



Short lives can't wait:

the state of children's palliative care in 2024

A 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

Executive Summary

- 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 and young people with life-limiting or life-threatening 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 the UK, we call for the parties contesting the general election to commit to this action too in the next parliament.

Key findings

- Far too often, children with life-limiting conditions with the most complex health needs – and their families – are experiencing care that is disjointed and uncoordinated.
- In many places across the UK, children's palliative care which meets national standards is not available.
- We have found huge differences across the UK in the way children's palliative care is planned, funded and provided.
- 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.
- We believe that key barriers in workforce, funding, leadership and accountability are preventing end of life care and wider symptom management for children with life-limiting conditions and their families being sustainably planned, funded and provided.

- 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 England.
- There are 52 children's nurses working in community services in Wales. Based on RCN modelling, an additional 208 community children's nurses are needed.
- 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 UK, 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.
- From the results of a Hospice UK survey, the average vacancy rate for clinical roles (including nurses) for children's hospices charities in England is 14.5%, which is higher than the NHS nursing vacancy rate of 10.3%.

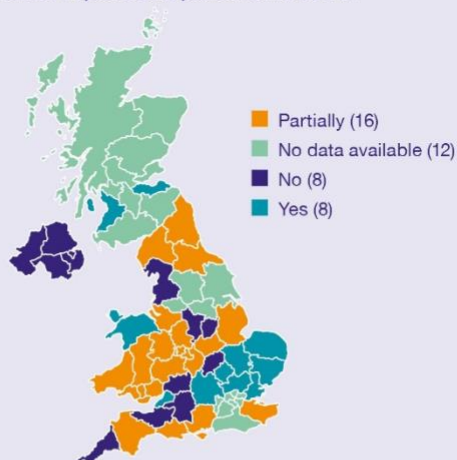
Key recommendations

- The UK Government and NHS England (NHSE) should fill the £295 million annual gap in NHS spending on children's palliative care in 2024/25.
- The UK Government and NHSE should fill the £2.4 million annual funding gap in GRID and special interest (SPIN) training in palliative care for paediatric consultants – in addition to other funding gaps in educating and training other professionals, including community children's nurses.
- The Welsh Government should fill the £11.1 million per year needed to fund an additional 208 NHS community children's nurses needed in Wales.
- We call for the action across the UK to use the existing children's palliative care workforce more effectively – and 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.
- We call on the UK's governments to fund lifeline voluntary sector providers in England, Northern Ireland, Scotland and Wales – including children's hospices – equitably and sustainably for the long-term as their costs increase. In England, this should include a commitment to maintaining ringfenced, centrally distributed NHSE funding for children's hospices beyond 2024/25 which increases by at least the rate of inflation.
- The UK's governments should hold local NHS bodies and councils to greater account for implementing the existing policy frameworks relating to children's palliative care.
- Time is short for children and young people with life-limiting or life-threatening conditions. If these actions are not taken now, more children with life-limiting conditions and their

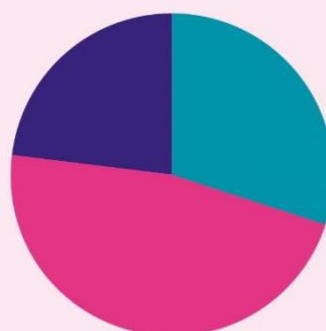
families will be denied choice and control over their palliative care, particularly at end of life, wasting vital NHS and local government resources.

Families of seriously ill children aren't getting the children's palliative care they need because of where they live. Despite this care being set out in standards, guidance and even the law, we have identified huge differences across the UK in the way children's palliative care is planned, funded and provided.

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 specially trained in paediatric palliative medicine.



We have found only a third of ICB areas in England are meeting this standard around 24-hour end of life care at home.



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| Completely meeting the standard | 30% |
| Partially meeting the standard | 47% |
| Not meeting the standard at all | 23% |

In England, we estimate the gap in NHS children's palliative care funding across hospital, community and children's hospice services in England will be **£295 million** in 2024/25.



Despite the pivotal role played by NHS community children's nurses (CCNs), we have found only **902** CCNs are currently employed by the NHS. For safe staffing levels to be met, **4960** CCNs would be working in England. In Wales, an additional **208** are needed.



Infographic is percentage based. Each icon = 50 CCNs.

Together for Short Lives is leading the movement to change this. We are calling on UK's governments, the NHS and others to act now, because time is short for seriously ill children and their families. They cannot wait any longer.

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About Together for Short Lives

Together for Short Lives is the UK's children's palliative care charity. Our purpose is to ensure every child with a life limiting or life-threatening condition has access to the best care and support, when and where they need it. We campaign for change, raise vital funds to fill the funding gap across healthcare systems and help families directly through our Family Support Hub which provides:

- **Practical support** such as advice and support with managing energy use and bills, emergency groceries from Morrisons and Rosie's Rainbow Pantry, access to legal advice, the provision of short breaks at Center Parcs or referrals to Make a Wish.
- **Financial support** including a dedicated Butterfly bereavement fund for grieving families, support for energy costs and referrals to other sources of funding.
- **Emotional support** via a national helpline for parents and carers which also acts as a gateway to other services.
- **Connection** with other families with children with life-limiting conditions via events, a closed Facebook group; and provision of information and resources.

Over the next two years, we plan to:

- **Double the number of families and children accessing our family support services.**
- **Improve delivery of children's palliative care** by uniting the services available in children's hospices, the NHS, voluntary organisations, and professionals who provide care for children with life-limiting conditions.
- **Campaign for system change** in the period leading up to the general election, calling for parties to address the annual NHS funding gap for children's palliative care in England.

There are currently **99,000 children in the UK living with life-limiting or life-threatening conditions**¹. This number has tripled in the last 20 years and is set to grow by a further 50% over the next decade. More seriously ill babies are surviving, and children and young people with complex conditions are living longer.

Introduction

Children's palliative care is defined as an active and total approach to care. Provided to children with life-limiting or life-threatening conditions, the philosophy of children's palliative care is to promote the best possible quality of life and care for every child with such a condition, and their family.²

As an active and dynamic approach to care, children's palliative care encompasses a wide variety of care and support. From the management of distressing symptoms to the provision of short breaks and psychological support, children's palliative care adopts a holistic and family-centred approach, thereby embracing the physical, emotional, social, and spiritual needs of the child and their family.³

Giving families real choice is therefore key to this approach: a choice of place of care; a choice of place of death; and a choice of emotional and bereavement support are all pivotal in the provision of children's palliative care.⁴

While palliative care can be introduced at any point throughout a child's life, in practice, it is completely dependent upon individual circumstances. Some children may require palliative care from birth; others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life.

Palliative care should be offered when a life-limiting condition is diagnosed or recognised. This could be in the antenatal period. It should also be offered when it is recognised that curative treatment for a life-threatening condition is not an option.⁵ However, each situation is different, and care should be tailored to the child.

Given the wide range of needs at any given point, children's palliative care often involves a wide range of services from health, social care, and education, both in the statutory and voluntary sector and should be available across universal, core and specialist services.⁶ As families will move between these levels of service provision, ensuring services are working in an integrated manner with good communication and join-up is crucial to providing the seamless care that is required.

Children's palliative care therefore plays a critical role in supporting children and families.

Despite this, the children's palliative care sector is often confronted with numerous challenges. Whether it be a shortfall of funding, an insufficient workforce, or a lack of accountability, these challenges are detrimental to children, young people, and their families in accessing high-quality palliative care that not only meets their needs but also aligns with national standards.

Children with life-limiting conditions and their families therefore often experience care that is disjointed, uncoordinated and lacking in many vital areas.

In 2022, integrated care systems (ICSs) were introduced in England, with the aim of bringing together NHS organisations, local authorities, and others in the planning of services across geographical areas.⁷ Within this new structure came integrated care boards (ICBs). As statutory bodies, ICBs replaced clinical commissioning groups (CCGs) and assumed the responsibility of planning and funding most NHS services in the area.⁸

Since their formation, ICBs have been tasked with developing joint forward plans. These plans describe how the ICB, and its partner trusts intend to arrange and provide NHS services to meet their population's physical and mental needs.⁹

Later that year, the Health and Care Act 2022 placed a legal obligation on ICBs to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.¹⁰

Whilst a recent review of all 42 joint forward plans by the palliative and end of life care team at NHS England (NHSE) found 69% of these plans to directly mention palliative and end of life care,¹¹ we know that in practice there is still a postcode lottery when it comes to accessing high quality children's palliative care that meets national standards.

To examine the extent to which children, young people and their families can access children's palliative care that meets national standards, we undertook the following:

- A family survey of bereaved parents and parents of children with life-limiting or life-threatening conditions to learn more about families' experiences of accessing children's palliative care and whether these experiences aligned with national guidance.
- A mapping exercise among paediatric palliative care networks to identify geographical areas where services that meet national standards are being provided.
- Freedom of information (FOI) requests of all 42 ICBs to understand the extent to which children's palliative care service specifications align with national standards.

Building on the network mapping work we carried out in 2021, and the subsequent report we published in 2022,¹² we were particularly interested in examining access to 24-hour end of life care at home. Our previous report found access to 24-hour end of life care at home to be dependent on a child's postcode. We were therefore intent on reassessing the situation to measure the current extent of this postcode lottery.

Terms used in this report

Throughout this report, when referring to national standards, we are referring to the quality statements as contained in the NICE quality standard for end-of-life care for infants, children, and young people, NHSE guidance, and Ambitions for Palliative and End of Life care framework.

The state of the sector in 2024

The experiences of children, young people, and their families

Children with life-limiting or life-threatening conditions and their families have a variety of specific needs. These needs can include: the management of pain and complex symptoms, emotional, psychological, and spiritual support, support with advance care planning or support with accessing education or employment that is right for them.

In order to meet these needs, a wide range of services from health, social care, and education, both in the statutory and voluntary sector are involved. Ensuring services are working in an integrated manner with good communication and join-up is therefore crucial to providing the seamless care that is required.

Children's palliative care also involves support for the parents and siblings of a child or young person with a life-limiting or life-threatening condition. To learn more about the experiences of parents when accessing children's palliative care, we conducted a survey of parents of children with life-limiting conditions and bereaved parents.

In this survey, we asked parents about the standards of care that were met for them and their family, whether they were involved in developing an advance care plan for their child or young person, and if there was anything further about the standard of palliative care, they experienced that they would like to mention.

In total, 26 parents (10 parents of a seriously ill child, 16 bereaved parents) responded to our survey. Whilst this number is not sufficient to form any absolute conclusions, it did nevertheless provide us with an insight into parents' individual experiences. Many of which aligned with the key themes drawn from parents' experiences captured in several research projects.

Lack of care coordination/care being driven

Despite the NICE quality statement that stipulates children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care,¹³ many parents have reported experiencing a lack of anyone coordinating or driving the care that their child or young person receives.

By examining the elements of care in the NICE quality statements that feature in families' experiences of palliative care, research has found that whilst parents talked about the many different professionals being involved in the planning of care, parents frequently reported not having one person or service co-ordinating or driving the care. In many cases, parents reported frustration at having to drive this themselves, often finding it stressful, time-consuming, challenging, and uncertain.¹⁴

The lack of a named person co-ordinating or driving care can also be seen in the responses to our survey with many parents reporting the fight and struggle they had to endure to get their child or young person the care they needed.

"It's a daily battle to provide the best we can to our daughter who has been in and out of end-of-life care for quite some time".

Parent of a child with a life-limiting or life-threatening condition.

“Disjointed, uncoordinated with local services”.

Bereaved parent.

“Once we accessed complex care and palliative care, the individual medical practitioners and carers were marvellous. However, getting referred into that system was not an easy process”.

Bereaved parent.

Research has also shown that parents have a profound need to fulfil the parental role and to be able to ‘be there’ for their child at the end of their life.¹⁵

In the absence of any named person coordinating or driving the care for the child or young person, parents will continue to assume this responsibility, thus denying them of the chance to fulfil this parental role and ‘be there’ for their child at the end of their life.

Lack of emotional and psychological support

Given the wide range of stressful and distressing circumstances that a family may face, emotional support can help the family cope with their distress and build resilience. It is therefore stipulated under the NICE quality standards that infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.¹⁶

Unfortunately, we are aware that in practice this quality standard is not always met with research showing that many parents experience a lack of psychological support, particularly after their child’s diagnosis.¹⁷

“I think there is an awful lot of bereavement support, but there is no pre-bereavement. There is nothing before”.

Bereaved parent.¹⁸

Providing this type of support to parents is critical for their wellbeing. Research has also shown that it can help prepare parents, so they are better enabled to be a parent to a seriously ill child or young person.¹⁹

“Looking after us, so we could better look after Ethan”.

Edward.²⁰

The importance of providing information about emotional and psychological support also extends to children and young people with life-limiting and life-threatening conditions.

Not only is the prevalence of anxiety and depression higher in children, adolescents and young people with life-limiting conditions compared with the general population,²¹ but it has also been found to be a key priority of young people with life-limiting conditions.²²

That said, our survey suggests that the majority of children and young people are unable to access information about emotional and psychological support with 66.6%-70% of parents reporting this to be the case.

Lack of involvement in advance care planning

Under the NICE quality standards, it is stipulated that infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.²³

An advance care plan provides an opportunity for people with life-limiting conditions to plan and receive care at the end of their life that is in line with their wishes. As wishes can change over time, it is important that advance care plans be reviewed and updated continuously throughout the delivery of care and support.

Notwithstanding this quality statement and the importance of involving children, young people and their parents when developing one, many parents have reported negative experiences when it comes to being involved in developing their child's advance care plan.

Whilst often described as a difficult and emotionally laden conversation, research has found many parents' experiences to be compounded by a lack of clear communication from professionals about planning one.²⁴ Some parents have even experienced professionals avoiding these difficult conversations.

Furthermore, many parents have described feeling somewhat abandoned and responsible for securing their child's care and support, especially when plans were not updated or reviewed regularly.²⁵ This was also evident in the responses to our survey.

"I do think that discussions around end-of-life scenarios could have come up earlier. In the end my daughter came to the end of her life more suddenly and sooner than we expected. But the risk was there, I felt like we'd never had a conversation with anyone to think about certain circumstances or advance care plans etc until the very end came. This made it harder to make already difficult decisions (switching off life support)".

Bereaved parent.

Lack of 24-hour end-of-life care at home

The provision of 24-hour children's nursing care and advice from a consultant in paediatric palliative care for infants, children, and young people approaching the end of life and being care for at home is also accounted for by the NICE quality standard.²⁶

Whilst home-based care has been linked with improved patient experience,²⁷ many parents have reported a lack of 24-hour end-of-life care at home with research showing the negative experiences endured by parents when trying to access 24-hour care at home.²⁸

One study showed that as a result of the limited amount to 24-hour end of life care that was offered to parents, this often resulted in periods of intensity of end-of-life care at home, thus reducing the quality of time parents had left with their children.²⁹

"I couldn't spend quality time with her during the day. Because her care was so intense it was basically ITU care at home..."

Bereaved parent.³⁰

The unequitable access to 24-hour care and support at home can be illustrated further by the responses to our survey.

Approximately 80% of parents of children with life-limiting or life-threatening conditions and 46.7% of bereaved parents reported not being able to access medications for their child or young person out of hours. Similarly, 60% of parents reported not being able to access advice in managing their child's symptoms 24-hours a day.

This further supports the claim that there are considerable inequalities in access to, and provision of, 24-hour care, dependent on age and postcode.³¹

Dan and Elisa's story

“Sometimes it feels like you have to prove your child's worth because they're disabled”.

Elisa's story, told by her dad Dan...

“Elisa was born with Cerebral Palsy. She also had epilepsy, dysphagia, was registered blind and deaf and had both central and obstructive sleep apnoea.” Elisa had no control over her body and required 24/7 care.

Elisa is one of four daughters and loved slapstick comedy and Futurama. “Despite everything, she loved to laugh.”

As Elisa grew, her care needs grew with her. Dan gave up work when Elisa was three so that he could manage her care. “It became like a small business, where I was a PA to Elisa and I was managing her day-to-day life and all her medicines, her schedule of appointments and who was caring.”

The family lived in Bournemouth and received a continuing health package, which entitled them to a carer most nights. But this was only as long as the family were able to find a carer for the shift. They were also supported by the paediatric team at their local hospital, two children's hospices, the community nursing team, a social worker, consultants, and staff at Elisa's school.

“We were lucky that our local hospital was quite small. We knew everybody and they had a good understanding of her needs. But whenever a new doctor was introduced, who hadn't met her, I'd have to tell her life story.

“Explaining that she's disabled, not stupid, sometimes comes into the equation as well. Sometimes it feels like you have to prove your child's worth because they're disabled.”

Elisa died in January 2023.

Most of the support Dan and his partner received came from other parents. But nobody was there to prepare the family for the practical side.

“DLA associated benefits were stopped five days after Elisa died. We hadn't even planned a funeral yet, and we were getting letters to say our subsidised council tax was being stopped. I had to go to a job centre to explain why I hadn't worked for eight years. There's no awareness of what we've been through as a family and what we might be trying to cope with. It's all automatic and very impersonal.

“Not having Elisa around now is challenging. For the entirety of her life, I was always in panic mode. And I don't think it ever goes away. I have moments of profound guilt where I think ‘could I have done things differently?’ How do we exist as individuals when we've given so much of our life to something that's no longer there?”

Access to services meeting national standards in England

In November 2023, we asked all paediatric palliative care networks in England to map the extent to which established children's palliative care standards are being met in hospitals, children's hospices, and in the community across England.

We wanted to examine why parents' experiences of accessing children's palliative care does not always align with national quality standards.

To do this, we provided each network with a spreadsheet to describe where the different service elements available in their region are provided. This spreadsheet was based on the South West Children's Palliative Care Network's mapping benchmarking tool for children and young people's palliative and end of life care. This is available to those who have access to the Future NHS Palliative and End of Life Care workspace.³²

By using this benchmarking tool, the standards from the NICE quality standards and Ambitions for Palliative and End of Life Care were all included. A copy of the tool can be found in the appendices.

Given the magnitude of the task and the time limitations attached to it, we asked networks to prioritise mapping the standards which relate to advance care planning and access to 24-hour end of life care at home.ⁱ

We know from the mapping work we conducted in 2021 and the subsequent report we published in 2022,³³ that there is a postcode lottery across England with some families of children with life-limiting conditions unable to access 24-hour end of life care at home that fully meets national standards. By asking networks to prioritise mapping the standards which relate to 24/7 end of life care at home, we sought to gather evidence enabling us to reassess the current extent to which children, young people, and their families can access 24-hour end of life care at home.

It is important to note that we asked networks not to map areas where services which are provided on the basis of goodwill by professionals, outside of the scope of their role. For example, we asked them to include out of hours services which are provided because professionals are contracted and/or paid overtime to provide them – but not those where professionals are delivering out of hours services free of charge as gestures of goodwill.

In total, nine networks from England completed the mapping exercise, providing us with data for the areas covered by 30 ICBs.ⁱⁱ Data for ICBs within the Lancashire and South Cumbria network was extracted from ICB FOI responses and Ambitions for Palliative and End of Life Care self-assessments given assurances of significant alignments between service commissioning and provision.

ⁱ According to the NICE quality statements for end-of-life care for infants, children, and young people 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.

ⁱⁱ The nine networks from England that completed the service mapping exercise include: Cheshire and Merseyside, East Midlands, East of England, Kent and Medway, North East England and North Cumbria, South West, Thames Valley, Wessex (providing data for Hampshire and Isle of Wight only), and West Midlands.

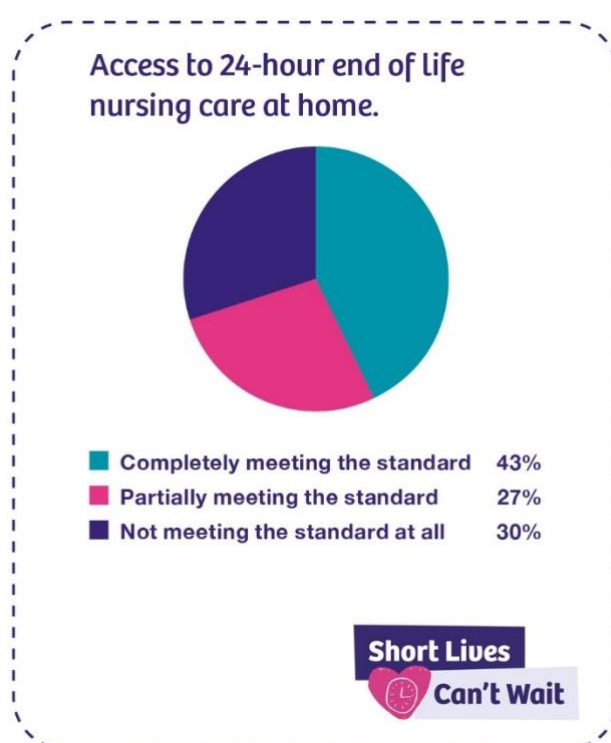
The West Midlands Paediatric Palliative Care Network updated their network mapping response in March 2024. The findings illustrated in this report are based off the previous network mapping response provided to us earlier in 2024. A copy of this response can be found in the appendices.

For each standard that networks were able to tell us about, we have assessed that they are being met completely, partially or not at all in the ICB areas they cover.

24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care

To assess the extent to which infants, children, and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care, we sought to break this standard down to examine individual components before assessing the standard as a whole.

From this mapping exercise, we have found that 24-hour end of life nursing care at home was available to families in 13 ICB areas (43.33%). We have found that this standard was partially met in a further eight ICB areas (26.67%).ⁱⁱⁱ



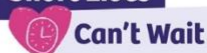
ⁱⁱⁱ Percentage figures are based on the number of ICBs we received data for rather than the total number of ICBs.

43% of regions in England are not providing access to 24-hour advice from a specialist consultant at the end of a child's life.



| | |
|-----------------------------------|-----|
| ■ Completely meeting the standard | 50% |
| ■ Partially meeting the standard | 7% |
| ■ Not meeting the standard at all | 43% |

Short Lives



With regards to 24-hour advice from specialist paediatric palliative care consultants, we have found this to be available in 15 ICB areas (50%). We have found that this standard was partially met in two ICB areas (6.67%).

From the information we have received from networks, we have established that both 24-hour end of life nursing care at home and 24-hour advice from specialist paediatric palliative care consultants at the end of life is fully available in nine ICB areas (30%). It is partially available in another 14 ICB areas (46.67%).

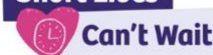
Whilst we recognise the mapping exercise did not result in a complete set of data covering all ICB areas, we believe that it has demonstrated huge variance in the extent to which children, and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

Only a third of regions in England are providing 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care at the end of life.



| | |
|-----------------------------------|-----|
| ■ Completely meeting the standard | 30% |
| ■ Partially meeting the standard | 47% |
| ■ Not meeting the standard at all | 23% |

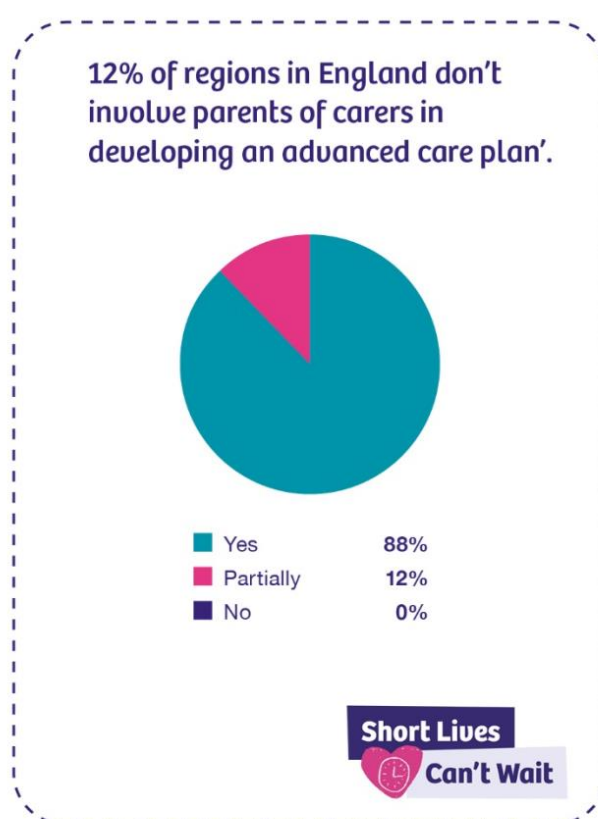
Short Lives



Children and young people with a life-limiting conditions and their parents or carers are involved in developing an advance care plan (ACP)

Through this mapping exercise, we also sought to examine the extent to which children and their families are involved in developing an advance care plan (ACP).

Of those networks that told us about advance care planning, we have found infants, children and young people with life-limiting conditions and their parents or carers to be involved in developing an ACP in 15 ICB areas (88%).^{iv} We have found that this standard was partially met in a further 2 ICB areas (12%).



The transition of young people with life-limiting and life-threatening conditions into adult health services

The transition of a young person into adult health and social care services is defined as *'The purposeful, planned process of transferring a young person's healthcare from a child-centred to an adult-orientated care setting that comprehensively addresses the medical, psychosocial, educational and vocational needs of that young person.'*³⁴

Given the complex and differing needs of each young person, the process of transition is often complex and challenging. This is particularly the case when a young person with multiple conditions is without an appropriate adult team to transfer to.

^{iv} Percentage figures are based on the number of ICBs we received data for rather than the total number of ICBs.

The process of transition can also bring challenges where children and young people's services end at the age of 16 and the adult service does not start until the age of 18. In these cases, the young person's care is often passed to primary care, which has the potential to be particularly impactful, especially on young people who may find it more challenging to access primary care.

Despite guidance being in place through various quality standards, including NICE, research by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) has found that this process is not working as well as it should. In particular, NCEPOD have found that due to significant fragmentation between services involved in the transfer, there is no clear pathway for the transition from healthcare services for children and young people into adult healthcare services.³⁵

In seeking to assess the barriers and facilitators to young people receiving a good transition to adult healthcare services, NCEPOD have found that transition from child into adult services is often perceived as the responsibility of the team the young person is leaving, rather than a combined responsibility of all healthcare professionals involved.³⁶

This was evident in NCEPOD's findings with only 9.6% (16/167) organisations reporting that transition is included in the job descriptions of all healthcare staff involved in the transition.³⁷

Similarly, NCEPOD have found that only 21.9% (37/169) organisations had mandatory training on transition in place for staff.³⁸ Therefore, raising the question as to whether adequate resources are in place to enable a good transition to adult healthcare services.

Good practice case study: Starling Service Pilot: 24/7 Palliative and End of Life Care for babies, children and young people in Bristol, North Somerset, and South Gloucestershire ICB

The Starling Service is a partnership between four palliative care providers in Bristol, North Somerset and South Gloucestershire (BNSSG) consisting of Children's Hospice South West (CHSW), Jessie May Children's Hospice at Home, Sirona Care and Health and University Hospitals Bristol and Weston HNS Foundation Trust. The pilot has been funded by NHSE and BNSSG Integrated Care Board. The service is the culmination of many years of consideration, planning and collaboration which has seen NHS and non-NHS providers come together to deliver a shared aim. The service is underpinned by an innovative Integrated Governance Framework and is strengthened by a shared digital clinical record and virtual ward.

The evaluation of the Starling Service pilot (to date) demonstrates the effectiveness of the pilot service in offering choice of location of care to children and families. The feelings of children and families involved with the pilot have been captured, with evidence the pilot has positively impacted families at a time of extreme difficulty. There is now a strong understanding of what good end of life care looks and feels like for bereaved families, and this understanding has helped strengthen existing services, in particular core bereavement services. The nursing and medical model has been tested, including over a challenging winter period, and has shown there is sufficient capacity and resource within the model to deliver a safe and effective service, underpinned by robust quality governance arrangements and cross-provider collaboration.

There is a sustainable system wide paediatric palliative care workforce who train and work collaboratively and can flex and respond to need. Their skills and responsivity are invaluable not only at the end of a child's life but also throughout their palliative journey. The impact on the clinical workforce delivering the service has been well understood through analysis of staff feedback on topics such as wellbeing, collaboration and specialist palliative and end of life skills confidence. Lessons learned have been captured and led to further improvements in service design and delivery.

Core palliative care services have been minimally impacted, with the cancellation of core activities at a significantly lower level than those prior to the pilot, in large part due to the bolstering of the existing workforce through pilot teams.

For the first time in BNSSG the palliative care workforce can offer 24/7 community management (and hospice / hospital avoidance) for ever-increasing numbers of complex children. The wider impact on the system has been considered through reflection on previous cases, prior to the pilot, the increased support given to families in the community outside of end of life provision, the bed night savings through the provision of community care under the Starling Service and the impact on professional's wellbeing across the system through the existence of a service which provides true choice to families at their time of greatest need.

A wide-reaching benefit of the Starling Service pilot on the system, which was not anticipated, yet not unexpected includes the strengthening of all existing core services through the collaborative nature of the pilot. Professionals across providers are working more collaboratively to provide a seamless service for families, both within and outside of the Starling Service pilot. Joint study days and a system wide training programme have created opportunities for the workforce to come together, build relationships, develop trust and share

skills and knowledge which is of benefit to staff wellbeing, retention, job satisfaction, career development and most of all to the children and families they support.

The Starling Service meets NICE guidelines in terms of offering real choice to families when it comes to end of life care for babies, children and young people and the pilot funding ends in March 2024. The investment (money and time) in understanding and navigating the complexities of innovative and collaborative working in its truest sense will be lost if the service is not continued.

Together for Short Lives calls for this important service to be sustainably funded by the ICB for the long-term.

Good practice case study: East of England Regional Advice and Facilitation Team

The East of England Regional Advice and Facilitation Team (RAaFT) was set up in response to growing numbers of babies, children and young people in the East of England with life-limiting and life-threatening conditions, following additional funding by NHS England.

RAaFT is spearheaded by Cambridge University Hospitals NHS Foundation Trust (CUH) and delivers a regional service working in partnership with East Anglia's Children's Hospices (EACH), Keech Hospice Care and Little Havens Hospice.

The highly specialist multi-disciplinary team consists of:

- Part time Consultant in Paediatric Palliative Medicine
- Part time Consultant Paediatrician with special interest in Paediatric Palliative Care
- Part time Consultant Nurse in Paediatric Palliative Care
- Part time Consultant Clinical Psychologist
- Part time Senior Paediatric Pharmacist
- Full time Clinical Nurse Specialists x2
- an Administrator
- Part time Specialist Play support.

This Regional service supports improved symptom management, advance care planning and end of life care for BCYP and their families needing support 24 hours a day seven days a week by working in partnership with those organisations and professionals operating in the East of England Children and Young People's Palliative and End of Life Care Managed Clinical Network (MCN). In addition, the Consultant Clinical Psychologist provides consultation, supervision and teaching for professionals to ensure their needs are met. The Children's Hospice Services provide 24/7 specialist nursing care face to face for all who need it with specialist clinical oversight and support coming from RAaFT during office hours and specialist telephone support from the MCN consultants out of hours.

The team supports those with a range of conditions, including:

- cancer
- those with extreme prematurity
- severe congenital heart disease
- Life-limiting metabolic conditions
- cerebral palsy
- neuromuscular issues.

The team offers support wherever babies, children and young people are being cared for, in hospital, hospice or at home. It also offers dedicated support for women and partners making difficult decisions about their unborn, and acutely unwell, babies.

The RAaFT service provides a critical component of the MCN which extends across hospitals, children's hospices and community services in Cambridgeshire, Peterborough, Norfolk, Suffolk, and Essex and reaching into Bedfordshire, Hertfordshire Luton and Milton Keynes.

RAaFT also has an educational and research role. Learning and Development opportunities are regularly delivered by RAaFT Clinicians to the many and varied Teams across the Region at universal, targeted and specialist levels of palliative care according to need. Support for Children's Palliative Care Research is also provided with the Children's Palliative

Outcome Scale Study (CPOS) an important opportunity to develop robust mechanisms to pursue a validated outcome measure and to capture BCYP and their families experiences of care.

Point prevalence surveys were carried out in 2022 and 2023 to provide information about the known number of children who need palliative care in the region at any one time. During 2024 the MCN hopes this survey will continue to inform both service developments and local commissioning.

Collectively the Network is beginning to standardise its clinical data across the Region in terms of caseload and outcomes. Based on data from one of the children's hospice services, in 2022/23, their clinical nurse specialists received 467 calls from families and professionals when 'on call' outside of normal working hours. Furthermore, their work across the 24/7 period led to 147 hospital admissions being avoided and 503 GP contacts avoided.

Good practice case study: The Kentown Children's Palliative Care Programme

The Kentown Children's Palliative Care Programme is a community focused initiative in North West England covering Lancashire and South Cumbria.³⁹

The groundbreaking and transformative project is reaching the growing numbers of children and young people with life-limiting conditions and their families in the region. In its first year, the project supported approximately 128 families.

The collaborative project combines nursing care, social care and information and awareness. Providing nursing, practical and emotional support to families and by signposting them to services in their communities and supporting them to access these, the project is reaching families more easily than ever before.

Funded by The Kentown Wizard Foundation, the programme comprises Rainbow Trust Family Support Workers, Together for Short Lives Family Service Coordinators and Specialist Children's Palliative Care Nurses from five NHS Trusts across the region.

A three-year study is underway to evaluate the impact this new approach to palliative care is having on families.

The needs of children and their families are at the core of The Kentown Children's Palliative Care Programme. Accessing children's palliative care should never depend on where families live.

The Kentown Children's Palliative Care Programme has a bold ambition to ensure every child and family has access to the right care and support, based around their individual needs ensuring families can make the most of every precious moment together.

It is designed to build and strengthen relationships with all communities, particularly those who are in greatest need and under-represented.

The project will build on established children's palliative care and support services, strengthening co-ordination and avoiding duplication to make life easier for families.

Local NHS commissioning in England

In November 2023, we also made a series of freedom of information (FOI) requests to all 42 ICBs. Given the legal duty on ICBs to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible,⁴⁰ we wanted to explore the extent to which ICBs are commissioning services that meet national standards.

In 2023, NHSE published a service specification for palliative and end of life care for children and young people. Grounded within the national standards for children's palliative care, the specification provided a service model for delivering specialist level palliative care (SLPC) services from identification of need through to end of life.⁴¹

These FOI requests therefore also provided us with an opportunity to examine the extent to which local service specifications differed from the national model.

To this end, we asked ICBs the following questions:

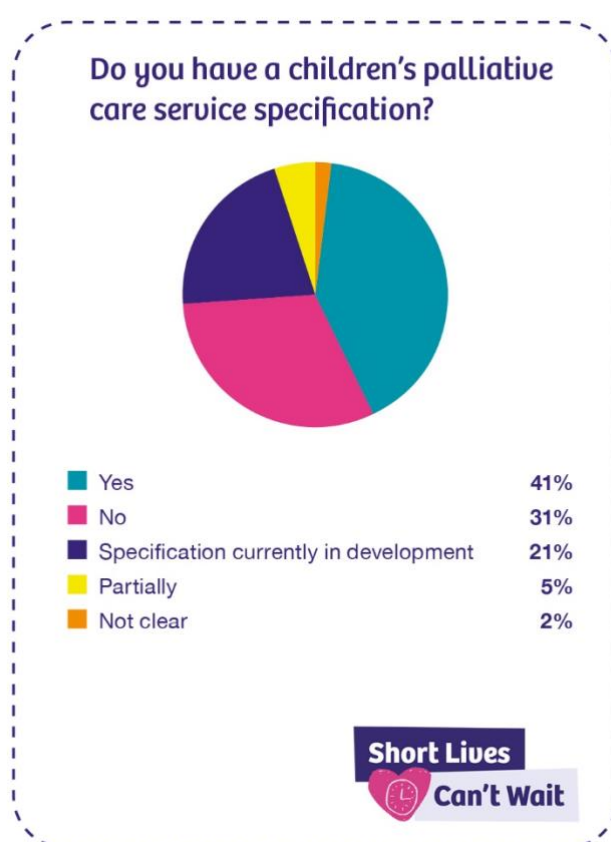
1. Do you have a children's palliative care service specification?
2. Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment?
3. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan?
4. Do you have a children's palliative care service specification which states that infants, children, and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care?
5. Do you have a children's palliative care service specification which states that infants, children, and young people with a life-limiting condition, their parents or carers and their siblings should be given information about emotional and psychological support, including how to access it?
6. Do you have a children's palliative care service specification which states that infants, children, and young people with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team?
7. Do you have a children's palliative care service specification which states that siblings and parents or carers of infants, children and young people 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?
8. Do you have a children's palliative care service specification which states that infants, children, and young people 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?

9. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite?

All 42 ICBs responded to our request. Scores were allocated based on the ICBs response to each question and the contents of any service specification provided.

Similar to the network mapping exercise, these FOI requests have uncovered a vast amount of regional variation in both the extent to which NHS integrated care boards (ICBs) have a specific service specification for children's palliative care and the extent to which these service specifications meet national standards.

When asked if they have a children's palliative care service specification, 17 ICBs (40.48%) responded yes, 13 ICBs (30.95%) responded no, whilst a further 9 ICBs (21.43%) outlined that their specification is currently in development.^v

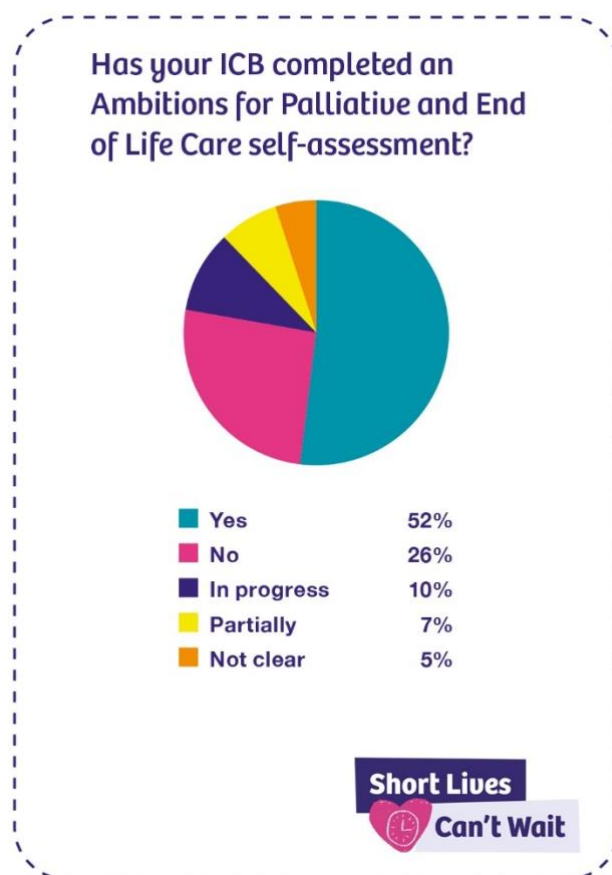


Service specifications define the standards of care expected from organisations funded to provide specialised care.⁴² It is therefore concerning to see that the majority of ICBs do not currently have a published service specification for children's palliative care. In the absence of a specific service specification, there is no guarantee that providers will deliver services capable of meeting the standards of care that are required.

Our FOI requests have also uncovered huge variance when it comes to ICBs completing an Ambitions for Palliative and End of Life Care self-assessment.

^v Percentage figures are based on the total number of ICBs (42 ICBs).

By providing a self-assessment framework, this tool supports localities to determine the extent to which their current level of service provision aligns with the six Ambitions for Palliative and End of Life Care. Despite this, only 22 ICBs (52.38%) have completed an Ambitions for Palliative and End of Life Care self-assessment.



When asked about the individual standards that the service specification meets, we have found that the majority of service specifications were not completely meeting these standards.

We found that just six ICB (14%) had a service specification that states that infants, children, and young people 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. 17 (41%) did not specify these services, while six (14%) were developing specifications to do so.

Similarly, when asked whether the service specification states that infants, children, and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care, we have found this was only met in 4 ICB (9.52%) service specifications. The majority of service specifications (23 ICBs, 54.76%) did not meet this standard.

The extent to which ICBs are specifying children's palliative care services



We have also found that, in some areas, key children's palliative care standards are being met despite the fact that they are not being specified by local ICBs. In some cases, this has resulted in a mismatch between the findings from our network mapping exercise and the responses to our FOI requests. We believe this is likely due to professionals proactively providing services despite not necessarily being commissioned to do so.

When considering the key themes that have emerged in relation to families' experiences of accessing children's palliative care, the responses to our FOI requests help explain why families may have had such negative experiences.

This is particularly the case when it comes to support with coordinating or driving care, accessing information about emotional and psychological support, being involved in the development of their child's advance care plan, and accessing 24-hour end of life care at home.

The service specification provided by NHSE for delivering specialist level palliative care services from identification of need through to end of life provides ICBs with a model example.⁴³

It is vital that ICBs ensure their service specifications for children's palliative care include the key components of NHSE's model. Doing so would not only ensure ICB's service specifications meet national standards, but it would also help eliminate the extent to which a child or young person's access to high quality palliative care is dependent on their postcode.

Local areas demonstrating good practice in commissioning care that meets standards

Whilst these FOI requests have revealed huge variance in the commissioning of children's palliative care services that meet national standards across England, they have also highlighted a number of ICBs that are performing very well. ICBs such as Buckinghamshire, Oxfordshire and Berkshire West (BOB) and Cheshire and Merseyside both have service specifications that are inclusive of national standards and have completed an Ambitions for Palliative and End of Life Care self-assessment.

The areas with the greatest challenges in commissioning care that meets standards

Meanwhile, ICBs such as Frimley, Humber and North Yorkshire and Black Country all lack a specific service specification for children's palliative care and have not completed an Ambitions for Palliative and End of Life Care self-assessment. As a result, in the absence of a specific commissioning framework for children's palliative care that is capable of meeting national standards, it is likely that infants, children and young people living in these areas will be unable to access commissioned services that meet national standards.

Table: the extent to which children and young people with life-limiting or life-threatening conditions being cared for at home have access to children's nursing and consultant for end of life care 24/7

| ICB | Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in England | Rank by cases | Total population of children and young people 0-24 | Prevalence of LLCs and LTCs per 10,000 children and young people in England aged 0-24 years old | Provided: Child with LLCs and LTCs cared for at home have access to children's nursing and consultant for end of life care 24/7 | Included within service specifications: Child with LLCs and LTCs cared for at home has access to children's nursing and consultant for end of life care 24/7 |
|------------------------------|---|---------------|--|---|---|--|
| Greater Manchester | 6241 | 1 | 873958 | 71.4 | | No |
| Cumbria and NE | 6019 | 2 | 880871 | 68.3 | Partially | Partially |
| West Yorkshire | 5318 | 3 | 763423 | 69.7 | | Not clear |
| Cheshire and Merseyside | 4856 | 4 | 721332 | 67.3 | Partially | Yes |
| North West London | 4068 | 5 | 568841 | 71.5 | | No |
| North East London | 4006 | 6 | 554599 | 72.2 | | Yes |
| Lancashire and South Cumbria | 3437 | 7 | 502922 | 68.3 | No | No |
| South East London | 3400 | 8 | 490600 | 69.3 | | Not clear |

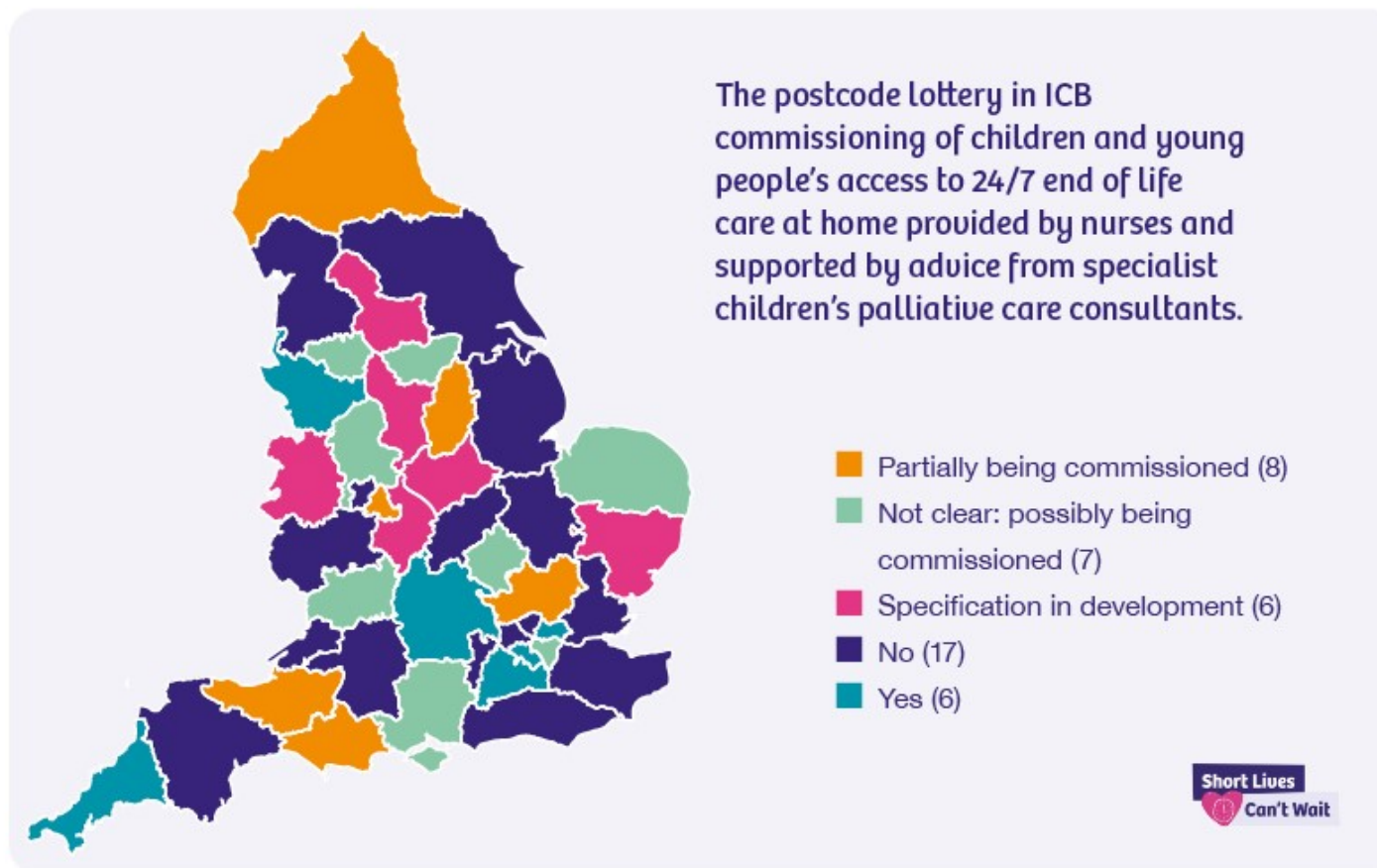
| | | | | | | |
|---|------|----|--------|------|-----------|-----------|
| Hampshire and the Isle of Wight | 3373 | 9 | 523136 | 64.5 | Partially | Not clear |
| Kent and Medway | 3301 | 10 | 517431 | 63.8 | Yes | No |
| South Yorkshire and Bassetlaw | 3270 | 11 | 454676 | 71.9 | | Not clear |
| The Black Country and West Birmingham | 3104 | 12 | 410934 | 75.5 | Partially | No |
| Sussex | 2980 | 13 | 442427 | 67.4 | | No |
| Buckinghamshire, Oxfordshire and Berkshire West | 2945 | 14 | 505501 | 58.3 | Yes | Yes |
| Birmingham and Solihull | 2871 | 15 | 386491 | 74.3 | Partially | Partially |
| South West London | 2860 | 16 | 411342 | 69.5 | | Yes |
| Humber Coast and Vale | 2755 | 17 | 492490 | 55.9 | | No |
| North Central London | 2719 | 18 | 399457 | 68.1 | | No |
| Hertfordshire and West Essex | 2552 | 19 | 417811 | 61.1 | Yes | Partially |
| Bedfordshire, Luton and Milton Keynes | 2101 | 20 | 278001 | 75.6 | Yes | Not clear |
| Mid and South Essex | 2079 | 21 | 335057 | 62.0 | Yes | No |

| | | | | | | |
|---|------|----|--------|------|-----------|--------------------------------------|
| Devon | 2075 | 22 | 329179 | 63.0 | Partially | No |
| Staffordshire & Stoke on Trent | 2027 | 23 | 316909 | 64.0 | Partially | Not clear |
| Nottingham and Nottinghamshire | 1926 | 24 | 311302 | 61.9 | Partially | Partially |
| Bristol, North Somerset and South Gloucestershire | 1859 | 25 | 285263 | 65.2 | Yes | No |
| Derbyshire | 1746 | 26 | 284652 | 61.3 | No | Service specification in development |
| Surrey Heartlands | 1744 | 27 | 288602 | 60.4 | | Yes |
| Leicester, Leicestershire and Rutland | 1739 | 28 | 322329 | 54.0 | Partially | Service specification in development |
| Coventry and Warwickshire | 1596 | 29 | 266058 | 60.0 | Partially | Service specification in development |
| Suffolk and North East Essex | 1553 | 30 | 267857 | 58.0 | Yes | Service specification in development |
| Cambridgeshire and Peterborough | 1540 | 31 | 255934 | 60.2 | Yes | No |
| Norfolk and Waveney | 1477 | 32 | 270388 | 54.6 | Yes | Not clear |
| Bath and North East Somerset, Swindon and Wiltshire | 1456 | 33 | 258463 | 56.3 | No | No |

| | | | | | | |
|--------------------------------------|---------------|----|-----------------|------|-----------|---|
| Northamptonshire | 1373 | 34 | 206193 | 66.6 | No | No |
| Frimley | 1297 | 35 | 221132 | 58.7 | | No |
| Herefordshire and Worcestershire | 1257 | 36 | 203879 | 61.7 | Partially | No |
| Dorset | 1251 | 37 | 200486 | 62.4 | Partially | Partially |
| Lincolnshire | 1113 | 38 | 199737 | 55.7 | Partially | No |
| Gloucestershire | 1105 | 39 | 173823 | 63.6 | No | Not clear |
| Cornwall and the Isles of Scilly | 1076 | 40 | 147483 | 73.0 | No | Yes |
| Somerset | 1011 | 41 | 147617 | 68.5 | No | Partially |
| Shropshire and Telford and Wrekin | 881 | 42 | 134598 | 65.5 | Partially | Service specification in development |
| TOTAL | 105357 | | 16023184 | | | |

Map: the extent to which ICBs are commissioning services which mean children and young people with life-limiting or life-threatening conditions being cared for at home have access to children's nursing and consultant for end of life care 24/7

You can access and explore this map [online here](#).



Good practice case study: Buckinghamshire, Oxfordshire and West Berkshire (BOB) ICB

BOB ICB's palliative and end of life care is to improve access and experience of these services to enable people of all ages to die well. It has taken a number of actions to commission palliative and end of life care for children and young people effectively.

Strategy

The ICB has added a separate Dying Well priority to its strategy. It has prioritised the following in its joint forward plan:

- Goal 1: A robust model of access to 24/7 Palliative and End of Life services for patients, their carers and relatives.
- Goal 2: A successful population health approach to early identify people needing Palliative and End of Life services.
- Goal 3: To co-design PEOLC through Provider Collaboratives and in partnership with people with lived experience.

The joint forward plan and the ICB's overall strategy both specifically reference children's palliative care. Its palliative and end of life care programme has been all-age from its inception and has been codesigned with patients and the public.

Working with providers

The ICB has:

- Funded extensive work by external experts to map services.
- Worked to join acute sector and community providers to try to improve the process of discharging children and young people with medical complexity and who technology dependent into the community in a programme known as the Homeward Bound Hub; this may lead to a wider pilot of a virtual ward model.
- Worked closely with providers (including the third sector) to ensure NHSE children's palliative care match funding has been awarded.
- Funded the medication budget of third sector hospices, which was previously sustained from on charitable sources.
- Begun moving providers onto long-term contracts, rather than funding them using grants, to make sure they are sustainable and engaged in the local health and care system.

Securing specialist medical services

The ICB has:

- Supported work to appoint a consultant paediatrician with a special interest in paediatric palliative care in Berkshire with work underway to secure a second for Buckinghamshire.

- Pump primed a second specialist, GRID-trained paediatric palliative care consultant post for the region for two years, with a future funding contribution from the regional tertiary centre (Oxford University Hospital NHS Foundation Trust) negotiated.
- Funded one session per week for three years to improve transition to adult services in palliative and end of life care patients.
- Created a children and young people's clinical lead post to work alongside the all-ages clinical lead for palliative and end of life care in the ICB footprint; this is funded at half a session per week for more than three years.

As a result of the above actions, children's palliative care is now embedded in the tertiary centre.

Other steps

The ICB:

- Has funded a network coordinator for the managed clinical network on a fixed term basis.
- Is supporting work to implement shared care records and advance care planning through Graphnet and connected care in the coming year.
- Made sure that all-age education has enabled adults to learn from children and young people's providers about managing patients with learning difficulties - and ensuring that children's and young people's services acknowledge frailty as an 'all-age concept'.
- Is well engaged with the NHS South East palliative and end of life care strategic clinical network.

The ICB was recognised as a finalist in the 2023 HSJ awards for its all-ages approach to palliative and end of life care.

Good practice case study: Cheshire and Merseyside ICB

NHS Cheshire & Merseyside Integrated Care Board (ICB) has begun to adopt the NHSE Specialist Palliative and End of Life Care Services Specification for children and young people. It has also implemented its own locally developed specifications, including the Children's Emergency Respite Service Specification and the Claire House Children's Hospice Rapid Response Service Specification. This was done via a consolidated contract across the nine Cheshire & Merseyside Places.

The clinical commissioning groups (CCGs) across Cheshire & Merseyside self-assessed their performance against the Ambitions for Palliative and End of Life Care between 2016 and 2018, using the information to develop local improvement plans.

Following the transition to ICBs in July 2022, local place-based partnerships are now operating in Cheshire & Merseyside. The partnerships will revisit and repeat the self-assessment as required.

Cheshire & Merseyside Public Health Collaborative (CHAMPS) has also been commissioned to undertake a population-based needs assessment for end-of-life care across the ICB footprint.

The Cheshire & Merseyside ICS Palliative & End of Life Care Programme Delivery Plan 2022-23, which aligns to NHSE's statutory guidance to help ICBs meet their legal duty to commission palliative and end of life care, is used as a reference point for service development.

The Claire House consolidated contract (nine Cheshire & Merseyside ICB Places) specifies the delivery of services which meet the NICE Quality standard [QS160] End of Life Care for Infants, Children and Young People. It also specifies that infants, children and young people with a life-limiting condition and their families should have access to regular short breaks for respite.

Access to social care in England

Provided by the local authority, social care enables all forms of personal care and other practical assistance for children and young people who need extra support. When provided alongside other health-related services, social care plays a pivotal role in ensuring children and young people with life-limiting and life-threatening conditions receive care that caters for all their needs.

Children with life-limiting and life-threatening conditions deserve a support system that enables them to flourish at whatever stage of their life they are at.⁴⁴ In spite of this, research by the Disabled Children's Partnership (DCP) has found that just one in seven disabled children receive the correct level of support, whilst three in four parent carers have had to give up employment or their whole careers due to the lack of support available.⁴⁵

As a result of this reduced support, disabled children are being negatively affected with increases in depression, anxiety and loneliness being well documented.⁴⁶ Likewise, in the absence of sufficient support from local authorities, parents are having to plug the gap, consequently resulting in their own mental health being negatively affected.⁴⁷

"The main impact is isolation. Because there are no activities suitable for her to take part in (because the LA doesn't commission them)."

Parent carer.⁴⁸

"As the parent - I have no friends or support network - my child has one friend that she sees every day at school. It's incredibly sad & lonely for both of us."

Parent carer.⁴⁹

Access to education in England

When provided correctly with suitable support in place, provision enables disabled children to access education in a setting that is capable of meeting their needs. For this to occur, mainstream education settings must have access to a broad range of specialist health, and care professionals.

Unfortunately, shortages in the specialist workforce has meant that many disabled children are not currently attending the correct setting to meet their needs.⁵⁰ These shortages have also meant significant delays in getting children's needs assessed by an educational psychologist.⁵¹ In response to the DCP's survey, one parent carer mentioned waiting over 12 months for an appointment with an educational psychologist to assess their child's needs.⁵²

As a result of disabled children's needs going unmet, many children are left struggling whilst at their setting.

"My son has been waiting for a new speech therapist since April. This is still not in place despite my requests. Otherwise, he is supported at college between the TAs and his PA who goes in with him." - Parent Carer.⁵³

"Even though my son has an EHCP he's been severely let down by the provision and that's supposed to be a legally binding document. He's in Yr2 and his school are still waiting for a ramp. A RAMP!!! A basic provision for his access." - Parent Carer.⁵⁴

Northern Ireland

In November 2016, the Department of Health in Northern Ireland published its strategy for children's palliative and end of life care. Within this strategy were 23 key objectives, including commitments around increasing access to 24/7 multidisciplinary community services and specialist palliative care advice, care coordination and information provision in a timely manner.⁵⁵

Despite these commitments, the Northern Ireland children's palliative care network response has revealed that these commitments may not be being delivered upon. When examining the extent to which children and young people can access 24-hour end of life nursing care at home and advice from a specialist paediatric palliative care consultant, it seems the services that are formally commissioned in Northern Ireland are not capable of meeting this standard.

This response aligns with a progress report published in 2021 by the Northern Ireland Department of Health. This report stated the following:

'24/7 access to palliative care advice and end of life services is available to children across Northern Ireland. However, much of this is done on an informal basis by clinicians, children's community nurses and staff from the Northern Ireland Children's Hospice. Whilst staff work tirelessly to meet the needs of each child, the Paediatric Palliative Care Network recognises that the absence of a formalised commissioned regionally agreed approach is not ideal.'

The strategy for children's palliative and end of life care also seeks to ensure that individual care plans are drawn up in partnership with children and young people requiring palliative care and their families.⁵⁶

We understand from the Northern Ireland children's palliative care network response, that when it comes to developing an advance care plan, children, young people, and their families are involved across all trusts.

Whilst some barriers were noted by the network, such as the difficulty in starting these conversations, and parents not wanting their child involved, it seems services are making progress in achieving this strategy objective and meeting the NICE quality standard around advance care planning.

That said, we remain concerned about the extent to which services that meet national standards and align with the Department of Health's strategy are being formally commissioned. It is vital that the Northern Ireland executive take the necessary steps to ensure that children with life-limiting conditions in Northern Ireland and their families can access the palliative care they need, when and where they need it.

Scotland

In Scotland there is a single-national provider of children's hospice care, with Children's Hospices Across Scotland (CHAS) working across hospices, hospitals, and children's homes. CHAS funds joint specialist teams in all the children's hospitals in Scotland (Aberdeen, Glasgow and Edinburgh).

In its manifesto document ahead of the 2021 Scottish Parliamentary elections, CHAS highlighted that not all families in Scotland are equally able to access consistent 24/7 support for end of life care at home, if they choose it.⁵⁷ Some NHS boards in Scotland are

able to consistently offer this service. In NHS Ayrshire and Arran, the Paediatric Supportive Care Team was put in place specifically to address this issue. The team provides round the clock out of hours medical and nursing support to families in their chosen place of care.

In NHS Lothian, CHAS has partnered with the Health Board to provide the Care 24 Lothian service, allowing children and their families access to specialist end of life care in their own home.

CHAS also highlights other challenges facing families in Scotland in:

- accessing social care
- managing the financial impact of caring for a seriously ill child – including extremely high energy costs
- ensuring smooth transitions between children's and adult services – and access to age and developmentally appropriate care
- access to appropriate bereavement support.⁵⁸

Wales

In June 2023, Wales's two children's hospices, Tŷ Hafan and Tŷ Gobaith launched a groundbreaking new report which explores trends within the population of children with life-limiting conditions in Wales from 2009 to 2019.⁵⁹ This report found that the number of young people aged between 0 and 26 years old living with a life-limiting condition in Wales between 2009 and 2019 rose by almost 33%.

Despite this increasing prevalence, the extent to which children and young people can access services that meets national standards still depends on where they live. This is particularly the case when examining the extent to which children with life-limiting conditions can access 24-hour end of life nursing care at home and advice from a specialist paediatric palliative care consultant.

From discussions with professionals working in the paediatric palliative care sector in Wales and from the response to our network mapping exercise, we have found that whilst 24-hour advice from a consultant in paediatric palliative care is widely available across Wales, the same cannot be said for 24-hour access to end of life nursing care at home, with this standard only being met in certain areas.

Even in these areas where 24-hour end of life nursing care at home is available such as Betsi Cadwaladr, services are still not as well funded as they should be and rely heavily on support from the children's hospice. Others are also largely dependent on the good will of professionals to provide and deliver a 24/7 service.

Equally, whilst 24-hour advice from a consultant in paediatric palliative care may be available across Wales, only staff can access this advice. As such, children in areas without 24-hour nursing cover may subsequently be unable to access this provision.

English Regions

East of England

The East of England NHS region covers six ICBs. From our network mapping exercise, we have found that many services across the ICSs are meeting national standards. 24-hour end of life nursing care at home and 24-hour advice from a specialist paediatric palliative care consultant is available in all areas across the region from the Regional Advice and Facilitation Team (RAaFT).

However, when examining the responses to our FOI requests, variance can be seen in the extent to which services that are being commissioned are meeting national standards.

Whilst all ICBs except for two have a specific service specification for children's palliative care, none of the service specifications provided explicitly stated that infants, children, and young people 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.

This may be because RAaFT has been funded directly by NHSE Specialised Commissioning rather than local ICBs.

London

The London NHS region covers five ICBs. Whilst we did not get a response to our mapping exercise, from our FOI requests, we have found that only two of these ICBs have a specific service specification for children's palliative care. As such, there is variance in the extent to which services that are being commissioned meet national standards.

Focusing on standards around advance care planning and 24-hour end of life care at home, we have found that only two ICB service specifications meet these standards.

From discussions with professionals working in the region, we understand that whilst all children can be referred to a specialist paediatric palliative care team, thereby gaining access to advance care planning and 24-hour specialist telephone advice for children at end of life, the ability to deliver 24-hour end of life care at home is very dependent on the availability of community children's nurses (CCN). In some areas, this can be managed fine but in other areas, struggles persist due to a lack of availability among CCN teams.

Midlands

The Midlands NHS region covers 11 ICBs. Responses to our network mapping exercise have again revealed variance in the extent to which services are meeting national standards.

Whilst some areas were able to ensure access to 24-hour end of life nursing care at home or 24-hour advice from a specialist consultant, no areas were able to provide both.^{vi}

Similarly, from the responses to our FOI requests, we have found that only two ICBs have specific service specifications for children's palliative care. Whilst five ICBs reported having a specification currently in development, none of the specifications provided stated that

^{vi} The West Midlands Paediatric Palliative Care Network updated their network mapping response in March 2024. The findings illustrated in this report are based off the previous network mapping response provided to us earlier in the year. A copy of this response can be found in the appendices.

infants, children, and young people 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 at the end of life.

Whilst our network mapping has also revealed that children, young people and their parents or carers are frequently involved in developing an advance care plan, our FOI requests have found that no service specifications in the Midlands specifically state for this to happen. Like the East of England, we believe this is likely due to professionals proactively providing services despite not necessarily being commissioned to do so.

North East and Yorkshire

The North East and Yorkshire NHS region covers four ICBs.

Our FOI requests have found that only one ICB has a specific service specification for children's palliative care, with West Yorkshire ICB reporting that their service specification is currently in development.

From examining the extent to which the service specifications meet individual quality standards, we have found variation in the extent to which these standards are met.

None of the service specifications state that infants, children, and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care.

Similarly, only one service specification partially meets the standard around 24-hour end of life care at home, with North East and North Cumbria ICB's service specification mentioning 24/7 advice and in-patient care but failing to include 24/7 care at home.

While we have not been able to obtain a network mapping response for Yorkshire and Humber, we understand from discussions with professionals working in the region that services are being delivered that meet national standards, both in the statutory and voluntary sector. We understand, for example, that 24-hour end of life care at home is available to children and young people who have been referred to Martin House Children's Hospice, including access to both 24-hour nursing care and consultant advice.

North West

The North West NHS region covers three ICBs.

Through our network mapping exercise, we have found great variance across the North West in the extent to which services are meeting national standards.

This is particularly the case when considering standards around 24-hour end of life care at home. Whilst services in Cheshire and Merseyside are partially meeting this standard with 24-hour access to end of life nursing care offered across the area, this is not the case for areas within Lancashire and South Cumbria ICS.^{vii}

From our FOI responses, we have found that only Cheshire and Merseyside ICB have a specific service specification for children's palliative care in the region. Highlighted as a good

^{vii} Data for ICBs within the Lancashire and South Cumbria network was extracted from ICB FOI responses and Ambitions for Palliative and End of Life Care self-assessments given assurances of significant alignments between service commissioning and provision.

practice example, Cheshire and Merseyside ICB adopted the NHSE Specialist Palliative and End of Life Care Services Specification for children and young people, thereby meeting national standards. Meanwhile, Lancashire and South Cumbria ICB reported that their service specification is currently in development.

South East

The South East NHS region covers six ICBs.

From our analysis of network mapping responses and responses to our FOI requests, we have yet again found variance in the extent to which services being provided and services being commissioned are meeting national standards.

Responses to our mapping exercise has showed that when it comes to accessing 24-hour end of life care at home, there is a postcode lottery with only Buckinghamshire, Oxfordshire, and Berkshire West (BOB) ICS and Kent and Medway ICS containing services capable of meeting this standard.

In terms of the responses to our FOI requests, we have found that only BOB ICB and Surrey Heartlands ICB have specific service specifications for children's palliative care in the region. Even then, having adopted the NHSE Specialist Palliative and End of Life Care Services Specification for children and young people, only BOB ICB's service specification meets all the national standards that we asked about.

South West

The South West NHS region covers seven ICBs.

Within this region, we have again found huge variance in the extent to which services are meeting national standards.

From our network mapping exercise, we have found that 24-hour access to children's nursing care and advice from a consultant in paediatric palliative care at the end of life is only available in one ICS. However, providing children, young people and their parents or carers with opportunities to be involved in advance care planning was said to take place in all ICSs.

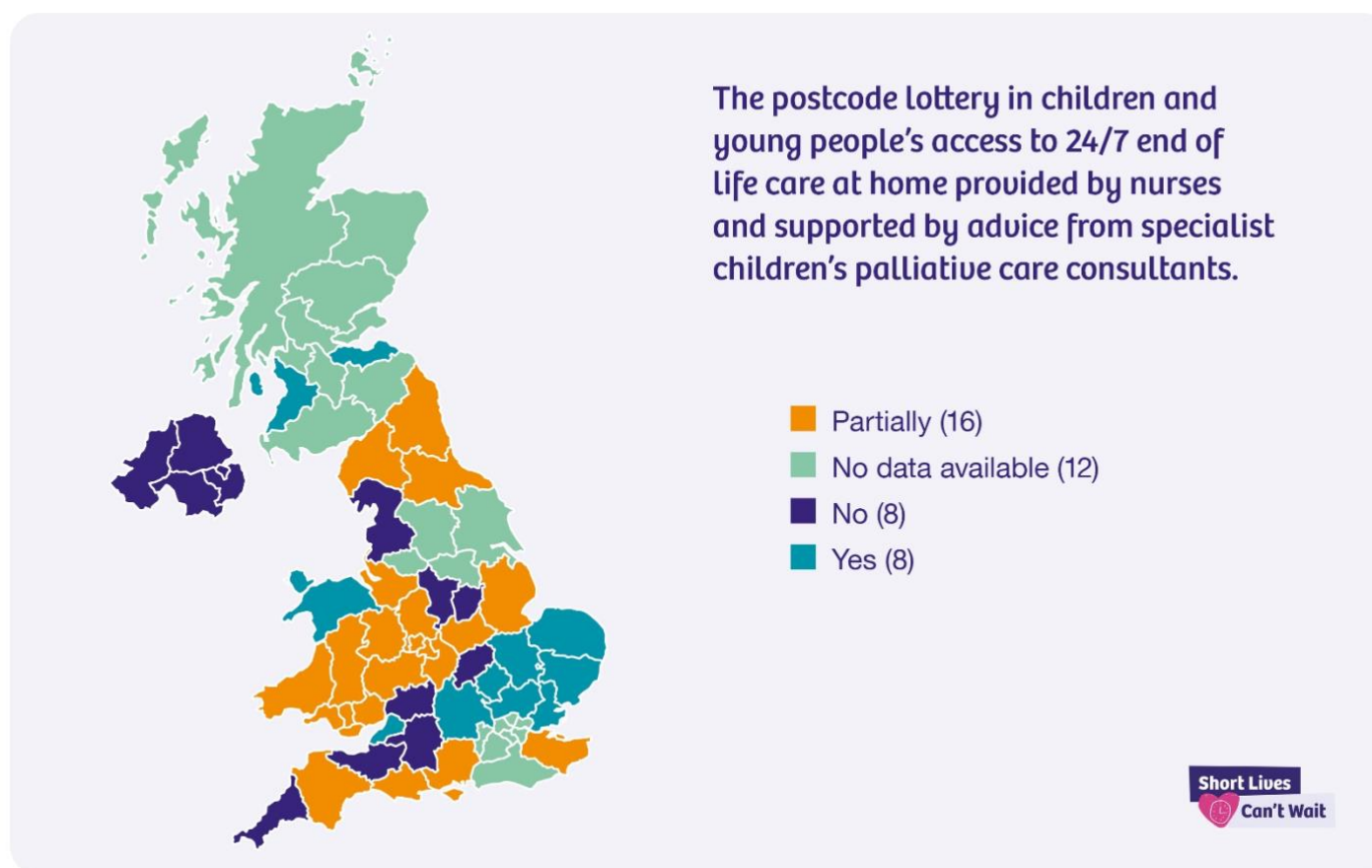
With regards to our FOI requests, these too have uncovered huge variance in the extent to which services being commissioned are meeting national standards.

Five ICBs in the region currently have a specific service specification for children's palliative care whilst another ICB reported currently having one in development. Despite the majority of ICBs having specific service specifications, only three ICB specifications state that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan. Similarly, only one ICB specification meets the national standard around end of life care at home.

With a fair amount of mismatch between what is being commissioned and what is being provided in the region, we believe 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 ICBs.

Map: the areas where children and young people with life-limiting or life-threatening conditions being cared for at home have access to children's nursing and consultant for end of life care 24/7 across the UK

You can access and explore this map [online here](#).



Stevi and Holly's story

"Her twin sister will always be missing her other half."

Holly's story, told by her mum Stevi...

"Holly required 24/7 care, she couldn't do anything for herself. Due to twin-twin transfusion syndrome, she was deprived of oxygen at birth which left her with very complex needs."

At 36 hours old Holly's family were told that she was not breathing on her own and that her prognosis was very bleak: "But amazingly, when the life support machines were turned off, Holly lived. She fought every day to live."

When she was two, she had her first seizure, and when she was three, she had a gastric tube fitted. Her care was 24/7, she was double incontinent, and her disabilities progressed as the years passed: "We spent so much time in our local hospital. They were like family.

Sometimes, she had to be sedated because her pain was so bad."

Holly loved the Frozen soundtrack, slime, and more than anything else, her sisters: "Despite everything, she had a great love for life."

Just before the first Covid lockdown, Holly was discharged from hospital, but she soon developed intestinal failure. "It was very painful and we knew it wasn't fixable. It was the beginning of the end for Holly."

The family live in rural Scotland and were supported by their local community nursing team, ward staff and their paediatrician. Holly also spent some time at CHAS, the family's most local hospice.

"We were constantly in and out of our local children's ward, but we always knew we wanted her to be at home when she died. The care we received was nothing less than phenomenal.

They all went above and beyond to care for us. The hospital was always Holly's happy place. We nominated one of her nurses and doctor for an award, because they meant so much to us.

"Near the end, the hospital team, community nursing team and CHAS worked together as one big team. A model they have since used for other families. We were delivering strong drugs through a syringe driver. But they were always there when we needed them. Always."

Holly died at home in October 2020 at 9 years old.

The community nurse continued to visit the family after Holly died: "I feel passionate that other families should have the care we had. We didn't need to fight for it thankfully. Nobody should have a child die, and nobody should have to fight for the care they deserve."

"We always knew Holly would not make it to adulthood. But now her twin sister is missing her other half. They were born to be a duo. They were always supposed to have each other."

The barriers to accessing children's palliative care – and the policy action we recommend

We have identified three policy barriers which explain why children with life-limiting conditions across the UK and their families are unable to access children's palliative care which meets national standards.

Workforce

The regional specialist children's palliative care workforce

Under the NICE quality standard, infants, children, and young people with a life-limiting condition should be cared for by a multi-disciplinary team that includes members of the specialist paediatric palliative care team.⁶⁰ According to NICE, this team should include the following as a minimum:

- A paediatric palliative care consultant.
- A nurse with expertise in paediatric palliative care.
- A pharmacist with expertise in specialist paediatric palliative care.
- Experts in child and family support who have experience in end-of-life care.

Research has shown that specialist paediatric palliative care can enable several benefits for children, young people and their families, such as:

- Improved quality of life.
- Improved symptom control.
- An increased likelihood that a preferred place of death is achieved.⁶¹

However, in practice, children and young people do not always have access to specialist paediatric palliative care services due to a system-wide shortage in the number of professionals with the skills and experience needed to provide children's palliative care in hospitals, children's hospices and in the community.

According to research published in 2023, only 35% of consultant led specialist paediatric palliative care teams in the UK have the minimum professional configuration as recommended by NICE.⁶² As a result, this is impacting on patient access to symptom management, support with legal and ethical issues and leadership across services and systems.

Six networks across the UK were able to tell us about how their specialist children's palliative care teams are comprised. Among these, most specialist roles appeared to be filled, with only a few networks reporting vacancies. However, a lack of NHS funding for posts is having a negative impact on services.

The East of England network has a 0.6 WTE consultant in paediatric palliative medicine post which has been vacant for 18 months. The network states that this vacancy means that there is a risk to sustainability of the second tier on call rota. However, an action plan is in place to address this across the region.

The Kent and Medway network reported the following vacancies:

- 1 WTE clinical nurse specialist (vacant for nine months)
- 1 WTE registered children's nurse (vacant for 12 months)
- 1 WTE children's support worker (vacant for 10 months)

The network states that if a member of staff does leave it takes a long time to recruit back into the post. This has a significant impact on service delivery.

The Northern Ireland network has no funded paediatric psychology provision within Palliative Care and End of Life Care Teams within the Southern HSC Trust.

The South West network states:

"We do not have an issue with vacancies as we do not have commissioned funding to create posts to fail to recruit to.

Our team is under-resourced. This has been escalated through all possible channels. The last increase in investment in our service was in 2016. From 2018 to 2023 we saw a 100% increase in referrals. This has had a significant impact on staff retention. We have amended our referral criteria to increase the threshold at which provide support.

If we had investment in posts I expect we may face some of the challenges you describe (particularly inability to recruit individuals with the required skills, knowledge, training) but funding for posts is our first barrier and one that we haven't yet solved in a sustainable way.

We require the NHS to recognise the need to invest in services that can provide PPC expertise within all settings but particularly to invest in teams that can fully embed themselves within hospitals in order to meet the clinical needs of children and young people."

Thames Valley reported the following vacancies:

- 0.1 WTE pharmacist
- Three social worker vacancies (two 0.8 WTE roles)
- 0.8 WTE social worker
- 0.4 WTE psychologist
- 0.8 WTW physiotherapist

West Midlands reported the following vacancies:

- a family support bereavement worker (vacant for two months)
- community clinical nurse specialists (vacant for six months)

- 2.8 WTE nursing posts which have been vacant for 12 months

It states:

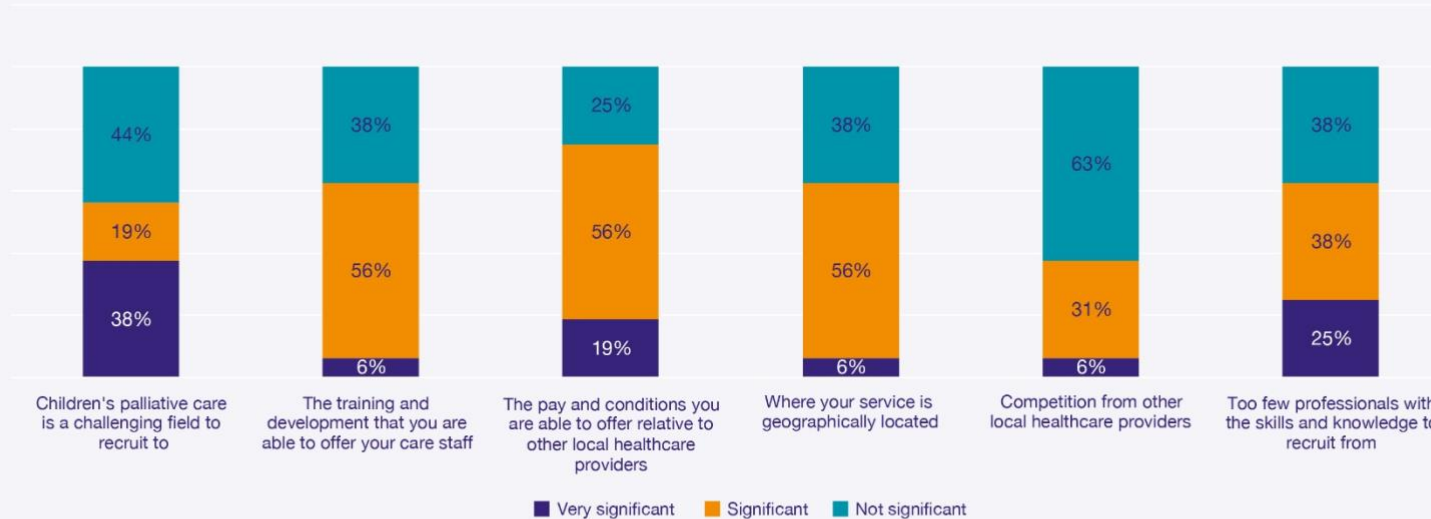
“We have a broad spectrum of patients who receive parallel planning (not necessarily recognised as such by all staff) but formal palliative care planning tends to happen for babies with anticipated shortened lives. We are building relationships with local hospice and palliative care consultant and very grateful for the support they offer, we do recognise that they are not necessarily commissioned for the support they provide and are doing this on top of their regular commitments. We have one community nurse who works alongside a hospice nurse to provide better community support - I think if this network was expanded and included some neonatal nurses then we would have a more robust package/team in place for families.”

16 representatives from the following children’s palliative care networks responded to our survey about regional specialist children’s palliative care workforces across the UK:

- East Midlands
- East of England Network
- Kent and Medway
- Scotland: The National Managed Clinical Network in Paediatric End of Life Care (PELiCaN) (Formal) and Scottish Children and Young People Palliative Care Network (Informal)
- North East and North Cumbria
- Northern Ireland Network
- South East Palliative and End of Life Care network
- South West
- Thames Valley
- West Midlands Paediatric Palliative Care Network
- All-Wales Paediatric Palliative Care Network

Where roles are vacant, those responding told us that the most significant factor was the pay and conditions that provider organisations were able to offer relative to other healthcare providers. 75% told us that this was significant or very significant. 63% told us that having too few professionals with the skills and knowledge to recruit from was significant or very significant. 62% identified the training and development on offer to staff as a significant or very significant factor

The significance of factors affecting vacancy rates in regional specialist children's palliative care teams



Nine (56%) of respondents told us that their team's vacancy rate had remained the same since 30 November 2022. One (6%) told us that theirs had increased, while six (38%) said it had decreased.

Specialist paediatric palliative care consultants across the UK

NHSE state that the specialist paediatric palliative care teams should be led by specialist consultants in paediatric palliative care. These specialist consultants are vital because they:

- Have specialist expertise in managing life-limiting and life-threatening conditions across the paediatric spectrum.
- Have the ability to manage the full range of symptoms experienced as disease and illness progresses.
- Can lead and develop services within their region.
- Can enable, support, teach, and train other health care professionals.

Whilst some palliative care comes into every doctor's work, a specialist palliative medicine consultant requires in-depth expertise in order to manage the increasingly complex clinical needs of children with life-limiting and life-threatening conditions.

To qualify as a specialist consultant capable of leading a specialist paediatric palliative care team, a professional must complete their sub-speciality level 3 (GRID) training in paediatric palliative medicine. Alternatively, a professional may complete a special interest (SPIN) module if they are particularly interested in paediatric palliative care but wish to remain as a general paediatrician.

Despite this, the Association for Paediatric Palliative Medicine (APPM) estimates there is a lack of GRID equivalent consultants across the UK. There are 21.4 WTE in the UK,⁶³ whereas the Royal College of Paediatrics and Child Health (RCPCH) has estimated that 40-60 are needed. This suggests a significant deficit of 20-40 consultants.

In addition, we are concerned by the low number of national GRID training posts available for paediatric palliative medicine consultants. The total number of these posts has increased from 1 WTE in 2022 to 7.2 WTE in 2024.⁶⁴ This is not enough to fill the number of consultant posts that are currently needed in the UK.

12 WTE SPIN training posts are currently being funded across the UK. The sites approved to offer GRID and SPIN training are:

- Evelina London Children's Hospital (Guy's and St Thomas' NHS Foundation Trust) and The Royal Marsden NHS Foundation Trust.
- Great Ormond Street Hospital for Children NHS Foundation Trust.
- Alder Hey Children's NHS Foundation Trust.
- University Hospitals Bristol and Weston NHS Foundation Trust.
- Birmingham Women's and Children's NHS Foundation Trust.
- Leeds Teaching Hospitals NHS Trust and Martin House Children's Hospice.
- Helen & Douglas House Children's Hospice.

- Royal Hospital for Children, Glasgow (NHS Greater Glasgow and Clyde).
- Noah's Ark Children's Hospital for Wales (Cardiff and Vale University Health Board).
- University Hospital Southampton NHS Foundation Trust and Naomi House and Jacksplace Hospices for Children and Young Adults.

We estimate that the number of these training posts could be doubled to 14.4 WTE GRID training posts and 24 SPIN training posts could be provided by the existing specialist paediatric palliative medicine consultant workforce – if funding was available from NHSE.

We estimate that each training place costs £124,924.64 per year; we have calculated this based on the cost of the time of the specialist consultants and senior nurses who would need to provide the training, in addition to the salary cost of the consultant undertaking the training. The training posts currently being funded cost a total of £2,398,553 per year to fund. To double these training places, we believe that NHSE should invest double this amount.

[You can view the model we have used to calculate this here.](#)

We therefore support the call from the Royal College of Paediatrics and Child Health (RCPCH) that, to meet the challenges of making sure that there are enough professionals who have the skills and experience to meet the needs and wishes of children and families, the existing workforce should be mapped to establish a baseline and service delivery assessed against required standard.

We also accept that specialist children's palliative care education and training places for health professionals, such as GRID and SPIN training, can only be expanded at a rate which is proportionate to an expansion to education and training for professionals in other areas of healthcare.

NHS community children's nursing

Community children's nurses (CCNs) provide the bedrock of children's palliative care. If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, there would be 4,960 community children's nurses in England.

Yet currently there are only 902 CCNs employed by the NHS in England.⁶⁵ While other NHS nurses do provide community-based care to children, this is an indicator of the shortages in such a crucial part of the sector.

Whilst progress has been made in increasing the number of CCNs employed by the NHS in England over the last few years, more still needs to be done to ensure sufficient community children's nurses are employed by the NHS.

There is also a shortage of CCNs in Wales. In September 2023, it was recorded that there were 52 children's nurses working in community services.⁶⁶

If the Royal College of Nursing recommendation were to be adhered to, being 20 whole time equivalent (WTE) CCNs per 50,000 children, an additional 208 community children's nurses would be needed to provide a holistic community children's nursing service in Wales.^{viii}

Children's hospices: clinical workforce

Children's hospices also play a pivotal role in providing children's palliative care. From the management of distressing symptoms to the provision of short breaks and end of life care, children's hospices provide vital care and support to children with life-limiting conditions and their families.

However, a recent survey of the hospice workforce by Hospice UK has revealed an average vacancy rate of 14.5% in the clinical workforce of children's hospices across the UK. 22 of 38 children's hospice organisations (58%) across the UK responded.

Nearly one in four (24%) posts for newly registered nurses or nurse practitioners within two years of qualification are vacant. One in five (20%) of healthcare assistant and support worker posts are vacant. 17% of other non-senior registered nursing posts are vacant.

These rates are higher than in the NHS in England, which had a vacancy rate of 10.3% as at 30 September 2023 within the Registered Nursing staff group.⁶⁷

Special educational needs and disability

In its letter in November 2022, the #SENDInTheSpecialists coalition called for investment in and better planning of the specialist workforce for children and young people.⁶⁸

It highlighted that across our sectors, we are seeing a variety of concerning issues impacting the specialist workforce, including:

- an insufficient number of specialists being trained to meet demand,
- a falling number of specialists, including through them failing to be retained and supported to further develop their specialisms, with some leaving the public sector,
- an increased demand for support in general and in more complex cases in particular,
- responding to the pressures of COVID-19, which has exacerbated pre-existing demands on the specialist workforce and increased waiting times to access them.

Children's social care

There are also shortages among other health and care professionals who support children with life-limiting conditions and their families. As of 30 September 2022, 7,900 child and

^{viii} In September 2023, it was recorded that there were 52 children's nurses working in community services. If the Royal College of Nursing recommendation were to be adhered to, being 20 whole time equivalent (WTE) CCNs per 50,000 children, an additional 208 community children's nurses would be needed to provide a holistic community children's nursing service in Wales. We assume that NHS community children's nurses are employed at Agenda for Change bands 5-7, at an average salary of £53,234.45, which includes an adjustment to reflect the fact that 69% of professional time will be, on average, spent providing care outside of normal working hours, at weekends and on bank holidays.

family social worker vacancies were recorded in England, an increase of 21% from the year before. Furthermore, the overall vacancy rate increased to 20% from 17% meaning that one in five social work positions are vacant.

Not only do these vacancies represent the highest reported rate in the data series but they also represent a key barrier preventing children with life-limiting conditions and their families from accessing the care and support they need.

Analysis of workforce and vacancy data by the Disabled Children's Partnership reveals that 1 in 3 local authorities consistently (meaning 4 or 5 out of 5 years) report children's social work vacancies above the national average.⁶⁹

Other key roles

In addition to the professional roles we have been able to quantify workforce gaps for, there are others where we hear anecdotally of shortages which are having a negative impact on the palliative care that children with life-limiting conditions are able to access. It is vital that all of the following are available in all areas of the UK to ensure access to high quality, sustainable children's palliative care:

- Senior specialist pharmacists with expertise in paediatric palliative care.
- Practice educators.
- Experts in child/young person and family support who have expertise in providing psychosocial support in the context of palliative, end of life care and bereavement (for example in providing social, practical, emotional, psychological and spiritual support).
- Physiotherapists.
- Occupational therapists.
- Speech and language therapists.
- Dieticians.
- Transition workers.
- Family support workers.
- Practitioners with recognised post graduate qualifications in psychological care with palliative care experience working at level 3 and 4.
- Practitioners with spiritual care experience at level 3 or 4.
- Practitioners providing family support in the context of bereavement.
- Administrative support.
- Managed clinical network co-ordinators.

- Data managers.

The policy framework relating to workforce

We believe that the workforce challenges we have set out limit the extent to which children with life-limiting conditions can access to high quality, sustainable palliative care.

In June 2023, the NHS published the Long Term Workforce Plan.⁷⁰ The plan sets out the actions and standards they would like to meet to enforce a sustainable workforce. Their actions fall within three key priorities:

- **Train:** NHS plans to increase education and training record levels, as well as increasing apprenticeships and alternative routes into professional roles, to deliver more professionals and meet the changing needs of patients and support the ongoing transformation of care.
- **Retain:** NHS would like to retain staff levels within the health service by better supporting people throughout their careers and offer flexibility and opportunities for growth within their roles and the NHS.
- **Reform:** NHS seeks to improve productivity by working and training in different ways to build broader teams with flexible skills. This will mean using technological innovations to provide care and assistance to patients more effectively and efficiently.

Key points from the plan include:

- 27% expansion in training places by 2028/29.
- Plans to double the number of medical school places.
- 10,500 increase in training places for nursing associates by 2031/32.
- extending dual registration courses in CYP and learning disability nursing.

Despite the shortages in NHS community children's nursing, in the plan NHSE has assessed that there is currently a sufficient number of training places to meet demand for children's nursing.

NHSE states that it recognises that the challenges described in this plan are not unique to the NHS, and that the NHS does not operate in a vacuum. However, it states that there are many different factors outside the NHS's control that impact services and patients experiences. Therefore, the plan only focuses on the workforce employed by the NHS and those delivering NHS-funded services in NHS trusts and primary care. This means that voluntary workforce concerns will not be focused on in this plan.

We welcome the 'Career Pathway, Core Capabilities in Practice and Education Framework, incorporating a Qualification in Specialism Standard, for Palliative and End of Life Care' that NHSE has drafted. While not yet published, we understand that it will aim to:

- ensure the future and existing supportive, assistive and registered workforce providing general and specialist palliative and end of life care have access to

education, learning and development opportunities and the underpinning knowledge and capabilities they need for their role

- develop and promote a career pathway and education framework for those aspiring to work at all levels in specialist palliative and end of life care
- improve the future supply of aspirant specialist nursing and allied health professions workforce with appropriate education and development opportunities.

The Northern Ireland Department of Health's 'Health and Social Care Workforce Strategy 2026', published in June 2022, refers to the children's palliative care strategy and states that the aim is to improve children's lives in real terms.⁷¹ It states that the children's nursing workforce has to reflect changing population health needs, increasing complexities of conditions, the opportunities of innovation in healthcare alongside similar demographic workforce issues to the other fields of nursing.

The Scottish Government's Health and Social care: National Workforce Strategy sets out its vision, based on its ambitions of recovery, growth and transformation of our workforce.⁷²

The Welsh Government states that responding to workforce challenge is also a priority for its palliative and end of life care programme team,⁷³ and it is a crucial part of its palliative and end of life care quality statement.⁷⁴

In March 2023, members of the #SENDInTheSpecialists coalition wrote to the UK Government setting out its response to the Special Educational Needs and Disability (SEND) and Alternative Provision (AP) Plan for England.⁷⁵ The coalition:

- welcomed the UK Government's commitment to work alongside children, young people, and their families, and those who work across every part of the SEND system to improve the SEND and AP system, and
- welcomed the announcement of the joint Department for Education and Department of Health and Social Care approach to SEND workforce planning, with a clear timeframe to establish a steering group in 2023 and complete its work by 2025.

The coalition also highlighted two key factors it thought the steering group should address:

- **Definition of SEND and specialist workforce:** given the minister's comments in her oral statement on the SEND and AP Improvement Plan in March 2023 about the importance of specialist support and the specialist workforce, there should be a broad approach to defining the SEND and specialist workforce, to consider all the different education, health and care professionals who work with children and young people to identify and support the totality of their needs.
- **Recruitment and retention:** consideration should be given to how the recruitment and retention issues facing the specialist workforce can be addressed.

Our policy recommendations on workforce

UK-wide

- The UK Government should fund action 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

UK Government:

- The UK Government should make sure that, using NHSE's children's palliative care service specification, NHSE and HEE work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible. This should include organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs), as is the case for neonatal critical care.⁷⁶
- Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament includes children's nurses with 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 NHSE 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 Royal College of Nursing in asking for:
 - the Secretary of State for Health and Social Care to have accountability for workforce planning and supply, as part of service and financial planning
 - the Secretary of State for Health and Social Care to undertake and publish a detailed assessment and analysis of future workforce demand and supply requirements for all health and care services across England.
 - an expansion in the number of nursing students and full financial support including abolition of self-funded tuition fees, and grants that reflect the real cost of living.
- We join the Disabled Children's Partnership in calling for ministers to increase the focus on disability within children's social work training.
- We join the #SENDInTheSpecialists coalition in asking for the joint Department for Education and Department of Health and Social Care approach to SEND workforce planning to take a broad approach to defining the SEND and specialist workforce, to consider all the different education, health and care professionals who work with children and young people to identify and support the totality of their needs. We ask

ask the steering group should consider how the challenges in recruiting and retaining specialist professionals can be addressed.

NHSE:

- Urgently assess the gaps in the children's palliative care workforce across the range of professions who care for children with life-limiting conditions, across hospitals, children's hospices, and community services.
- Assess the demand for nurses from children's hospice organisations and the independent sector and include it in their planning models.
- Fund NHS trusts to create more specialist medical training posts. This would help to make sure that paediatric palliative medicine GRID and SPIN training can take place.

Education Providers:

- Education providers should make sure that children's palliative care is embedded in undergraduate and postgraduate medical and nursing courses; we note that children's palliative care should be embedded in nursing courses in a way that is consistent with existing regulations.⁷⁷
- If it is found that there are too few children's nurses likely to fill posts across all types of healthcare provider, for example, universities should increase the number of places they offer to undergraduates.

ICBs:

- We believe that, in carrying out their people function,⁷⁸ ICSs should develop action plans to make sure children with life-limiting conditions and their families are well supported by children's palliative care professionals. The NHS Long Term Plan states that children's palliative care is a priority. Statutory, voluntary, and independent sector providers will all be crucial in making sure that children with life-limiting conditions are able to access the palliative care they need. On this basis, it is vital that ICSs secure sustainable children's palliative care workforces across all of these sectors.

Northern Ireland

- As part of its work to implement Health and Social Care Workforce Strategy 2026, 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 establish a multi-disciplinary palliative and end of life care workforce plan, covering the next 20 years. This should specifically consider how a specialist 24/7 at-home service at the end of a child's life could be sustainably resourced and delivered - supported by the Paediatric End of Life Care Network (PELiCaN), CHAS, and other partners.

- 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.⁷⁹
- 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

Funding is one of the most significant barriers to children and young people being able to access services capable of meeting national standards in England. Research has even highlighted the difficulty in obtaining consistent and sufficient funding, with network chairs stressing the lack of NHS funding, and reliance on the charitable sector in providing important services and key posts for their region.⁸⁰

England

In England, we have estimated there to be a significant funding gap in the provision of children's palliative care. Based on the specialist and core professionals that NICE state should comprise children's palliative care multidisciplinary teams – and the population that needs access to them – we estimate that the NHS should spend approximately £376 million every year to meet this standard in 2024/25.

We believe that the NHS will spend £81 million in 2024/25, which means that there will be a £295 million funding gap in 2024/25. [You can view the model we have used for calculating the gap here.](#)

There have been positive developments in NHS funding for children's palliative care services in recent years, such as ministers' decision to continue the £25 million NHSE Children's Hospice Grant for 2024/25. However, future statutory funding for children's palliative care beyond 2024/25 is not clear.

Children's hospices are integral to local health and care systems across England. However, our recent report found that approximately only a third of children's hospices charitable expenditure is paid for by the state, with the NHS Children's Hospice Grant accounting for about 15% of that figure.⁸¹ Whilst the commitment by the UK Government to continue the Grant in 2024/25 is welcome, the future of the grant beyond 2024/25 remains unclear.

This grant is vital to the sustainability of children's hospices. It underpins their ability to work with their statutory sector partners to ensure that children with life-limiting conditions can exercise choice over how and where they receive palliative care.

Children's hospices told us what the impact on their services would have been if the Children's Hospice Grant was not available from 2024/25 onwards as a ringfenced grant from NHSE. The results are very worrying:

- Nearly two in five (38%) children's hospices would cut end of life care they provide. One would stop providing it altogether.
- Nearly four fifths (79%) would cut the respite or short breaks they provide. One would stop providing them altogether.
- Two thirds (66%) would cut the hospice at home services they provide. One would stop providing them altogether.

In addition to concerns around the future of the grant, the NHSE match funding scheme ends in March 2024. Under the NHS Long Term Plan, NHSE was committed to matching up to £7 million of ICB (formerly CCG) funding for children's palliative care, including children's hospice services, by 2023/24. Available to NHS and voluntary sector providers, the money has been used to fund children's hospice and palliative care services and has seen the following amounts providing during this period:

- 2020/21: £2 million.
- 2021/22: £3 million.
- 2022/23: £5 million.
- 2023/24: £7 million.

We believe that the absence of this match funding will make it harder for ministers and officials to reduce the size of the NHS children's palliative care funding gap in England.

Children's hospices also derive funding from their local ICB. For many, this funding source amounts to approximately 13% of the total amount of statutory funding that they receive.

However, from a series of FOI requests issued to ICBs in May 2023, we have found NHS funding for local children's hospices in England to vary by as much as £483 per child in 2022/23⁸². 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.

Whilst slight variation may be explained through differing levels of local need for care and support along with how local children's palliative care services are configured across hospital, community, and children's hospice services, we do not believe that the extent to which funding varies between ICBs can be justified.

We are also concerned by the extent to which the sustainability of core and specialist care for children with life-limiting conditions and their families depends on the generosity of individual donors, sales made in charity shops and the success of fundraising events.

As our network mapping exercise and FOI requests show, there are some areas where standards are being met without commissioned service specifications being in place. This suggests that the costs of some 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 ICBs.

We do not believe this is right. Given the legal duty imposed on ICBs by 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,⁸³ ICBs should have access to the financial resources to meet this legal obligation.

In February 2024, the UK government confirmed that an additional £500 million for social care services will be allocated through the Social Care Grant and will be ringfenced for adult and children's social care. This takes the total amount of grant funding for social care up to £8.7 billion through the 2024-25 settlement.⁸⁴

Whilst the additional funding is welcome news, analysis commissioned by the charity, Scope and the DCP in 2021 found a £573 million funding gap in disabled children's social care. There is therefore still more that needs to be done if this funding gap is to be closed.

To this end, it is vital and health and social care support for children with life-limiting and life-threatening conditions is prioritised. Not only do the funding shortfalls need addressing, but there needs to be greater accountability within the SEND system if education settings are to become truly inclusive and capable of providing children and young people with the support that they need.

The policy action we recommend

- We call on the UK Government to commit to multi-year long term NHS funding for children's palliative care in England that fills the £295 million gap that we have identified and sustains lifeline services including children's hospices.
- This should include a commitment to maintaining ringfenced, centrally distributed NHSE funding for children's hospices beyond 2024/25 which increases by at least the rate of inflation each year.
- We call on NHSE to model for each ICB how much it should be spending on children's palliative care – and then hold them to account for the extent to which they spend money for this purpose.

- The government should fill the £573 million annual funding gap in disabled children's social care.

Northern Ireland

Children's palliative care in Northern Ireland is funded unsustainably. Northern Ireland Children's Hospice has forecast a budget deficit of £1.46 million for 2023/24⁸⁵.

This is due in part to a 6% cut in the children's hospices statutory income from the Northern Ireland Health and Social Care system from £2,030,436 in 2022/23 to £1,904,608 in 2023/24. Over this same period, the children's hospices' direct costs have been forecast to rise by 8% from £3,347,515 in 2022/23 to £3,629,514 in 2023/24.⁸⁶

In February 2024, the children's hospice announced that, as a result of the loss of government funding for one of its beds, it now intends to run six beds Monday to Friday and three beds Saturday and Sunday. This represents a reduction from the existing seven-beds, seven-nights model.⁸⁷

Following the announcement, the Robin Swann MLA, the Northern Ireland Health Minister, asked Department of Health officials to investigate these issues further. He then published a statement setting out the following:⁸⁸

- his belief that the financial pressures facing NI Children's Hospice (NICH) go much deeper than any reduction of departmental support
- the reduction in departmental funding involved the ending (in the summer of 2023) of an additional but temporary annual payment of £170,000.
- this decision was notified to the NICH in June 2023 and took effect from September 2023 - resulting in an £85,000 reduction in the (2023/24) financial year.

The minister stated that he decided to reinstate this £85,000 funding for 2023/24. This payment would be addition to the core annual funding of £1.6m which the department was providing directly to NICH in 2023/24.

This core funding included a £420,000 component which had not been recurrent, meaning it would have to be subject to confirmation each year. He confirmed that, going forward, this would be made recurrent, giving the hospice greater certainty.

The children's hospice advised the department that the restoration of the full £170,000 for 2023/24 would not lead to the decision to reduce services being reversed. The minister recognised that Northern Ireland Hospice would need to develop longer-term solutions, to which the minister said the government would want to be supportive.

He stated that he had written to the Finance Minister to seek further discussions between the charities, the Department of Health and the Department of Finance.

Beyond the support it provides to Northern Ireland Children's Hospice, it is not clear how much the Northern Ireland Executive is spending to make sure children and young people with life-limiting or life-threatening conditions can access high quality, sustainable palliative and end of life care.

The policy action we recommend

- 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 2016-26' 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

Scotland has a national model with Children's Hospices Across Scotland (CHAS) as the single national provider of hospice care to children, with staff working across hospices, hospitals, and local communities. CHAS supports children and their families with medical, nursing, social work, and emotional and family support.

For every £1 of statutory funding CHAS receives from the Scottish Government and the Convention of Scottish Local Authorities (COSLA), CHAS generates £6.24 of public value in return.⁸⁹

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."⁹⁰

While this funding is highly welcome, 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.

NHS pay awards have further added to the pressure on CHAS's finances.

Beyond the support it provides to CHAS, it is not clear how much the Scottish Government is spending to make sure children and young people with life-limiting or life-threatening conditions can access high quality, sustainable palliative and end of life care.

The policy action we recommend

- 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

In 2022, the Welsh Government allocated an extra £2.2 million to hospices in Wales with £888,000 going to the two children's hospices, Tŷ Hafan and Tŷ Gobaith. This was the first time additional statutory funding had been made available to Wales's two children's hospices since 2007. The additional funding, which arose out of phase one of the end-of-life care review, meant that hospices would receive around 21% of the costs of providing palliative care to children and families in Wales.

At the time, providing this additional statutory funding represented an important step in building towards a sustainable future for the two hospices, allowing them to:

- Recruit more nurses and to build more resilience into their services in the hospices and in the community.
- Extend the breadth and depth of their services and to provide more respite care for those families who so desperately need it.
- Reduce the burden of unplanned and crisis admissions on the NHS.

Despite this progress, along with Tŷ Hafan and Tŷ Gobaith, we are concerned that the second phase of the Welsh Government's hospice funding review has not resulted in any additional funding to enable the children's hospices to sustainably provide community-based hospice and palliative care. Given the inflationary pressures that are currently being experienced by children's hospices in Wales, it is vital that children's hospices see an increase in funding that takes account of inflationary pressures.

The Welsh Government states that, in response to the second phase of the review, funding is being made available to increase the capacity of district nursing and community clinical nurse specialists,⁹¹ some specifically focused on end of life care as part of the Further Faster programme.⁹²

However, we understand that the Palliative and End of Life Care Programme is experiencing challenges in being able to access this funding to invest in community-based children's palliative care.

The Palliative and End of life Care Programme team is now working to deliver the third and final phase of the funding review. This seeks to understand and interpret the differences, the inequities and the risks to current funding and commissioning arrangements.

This phase will consider:

- Inflationary uplifts to current funding streams.
- The service level agreements and improving equity for hospice funding.
- An appreciation of the workforce challenges to enable more effective planning for future needs.

The Welsh Government expect the final version of the interim phase 3 report to provide recommendations for the short to medium-term. Those for the long term will also be completed later in 2024.

The policy action we recommend

- 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.^{ix}

^{ix} In September 2023, it was recorded that there were 52 children's nurses working in community services. If the Royal College of Nursing recommendation were to be adhered to, being 20 whole time equivalent (WTE) CCNs per 50,000 children, an additional 208 community children's nurses would be needed to provide a holistic community children's nursing service in Wales. We assume that NHS community children's nurses are employed at Agenda for Change bands 5-7, at an average salary of

- 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.

Leadership and accountability

England

In England, there is an array of clear health policy imperatives for children's palliative care. These are set out in:

- 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.⁹³
- NHSE's [Palliative and End of Life Care Statutory Guidance for Integrated Care Boards \(ICBs\)](#) sets out a series of key actions that ICBs should consider to meet the palliative and end of life care duty.⁹⁴
- The Ambitions for Palliative and End of Life Care Framework.⁹⁵
- The NHSE Service Specifications for Palliative and End of Life Care: Children and young people (CYP)⁹⁶
- The government's end of life care choice commitment: 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.⁹⁷
- The National Institute for Health and Care Excellence (NICE) guideline and quality standard on end of life care for children.⁹⁸
- The NHS Long Term Plan, which on paragraph 3.41 states that children's palliative and end of life care is an important priority for the NHS.⁹⁹

Focused on meeting the needs of children with life-limiting conditions and their families, we welcome these policy imperatives. We also support NHSE's palliative and end of life care programme. Not only does this programme have the potential to realise the Long Term Plan commitment to improve the extent to which children and families can access palliative care when and where they need it, but it can also help:

£53,234.45, which includes an adjustment to reflect the fact that 69% of professional time will be, on average, spent providing care outside of normal working hours, at weekends and on bank holidays.

- 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.

We also believe that NHSE's work to develop regional palliative care strategic clinical networks (SCNs) has provided an important opportunity to improve the way in which England-wide guidelines, standards and best practice examples are shared with ICSs. We welcomed NHSE's decision to fund a dedicated children and young people's palliative care lead in each of the seven strategic clinical network (SCN) regions in England. This funding has now been withdrawn.

We also welcome the recent government commitment to invest £3 million in a new Palliative and End of Life Care Policy Research Unit, helping to build the evidence base and inform policy making in the palliative and end of life care sector.¹⁰⁰

However, as was the case when we published our '24/7 access to children's palliative care in England' report, we remain concerned about the extent to which the government and NHSE holds ICBs to account for the way in which they commission children's palliative care. We believe that this is, in part, contributing to the postcode lottery in the way in which it is planned, funded, and provided.

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, this should never depend on where they live.

Our cause for concern grows even stronger when considering the lack of local data that was revealed by the FOI requests, we issued to ICBs in May 2023. Only 13 ICBs (31%) were able to tell us how many children and young people with life-limiting or life-threatening conditions who live in the areas they serve accessed hospice care in 2022/23.

Given the legal duty imposed on ICBs to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible,¹⁰¹ we question how this can be achieved in the absence of this data.

A number of other policy imperatives have an impact on the health, education and social care that children and young people with life-limiting or life-threatening conditions are able to access.

As set out in the [National Framework for Children and Young People's Continuing Care](#), a continuing care package will be required when a child or young person has needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone.

In the framework, the government states that children and young people who require fast-track assessment because of the nature of their needs (such as a palliative and end of life care need) should be identified early and the child or young person or young person's needs met as quickly as possible.

Despite this, research by the BBC has found that there is huge variation in the numbers found eligible - it depends on where they live.¹⁰²

NHS data shows that eligibility rates ranged from 14% to 96% in 2022-23, according to data obtained from 33 of 42 ICBs.

To enable short breaks for carers of disabled children section 2.10 of the [‘Short breaks for carers of disabled children: departmental advice for local authorities’](#) states:

Health services have multiple roles to play in the provision of short breaks for disabled children in their areas. They will directly provide and commission some services, for example, short breaks for children with complex health needs. (For some children, this may involve spending some time in a hospice.) They will also support local authority and voluntary and Community sector provision, for example, by training the workforce and providing nursing support and timely access to necessary equipment.

There is a legal precedence which establishes that the NHS is responsible for short breaks where the ‘scale and type of nursing care’ is such that it is outside that which can be provided by the local authority (*R (T, D and B) v Haringey LBC*).

Many children and young people who need palliative and end of life care also have a special educational need or disability (SEND). The [Children and Families Act 2014](#) is clear that ICBs have legal duties in respect of children and young people with SEND. This includes children who need palliative and end of life care.

NHS and local authorities have a legal duty to jointly commission education, health and care for children and young people with SEND.

The [Special Educational Need and Disability \(SEND\) Code of Practice](#) sets out in detail what local areas must and should do to jointly commission services for children and young people aged 0 – 25 with SEND.

Local authorities must publish a local offer, setting out in one place information about provision they expect to be available across education, health and social care for children and young people in their area who have SEN or are disabled, including those with and without EHC plans. This includes both universal and specialist services.

ICBs, NHSE, NHS Trusts or NHS Foundation Trusts and local health boards must co-operate with local authorities in the development and reviewing of the local offer.

Education, health and care (EHC) plans specify additional provision for those children or young people who a local authority decides to require such a plan and whose educational needs cannot be met solely by their early years setting, school or college. EHC plans must focus on outcomes and local authorities must seek advice from a range of partners, including health, when assessing needs and drawing up plans.

ICBs have a legal duty to have mechanisms in place to ensure practitioners and clinicians will support the integrated EHC needs assessment process.

Parents and young people with EHC plans can request a personal budget, which can include funding from education, health and social care. The scope for personal budgets will vary according to individual needs.

Decisions in relation to the health element (personal health budget) remain the responsibility of the ICB or other health commissioning bodies and where they decline a request for a direct payment, they must set out the reasons in writing and provide the opportunity for a formal review.

Children and young people who have a continuing care package have a legal right to a personal health budget.

The Department of Health and Social Care and the Department for Education provide and maintain [0 to 25 SEND code of practice: a guide for health professionals: Advice for Clinical Commissioning Groups, Health Professionals and Local Authorities](#)

In terms of children's social care, the Children's Social Care National Framework¹⁰³ is statutory guidance from the Department for Education and is central to setting direction for practice in children's social care as part of the reforms set out in *Stable Homes, Built on Love*.

Through the National Framework, the UK Government aims to bring together:

- The purpose of local authority children's social care.
- The principles by which children, young people and families should be supported.
- The enablers that should be in place so the system is effective.
- The outcomes that should be achieved so that children and young people can grow up to thrive.

Under the Children Act 1989, local authorities have a legal duty to provide certain services to disabled children.¹⁰⁴ Furthermore, the Act also places a duty on each local authority to 'open and maintain a register of disabled children in their area'.¹⁰⁵ Despite these legal duties, DCP's research in addition a series of FOI requests submitted by the DCP has shown a large proportion of local authorities are not meeting these legal requirements.¹⁰⁶

Children and young people who need palliative care are legally entitled to education. They access education at early years, schools and further education settings depending on:

- The nature of their condition.
- The way in which it develops.
- The treatment that they need and the impact it has on them.

ICBs can take a system-wide approach with local authorities and education providers to help make sure children and young people receive coordinated palliative care in education settings. They can enable children and young people to access education and move seamlessly between home, hospital, children's hospices and education settings, taking into consideration the extent to which a child's condition interferes with their engagement with school.

The policy action we recommend

National level:

- We call on the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act to direct NHSE to make sure that all children with life-limiting conditions in England and their families should be able to receive palliative

care at home, 24 hours a day, seven days a week. 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 responsible.

- We call on the Secretary of State for Health and Social Care to direct NHSE to hold ICBs to greater account for the way in which they commission children's palliative care, including the way they work together to plan and fund these services at regional level.
- We call on NHSE to direct ICBs to work with neighbouring ICBs in their region to plan and fund these services.
- We call on the Secretary of State for Health and Social Care to mandate the Care Quality Commission (CQC) to assess the extent to which ICBs are commissioning children's palliative care effectively.
- We call for the government's mandate and planning guidance to NHSE to specify that services must be provided to achieve national standards.
- We call on NHSE to regularly monitor the extent to which ICBs are commissioning this care – and hold them to account if they fail to do so.

Local level:

- We call on health and wellbeing boards to make sure that the 24/7 palliative care needed by children with life-limiting conditions is included within their joint strategic needs assessments; the JSNA should consider the most recent data on the number and prevalence of children and young people with life-limiting or life-threatening conditions.¹⁰⁷

System level – integrated care partnerships (ICPs):

- Recognise that children with life-limiting conditions and their families need coordinated palliative care which is jointly commissioned by the NHS and local authority areas; ICPs should challenge partners to deliver the action required to implement the existing national children's palliative care policy framework.
- Develop strategies focused on addressing the needs and preferences of children with life-limiting conditions and their families – and, in particular, consider adding them to their integrated care strategies if not already included.
- Make sure they receive input from across the children's palliative care sector, including the statutory and voluntary sector, in addition to children and young people who need palliative care and their families.

System level – integrated care boards (ICBs):

- Commission children's palliative care services in a way which is consistent with their new legal duty, the NHSE service specification, commissioning and investment framework and contracting guidance and methodologies.

- Make sure that their forward plans to meet the healthcare needs of their populations include children's palliative care; in doing so, they should fill the gaps identified in our new maps.
- Allocate resources sufficient to make sure that children's palliative care services can achieve the NICE outcomes for children with life-limiting conditions and their families.
- Establish joint working arrangements between children's palliative care providers in acute, community and children's hospice settings and across the statutory and voluntary sectors.
- Make sure that their People Plans and People Promises include action to make sure that there are sufficient professionals with the skills and experience needed to provide palliative care to children, young people, and families.

Northern Ireland

In 2016, the Department of Health published 'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life care 2016-26'.¹⁰⁸

The recommendations were produced by a project group of healthcare professionals, officials, and representatives of the Northern Ireland Children's Hospice.

In 2020, The New Decade, New Approach Deal for restoring the Executive stated that it would "provide increased investment to fully implement service improvements for palliative and end of life care including enhancing the contribution of hospices; and to increase support for palliative perinatal care."

In June 2022, the Department of Health published its 'Health and Social Care Workforce Strategy 2026'. This refers to the children's palliative care strategy and states that the aim is to improve children's lives in real terms. It states that the children's nursing workforce has to reflect changing population health needs, increasing complexities of conditions, the opportunities of innovation in healthcare alongside similar demographic workforce issues to the other fields of nursing.

Despite these imperatives, we know from our network mapping exercise that children with life-limiting conditions are unable to access care and support that is capable of meeting national standards.

It is vital that these commitments are delivered upon. In particular, it is crucial that the Department of Health in Northern Ireland allocates sufficient funding and the required infrastructure to implement the strategy.

The policy action we recommend

- 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 2016-26¹⁰⁹ 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

Recent years has seen good progress made in Scotland. In November 2012, the Scottish Government published a Framework for the Delivery of Palliative Care for Children and Young people in Scotland. In 2015, the Scottish Government published a new Strategic Framework for Action for Palliative and End of Life Care.

We are pleased that in its programme for 2021/22, the Scottish Government stated:

"To provide the very highest standards of care right up to the end of life, we will ensure that everyone who needs it can access seamless, timely and high quality palliative care. Over the coming year, we will develop and publish a new national strategy for palliative and end of life care that takes a whole system, public health approach. And we will ensure provision of high quality children's palliative care, regardless of location, supported by sustainable funding of at least £7 million per year through Children's Hospices Across Scotland."¹¹⁰

The strategy will aim to ensure that everyone in Scotland receives well-coordinated, timely and high-quality palliative care, care around death and bereavement support based on their needs and preferences including support for families and carers.¹¹¹

Despite this progress, challenges remain with many seriously ill children and their families reporting that there are gaps in their care.¹¹² With the strategy due to be published in 2024, it is vital that this strategy not only meets the needs of children and young people with life-limiting and life-threatening conditions but also that it provides the relevant funding and infrastructure required to ensure a successful implementation.

The policy action we recommend

- 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 new plan should build on the previous framework.
- 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 this 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.
- In order to receive timely clinical information and deliver better care, the Scottish Government should make sure that NHS Scotland and all the NHS boards work with CHAS to secure a single national data sharing agreement to facilitate CHAS's access to Health Board clinical portals.
- The Scottish Government should ensure that all health and social care professionals involved in the care of a child are able to access, enter and update information on the National Digital Platform.

- The Scottish Government, local authorities and integration authorities should support families to access more dedicated, specialised and streamlined support, including ensuring that:
 - Children with complex needs are assessed quickly for Self-Directed Support.
 - Decisions about social care entitlements are focussed primarily on quality and outcomes for the child and family, recognising this may require additional support to recruit and retain highly skilled care assistants.
 - Families are supported in line with guidance and standards to work out what they need to improve their lives, and what options are available to them, so that they can have the skilled care they need in place quickly when they need it.

Each child with a life-limiting condition is allocated a dedicated, named social worker at a local authority level.

 - NHS boards, local authorities and integration authorities all reinforce the critical role of the lead professional, and the team around the child.
- The Scottish Government, local authorities, integration authorities and health boards should develop a national, standard pathway for children with complex medical needs transitioning between child and adult services. This should be multi-disciplinary, needs-led, adhere to the Principles of Good Transition,¹¹³ and include scoping of and access to age-appropriate services.

Wales

In Wales, the National Palliative and End of Life care programme provides national leadership and guidance to help drive change whilst overseeing health boards' efforts to deliver the Welsh Government's ambition for improving end of life care in Wales.¹¹⁴

Informed by the Quality Statement for Palliative and End of Life Care¹¹⁵, the programme aims to ensure that people have choice over where they die. It also seeks to ensure people have access to high quality care wherever they live and whatever their underlying disease or disability is.¹¹⁶

The quality statement describes what good quality palliative and end of life care services should look like. In particular, the statement aims to ensure people can have a 24/7 single point of access to coordinated care, medication, and advice about end of life care, wherever they are located in Wales to reduce distress and the likelihood of unwarranted admission to secondary care.

The programme team is also considering whether it would be possible to develop a national commissioning framework for hospices.¹¹⁷ Such a framework would seek a sustainable financial solution for the longer term regarding the partnership with the hospice sector, and it would also provide a national service specification for palliative and end-of-life care.

Despite this policy intention, there is still a postcode lottery in Wales when it comes to accessing children's palliative care that meets national standards. It is therefore vital that sufficient funding and adequate measures are put in place enabling NHS Wales to achieve

this vision and ensure children with life-limiting conditions in Wales can access the care they need.

The policy action we recommend

- 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.

The action that Together for Short Lives will take

Working closely with the UK's governments, NHS bodies, children's palliative care professionals and providers and our partner charities, Together for Short Lives commits to playing a full role to ensure children and families receive the palliative care they need, when and where they need it.

We are here to make sure the UK's 99,000 children with life-limiting conditions and their families can make the most of every moment they have together, whether that's for years, months or only hours.

Our 10-year strategy focuses on achieving positive change for babies, children and young people with life-limiting conditions, their families, and those that support and care for them.

We want to ensure that every seriously ill child and their family gets high quality children's palliative and end of life care, when and where they need it.

Our 10-year strategy, Making Every Moment Count¹¹⁸, shows how we will make that happen.

To steer our work over the next decade, we have set three strategic ambitions to make sure more children and families are able to get the support they need:

1. No family faces the journey alone: increase reach so that more children and families can **access** 24/7 palliative care
2. The best care and support: improve the **quality** of palliative care so families have the best support.
3. Support today, tomorrow and every day: Strengthen the **sustainability** of children's palliative care so families can rely on support.

Together for Short Lives has significantly increased its size and impact in recent years, with new programmes to support children with life-limiting illnesses, their families and the services and professionals that support them. We focus on:

1. **Direct support for families through our family hub** – our practical, emotional, financial and connecting support
2. **System change through lobbying and advocacy** – to improve access, quality and sustainability of children's palliative care
3. **Supporting professionals to connect and build effective networks** – to share best practice and latest developments in children's palliative care

Family support

During 2022-23, we supported 656 families with information and advice and 413 received enhanced support in the form of grants, legal advice and local outreach support.

There are **two ways that families can access support**.

One is directly through our **Helpline, online chat and website** resources (also accessed by children's palliative care professionals acting on behalf of families).

The other is via our **outreach and coordination staff**, who are focused on reaching families in communities where there is a higher prevalence of children with life-limiting illnesses and inconsistent service provision.

Over the next two years we will increase this reach, continuing to offer four key services for families:

1. **Practical support** – providing a range of practical support with and through partners, such as emergency groceries from Morrisons and Rosie's Rainbow Pantry, access to legal advice, and the provision of short breaks at Center Parcs and referrals to Make a Wish for granting wishes. Also, advice and support with managing energy use and bills.
2. **Financial support** - we operate a dedicated Butterfly bereavement fund for grieving families, giving families a special one-off gift to help when they need it most; supporting families with energy costs and by referring families to other sources of funding and support through a series of unique third-party relationships with organisations such as Turn2Us and accessing mobility funding.
3. **Emotional support** - including a national helpline which offers confidential emotional support for parents and carers and acts as a gateway to other services.
4. **Connecting families** with others who understand what they are going through, via events and a closed peer-to-peer Facebook group; as well as providing helpful information and resources and signposting to relevant services they might need.

Further development of family support over the next two years

In addition, we see further development and growth opportunities in the following areas over the next two years.

Firstly, we want to **widen access to existing support** – for example, this might include exploring:

- continuation funding for the existing Kentown team and a funded extension of the programme to a new geographical area,
- continuation funding for outreach (currently funded through the Morrisons partnership) and exploration of funding to expand into new areas,
- extending the reach of our funded energy support (SGN) into new geographical areas.

Secondly, we want to **develop our family hub offer to ensure it meets the needs of families**. This might include:

- reviewing services in light of the current scoping and discovery work currently being undertaken
- exploring the development of advice and support for siblings through the family hub, so that we can provide advice and support to the wider family

Our ambitions and plans for family support

By 2026, we are committed to **doubling the number of families and children accessing our family support services.**

In 2022-23, we supported **656** families with information and advice and **413** received enhanced support in the form of grants, legal advice and local outreach support.

By 2026-27, we aim to reach **2,100** families and provide enhanced support to **800** families across the UK. This includes families through our Helpline, outreach work and energy support service.

Improving delivery of children's palliative care

In 2022-23, we reached 808 professionals through our engagement events activity.

As the leading UK charity and membership body for children's palliative care, we want to reach more professionals involved in caring for children and families. We aim to unite the services available in children's hospices, the NHS, voluntary organisations, and professionals who provide care for children with life-limiting conditions.

Bringing these services together and working in partnership means we can ensure that children's palliative care not only continues but improves long into the future.

In the next two years we will focus on delivering our fully funded programmes which aim to improve how children's palliative care is delivered. We will deliver:

- The **Kentown Children's Palliative Care programme** pilot in Lancashire and South Cumbria and explore the potential to extend this into other areas
- **The Simply Learning To Talk** programme - a communication training package for professionals working at universal and generalist level
- **Identifying children who need palliative care** – our work on updating the categories of children with life-limiting conditions and supporting the sector to assess and prioritise the right support
- **Reviewing perinatal pathways and resources** to support professionals caring for babies with life-limiting conditions

In addition, we will continue to explore ways to bring networks together to share innovations and good practice. This will build towards the next Together for Short Lives UK conference in May 2025.

Our ambitions and plans for improving delivery of children's palliative care

The funded Kentown and Simply Learning to Talk programmes have specific outcome measures which should be referred to.

Overall, we want to see improvements in how services are working together to deliver children's palliative care, and our reach to professionals increase.

In 2022-23, we reached **808** professionals through our engagement events activity.

By 2026-27, we want to more than double this to **2,000** professionals, helping to ensure more understand children's palliative care and can better support children and families.

Changing the system through campaigns and advocacy

We will **campaign, build partnerships and influence politicians and policymakers** in the following way:

- Influencing how children's palliative care is commissioned and funded at a national and local level.
- Act as the Secretariat for the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care at Westminster; we seek to educate, inform and motivate parliamentarians to take action on issues which affect children and families and those who support them.
- Pressing the UK Government to allocate an additional £295 million to fill the gap in NHS funding for children's palliative care in England in hospitals, hospices and homes. This includes securing the future of the children's hospice grant in England.
- Growing the number of professionals who have the knowledge and skills to provide children's palliative care.
- Gathering and publishing insights and evidence to support our work, including in future editions of this report.

Our ambitions and plans for campaigning and advocacy

We are committed to playing our part in ensuring **the availability of 24/7 end of life care at home increases by 30%**. In 2023, only **one fifth** of areas were able to offer support round the clock.

By 2027, we want **half of all areas** to be offering this support.

We are committed to playing our part in ensuring **the per head spend by integrated care boards increases by 25%**. In 2023, ICBs were spending on average **£151** per child on children's hospice care.

By 2027, we want ICBs to be spending an average of **£189**.

We are committed to **closing the £295 million shortfall in funding for children's palliative care**, including securing the future of the children's hospice grant.

We cannot do this alone

We need the support of the public now to help us achieve our ambition 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 ensure families get the care they need.

Summary of our recommendations by nation and region

We ask the UK's governments, NHS organisations and others to work with us to take the following actions to make sure children and young people with life-limiting or life-threatening conditions can access high quality, sustainable palliative and end of life care.

UK-wide

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

England

Workforce

UK Government:

- The UK Government should make sure that, using NHSE's children's palliative care service specification, NHSE and HEE work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible. This should include organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs), as is the case for neonatal critical care.¹¹⁹
- Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament includes children's nurses with 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 NHSE 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 Royal College of Nursing in asking for:
 - the Secretary of State for Health and Social Care to have accountability for workforce planning and supply, as part of service and financial planning
 - the Secretary of State for Health and Social Care to undertake and publish a detailed assessment and analysis of future workforce demand and supply requirements for all health and care services across England.

- an expansion in the number of nursing students and full financial support including abolition of self-funded tuition fees, and grants that reflect the real cost of living.
- We join the Disabled Children's Partnership in calling for ministers to increase the focus on disability within children's social work training.
- We join the #SENDInTheSpecialists coalition in asking for the joint Department for Education and Department of Health and Social Care approach to SEND workforce planning to take a broad approach to defining the SEND and specialist workforce, to consider all the different education, health and care professionals who work with children and young people to identify and support the totality of their needs. We ask the steering group should consider how the challenges in recruiting and retaining specialist professionals can be addressed.

NHSE:

- Urgently assess the gaps in the children's palliative care workforce across the range of professions who care for children with life-limiting conditions, across hospitals, children's hospices, and community services.
- Assess the demand for nurses from children's hospice organisations and the independent sector and include it in their planning models.
- Fund NHS trusts to create more specialist medical training posts. This would help to make sure that paediatric palliative medicine GRID and SPIN training can take place.

Education Providers:

- Education providers should make sure that children's palliative care is embedded in undergraduate and postgraduate medical and nursing courses; we note that children's palliative care should be embedded in nursing courses in a way that is consistent with existing regulations.¹²⁰
- If it is found that there are too few children's nurses likely to fill posts across all types of healthcare provider, for example, universities should increase the number of places they offer to undergraduates.

ICBs:

- We believe that, in carrying out their people function,¹²¹ ICSs should develop action plans to make sure children with life-limiting conditions and their families are well supported by children's palliative care professionals. The NHS Long Term Plan states that children's palliative care is a priority. Statutory, voluntary and independent sector providers will all be crucial in making sure that children with life-limiting conditions are able to access the palliative care they need. On this basis, it is vital that ICSs secure sustainable children's palliative care workforces across all of these sectors.

Funding

- We call on the UK Government to commit to multi-year long term NHS funding for children's palliative care in England that fills the £295 million gap that we have identified and sustains lifeline services including children's hospices.

- This should include a commitment to maintaining ringfenced, centrally distributed NHSE funding for children's hospices beyond 2024/25 which increases by at least the rate of inflation each year.
- We call on NHSE to model for each ICB how much it should be spending on children's palliative care – and then hold them to account for the extent to which they spend money for this purpose.
- The government should fill the £573 million annual funding gap in disabled children's social care.

Leadership and accountability

England

National level:

- We call on the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act to direct NHSE to make sure that all children with life-limiting conditions in England and their families should be able to receive palliative care at home, 24 hours a day, seven days a week. 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 responsible.
- We call on the Secretary of State for Health and Social Care to direct NHSE to hold ICBs to greater account for the way in which they commission children's palliative care, including the way they work together to plan and fund these services at regional level.
- We call on NHSE to direct ICBs to work with neighbouring ICBs in their region to plan and fund these services.
- We call on the Secretary of State for Health and Social Care to mandate the Care Quality Commission (CQC) to assess the extent to which ICBs are commissioning children's palliative care effectively.
- We call for the government's mandate and planning guidance to NHSE to specify that services must be provided to achieve national standards.
- We call on NHSE to regularly monitor the extent to which ICBs are commissioning this care – and hold them to account if they fail to do so.

Local level:

- We call on health and wellbeing boards to make sure that the 24/7 palliative care needed by children with life-limiting conditions is included within their joint strategic needs assessments; the JSNA should consider the most recent data on the number and prevalence of children and young people with life-limiting or life-threatening conditions.¹²²

System level – integrated care partnerships (ICPs):

- Recognise that children with life-limiting conditions and their families need coordinated palliative care which is jointly commissioned by the NHS and local authority areas; ICPs should challenge partners to deliver the action required to implement the existing national children's palliative care policy framework.
- Develop strategies focused on addressing the needs and preferences of children with life-limiting conditions and their families – and, in particular, consider adding them to their integrated care strategies if not already included.
- Make sure they receive input from across the children's palliative care sector, including the statutory and voluntary sector, in addition to children and young people who need palliative care and their families.

System level – integrated care boards (ICBs):

- Commission children's palliative care services in a way which is consistent with their new legal duty, the NHSE service specification, commissioning and investment framework and contracting guidance and methodologies.
- Make sure that their forward plans to meet the healthcare needs of their populations include children's palliative care; in doing so, they should fill the gaps identified in our new maps.
- Allocate resources sufficient to make sure that children's palliative care services can achieve the NICE outcomes for children with life-limiting conditions and their families.
- Establish joint working arrangements between children's palliative care providers in acute, community and children's hospice settings and across the statutory and voluntary sectors.
- Make sure that their People Plans and People Promises include action to make sure that there are sufficient professionals with the skills and experience needed to provide palliative care to children, young people, and families.

Northern Ireland

Workforce

- As part of its work to implement Health and Social Care Workforce Strategy 2026, 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.

Funding

- 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 2016-26' 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.

Leadership and accountability

- 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 2016-26,¹²³ 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

Workforce

- The Scottish Government should establish a multi-disciplinary palliative and end of life care workforce plan, covering the next 20 years. This should specifically consider how a specialist 24/7 at-home service at the end of a child's life could be sustainably resourced and delivered - supported by the Paediatric End of Life Care Network (PELiCaN), CHAS, and other partners.
- 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.

Funding

- 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.

Leadership and accountability

- 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 and is implemented in full. The new plan should build on the previous framework.
- 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 this 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.
- In order to receive timely clinical information and deliver better care, the Scottish Government should make sure that NHS Scotland and all the NHS boards work with CHAS to secure a single national data sharing agreement to facilitate CHAS's access to Health Board clinical portals.
- The Scottish Government should ensure that all health and social care professionals involved in the care of a child are able to access, enter and update information on the National Digital Platform.
- The Scottish Government, local authorities and integration authorities should support families to access more dedicated, specialised and streamlined support, including ensuring that:
 - Children with complex needs are assessed quickly for Self-Directed Support.
 - Decisions about social care entitlements are focussed primarily on quality and outcomes for the child and family, recognising this may require additional support to recruit and retain highly skilled care assistants.
 - Families are supported in line with guidance and standards to work out what they need to improve their lives, and what options are available to them, so that they can have the skilled care they need in place quickly when they need it.

Each child with a life-limiting condition is allocated a dedicated, named social worker at a local authority level.

- NHS boards, local authorities and integration authorities all reinforce the critical role of the lead professional, and the team around the child.

- The Scottish Government, local authorities, integration authorities and health boards should develop a national, standard pathway for children with complex medical needs transitioning between child and adult services. This should be multi-disciplinary, needs-led, adhere to the Principles of Good Transition,¹²⁴ and include scoping of and access to age-appropriate services.

Wales

Workforce

- 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.¹²⁵
- 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

- 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.

Leadership and accountability

- We call on the Welsh Government to ensure that all children in Wales who need palliative care, including babies, can access community children's nurses 24/7. These services can be provided by NHS children's community nursing teams, hospice at home teams, hospital outreach teams, or a combination.
- 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.

Disabled Children's Partnership manifesto

In addition to the above, we support the manifesto of the Disabled Children's Partnership,¹²⁶ of which we are a steering group member. The key asks:

- **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.

Joint manifesto for palliative and end of life care

We have also developed a joint manifesto for palliative and end of life care¹²⁷ 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.

Appendices

Appendix one: children's palliative care network mapping forms

[Cheshire and Merseyside Network Service Mapping Form.pdf](#)

[East Midlands Network Service Mapping Form.pdf](#)

[Kent and Medway Network Service Mapping - HitW.pdf](#)

[Kent and Medway Network Service Mapping - KCHFT.pdf](#)

[Kent and Medway Network Service Mapping Form - Demelza.pdf](#)

[Kent and Medway Network Service Mapping Form - Ellenor.pdf](#)

[North East England and North Cumbria Network Service Mapping Form.pdf](#)

[Northern Ireland Network Service Mapping Form.pdf](#)

[South West Network Service Mapping Form.pdf](#)

[Thames Valley Network Service Mapping Form.pdf](#)

[Wales Network Service Mapping Form.pdf](#)

[Wessex Network - Hampshire and Isle of Wight - Service Mapping Form.pdf](#)

[West Midlands Network Service Mapping Form.pdf](#)

Appendix two: regional specialist children's palliative care service workforce mapping forms

[West Midlands Network Service Mapping Form.pdf](#)

[Kent and Medway Network Workforce Mapping Form - HitW.pdf](#)

[Kent and Medway Network Workforce Mapping Form - KCHFT.pdf](#)

[Kent and Medway Network Workforce Mapping Form - Ellenor.pdf](#)

[Northern Ireland Network Workforce Mapping Form.pdf](#)

[Scotland Network Workforce Mapping Form.pdf](#)

[South West Network Workforce Mapping Form.pdf](#)

[Thames Valley Network Workforce Mapping Form.pdf](#)

[Wales Network Workforce Mapping Form.pdf](#)

[Wales Network Workforce Survey 2024.pdf](#)

[West Midlands Network Workforce Mapping Form.pdf](#)

Appendix three: responses from ICBs to our freedom of information requests

East of England

[Bedfordshire, Luton and Milton Keynes ICB Response.pdf](#)

[Cambridgeshire and Peterborough ICB Response.pdf](#)

[Hertfordshire and West Essex ICB Response.pdf](#)

[Mid and South Essex ICB Response.pdf](#)

[Norfolk and Waveney ICB Response.pdf](#)

[Norfolk and Waveney ICB Follow up response.pdf](#)

[Suffolk and North East Essex ICB Response.pdf](#)

London

[North Central London ICB Response.pdf](#)

[North East London ICB Response.pdf](#)

[North West London ICB Response.pdf](#)

[North West London ICB Follow up response.pdf](#)

[South East London ICB Response.pdf](#)

[South West London ICB Response.pdf](#)

Midlands

[Birmingham and Solihull ICB Response.pdf](#)

[Black Country ICB Response.pdf](#)

[Coventry and Warwickshire ICB Response.pdf](#)

[Coventry and Warwickshire ICB Follow-up response.pdf](#)

[Derby & Derbyshire ICB FOI Response.pdf](#)

[Herefordshire and Worcestershire ICB Response.pdf](#)

[Leicester, Leicestershire and Rutland ICB Response.pdf](#)

[Lincolnshire ICB Response.pdf](#)

[Lincolnshire ICB Follow up response.pdf](#)

[Northamptonshire ICB Response.pdf](#)

[Northamptonshire ICB Follow up response.pdf](#)

[Nottingham and Nottinghamshire ICB Response.pdf](#)

[Shropshire, Telford and Wrekin ICB Response.pdf](#)

[Staffordshire and Stoke on Trent ICB Response.pdf](#)

North East and Yorkshire

[Humber and North Yorkshire ICB Response.pdf](#)

[North East and North Cumbria ICB Response.pdf](#)

[South Yorkshire ICB Response.pdf](#)

[South Yorkshire ICB Follow up response.pdf](#)

[West Yorkshire ICB Response.pdf](#)

North West

[Cheshire and Merseyside ICB Response.pdf](#)

[Cheshire and Merseyside ICB Follow-Up Response.pdf](#)

[Greater Manchester ICB Response.pdf](#)

[Lancashire and South Cumbria Response.pdf](#)

South East

[Buckinghamshire, Oxfordshire and Berkshire West ICB Response.pdf](#)

[Buckinghamshire, Oxfordshire and Berkshire West ICB Follow-up response.pdf](#)

[Frimley ICB Response.pdf](#)

[Hampshire and Isle of Wight ICB Response.pdf](#)

[Kent and Medway ICB Response.pdf](#)

[Kent and Medway ICB Follow up response.pdf](#)

[Surrey Heartlands ICB Response.pdf](#)

[Sussex ICB Response.pdf](#)

South West

[Bath and Northeast Somerset, Swindon and Wiltshire ICB Response.pdf](#)

[Bristol, North Somerset and South Gloucestershire ICB Response.pdf](#)

[Cornwall and Isles of Scilly ICB Response.pdf](#)

[Cornwall and Isles of Scilly ICB Follow-up response.pdf](#)

[Devon ICB Response.pdf](#)

[Dorset ICB Response.pdf](#)

[Gloucestershire ICB Response.pdf](#)

[Somerset ICB Response.pdf](#)

Appendix four: ICB service specifications

East of England

[Bedfordshire, Luton and Milton Keynes ICB CPC Service Specification.pdf](#)

[Cambridgeshire and Peterborough ICB CPC Service Specification.pdf](#)

[Hertfordshire and West Essex ICB EACH Service Specification.pdf](#)

[Hertfordshire and West Essex ICB KEECH Service Specification.pdf](#)

[Norfolk and Waveney ICB CPC Service Specification.pdf](#)

[Suffolk and North East Essex ICB CPC Service Specification.pdf](#)

London

[North East London ICB CPC Service Specification.pdf](#)

[South West London ICB CPC Service Specification.pdf](#)

Midlands

[Birmingham and Solihull ICB Acorns Hospice Service Specification.pdf](#)

[Birmingham and Solihull ICB CCN Service Specification.pdf](#)

[Birmingham and Solihull ICB CCN Service Specification 2.pdf](#)

[Birmingham and Solihull ICB Community Paediatrics Service Specification.pdf](#)

[Birmingham and Solihull ICB Paediatric Services Service Specification.pdf](#)

[Nottingham and Nottinghamshire ICB CCN Service Specification.pdf](#)

[Nottingham and Nottinghamshire ICB Hospice Service Specification.pdf](#)

[Nottingham and Nottinghamshire ICB Support Services Service Specification.pdf](#)

North East and Yorkshire

[North East and North Cumbria ICB CPC Service Specification.pdf](#)

North West

[Cheshire and Merseyside ICB Response and CPC Service Specification.pdf](#)

South East

[Buckinghamshire, Oxfordshire and Berkshire West ICB CPC Service Specification.pdf](#)

[Surrey Heartlands ICB CPC Service Specification.pdf](#)

South West

[Bath and Northeast Somerset, Swindon and Wiltshire ICB CPC Service Specification.pdf](#)

[Bath and Northeast Somerset, Swindon and Wiltshire ICB Hospice Provision Service Specification 1.pdf](#)

[Bath and Northeast Somerset, Swindon and Wiltshire ICB Hospice Provision Service Specification 2.pdf](#)

[Bristol, North Somerset and South Gloucestershire ICB CPC Service Specification.pdf](#)

[Cornwall and Isles of Scilly ICB CCN Service Specification.pdf](#)

[Cornwall and Isles of Scilly ICB Overarching Specification.pdf](#)

[Cornwall and Isles of Scilly ICB Short Breaks Service Specification.pdf](#)

[Devon ICB Community Nursing Service Specification.pdf](#)

[Dorset ICB CPC Service Specification.pdf](#)

[Gloucestershire ICB Acorns Service Specification.pdf](#)

[Gloucestershire ICB CCN Service Specification.pdf](#)

[Gloucestershire ICB CPC Service Specification.pdf](#)

[Somerset ICB CPC Service Specification.pdf](#)

Appendix five: ICB ambitions self-assessments

East of England

[Bedfordshire, Luton and Milton Keynes ICB Ambitions self-assessment.pdf](#)

[Cambridgeshire and Peterborough ICB Ambitions Self-Assessment.pdf](#)

[Mid and South Essex ICB Ambitions self-assessment.pdf](#)

London

[North Central London ICB Ambitions self-assessment - Barnet.pdf](#)

[North Central London ICB Ambitions self-assessment - Camden.pdf](#)

[North Central London ICB Ambitions self-assessment - Enfield.pdf](#)

[North Central London ICB Ambitions self-assessment - Haringey.pdf](#)

[North Central London ICB Ambitions self-assessment - Islington.pdf](#)

[North East London ICB Ambitions self-assessment.pdf](#)

[South East London ICB Ambitions self-assessment - Lambeth and Southwark.pdf](#)

[South West London ICB Ambitions self-assessment.pdf](#)

Midlands

[Birmingham and Solihull ICB Ambitions self-assessment.pdf](#)

[Coventry and Warwickshire ICB Ambitions self-assessment.pdf](#)

[Herefordshire and Worcestershire ICB Ambitions self-assessment.pdf](#)

[Leicester, Leicestershire and Rutland ICB Ambitions self-assessment.pdf](#)

[Lincolnshire ICB Ambitions self-assessment.pdf](#)

[Shropshire, Telford and Wrekin ICB Ambitions self-assessment 1.pdf](#)

[Shropshire, Telford and Wrekin ICB Ambitions self-assessment 2.pdf](#)

[Shropshire, Telford and Wrekin ICB Ambitions self-assessment 3.pdf](#)

[Shropshire, Telford and Wrekin ICB Ambitions self-assessment 4.pdf](#)

[Shropshire, Telford and Wrekin ICB Ambitions self-assessment 5.pdf](#)

[Shropshire, Telford and Wrekin ICB Ambitions self-assessment 6.pdf](#)

North East and Yorkshire

[South Yorkshire ICB Ambitions self-assessment.pdf](#)

North West

[Lancashire and South Cumbria ICB Ambitions self-assessment.pdf](#)

South East

[Buckinghamshire, Oxfordshire and Berkshire West ICB Ambitions self-assessment.pdf](#)

South West

[Bristol, North Somerset and South Gloucestershire ICB Ambitions self-assessment 1.pdf](#)

[Bristol, North Somerset and South Gloucestershire ICB Ambitions self-assessment 2.pdf](#)

[Bristol, North Somerset and South Gloucestershire ICB Ambitions self-assessment 3.pdf](#)

[Cornwall and Isles of Scilly ICB Mapping Summary.pdf](#)

[Devon ICB Ambitions self-assessment.pdf](#)

[Gloucestershire ICB Ambitions self-assessment.pdf](#)

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