inflation, to secure the future operation and sustainability of paediatric palliative care managed clinical networks.

    - DHSC and NHS England should establish a national outcomes and assurance framework for children's palliative care commissioning, including measures on 24/7 support, advance care planning, workforce capacity, family experience and compliance with national standards.

52. By ensuring these actions are taken, the government and local systems can begin to address the many inconsistencies in children's palliative care commissioning across England. In doing so, they can then help to ensure children with serious illness and their families receive the high-quality care and support they need, when and where they need it.

53. Action to bring about a more sustainable funding model and workforce for children's palliative care is also vital.

[9] **NHS England**. (2023). Specialist palliative and end of life care services: Children and young people service specification. Available at: https://www.england.nhs.uk/publication/service-specifications-for-palliative-and-end-of-life-carechildren-and-young-people-cyp/

54. As we lead our sector to develop a whole-system vision for the future of UK children's palliative care, we will produce proposals to enable the government and the NHS to work with providers to make sure they have the resources they need to deliver the MSF and achieve a system which truly puts families at the centre.

55. More broadly, as part of the Specialised Healthcare Alliance[10], we call on ministers to clarify how ICBs will be held to account for the specialised health services they commission.

56. We also call on them to set out whether existing clinical leadership and patient involvement infrastructures be retained and ideally strengthened.

For more information

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[10] **Specialised Healthcare Alliance.** 2026. A guide to specialised commissioning in 2026/27. Available to download from: https://shca.info/wp-content/uploads/2026/03/260309-A-guide-to-specialised-commissioning-in-2026-27-FINAL.pdf