



Short lives can't wait:

the state of children's palliative care in 2024

A SUMMARY REPORT BY TOGETHER FOR SHORT LIVES

together
for
short
lives 



Foreword

Imagine sitting in a hospital consulting room being told that your child has a life-limiting condition and is unlikely to live to reach adulthood. Imagine being told that this means you will need to learn complex clinical skills akin to those of an experienced nurse just so you can care for your child at home and live as a family.

Care that includes administering complex medicine regimes. Changing tracheostomy tubes. Monitoring oxygen levels. Lifting with hoists. Using suction machines. Picture being told that you will have to provide that care having had little if any sleep, day and night, seven days a week, year on year.

Then you are told that, despite this, children with life-limiting conditions – and their parents and siblings – can and should expect to experience moments of great joy just like any other family. That this can be achieved by lifeline palliative care provided by the NHS and the voluntary sector, in hospitals, homes and children's hospices.

You learn that palliative care could help you manage your child's symptoms. Help manage the emotional and psychological impact on you and your family. Help give you and your family the regular breaks you need to stay resilient, safe in the knowledge that your child's needs are being met.

Help that is clearly set out in standards, guidance and even the law.

Now imagine being told that only some of this support is not available to you – not because you do not need it – but because of where you live.

This report shows that, shockingly, this postcode lottery is a reality for thousands of families of children and young people with life-limiting and life-threatening conditions across the UK right now. This is unacceptable.

Together for Short Lives is leading a movement to change this. Our purpose is to ensure that every child and family has high quality children's palliative and end of life care, when and where they need it. We have a long-term vision for how we want to change the lives of children and families.

We have had incredible success in developing and funding programmes focused on reaching families in communities where there is a higher prevalence of children with life-limiting illnesses and inconsistent service provision. Through our campaigning, we have influenced and been part of important work by the UK's governments, NHS bodies and provider organisations to improve care and support. And every day we are speaking to families who need emotional, financial and practical support and helping them find it. By 2027, we are committed to doubling the number of families and children accessing our family support services and doubling the number of professionals we reach. We want families in at least half of all areas in the UK to be able to access 24/7 end of life care at home as part of our long term commitment to ensuring every child and family has this support.

But we cannot do this alone. We need the public to support us now to help achieve these bold ambitions for children and families. We need the UK's governments, the NHS, and others to act urgently to make sure we have the workforce, funding and accountability in place to give families the care they need. Read our report to find out how you can help.

These children and families do not have time to waste. Together we must work to make sure that every child and young person has access to high quality, sustainable palliative care when and where they need it.

Andy Fletcher
Chief Executive, Together for Short Lives

Summary report

- **We have found that only a third of local areas in England are meeting the required standard for 24/7 end of life care for children and young people at home.**
- **The postcode lottery is one of several wider issues affecting children with life-limiting conditions. There is an estimated £295 million funding gap in England. Across the UK there are significant workforce shortages and inconsistencies in the way support is planned and funded by local NHS and council bodies, which are not being held to account by the UK's governments.**
- **Together for Short Lives is calling for the UK's governments, NHS bodies and local authorities to take immediate action for the UK's 99,000 seriously ill children and their families. In England, we call for the parties contesting the general election to commit to this action too in the next parliament.**

Far too often, children with life-limiting conditions with the most complex health needs – and their families – are experiencing care that is disjointed, uncoordinated and not provided when and where they need it. Across the UK, we have found huge variance both in the extent to which children's palliative is being planned, funded and provided in ways that meet national and regional standards.

We cannot accept this.

Patchy access to end of life care at home, 24 hours a day, seven days a week

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). This standard is met in just a third (30%) of local NHS areas (known as integrated care board, or ICB, areas) in England, with nearly a half (47%) partially meeting it and almost one quarter (23%) not meeting it at all.

In England, only 6 ICBs (14%) are funding and delivering (a process known as commissioning) services to provide 24-hour access to both children's nursing care and advice from a specialist consultant in paediatric palliative care. Two in five (41%) of ICBs do not commission this at all.

The 24/7 end of life care at home standard is not met at all in Northern Ireland and only in a minority of areas in Scotland and Wales.

The lack of access to 24/7 community children's nursing and/or GRID-trained specialist paediatric palliative medicine consultants means that too many children with life-limiting conditions 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.

We believe that key barriers preventing end of life care and wider symptom management for children with life-limiting conditions and their families being sustainably planned, funded and provided are:

Workforce gaps

In the short term, there are currently too few nurses, paediatricians and other professionals with the skills and experience to provide children’s palliative care in hospitals, children’s hospices and in the community.

If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 4,960 community children’s nurses (CCNs) would be working in England. Yet there are only 902 CCNs employed by the NHS in England¹.

There are 52 children’s nurses working in community services in Wales². Based on RCN modelling, an additional 208 community children’s nurses are needed³. There is currently no training course for CCNs in Scotland.

There are only 21.4 whole time equivalent (WTE) GRID-trained specialist paediatric palliative medicine (PPM) consultants in the UK⁴, when the Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 are needed. Northern Ireland does not currently have a specialist GRID-trained PPM consultant.

The average vacancy rate for clinical roles (including nurses) for children’s hospices charities in England is 14.5%⁵, which is higher than the NHS nursing vacancy rate of 10.3%.

We estimate that there are 12 sites across the UK that can provide GRID and special interest (SPIN) training in PPM to consultant paediatricians – and there are

many who wish to undertake this training. There are 7.2 WTE GRID and 12 WTE SPIN training places funded in the UK in 2024, which is a welcome increase from the 1 WTE GRID post funded in 2022.

However, we estimate that there is a funding gap of £2.4 million in investment in GRID and SPIN training – in addition to other funding gaps in educating and training other professionals, including children’s nurses.

We call for the action across the UK to increase the number of professionals who have the skills and experience to provide palliative care to children with life-limiting conditions across a range of different roles. In particular, we call for the following:

UK-wide

- The UK Government should fund work to expand the children's palliative care workforce. This should include an aspiration to increase spending on specialist paediatric palliative medicine GRID and SPIN training to £2.4 million per year, proportionate to an expansion in the overall medical education and training budget.

England

- The UK Government should make sure that, using the NHSE children's palliative care service specification, NHSE work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible, which includes organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs).
- Ministers should also make sure that more children's nurses are trained and educated so that they have the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.
- When it is finalised, the UK Government should fund education providers to implement the NHS England qualification in specialism standard for palliative and end of life care practice, career pathway and core capabilities in practice for nursing and allied health professions in full.
- We join the Disabled Children's Partnership in calling for ministers to increase the focus on disability within children's social work training – and join the #SENDInTheSpecialists coalition in asking for the Department for Education and Department of Health and Social Care to take a broad approach to defining the SEND and specialist workforce.

Northern Ireland

- As part of its work to implement Health and Social Care Workforce Strategy 2026⁶, the Department of Health should publish the number of community children's nurses employed by the Health and Social Care service – and fund any additional posts needed to fill gaps.
- The Department of Health should make sure that more children's nurses are trained and educated so that they have the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.
- The Department of Health should invest in GRID training for at least one paediatric consultant in Northern Ireland.
- The Department of Health should make sure that there is a focus on disability within children's social work training.

Scotland

- The Scottish Government should fund more specialist children's palliative care training for health and social care staff to meet children's increasingly complex needs.
- The Scottish Government should publish the number of CCNs employed by the NHS in Scotland, fund any additional posts needed to fill gaps.
- The Scottish Government should support the development of a Specialist Practitioner Qualification, at Masters level, for community children's nursing in Scotland.
- The Scottish Government should make sure that there is a focus on disability within children's social work training.

Wales

- We call on the Welsh Government to invest in education and training for professionals to make sure they have the skills and knowledge needed to meet the Quality Statement for Palliative and End of Life Care for children and young people.⁸
- We call on the Welsh Government to act to make sure that there are enough children's nurses with the skills, knowledge and experience needed to provide palliative care to children in the community.
- The Welsh Government should make sure that there is a focus on disability within children's social work training.

Funding shortfalls

Positive progress has been made in recent years, including NHS England's (NHSE) decision to ringfence and increase the Children's Hospice Grant to £25million by 2023/24 – and the commitment in the Long Term Plan to match fund ICB children's palliative care funding by up to £7million a year by 2023/24.

While the recent commitment by the UK Government to continue the grant in 2024/25 is welcome, its future beyond that remains unclear. This is making it very challenging for children's hospices to budget for the long-term. NHSE's children's palliative care match funding scheme is also due to end in March 2024, which could have a negative impact on the sustainability of lifeline care and support

We estimate that the NHS should spend approximately £376million in 2024/25 to meet the NICE children's palliative care standards. Yet it will be spending only £81 million. We therefore estimate that there will be a £295 million gap in NHS spending on children's palliative care in 2024/25.

The lack of NHSE match funding for children’s palliative care in 2024/25 will make it harder for ministers and officials to reduce the size of the funding gap.

We have previously found that NHS funding for local children’s hospices in England varied by as much as £483 per child in 2022/23⁹. While Norfolk and Waveney ICB spent the most (an average of £511 per case) in 2022/23, South Yorkshire ICB spent an average of just £28 per case.

In Northern Ireland, the children’s hospice has recently announced that, as a result of the loss of government funding for one of its beds, it now intends to reduce the services it can provide.¹⁰

The Scottish Government has committed that it will ensure provision of high-quality child palliative care, regardless of location, supported by sustainable funding of at least £7 million per year through Children’s Hospices Across Scotland. However, inflationary costs and the expansion of services to meet demand (including in hospital) have increased CHAS’ cost base. £7 million per year is therefore no longer sustainable. Beyond the support it provides to CHAS, it is not clear how much the Scottish Government is spending on children’s palliative care.

We estimate that £11.1 million per year is needed to fund an additional 208 NHS community children’s nurses needed in Wales. We understand that the Palliative and End of Life Care Programme is experiencing challenges in being able to access Further Faster Programme funding to invest in community-based children’s palliative care.

Scope and the Disabled Children’s Partnership in 2021 found a £573 million funding gap in disabled children’s social care.

We call for the following action to make sure children’s palliative care is sustainably funded across the UK for the long-term:

England

- The UK Government should make sure that the NHS invests an additional £295 million in children’s palliative care in England every year to meet the funding gap for services.
- This should include a commitment to maintaining ringfenced, centrally distributed NHS England funding for children’s hospices beyond 2024/25 which increases by at least the rate of inflation each year.
- The UK Government should fill the £573 million annual funding gap in disabled children’s social care.

Northern Ireland

- The Northern Ireland Executive should make sure sustainable funding is in place to implement Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life care 2016-26¹¹ in full.
- This should include funding for a GRID-trained specialist paediatric palliative care consultant in Northern Ireland.
- The Northern Ireland Executive should sustainably fund Northern Ireland Children's Hospice for the long-term to make sure it can provide lifeline care and support to children and families amid rising cost and rising demand for its services.

Scotland

- The Scottish Government should provide sustainable funding so that its new national strategy for palliative and end of life care is implemented in full.
- The Scottish Government should sustainably fund Children's Hospices Across Scotland (CHAS) for the long-term to make sure it can provide lifeline care and support to children and families amid rising cost and rising need for its services.

Wales

- We call on the Welsh Government to invest £11.1 million per year to employ the additional 208 NHS community children's nurses that we estimate are needed.
- The Welsh Government should make sure that the Palliative and End of Life Care Programme is able to access Further Faster programme funding to invest in community-based children's palliative care.
- We call on the Welsh Government to provide additional and sustainable statutory funding to Tŷ Hafan and Tŷ Gobaith for the long term in the third phase of the funding review. This funding should be sufficient to make sure the hospices can provide lifeline care and support to children and families amid rising costs and rising demand for their services.

Lack of leadership and accountability

In England, we welcome the legal duty on integrated care boards (ICBs) in the Health and Care Act 2022 to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.

However, we have specific concerns about the extent to which the government and NHSE are holding ICBs to account for the way in which they commission children's palliative care.

Despite national and regional strategies being in place, we do not believe that any of the UK's governments are sufficiently holding local NHS bodies and councils to account for the way they implement them.

We call for the following action to make sure that these strategies are fully realised:

England

- We call on the UK Secretary of State for Health and Social Care to direct the NHS to make sure that all children with life-limiting conditions in across England and their families are able to choose to receive palliative care at home, 24 hours a day, seven days a week, if it is in their best interests.
- This should build on the legal duty on integrated care boards (ICBs) in the Health and Care Act to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible¹².
- Integrated care systems (ICSs) across England should take our findings into account as they determine the health and healthcare needs of their population.
- Integrated care boards (ICBs) should commission children's palliative care services in a way which meets the NICE standards.
- NHSE should regularly monitor the extent to which ICBs do this – and hold them to account if they fail to do so.

Northern Ireland

- The Department of Health should hold Health and Social Care Northern Ireland to account in implementing 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life care 2016-26' in full.
- This should include making sure that all children with life-limiting conditions across Northern Ireland and their families are able to choose to receive palliative care at home, 24 hours a day, seven days a week, if it is in their best interests.
- The Department of Health should commission children's palliative care services in a way which meets the NICE standards.

Scotland

- We call on the Scottish Government to make sure that its new national strategy for palliative and end of life care addresses the needs of children.
- The Scottish Government should make sure that all children with life-limiting conditions across Scotland and their families are able to choose to receive palliative care at home, 24 hours a day, seven days a week, if it is in their best interests.
- To inform its plan, Scottish ministers should ensure that its work to map children's palliative care in Scotland shows where 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care is available to children and young people receiving end of life care at home.

Wales

- We call on the Welsh Government to hold regional partnership boards and local health boards to account in ensuring that the Quality Statement for Palliative and End of Life Care is implemented in full for children and young people.
- The Welsh Government should make sure that all children with life-limiting conditions across Wales and their families are able to choose to receive palliative care at home, 24 hours a day, seven days a week, if it is in their best interests.

As well as asking the UK Government to take action now, we ask the parties contesting the next general election to commit to these actions should they form the next government.

In addition to the above, we support the manifesto¹³ of the Disabled Children's Partnership, of which we are a steering group member. The key asks are:

- **Make disabled children a priority.** Those at the heart of politics need to prioritise the needs of disabled children and their families and to acknowledge disabled children and their families as equal, valued members of society. We want all parties to commit to the appointment of a Minister for Disabled Children and to producing a cross party disabled children's strategy.
- **Clarify and enforce rights, and review the law.** The next Government must commit to stronger accountability within the SEND system; to making the education system inclusive; and to ensuring that disabled children and young people receive the support they need across the education, health and social care systems.
- **Address funding shortfalls and create a dedicated fund for disabled children.** Making disabled children the priority and having a system that is fit for purpose with effective accountability will help make this happen; but the right level of funding is also vital.

We have also developed a joint manifesto for palliative and end of life care¹⁴ in partnership with Hospice UK, Marie Curie, the National Bereavement Alliance and Sue Ryder.

Ahead of the next UK general election, we call upon all political parties and candidates to commit to policies aimed at making sure everyone affected by dying, death and bereavement gets the best possible care and support.

We are proud to work jointly with friends and partners across our sector to ensure that politicians from all parties are aware of the challenges we are facing in providing high quality end of life care in the UK. As representatives and providers of end of life care and bereavement support in communities across the country, we have worked together to identify solutions that will make sure families who need us are well supported long into the future.

Palliative and end of life care is a vital part of a healthcare system, and we look forward to working with NHS and government partners to achieve our five goals:

- Deliver a new funding solution for hospices and palliative and end of life care to end the postcode lottery in access.
- Introduce a national delivery plan for palliative and end of life care in every nation to support delivery of local services.
- Guarantee that palliative and end of life care services meet each individual's needs, including those of people dying at home.
- Act to ensure that nobody dies in poverty and tackle inequalities in palliative and end of life care.
- Improve support for families and carers of people with a terminal illness.

Whether or not children with life-limiting conditions and their families can access the palliative care they need at home, out of hours and at weekends should never depend on where they live. It cannot be right that the costs of some children's palliative care services – particularly some specialist services provided by NHS trusts in England – are being absorbed by the NHS trusts themselves or funded from charitable sources without being fully reimbursed by ICBs. Time is short for children and young people with life-limiting or life-threatening conditions.

Seriously ill children need action now

If these actions are not taken now, more children with life-limiting conditions and their families will be denied choice and control over their palliative care, particularly at end of life, as the number of cases of life-limiting and life-threatening conditions in children increases. By implementing guidance in full, valuable non-cash savings could be generated for the NHS, created by fewer unplanned, emergency admissions to hospital among children with life-limiting conditions, some of whom may prefer to access palliative care at home.

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 2. **Stats Wales.** (2024). Nursing, midwifery and health visiting staff, by grade and area of work. Available at: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Staff/Non-Medical-Staff/nursingmidwiferyandhealthvisitingstaff-by-grade-areaof-work-year>.
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