Built to last?

The state of children's palliative care in 2025

together for short lives

Foreword

Every child deserves the chance to live a full life, supported by care that enables them and their families to thrive. Children's palliative care provides this essential support to children with life-limiting and life-threatening conditions and their families—helping them spend precious time together, creating memories, and accessing the care they need, when and where they need it.

Yet, despite some progress in the past year, families struggle to access this support. Not because of the complexity of their needs, but because of the area in which they choose to live. Our system is not built to last, and it is continuing to fail too many seriously ill children.

Across the UK, workforce shortages, funding shortfalls, and a lack of leadership and accountability have created an unacceptable postcode lottery in access to children's palliative care. Precious NHS resources are being wasted as families have to endure unnecessary hospital admissions, delayed discharges and a lack of choice and control.

That's why Together for Short Lives is here. Step by step, hand in hand, day by day, making sure that no one has to face living through their child's short life – and death – alone.

Together we support families through the most difficult times, offering lifeline practical, emotional and financial help. And, when they're ready, we connect them to our incredible community—people who really get what they are going through.

Together we unite our sector. We help professionals and services to pool their knowledge and expertise, to deliver outstanding children's palliative care. We are collaborative and inclusive; we push boundaries and lead the conversation to find better ways of doing things.

Together we campaign to make sure that seriously ill children and their families get the care and support they need, when and where they need it. We rally the community and give people a voice. And where the system falls short, we demand change.

But we cannot do this alone. Governments across the UK must invest in children's palliative care, expand the workforce and hold local NHS bodies and councils accountable for delivering the care families are entitled to. With the UK Government developing a NHS 10-Year Plan for England, and other promising developments in Northern Ireland, Scotland and Wales, we have a real, tangible opportunity to secure the change that is urgently needed.

Our campaigning has already achieved so much. The profile of palliative care has never been higher, and we are grateful for the recent government and NHS investment in children's hospice care in England. The examples we feature in our report show that much is possible when the NHS works with families and services to put high quality, sustainable support in place.

This report sets out the actions that we can all take now to build a children's palliative care sector that lasts. Supporting, uniting, campaigning, together. Because time is short.

Nick Carroll
Chief Executive, Together for Short Lives

Executive Summary

• Despite improvements in the past year, major gaps in 24/7 end of life care at home mean too many seriously ill children and their families are still unable to access the care they need because of where they live.

• Workforce shortages, funding shortfalls and a lack of accountability have resulted in high vacancy rates, underfunded services and inconsistent local leadership. This is driving a postcode lottery, with families increasingly feeling abandoned and overwhelmed in a system that is not built to last.

• The UK's governments must act now to build a children's palliative care sector to last. Closing the £310 million funding gap in England—which is just a fraction of the overall NHS budget—would ensure families can access high quality children's palliative care, when and where they need it.

Key findings

- The needs of families caring for children with life-limiting and life-threatening conditions are often wide-reaching but can be met with by access to high quality children's palliative care. Yet far too often they go unmet.

- Only half (50%) of families that completed our survey reported feeling well supported. Over a quarter (29%) feel poorly supported. 9% do not feel supported at all.

- Many families feel abandoned by a complex system which should support them to provide care once their child is diagnosed with a life-limiting condition; they are often left to navigate it alone.

- Despite some improvements, significant variation persists in the way children's palliative care is planned, funded and provided. As a result, the care and support seriously ill children can receive still depends on where they live.

- We have found the postcode lottery to be particularly stark in children and families' access to 24/7 end of life care at home, provided by nurses and supported by advice from specialist consultants in paediatric palliative medicine.

- In England, despite a 33% increase in the past year, only 19% of local NHS organisations (known as integrated care boards, or ICBs) currently commission these services on a formal basis. While the number of ICBs that do not commission these services at all has fallen by 18%, over a third (33%) are still failing to meet this established national standard.

- The standard for 24/7 end of life care at home is not fully met anywhere in Northern Ireland, is only partially met in some areas of Scotland, and is fully met in just a minority of areas in 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 skilled, educated and experienced in the field of children's palliative care to provide it in hospitals, children's hospices and in the community.

- There are only 24.4 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.

- 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 973 CCNs employed by the NHS in England.

- Similar shortages also persist in the devolved nations with another 90 CCNs required in Northern Ireland, 259 needed in Scotland and 220 in Wales.

Key recommendations to build a children's palliative care sector that lasts

- Through the NHS 10-Year Plan, the UK Government should commit to review the way in which children's palliative care is planned and funded, to identify how the £310 million annual gap in NHS spending on children's palliative care in 2025/26 can be filled.

- The UK Government should also 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.

- Across the UK, governments and relevant bodies should use the existing children's palliative care workforce more equitably—and increase the number of professionals who are educated and trained with the skills and experience to provide palliative care to children with life-limiting conditions across a range of different roles.

- The UK's governments should 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 funding for children's hospices beyond 2025/26 as part of a transition to a sustainable funding system.

- In addition to filling funding gaps in local NHS and council budgets, the UK's governments should hold them to greater account for implementing the existing policy frameworks relating to children's palliative care.

- The devolved governments should close relevant funding shortfalls to ensure the recruitment of additional NHS community children's nurses and meet safe staffing levels.

The extent to which 24/7 end of life care at home is formally planned and funded across the UK

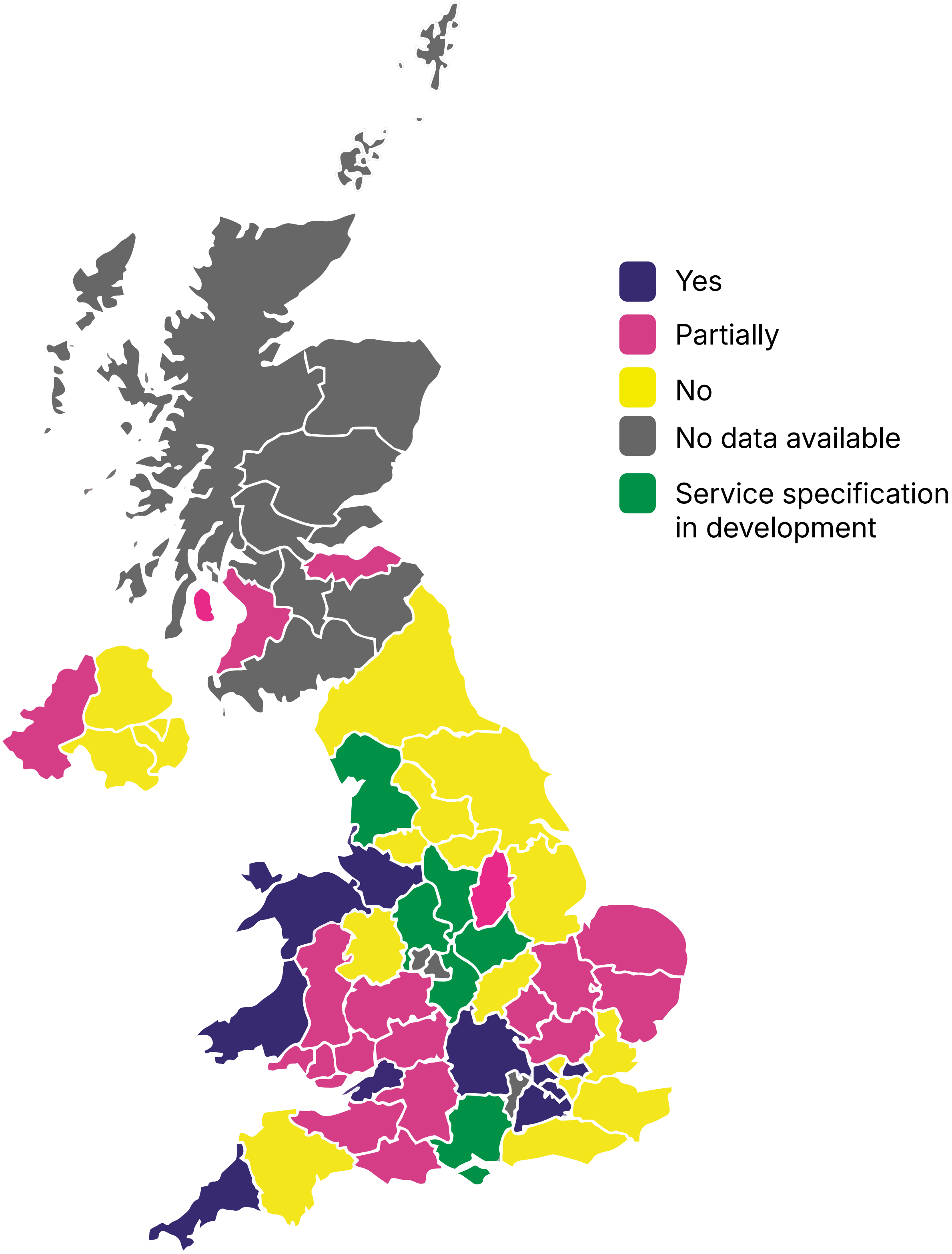


Table of contents

Introduction

Across the UK, there are 99,000 children and young people with life-limiting and life-threatening conditions.[1] This figure has risen significantly in recent years due to advances in medical treatment strategies, an increased number of early diagnoses, and improvements in health services.[2] Furthermore, it is widely expected to continue increasing in years to come, making it more important than ever to ensure that these children and their families are able to receive the care and support they need, when and where they need it.

Seriously ill children and their families deserve the chance to live a full life, supported by care that enables them to thrive. By adopting a holistic approach and bringing together numerous services and professionals, children's palliative care is well-placed to address these diverse needs and support families

But for many, it is a lonely and isolating experience. Parents and siblings struggle in a system that doesn't meet their uniquely challenging needs.

In 2024, we published research that revealed significant variation when it comes to accessing high quality children's palliative care that meets national quality standards.[3] We demonstrated that the care and support that children and families can access often depends on where they live.

Across the UK, there are many examples of services and local NHS areas providing excellent care. However, workforce shortages, funding shortfalls and a lack of accountability among NHS bodies and local councils often prevents this level of care from being consistently available throughout. Through this report, we provide a comprehensive picture of the state of children's palliative care in the UK, while also examining how the situation has changed in the past year.

Drawing on new research conducted by DJS Research and findings from our own freedom of information (FOI) requests, we aim to show what families need, the extent to which these needs are being met, and the persistent variations in care being formally provided across different NHS areas. Finally, the report will conclude by exploring the policy barriers that are hindering equitable access to care and setting out a series of recommendations for governments and relevant bodies across the UK. By taking these steps, we can ensure that children and young people with life-limiting and life-threatening conditions and their families can receive the care and support they need, when and where they need it.

Terms used in this report

When referring to national quality standards, we mean the quality statements as set out in:

- the National Institute for Health and Care Excellence (NICE) quality standard for end-of-life care for infants, children, and young people;[4]
- the NHSE service specification;[5]
- the Ambitions for Palliative and End of Life care framework;[6] and
- the Quality statement for palliative and end of life care for Wales.[7]

Throughout the report, we use the term ‘children with life-limiting conditions’ to refer to children and young people with life-limiting and life-threatening conditions aged 0-24 years.

We define life-limiting conditions as those for which there is no reasonable hope of cure and from which children will die.[8] Life-threatening conditions are defined as those for which curative treatment may be feasible but may fail.[9]

By local NHS areas that commission or provide services meeting national quality standards, we mean ICBs in England with a relevant service specification explicitly addressing these standards, or other NHS bodies in Northern Ireland and Wales that have indicated compliance in their response to the freedom of information request.

Oliver's story

Told by his mum Clare

In the Autumn of 2022, "Oliver suddenly became very tired and would vomit. He had a massive seizure and after treating him for various conditions, a diagnosis of high grade glioma finally came on 1 December 2022. It was truly shocking. We clung onto hope that he could be cured, but we knew it was going to be an uphill battle."

After radiotherapy, chemotherapy and a successful surgery to remove the main tumour, "everything was positive for a while, and we believed we had taken a big step forward." But a few short weeks later, the tumour grew back with vengeance to the point there were no other treatments available. In September 2023, Oliver was then put on a palliative journey and referred to Francis House Children's Hospice in Manchester: "I was very resistant to get involved with a hospice, it was like we were giving up, I think that's a pretty common thought with parents. But I wish I hadn't been, because we gained so, so much."

The importance of 24/7 end of life care at home

A critical part of the family's end of life wishes was for Oliver to remain at home for as long as possible before being moved to his grandparents' house. "Their house held lots of very special memories, had all the space we needed to welcome family and friends and Oliver could look out over the fields and hills and see the sun rise and set. But our amazing nurse was struggling to piece together a care package to ensure he could end his life at home. I honestly thought that when your child is dying, you would have 24/7 care at home. But it turns out, that just isn't the case. Most of the time it was done by myself and my family, and a patchwork of nursing care from various providers. We never knew if we would be able to staff the next week of care. It was all down to the compassion of some lovely nurses."

Fighting for care

Clare made herself heard to get access to the care she felt that Oliver needed: "Honestly I made a nuisance of myself. I had a friend who had a good job at our local NHS Trust, so I called her to try and get things moving. It was the goodwill of nurses who wanted to help in spite of, you know, barriers. But whatever stress and struggle they went through to deliver that plan, I didn't see it. It was not visible to us. In the end, we had the best experience possible, given the circumstances. It was everything we could have hoped for."

In the middle of November 2023, Oliver deteriorated rapidly: "Some dementia started to creep in towards the end of the year, and there was a massive seizure in there too." From this point on, Oliver was completely wheelchair bound with his family and nurses managing all his personal care from bed.

Creating special memories

As the year progressed further, the family took a final holiday to Anglesey to celebrate an early Christmas: “We knew he wouldn’t make it to the end of December, so we wanted to have the memory. When we got home, I called our Macmillan nurse and told her that the decline was so rapid, she came and installed a morphine driver. We knew time would be very short with him.” However, just over two weeks before he died, he was moved to his grandparents’ house: “It was where we wanted him to die, surrounded by the love of his family, green fields, the sound of nature and just peace.”

At this point, despite being conscious, Oliver was completely uncommunicative. He had lost his ability to speak but was still able to squeeze hands.

Friends and family would take it in shifts to stay awake with him overnight: “By now, he had to be constantly watched, so they would work in three hour shifts. I slept next to him on a mattress, but I couldn’t be awake 24 hours a day. Without my loved ones, I think we would have had to go to the hospice or hospital.”

On 2 December 2023 at 9:15am, Oliver passed away: “Oliver died peacefully and without pain. It was a good experience if you can describe it as that. I am very aware of how this time can unravel for families. So, we count ourselves lucky.”

The experiences of seriously ill children and their families

The needs of families caring for children with life-limiting and life-threatening conditions are often wide-reaching, requiring support from multiple services. Unfortunately, despite the growing need and involvement of various services, we know that far too often, families experience care that is disjointed and uncoordinated, lacking in many vital areas.

To improve our understanding of the needs of families caring for seriously ill children and the areas where they are going unmet, we commissioned DJS Research to conduct exploratory research. We hoped that by commissioning this research, we would generate key insights to help policymakers and providers reach more families and better meet their needs.

Specifically, we sought to achieve the following objectives:

- To understand the current and unmet support and access needs of families.

- To identify any key barriers to accessing support currently and any barriers experienced previously.

- To explore what the ideal support services would look like for families and how it could be made as accessible as possible.

To gather data and information, DJS adopted a two-step approach. Step one involved an online survey completed by 45 different families, with each survey taking approximately 10-15 minutes to complete. Step two then saw DJS conduct 10 interviews with 10 different adults, each lasting for one hour.

By conducting both an online survey as well as several in-depth follow-up interviews, DJS were able to gain a robust measurement of families' current views and experiences, while also gathering further insight into family experiences and the drivers of their opinions.

Of the families that took part in the research, nearly three quarters (69%) were currently caring for a child with a life-limiting or life-threatening condition, one quarter (24%) were bereaved and almost one tenth (7%) were caring for a child with complex care needs.

What families of children with life-limiting conditions need

Families caring for children and young people with life-limiting and life-threatening conditions often face complex and evolving challenges. While every family's journey is different, our research with DJS has revealed a number of common themes in the types of support that families need to navigate daily life and plan for the future.

Access to high quality external support services

Through our research, families shared their experiences and highlighted key areas where external support could make a meaningful difference. We have found that the key to families feeling well supported appears to rest on their ability to tap into, successfully apply for, and receive good support services, or have their needs met in their child's educational setting.

Care support is most needed, followed by emotional support

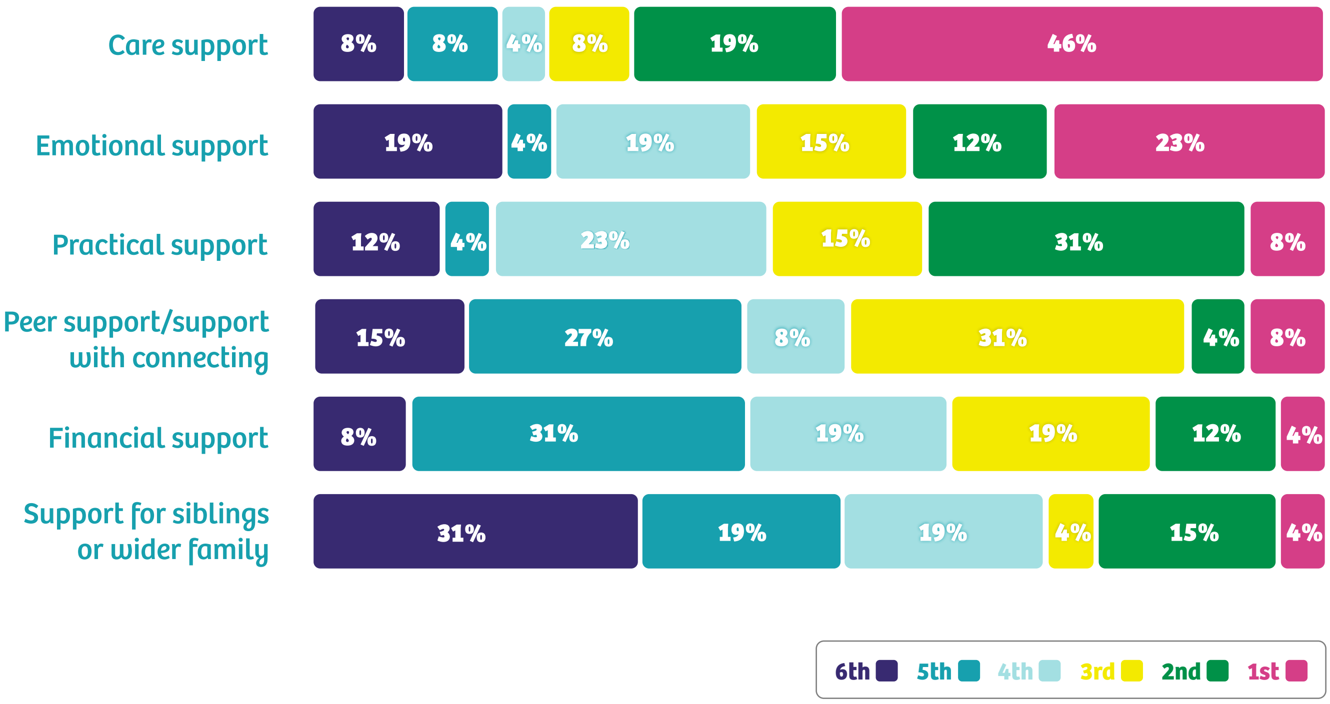
Caring around the clock for a child with a life-limiting condition can be exhausting and isolating. Families often feel pushed to their limits, consequently requiring both practical and emotional support to cope.

While we have found care support is the most urgently needed, families also stressed the need for greater emotional and psychological support, including:

- anticipatory grief support;
- counselling tailored to families of a child with a life-limiting or life-threatening condition; and
- someone to talk to who understands what they are going through.

The table below shows how parents and carers ranked the support needed most.

Support needed the most, ranked 1st most needed to 6th least needed



Support with signposting and advocating

Given the wide array of professionals and services that a family will encounter when caring for their child, families specifically need assistance with navigating these services and making the case required to qualify for different types of support.

Specifically, families need:

- support with applying for benefits and funding;
- support with battles for equipment and transport; and
- support with dealing with local NHS bodies and appealing decisions.

With much of families' time and energy going into researching advice, assessing what services are available to them and then how to apply to said services, there is a clear need for a single point of contact. This point of contact could support with assessing families' needs and signposting them on to all types of eligible support.

Families want a chance to socialise and connect

As families can find the experience of having a child with a life-limiting or life-threatening condition a very isolating one, it is important for them to be able to make connections with other families. Often families want the opportunity to speak with other parents who also have a child with a life-limiting or life-threatening condition as they have a shared experience and understanding.

Access to short breaks for respite

Through our research, families consistently reported that the demanding nature of caring for a child with a life-limiting condition leaves little time or energy for activities with siblings, leading to feelings of isolation and resentment among both children and parents.

Respite care is invaluable to families of children with life-limiting conditions. Not only does it provide parents and carers with a break from their caring duties allowing them the opportunity to engage in other activities they may enjoy, but according to one study, it can also help reduce the risk of emotional exhaustion and mental health problems.[10]

This is particularly important when considering the findings of research published in 2021. Here it was found that mothers of children with life-limiting conditions are significantly more likely to experience common and serious physical and mental health problems. Furthermore, it was found that the risk of premature death is 50% higher among mothers of children with life-limiting conditions than mothers of children with no-long-term health conditions.[11]

Social care is therefore vitally important to help families relieve this stress, spend time as a family and do the things that other families do.

Support with future planning

Advances in medical treatment, early diagnoses, and improved health services mean more young people with life-limiting conditions are surviving into adulthood.[12] As a result, effective transition programmes from children to adults' services are increasingly vital.[13]

It is therefore no surprise that families expressed a need for greater support in transitioning to adulthood. Specifically, families told us that they need:

- guidance and advice through the process of their young person transitioning from children to adults' services;

- support with returning to work or finding care solutions; and

- assistance with preparing for the end of life and helping them understand what that process will be.

With many different interventions seeking to aid a successful transition, research by Kerr et al (2018) demonstrated the need for a combination of interventions.[14]

Specifically, they found that no single intervention can guarantee a successful transition. Instead, service providers should take a diagnostic approach. They should consider how a range of interventions, in light of the organisational and human resources available to them, might be best implemented to achieve the desired outcome.[15]

Families can clearly envisage what the ideal support service would look like

Based on what families have told us, there is a clear vision for an ideal support service. This service would be highly personalised, offering expert advice, interactive online events and resources, and opportunities for families to connect with others in similar situations.

Specifically, families expressed a need for a range of resources, including information sessions on benefits, Q&A sessions with experts, virtual drop-in sessions, and the ability to consult with medical professionals online. They also emphasised the importance of a personal point of contact who would proactively reach out and check in with families, as well as opportunities to connect with other parents in similar situations.

In addition, families highlighted the need for online resources and events, such as buddy schemes, local peer groups, and online support groups. They also requested practical resources like a list of all services available locally, checklists of equipment needed for different conditions, and support with applications.

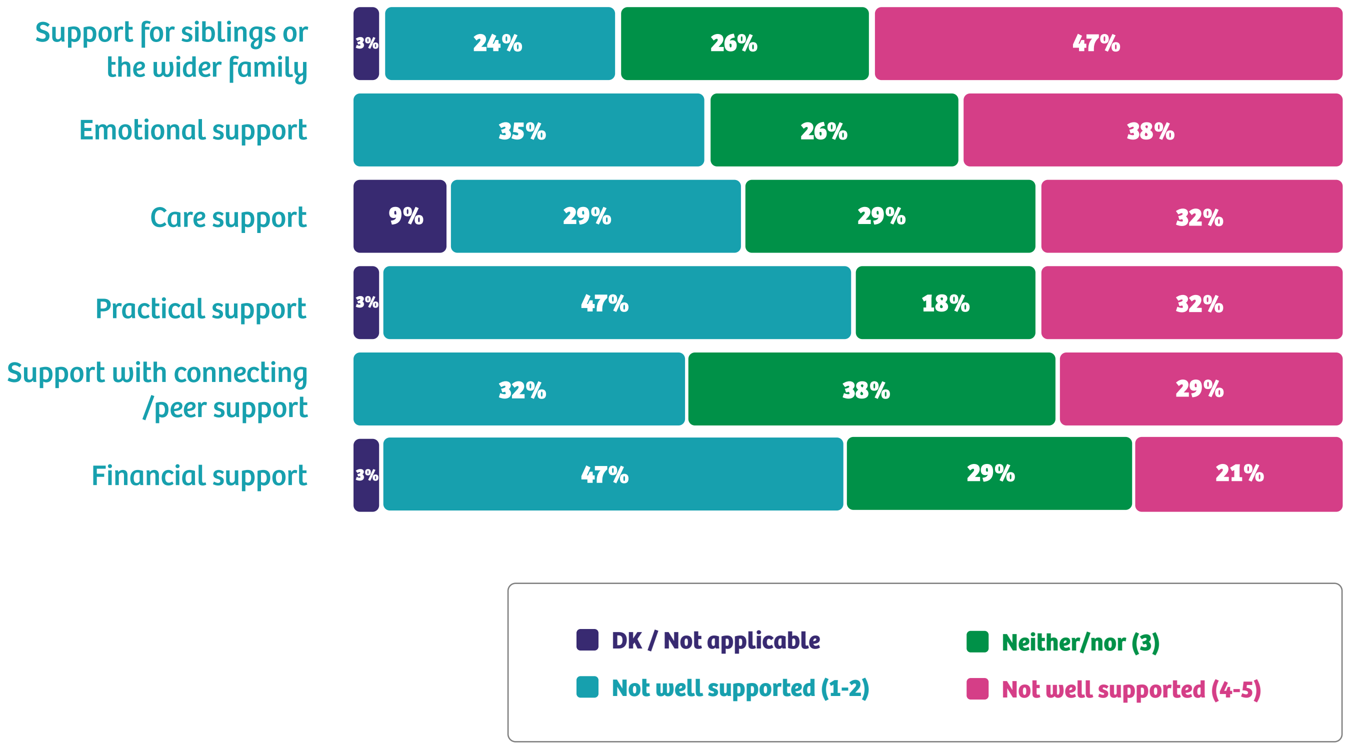
Overall, the ideal support service would provide families with the information, advice and peer support they need to navigate the system and navigate life with a child who has a life-limiting or life-threatening condition.

The extent to which families are receiving the support they need

Overall, the data gathered from the survey and follow-up interviews highlights a significant gap in the support provided to parents and carers of children with life-limiting conditions. Despite the diverse range of support areas assessed, no single area received a majority of families indicating they felt well supported. This suggests a substantial lack of adequate support across the board.

Parents reported feeling particularly unsupported in practical and financial matters. These areas are crucial for navigating the challenges associated with caring for a child with complex needs, including medical appointments, specialised equipment and additional expenses.

Addressing these specific needs is essential for improving the overall wellbeing of both children with

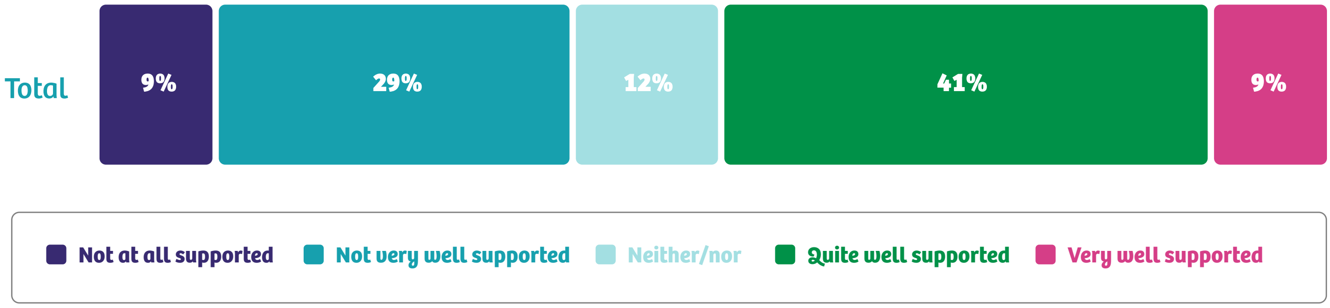


Families feel abandoned after diagnosis

For many families, the road to receiving an accurate diagnosis for their child or young person can be a long and difficult one. With numerous professionals to engage with and a complex health and care system to navigate, the challenges in obtaining a diagnosis can seem never-ending.

Unfortunately, the difficulties do not end there. Our research with DJS has found that following a child's diagnosis, many families feel abandoned by the health and care system and left to navigate the complex system themselves.

We have found that only half (50%) of the families that took part in the interviews feel well supported. Less than a tenth (9%) of families feel very well supported and nearly two fifths (38%) feel poorly supported.



Families feel incredibly isolated

Through our research, we have witnessed the heightened prevalence of isolation among families, with less than a third (29%) feeling well supported when it comes to connecting with peers. Every family that took part in the interviews mentioned experiencing feelings of physical, social and emotional isolation.

Many families spoke of feeling cut off from the world, unable to engage in hobbies or social activities due to their caregiving responsibilities. Meanwhile, some reported the strain and added complexity leading to the breakdown of personal relationships, including friendships, relationships and family ties.

The transition to adult services further exacerbates this isolation, with the withdrawal of education and child support services often leaving families feeling even more alone.

Families also spoke about how they struggle to find support networks. Many expressed a strong desire to meet others who understand their experiences. However, geographic barriers, a lack of suitable support groups and the sheer demands of caregiving make it particularly difficult to do so.

Given the lack of suitable groups, some families have taken matters into their own hands. Around a third of families that DJS surveyed reported creating their own support groups to fill this gap.

A lack of emotional support

Despite being their child's lifeline of support and in most cases having other dependents, over a third of families (35%) claimed they do not feel well supported when it comes to their emotional and psychological needs.

According to many families, the weight of responsibility combined with social isolation and a lack of formal support, takes a severe toll on their mental health and emotional wellbeing. Many parents described experiencing depression, breakdowns and post-traumatic stress disorder, with some even contemplating taking their own life. The relentless stress, sleepless nights and lack of crisis support, especially in the evenings and at night, has left families feeling overwhelmed and alone.

Published research further supports these concerns. One study conducted by O'Dwyer et al (2024) found that more than 40% of parents had considered suicide while caring for a disabled or chronically ill child. The study identified depression, entrapment, dysfunctional coping and having a mental health diagnosis prior to caring as significant risk factors.[16]

Many families that DJS spoke to also reported struggling with feelings of grief in several different ways. While some parents spoke about their experience of grieving the life their child won't be able to lead, others reported feeling a sense of grief for losing the life they once had before caregiving. Some parents also mentioned struggling with anticipatory grief for the likely loss of their child within the coming months or years.

Despite these ongoing feelings of grief, families reported that anticipatory grief support services are hard to come across.

Providing emotional and psychological support to parents is therefore critical for their wellbeing. But according to research, it can also help prepare them, so they are better enabled to be a parent to a child or young person with a life-limiting condition.[17]

Further research has also illustrated the importance this type of support can have for siblings of children with life-limiting conditions. A study by Goudie et al (2013) found that siblings of disabled children were almost three times (2.77) more likely to have significant levels of problems in interpersonal relationships, their psychological wellbeing, school performance, or use of leisure time compared to other siblings.[18]

Families caring for children with life-limiting conditions are therefore in urgent need of improved emotional and psychological support. This was particularly evident in our research when parents and carers were asked about the types of support they need most. Here, emotional support was ranked as the most needed form of support alongside care support, advocacy and future planning.

Lack of information or guidance

Receiving little in the way of support or guidance from hospitals, families taking part in our research reported being left alone to navigate the complexities of life caring for a child with a life-limiting condition, while also trying to understand the care, benefit, and support systems they need to function going forward.

To make matters worse, when asked to rate the extent to which they feel well supported across an array of areas, nearly half (47%) of all families reported not feeling well supported when it comes to their practical and financial needs.

As a result of this lack of information and guidance, many families have found themselves not accessing the support or services they're entitled to for many years. They claimed this was either because they either weren't aware of it, had been wrongly advised or incorrectly told they're not eligible initially.

Of the support that families did have in place, whether that be from their local children's hospice or nursing service, families claimed that it simply is not enough to meet the needs of their family.

An endless battle for what families need

For families who are aware of the support they are entitled to, securing it is often an exhausting and ongoing battle. Parents frequently described having to relentlessly advocate for themselves to obtain the care, benefits, transport, medication and equipment their child needs.

A major challenge is the lack of a named professional to coordinate care. Instead, parents must manage everything themselves, adding to their already overwhelming responsibilities. Some families even reported the problems they face engaging with systems, with many feeling that integrated care boards (ICBs) and local authorities often purposely try to obstruct access to support and provision. This constant struggle consumes time and energy, inevitably detracting from the precious time they could spend making happy memories with their child.

Research by Fields et al (2023) has emphasised this issue, finding that despite many professionals being involved in a child's care, parents often feel there is no single person driving or coordinating it. As a result, parents are denied the opportunity to fulfil the parental role and to be able to 'be there' for their child at the end of their life.[19]

Families therefore need support with signposting and advocating specifically. They need a clear single point of contact to assess families' needs, signpost them onto all types of eligible support, and support with applications and making the case required to qualify for different types of support.

Trouble with transitioning

An effective transition provides high quality, coordinated, uninterrupted health care that is patient-centred, age and developmentally appropriate, culturally competent, flexible, responsive and comprehensive.[20] The process of transitioning to adults' services should start as early as the age of 14 and should involve the young person and their family in every step of the way.[21]

Unfortunately, our research with DJS has highlighted the negative experiences or challenges that many families contend with when their child is transitioning from paediatric to adult services.

Transitioning from children to adults' services is a difficult and worrying time. In addition to noting the impact that the harsh removal of activities, education and support can have on their child, we have witnessed parents express a lack of confidence in the adult services' ability to manage their child's life-limiting conditions.

On many occasions, families noted that not all services are equipped or particularly experienced at dealing with some life-limiting conditions. Furthermore, given the clinical focus of many adult services, families also noted that services are not geared up to meet their child's emotional or wellbeing needs.

As a result, when transitioning, many young people find themselves no longer going to the places they once enjoyed, seeing other young people with similar conditions or being stimulated through development activities and therapies. Some families also reported that those with learning disabilities may not be able to understand why this is the case.

Wider research has also found significant fragmentation between services involved in the transfer. As a result, there is no clear pathway for the transition from healthcare services for children and young people into adult healthcare services.[22]

In seeking to assess the barriers and facilitators to young people receiving a good transition to adult healthcare services, National Confidential Enquiry into Patient Outcome and Death (NCEPOD) has 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.[23]

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.[24] Similarly, NCEPOD has found that only 21.9% (37/169) organisations had mandatory training on transition in place for staff.[25]

Lack of access to short breaks for respite

We have found a critical gap in the availability and adequacy of short breaks and respite care and support for families caring for children with life-limiting conditions.

While it was found that families who are able to advocate well for themselves appear to receive some respite support, all families generally feel it is not sufficient enough to provide quality of life for them, their child and particularly siblings.

The lack of respite care options, particularly for those over the age of 18 and living in remote areas, exacerbates the challenges faced by families. This is especially true for families who do not qualify for hospice care despite in some cases being told their child's condition is life limiting and have complex needs.

Furthermore, the burden of care often falls on mothers who may feel unable to leave their child with fathers due to concerns that their partner is less knowledgeable or engaged about their child's care needs.

Feelings of being unsupported are low across individual support areas

Overall, the data gathered from the survey and follow-up interviews highlights a significant gap in the support provided to parents and carers of children with life-limiting conditions. Despite the diverse range of support areas assessed, no single area received a majority of families indicating they felt well supported. This suggests a substantial lack of adequate support across the board.

Parents reported feeling particularly unsupported in practical and financial matters. These areas are crucial for navigating the challenges associated with caring for a child with complex needs, including medical appointments, specialised equipment and additional expenses.

Addressing these specific needs is essential for improving the overall wellbeing of both children with life-limiting conditions and their families.

The barriers preventing families from accessing the support they need

From our research with DJS, we have identified several key barriers that hinder families of children with life-limiting conditions from accessing the support they require. While many families reported having some level of support in place, such as hospice or nursing care, they often expressed that this support is insufficient and difficult to access.

Reduced services

One major challenge is the reduction of services during the pandemic, which has led to a decline in respite care and face-to-face support. This decrease has had a long-lasting impact, making it harder for families to receive the same level of care as before. Furthermore, respite care is often limited in availability, both in frequency and duration, making it difficult for families to manage their responsibilities effectively.

Complex processes

Another considerable barrier is the complex and time-intensive process of obtaining support. Families frequently encounter numerous obstacles, including extensive paperwork and the need to manage their own care coordination. This can be overwhelming and emotionally taxing, especially when different support services lack coordination, causing confusion and frustration.

Uncertainty about where to turn

Above all else, families told us that the greatest barrier to accessing support is simply not knowing where to turn. Many families reported being unaware of the range of available services and support options, leading them to believe that they are not eligible or that suitable support is not available. This lack of awareness is often compounded by previous negative experiences with support organisations. As already mentioned, families may be reluctant to approach services they are specifically signposted to by professionals due to fear of rejection and exhaustion from past battles for support.

Challenges in finding support services

Despite the emotional toll of caring for a child with a life-limiting condition, many parents and carers face significant difficulties when trying to access support services. Feelings of isolation, emotional overwhelm, and exhaustion are common, and these challenges highlight the need for improvements in making relevant support services more visible and accessible.

Impersonal and inaccessible support services

Another critical issue identified is the lack of personalisation and accessibility in support services. Families are increasingly dissatisfied with the impersonal and impractical nature of the support they receive. The reduction in face-to-face interactions since the pandemic has led to a sense of disconnection, making it harder to address complex issues.

Families expressed a strong preference for more personalised support, particularly when dealing with emotionally challenging situations or navigating complicated forms and processes. Building trust and rapport with service providers is essential, but this can be difficult to achieve through online or phone-based interactions alone.

Our research also revealed that families feel there is a lack of choice in how they can access support. While online forms and office hours may be convenient for some, many families prefer video calls or in-person meetings for more in-depth and tailored discussions.

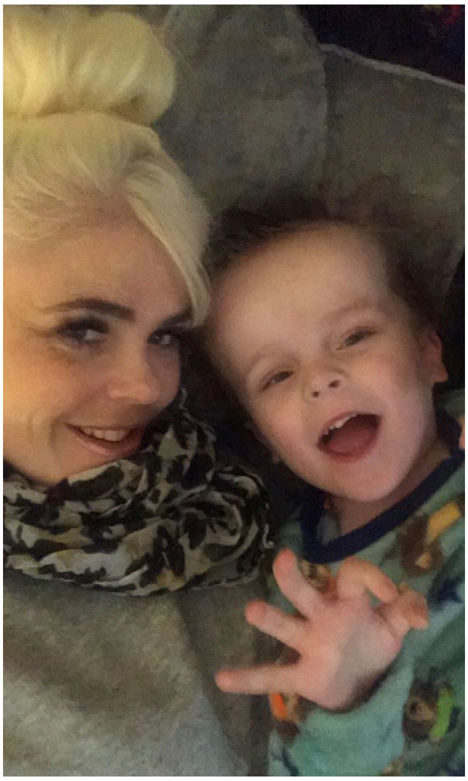
Hesitation to seek support

Many families are hesitant to seek support due to previous negative experiences with professionals and organisations. A significant number reported feeling emotionally drained and apprehensive about asking for help, especially after being denied services in the past.

This fear of rejection becomes a major barrier, as families worry they will not be taken seriously or might be dismissed, leading them to avoid seeking assistance altogether. The idea of speaking with a call handler who may not fully understand their situation can also be intimidating, further discouraging families from reaching out.

George's story

Told by his mum, Carrie.



"George was born six weeks early on 27 December. We knew from the moment he was born that something wasn't right. He wasn't my first baby, but he was the first to be rushed to another hospital within hours of his birth."

Mum Carrie didn't have to wait long for the diagnosis and, in less than 24 hours after his birth, the doctors delivered the devastating news that George had Cerebral Palsy and severe bleeding on the brain. George spent the first five months of his life in hospital, with Carrie constantly travelling between the hospital and home.
"George was baby number eight out of what would soon be nine children, and the hospital wasn't local to our home. I had other children to look after who needed me too. There was so much travelling, I was always back and forth between the hospital and home."

Carrie describes George as the happiest boy, who loved to just be with his family. "George was disabled but he wasn't ill. He never hit milestones, but he was happy. He'd babble all day long to you – rolling around and babbling."

As George grew, his health stabilised. He was finally able to start school and the family settled into a new routine. But the routine was short-lived: George suffered two seizures at school, with a third leading him into a coma. Life was about to get extremely difficult.

Fighting for care

Over the next 15 months, Carrie fought constantly to get the care and support George needed. "I could see George's seizures were getting worse and he wasn't being given the medical attention he so needed. One seizure even lasted three days. It felt like nobody was listening to me. It wasn't until the doctors finally did a brain scan that they realised something was very wrong."

George was transferred to six different hospitals while the care teams worked to find the best support for George. The hospitals were all far away from the family's home and Carrie found herself travelling backwards and forwards again so that she could be by George's side. "You couldn't touch George without him being in pain. It hurt me to see him in that much pain."

After weeks of fighting to be heard, Carrie finally received the news that George's care was being escalated, and he was scheduled to have another brain scan. The scan revealed fluid in George's brain. Tragically, George was not strong enough to undergo the surgery needed to remove the fluid. There was nothing more that could be done to keep George alive.

A lifeline

Facing the unbearable conversation of where they wanted George to die, George's family were introduced to their local children's hospice.

“They told us we likely had 48 hours left with him. We were given twelve precious days. George was a fighter.”

George was eight years old when he died.

The extent to which services meet national quality standards across the UK

The extent to which families caring for children and young people with life-limiting and life-threatening conditions struggle to access the care and support they need is closely tied to how well local services are commissioned and delivered.

While some areas provide comprehensive support, others fall short, leaving families without the care they need. Understanding how well local NHS bodies and councils are meeting their responsibilities is key to addressing these disparities.

England

In England, integrated care boards (ICBs) have a legal duty to commission palliative care as they consider appropriate to meet the reasonable requirements of the people for whom they are responsible.[26]

Despite this legal duty, research we published in March 2024 revealed that many ICBs are failing to commission high quality children's palliative care services capable of meeting local need.[27]

Specifically, through this research, we found significant variation in:

- the number of ICBs that had a service specification for children's palliative care;
- the number of ICBs that had a service specification compliant with national quality standards; and
- the number of ICBs that had completed an Ambitions for Palliative and End of Life Care self-assessment.

Service specifications define the standards of care expected from organisations funded to provide a specific service.[28] In 2023, NHSE published a service specification for palliative and end of life care for children and young people.[29] This model, based on national standards, outlined a framework for delivering specialist level palliative care (SLPC) from identification of need through to end of life. It was therefore deeply concerning to find such a high level of variance across ICBs.

In October 2024, we reassessed the situation through freedom of information (FOI) requests issued to all 42 ICBs in England.[i] We asked ICBs:

1. Do you have a children's palliative care service specification?

---

[i] Our FOI request aimed to benchmark local service specifications against the National Institute for Health and Care Excellence (NICE) quality standard on end of life care for infants, children, and young people (QS160). This guidance sets out key principles for high quality care, including ensuring that all children with life-limiting conditions have a named lead responsible for coordinating their care and that they can access 24-hour end of life care at home.

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?

In total, all 42 ICBs responded to our request.[ii]

We analysed their responses and scored them on the basis of their response to each question and the contents of any service specification provided. We identified ICBs as formally commissioning services that meet national quality standards if they supplied a relevant service specification explicitly addressing the specific standard in question.

[ii] Please see appendix 1 for individual ICB responses to our FOI request.

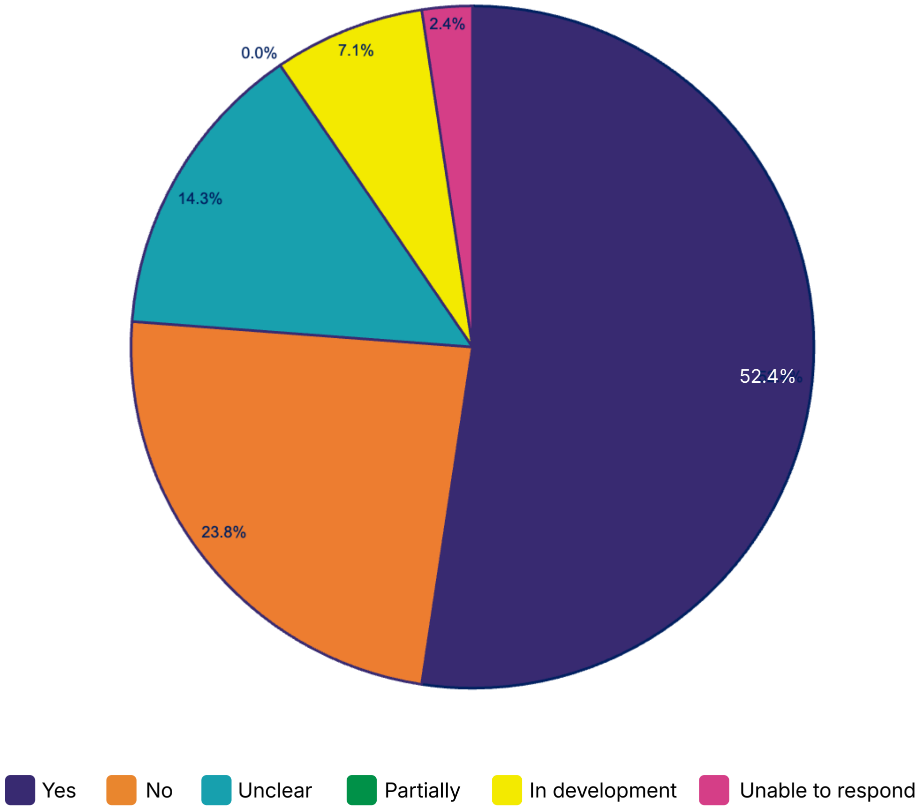
ICB FOI findings: October 2024

Over the past year, there have been several improvements, particularly in the number of ICBs possessing a relevant service specification and the number completing an Ambitions self-assessment. Despite these improvements, our FOI requests have revealed that significant variation remains in the extent to which ICBs are formally commissioning services that meet national quality standards.[iii]

Possession of a service specification for children's palliative care

Through these FOI requests, we have found that 22 (52.4%) ICBs now have a service specification relevant to children's palliative care.[iv] Meanwhile, 10 (23.8%) ICBs reported having no specification and a further six (14.3%) noted that their specification is currently in development.[v]

Does your ICB have a children's palliative care service specification?



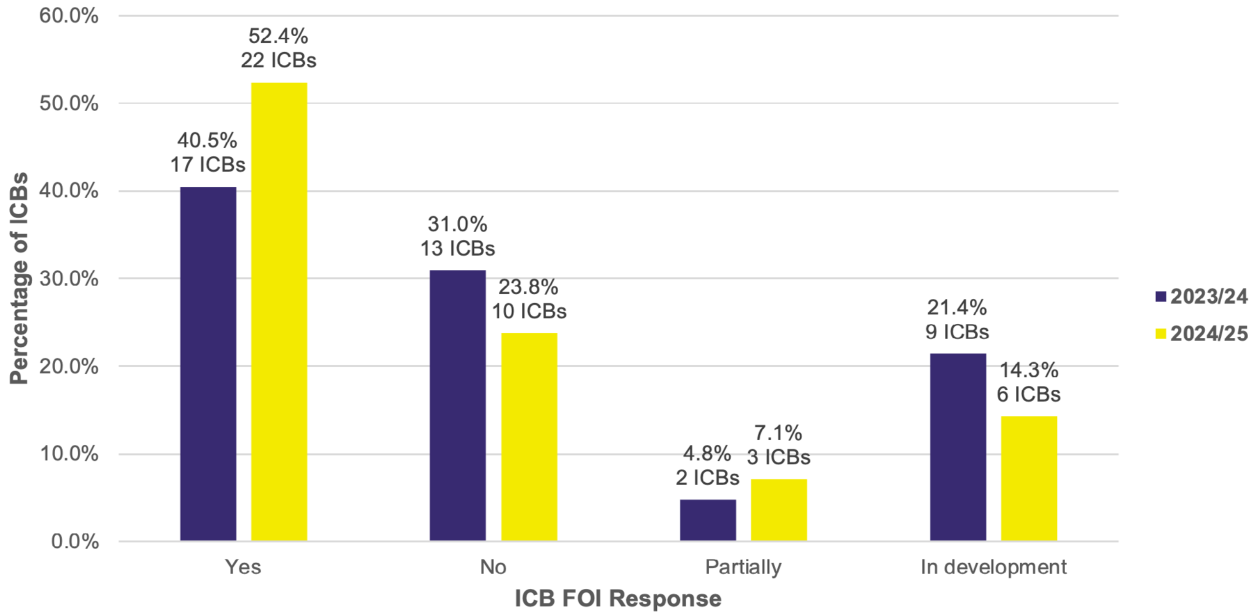
[iii] Please see appendix 4 for a summary of ICB FOI responses to key questions.

[iv] This figure includes all ICBs that provided service specifications for individual services (e.g., children's hospices, community children's nursing) as well as those with an overarching service specification for children's palliative care.

[v] Please see appendix 2 for individual ICB service specifications provided through this FOI request.

When compared to last year's findings, it is clear improvements have been made. The number of ICBs in possession of a relevant service specification has increased by 29% from 17 to 22, while the number without a specification has decreased by 23% from 13 to 10.

The number of ICBs that have a children's palliative care service specification: 2023/24 vs 2024/25



Completion of the Ambitions for Palliative and End of Life Care self-assessment tool

The Ambitions for Palliative and End of Life Care framework sets out a vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England.

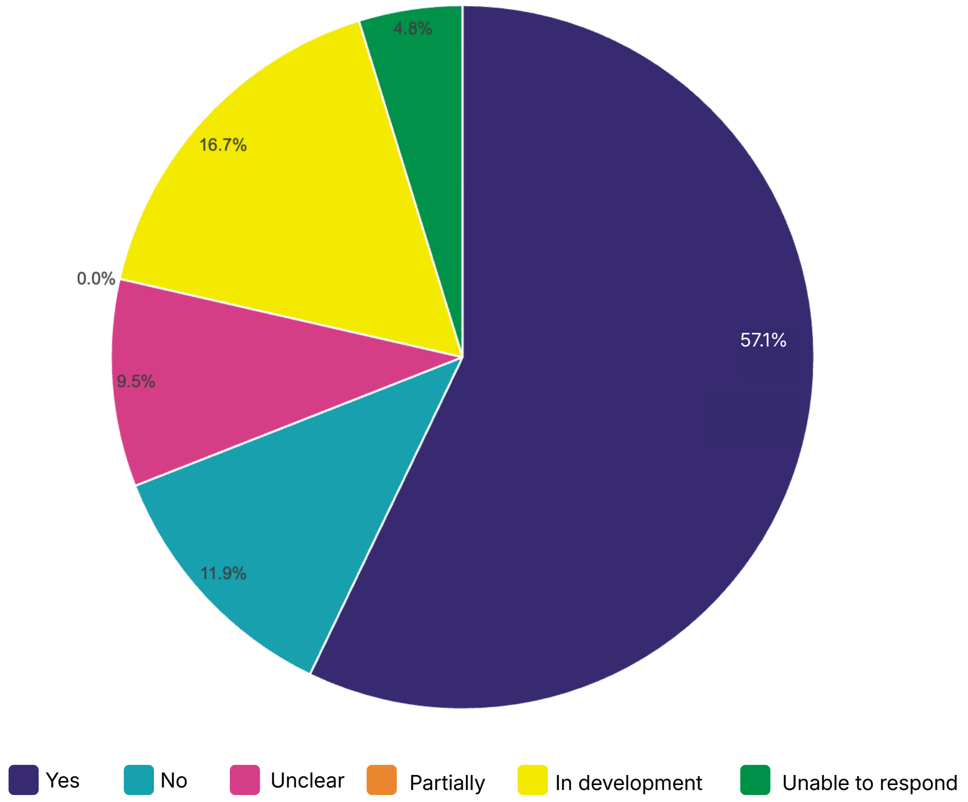
The self-assessment tool provides a self-assessment framework to support localities to determine their current level of delivery of services against the 'Ambitions for Palliative and End of Life Care—A national Framework for local action'.[30]

Continuing the theme we found last year; our FOI requests have yet again shown successful completion of the self-assessment to vary amongst ICBs. Over half of ICBs (24, 57.1%) in England have now completed an Ambitions self-assessment, increasing by 9.1% on last year.[vi] Meanwhile the number of ICBs yet to complete a self-assessment has decreased by 54.5% from 11 to five.

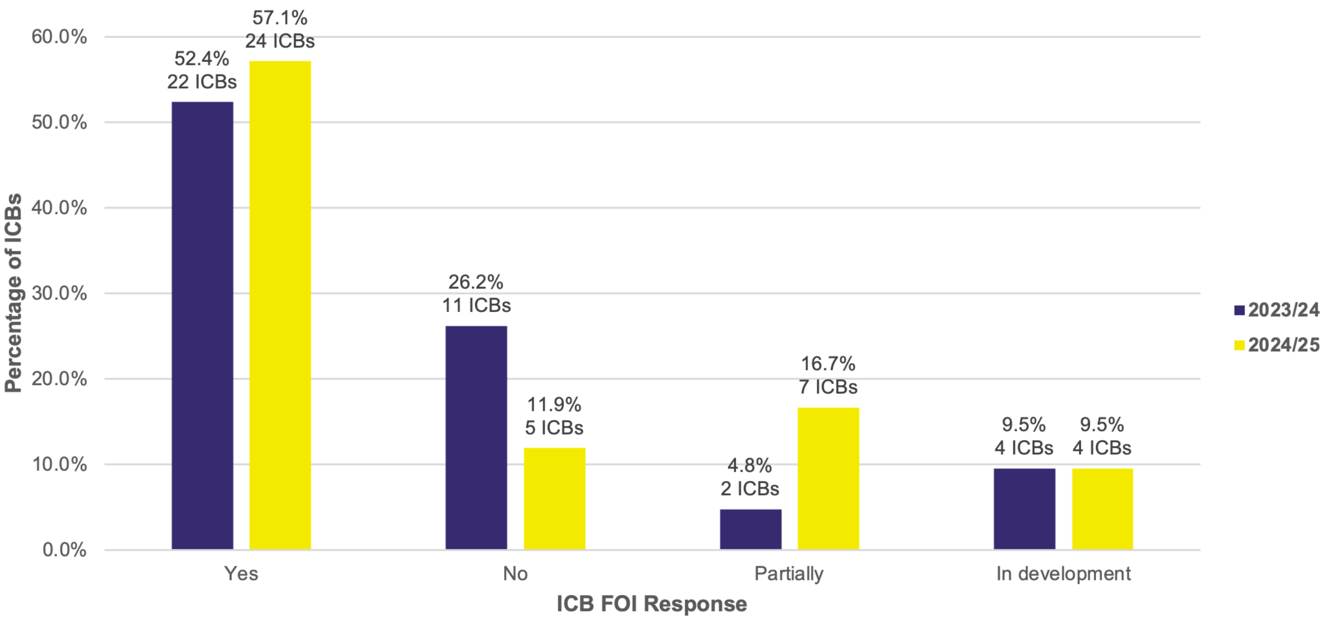
Like last year, one tenth (four, 9.5%) of ICBs reported that they are currently in the process of completing a self-assessment.

[vi] Please see appendix 3 for Ambitions for Palliative and End of Life Care self-assessments completed by ICBs.

Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment?

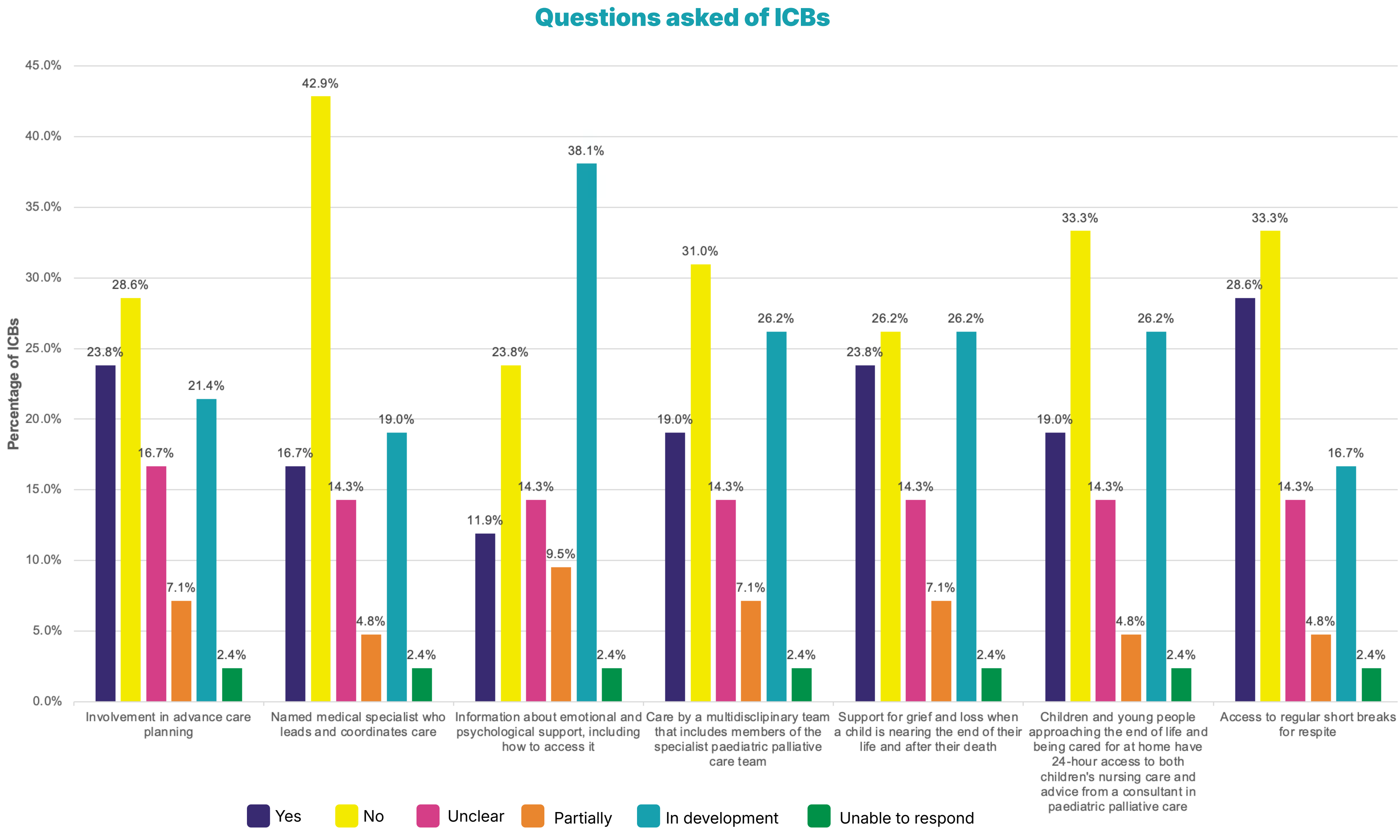


The number of ICBs that have completed an Ambitions for Palliative and End of Life Care self-assessment: 2023/24 vs 2024/25



The extent to which service specifications meet individual quality standards

Despite improvements being made by many ICBs, when asked about the individual standards that the service specifications meet, we have found that many service specifications are still falling short.

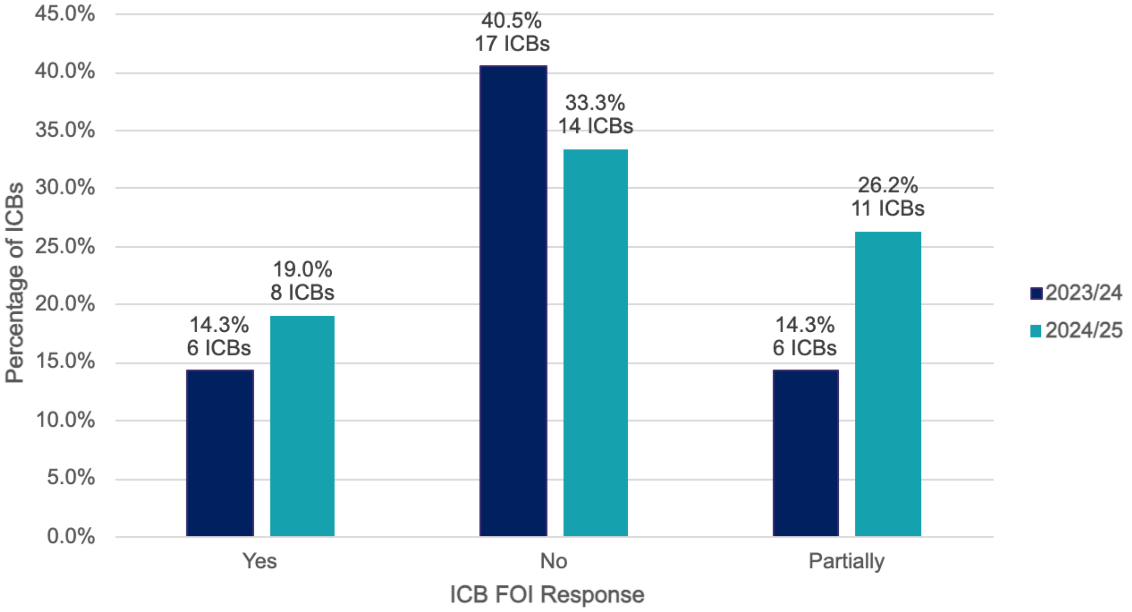


Only seven (16.7%) ICBs have a service specification that explicitly stated that a named medical specialist should be in place to lead and coordinate care. Meanwhile, nearly one third (13, 31.0%) of ICBs do not have a service specification that states children, and young people should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.[vii]

Similarly, when asked about whether the service specification accounts for 24-hour access to end of life care at home, we have found that less than a fifth (eight, 19.0%) of ICB service specifications met this standard. While this figure has increased by 33.3% and is an improvement on last year, we remain concerned by the persistent variation across the nation.

As was mentioned earlier in the report, the complexity of caregiving is magnified during the evenings and at night. The fact that over a third (14, 33.3%) of ICBs do not account for this level of care at all in their service specifications, and a further 11 (26.2%) only partially account for it, presents considerable challenges for families caring for seriously ill children[viii]

The number of ICBs that have a service specification which states that children and young people should have 24-hour access to end of life care at home: 2023/24 vs 2024/25



Here it is important to note that in many areas, key children's palliative care standards are being met despite not being specified by local ICBs. In these instances, we believe this is likely due to professionals proactively providing services despite not necessarily being commissioned to do so.

[vii] Whilst some service specifications referenced a multidisciplinary team, the majority did not explicitly include the provision of a specialist children's palliative care team, as recommended by NICE guidelines.

[viii] Service specifications were scored as partially meeting this standard if they explicitly accounted for either 24/7 nursing provision or 24/7 access to consultant advice, but not both.

Nevertheless, the findings from these FOI requests help explain why families caring for seriously ill children continue to report needs going unmet as they navigate the ever-complex health and care system.

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.

We are encouraged by the steps that ICBs such as Cheshire and Merseyside, North West London and South West London have taken in adopting the NHSE model service specification. Meanwhile, Lancashire and South Cumbria ICB have developed a children's palliative care framework setting out the strategic vision and are currently in the process of developing a service specification to reflect this.

With progress being made by several ICBs, it is vital that others follow the same trajectory and ensure their service specifications for children's palliative care are inclusive of the key components of NHSE's model.

Doing so would not only ensure ICB's service specifications meet national standards, but it also help eliminate the extent to which a child or young person's access to high quality palliative care is dependent on their postcode.

Specialised commissioning of paediatric palliative and end of life care

In England, specialised commissioning also plays a key role in ensuring that children and young people with life-limiting and life-threatening conditions receive high quality palliative and end of life care.

Responsible for funding and overseeing services that require a national or regional approach due to their complexity, specialised commissioning can support access to specialist services within NHS Trusts. This helps ensure that children receive appropriate symptom management, holistic support, and end of life care.

Although ICBs are now increasingly taking on a bigger role in commissioning some specialised services, NHSE maintains a critical role when it comes to the commissioning of specialist paediatric palliative care services.[ix] However, the extent to which funding is provided, and the transparency of its allocation remains unclear.

To better understand how NHS Trusts providing specialist palliative and end of life care to children and young people are commissioned, we issued a series of FOI requests to eight NHS Trusts.[x]

We asked trusts the following:

1. Does your NHS trust receive any funding from NHS England Specialised Commissioning to fund specialist palliative and end of life care to children and young people? (Yes/No)

2. If you answered yes to question one, how much money did you receive for this in 2023/24, and how much do you expect to receive in 2024/25?

3. If you answered yes to question one, are you contracted by NHS England Specialised Commissioning to provide specialist palliative and end of life care for children and young people? (Yes/No)

4. If you answered yes to question three, please provide details of this contract.

[ix] On the 13 March 2025, the UK Government announced that NHSE will be abolished as an arms-length body and will be brought back under back under the Department of Health and Social Care (DHSC) within the next two years. It remains to be seen how specialised paediatric palliative care will be commissioned once the structural changes are complete.

[x] The following NHS Trusts were identified as possibly being directly commissioned by NHSE for specialised children's palliative care using the joint workforce statement published by the Association for Paediatric Palliative Medicine (APPM) and the Royal College of Paediatrics and Child Health (RCPCH):

- Alder Hey Children's Hospital Trust
- Birmingham Women's and Children's NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Great Ormond Street Hospital Trust
- Guy's and St Thomas' NHS Foundation Trust
- The Leeds Teaching Hospitals NHS Trust
- The Royal Marsden NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust.

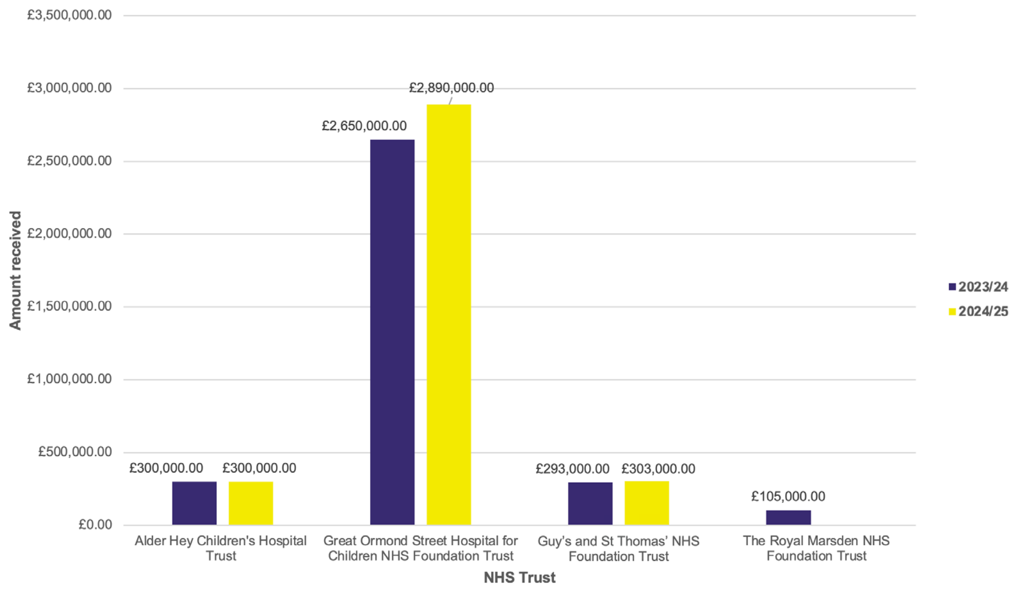
5. How much money did your trust spend on providing specialist palliative and end of life care to children and young people in 2023/24, and how much will you spend in 2024/25?

In total, seven trusts responded, revealing significant variation in both the funding received from NHSE and the amount spent on specialist paediatric palliative care.[xi]

While over two thirds (five, 71.4%) of trusts that responded confirmed receiving funding from NHSE, only three (42.9%) were able to specify how much they received in both 2023/24 and 2024/25, with one (14.3%) providing figures for 2023/24 only. Despite receiving funding from NHSE, University Hospital Southampton NHS Foundation Trust was unable to confirm the amount.

On average, trusts received approximately £837,000.00 in 2023/24 from NHSE Specialised Commissioning. However, this figure varied from £105,000.00 (The Royal Marsden NHS Foundation Trust) to £2,650,000.00 (Great Ormond Street Hospital for Children NHS Foundation Trust)

The extent to which funding received from NHS England Specialised Commissioning for specialist children's palliative and end of life care varies across NHS Trusts

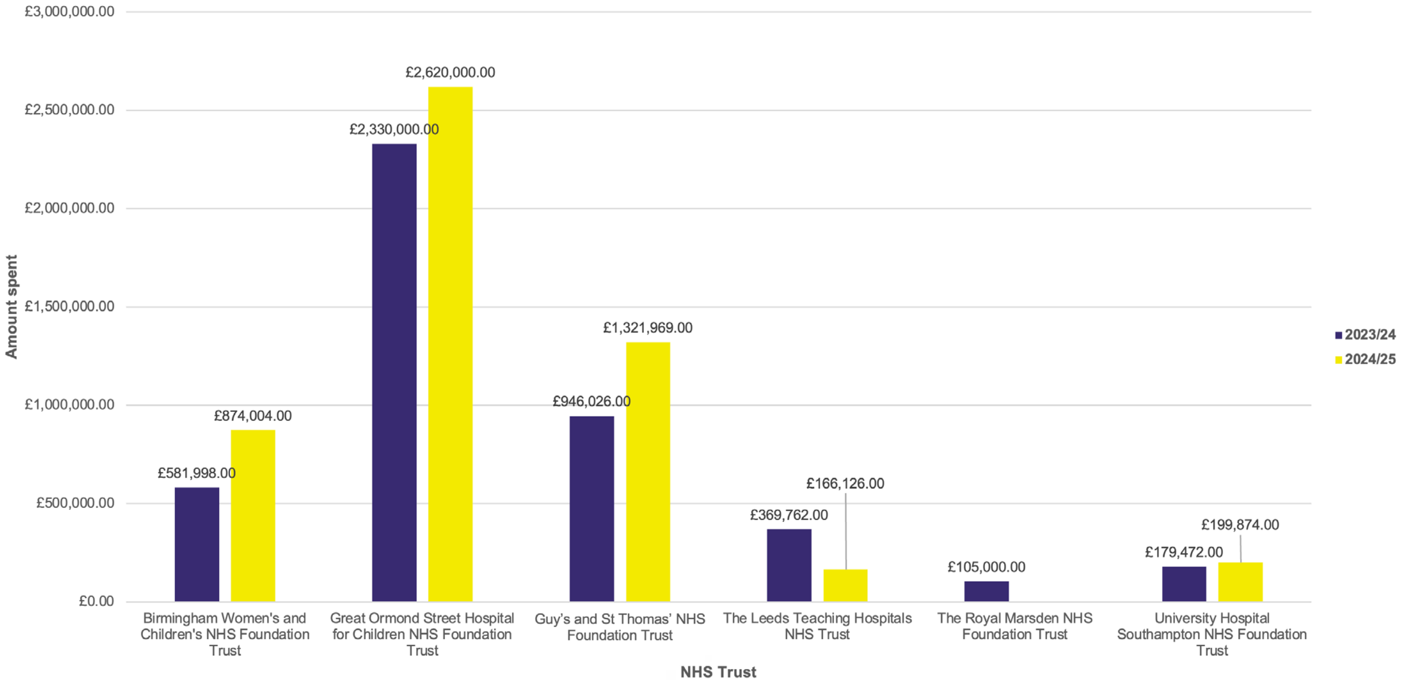


There were also disparities in expenditure. Five (71.4%) trusts provided figures for both years, while one (14.3%) could only confirm spending in 2023/24. Meanwhile, Alder Hey Children's Hospital Trust was unable to provide any information on expenditure.

The amounts spent by NHS Trusts varied significantly too. Despite trusts spending an average of £752,043.00 in 2023/24, this figure varied by much as £2,225,000.00. While Great Ormond Street Hospital for Children NHS Foundation Trust spent approximately £2,330,000.00, the Royal Marsden NHS Foundation Trust spent £105,000.00.

[xi] Please see appendix 9 for individual NHS Trust responses to our FOI request

The extent to which the amounts spent on specialist children's palliative and end of life care varies across NHS Trusts



Further discrepancies were identified in how these services are commissioned and funded. Two of the seven responding trusts stated that they do not receive any funding from NHSE for specialist paediatric palliative and end of life care.

Of these trusts, Birmingham Women's and Children's NHS Foundation Trust reported that, despite being listed as service that they provide under the NHSE contract, their service is primarily funded by charitable organisations and the trust itself rather than NHSE. Likewise, Leeds Teaching Hospitals NHS Trust clarified that it does not operate its own dedicated specialist palliative care service but instead hosts a regional palliative care project funded on a non-recurrent basis by the Integrated Care Board (ICB).

Overall, these findings indicate a lack of consistency in how specialist children's palliative and end of life care is funded and commissioned across NHS Trusts, suggesting a need for a more coordinated approach. Without such, there is a risk that seriously ill children may not have equitable access to the specialist support they need, regardless of where they live.

Access to social care and education in England

For children and young people with life-limiting and life-threatening conditions, children's social care plays a crucial role in enhancing their quality of life. Services such as respite care, practical support and assistance with accessing suitable education help children and their families make the most of the moments they have together.

Despite the fundamental importance of high quality children's social care, research by the Disabled Children's Partnership (DCP) has found significant failings in service provision. Only one in seven disabled children receive the correct level of support, while three in four parent carers have had to give up employment or their whole careers due to the lack of support available.[31]

The consequences of this inadequate level of support are severe. Disabled children face increased levels of depression, anxiety and loneliness. Meanwhile, the failure of local authorities to provide adequate care forces families to plug the gap themselves, resulting in their own mental health being negatively affected.[32]

> **"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**

> **"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**

In response to these critical gaps, the Law Commission has been tasked with reviewing disabled children's social care law. Preliminary findings have indicated that the existing legal framework is outdated, inaccessible and potentially unfair.[33]

Feedback from parents and carers provided to the Law Commission have also highlighted key concerns. These include:

- a lack of expertise in disability among those assessing children's needs,
- strict eligibility criteria that exclude many children from receiving support; and
- fragmentation among different teams, departments and organisations, leading to ineffective service delivery.[34]

Being able to access a suitable educational setting is also pivotal in meeting families' needs. However, for many families, there is an ongoing struggle to access such a setting.

According to a recent report published by the Public Accounts Committee, families face prolonged waiting times for assessments and support. In 2023, only 50% of Education, Health and Care (EHC) plans were issued within the statutory 20-week period. Furthermore, obtaining support is often dependent on a family's postcode or the ability of the parents to navigate a complex and adversarial system.[35]

Simply put, the current system is failing to deliver meaningful outcomes for children with special educational needs and disabilities. While high needs funding for the Department for Education has increased by 58% over the past decade, a 140% rise in the number of children requiring EHC plans has meant additional funding is still required to deliver the outcomes children desperately need.[36]

The need for additional funding is particularly evident when considering the impact funding such services has had on local authority finances.

According to the Public Accounts Committee, the inability to afford the current SEN system has placed significant strain on local authorities leading to many substantial deficits.[37] It is widely expected that by March 2026, these accumulated deficits could total £4.6 billion, not only impacting wider finances but also causing nearly half of English local authorities to be at risk of bankruptcy.[38]

Northern Ireland

In October 2024, we also issued a series of FOI requests to health and social care (HSC) trusts in Northern Ireland. While HSC trusts do not necessarily have the same legal duty as ICBs, they are nevertheless responsible for providing palliative care in hospitals, clinics and in the community.

We therefore wanted to examine the extent to which trusts are providing palliative care for children and young people that meets NICE standards.

To this end, we asked HSC trusts the following:

1. Does your Trust provide children's palliative care services that involve infants, children, and young people with life-limiting conditions, along with their parents or carers, in the development of advance care plans?

2. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care?

3. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it?

4. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team?

5. Does your Trust provide children's palliative care services that ensure siblings and parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death?

6. Does your Trust provide children's palliative care services that ensure 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?

7. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition and their families have access regular short breaks for respite?

In total, all five HSC trusts responded to our FOI request.[xii]

[xii] Please see appendix 6 for individual HSC Trust responses to our FOI request.

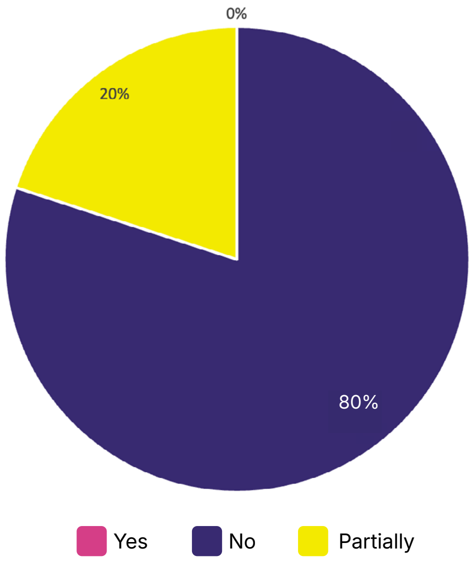
As is the case in England, the level of care available across HSC trusts in Northern Ireland varies greatly, with many services reliant on the goodwill of staff, rather than secure, formal funding.[xiii] This dependence was particularly evident in responses to individual questions.

When asked if the trust provides services that ensures the presence of a named medical specialist to lead and coordinate care, while two trusts stated that this is available, Belfast Health and Social Care Trust emphasised their reliance on a community paediatrician whose input has largely been given on the basis of good will.

The extent to which systems are reliant on good will becomes even more evident when examining the responses to question six, asking about the availability of 24/7 end of life care at home.

Here we have found that across Northern Ireland, 24-hour end of life care at home, provided by nurses and supported by advice from specialist consultants is not fully available in any HSC trust on a formal basis. In fact, only one trust reported being able to provide services that partially meets this standard.[xiv]

The extent to which children and their families can access 24/7 end of life care at home provided by nurses and supported by advice from specialist consultants across HSC trusts



While the Southern Health and Social Care Trust has established an on-call rota within its community children's nursing (CCN) team, this service is not formally funded.

Similarly, the Western Health and Social Care Trust reported that while a consultant can be contacted out of hours for advice and may occasionally provide home visits, this is dependent on the willingness of that individual rather than structured service provision.

[xiii] Please see appendix 5 for a graph illustrating how the level of care provided by HSC Trusts varies across Northern Ireland.

[xiv] Western Health and Social Care Trust was scored as partially meeting this standard because out-of-hours nursing support is provided on an overtime basis, rather than through a dedicated 24/7 service. This support is delivered jointly by the Community Children's Nursing (CCN) Team and a palliative care nurse specialist.

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 maintains a permanent presence in five Scottish hospitals, collaborating closely with NHS teams to deliver complex care through palliative care teams and CHAS-funded specialists.

Despite a range of services being available, inequities persist in children's palliative care provision, particularly when it comes to accessing support outside standard working hours. Across health boards, the provision of services varies considerably leading to inconsistencies in both the availability of care, and the quality.[39] As a result, 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.

That said, some NHS Boards have made good progress in expanding 24/7 end of life care support for seriously ill children and their families. In NHS Ayrshire and Arran, a Paediatric Supportive Care Team provides some out-of-hours support, and in NHS Lothian, CHAS has partnered with the Health Board to deliver the Care 24 Lothian service, enabling children and their families to access specialist end of life care at home.

While these initiatives represent progress, significant gaps remain across Scotland.

Fortunately, efforts are underway to improve out-of-hours support. With CHAS-funded staff from NHS Greater Glasgow and Clyde, and NHS Lothian, CHAS is developing a national specialist clinical advisory service, featuring a single national medical on-call multidisciplinary team (MDT).

This initiative will offer telephone support from specialist paediatric palliative medicine doctors and other specialists to any setting in Scotland. The medical staff involved in this service will be GRID/SPIN trained in paediatric palliative care, and will all be either CHAS employees or in posts funded by CHAS. Other clinicians involved have significant experience in the fields of paediatrics, neurodisabilities and palliative care.

By developing such a service, it is hoped that support for healthcare professionals will be enhanced, thereby ensuring consistent and high quality palliative care for seriously ill children and their families.

Beyond medical care, CHAS has highlighted a range of challenges that seriously ill children and their families face in Scotland. All of which extend beyond clinical support and impact their overall quality of life. These include:

- Difficulties in accessing skilled social care: Even when granted a package of care, recruiting to fulfil the package can be extremely difficult for families due to a range of factors including staff shortages, lack of staff with the right skills, unattractive pay and conditions, location of the family.

- The financial impact of caring for a seriously ill child: Life with a seriously ill child with child with complex medical needs can result in additional expenses – such as specialist equipment, adaptations, and higher energy bills – at a time when family members are often less able to work due to their caring responsibilities.

- Barriers to a smooth transition between children and adult services: The move from paediatric to adult palliative care can be distressing for young people as familiar teams and support networks change or disappear. Unfortunately, many young people struggle to access age and developmentally appropriate care, leading to gaps in their support as they move into adulthood. While CHAS helps bridge this gap by supporting young people up to the age of 21 across health, social care, legal, financial, and social matters, adult services must develop the necessary training, processes and services to meet the growing demand for seamless transitions.[40]

- Limited access to specialist bereavement support: The grief experienced by families when a child dies is complex and affects parents, siblings, extended family, and social networks. While bereavement services exist, access remains inconsistent across Scotland, particularly when it comes to dedicated support for siblings. While efforts are being made by the Scottish Government's National Hub, third-sector organisations and independent hospices,[41] further investment is desperately needed to ensure all families can access the bereavement care they need.

Wales

In Wales, as in the rest of the UK, the number of children and young people with a life-limiting condition in Wales is rising rapidly. According to a 2023 report, this figure rose by almost 30% between 2009 and 2019.[42] As more children and families require palliative care, it is essential to ensure that services are accessible, equitable and meet national quality standards.

Healthcare

Across Wales, local health boards (LHBs) are responsible for planning and delivering NHS healthcare services, including specialist paediatric palliative care, community nursing, and hospital-based support.

To assess local children's palliative care provision, in November 2024, we therefore issued a series of FOI requests to local health boards. We asked LHBs the following:

1. In your local health board area, are infants, children and young people with life-limiting conditions, along with their parents or carers involved in the development of advance care plans?

2. In your local health board area, do infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care?

3. In your local health board area, are infants, children and young people with a life-limiting condition, their parents or carers and their siblings given information about emotional and psychological support, including how to access it?

4. In your local health board area, are infants, children and young people with a life-limiting condition cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team?

5. In your local health board area, are siblings and parents or carers of infants, children and young people approaching the end of life offered support for grief and loss when their child is nearing the end of their life and after their death?

6. In your local health board area, do 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?

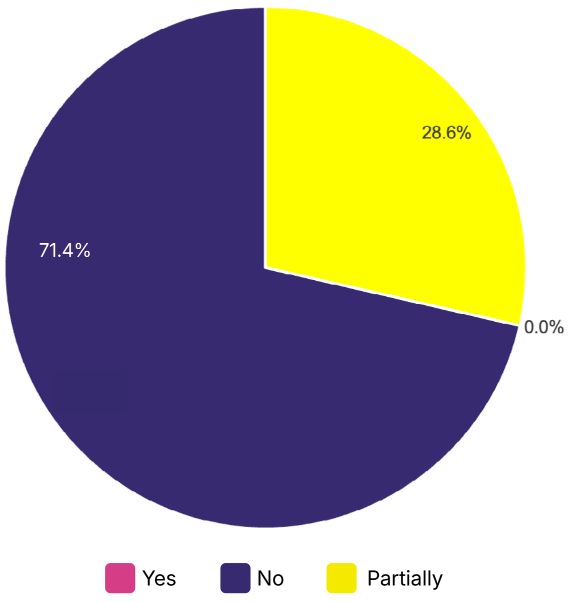
7. In your local health board area, do infants, children and young people with a life-limiting condition and their families have access regular short breaks for respite?

8. In your local health board area, how many infants, children and young people are there with life-limiting and life-threatening conditions?

In total, all seven LHBs responded to our FOI request [xv]

While all LHBs reported that children and young people, and their families are involved in developing advance care plans and do have a named medical specialist who leads and coordinates their care, we are concerned by the high level of variation in access to 24/7 end of life care at home.

The extent to which children and their families can access 24/7 end of life care at home provided by nurses and supported by advice from specialist consultants across LHB areas



Here, we have found that this particular quality standard is only met in two LHB areas (Betsi Cadwaladr and Hywel Dda). While 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.

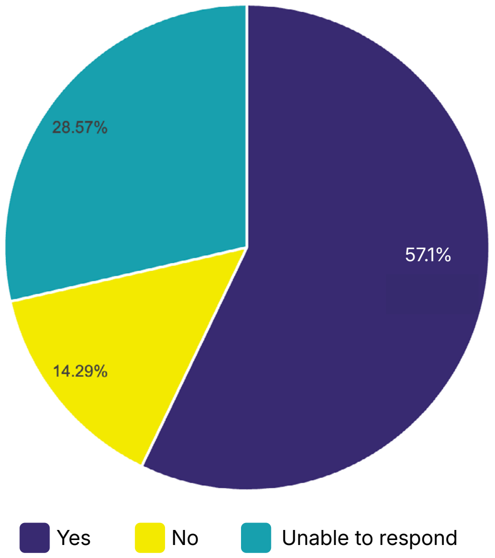
As such the majority of LHB areas are unable to meet this standard. Even in areas where 24-hour end of life nursing care at home is available such as Betsi Cadwaladr, services are still not as well funded as they should be and rely heavily on support from the children's hospice. Others are also largely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

In our FOI request, we also asked LHBs to tell us how many children and young people with life-limiting and life-threatening conditions there were in their area.

While the majority (four, 57.1%) of LHBs were able to provide a figure, we are concerned by the lack of data held by the remaining LHBs. Over a quarter (two, 28.6%) of LHBs were unable to provide a figure while a further one was only able to provide the current number on their active caseload.

[xv] Please see appendix 7 for individual LHB responses to our FOI request.

The extent to which LHBs are able to say how many children and young people with life-limiting and life-threatening conditions there are in their area



We are also concerned by the extent to which the figures provided differ from the published prevalence data for Wales.[43] According to the four LHBs that responded to our FOI requests, there is an average of 321 children and young people with life-limiting and life-threatening conditions per LHB (ranging from 32 to 750). When extrapolated across all seven LHBs, these responses indicate that there is 2,250 seriously ill children and young people across Wales.[xvi]

In contrast, the published prevalence data found that there were 3,655 children and young people under the age of 18 with a life-limiting condition in 2019.[44] This equals an average of 522 children and young people under the age of 18 with a life-limiting condition per LHB.

Here it is important to note that when responding, many LHBs provided figures to reflect their current caseloads. Furthermore, at any one time, many children and young people with life-limiting or life-threatening conditions are relatively stable and will not need active care and support. As such, the caseload figures may not be reflective of the full prevalence numbers.

Nevertheless, given the increasing prevalence of children with life-limiting and life-threatening conditions, we believe it is reasonable to expect LHBs to hold data detailing the current prevalence. We therefore remain concerned by the high level of variance to this end.

[xvi] Only Betsi Cadwaladr University Health Board and Cardiff & Vale University Health Board specified that the data they provided was for children and young people up to the age of 17 years.

Social care

Under the Social Services and Well-being (Wales) Act 2014, local authorities have a statutory duty to assess and provide care and support to children with additional needs and their families, including respite care or short breaks.[45]

Furthermore, under the Act, local authorities must promote preventative services, which may include short breaks, to support and sustain caregiving families.[46]

Given this legal duty, we wanted to examine the extent to which families caring for seriously ill children are able to access short breaks for respite. To this end, we asked all 22 local authorities the following:

1. In your local authority area, do infants, children and young people with a life-limiting or a life-threatening condition and their families have access to regular short breaks for respite?

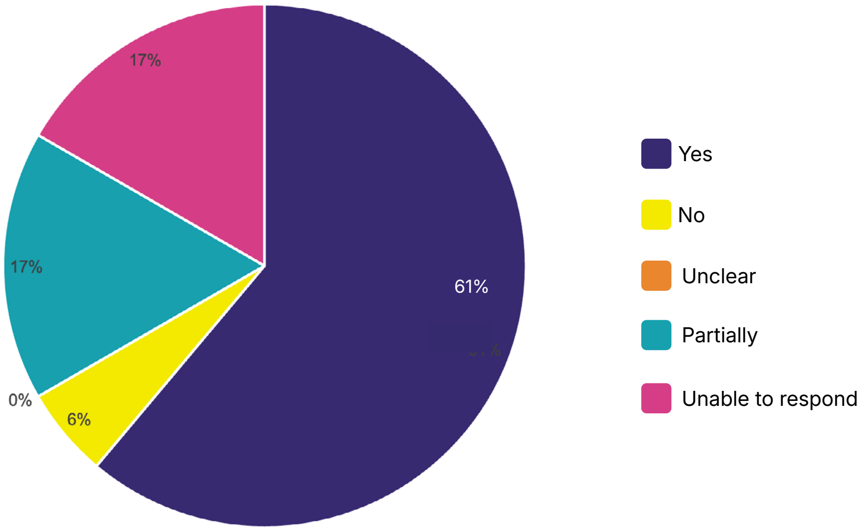
2. In your local authority area, what is the average waiting time for families of infants, children, and young people with life-limiting and life-threatening conditions to access short breaks for respite care?

3. In your local authority area, how many infants, children and young people are there with life-limiting and life-threatening conditions?

Overall, 18 local authorities responded to our FOI request.[xvii]

When asked about the availability of respite care, over half (11, 61%) of local authorities that responded reported that respite is available. Meanwhile three (17%) local authorities solely referred to the respite provision provided by children's hospices, and one (6%) noted it was not available at all. None of these responses provided any indication or assurance regarding the suitability, duration, or quality of the respite offer.

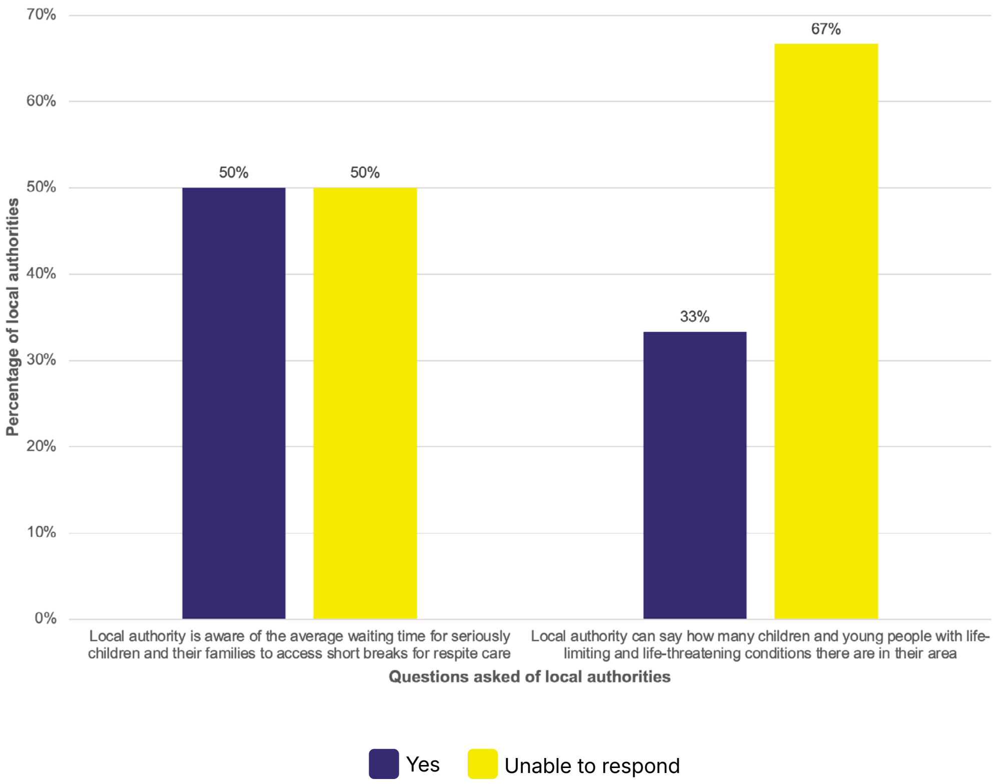
The extent to which children and their families can access regular short breaks for respite across local authority areas



[xvii] Please see appendix 8 for individual local authority responses to our FOI request.

When asked about the average waiting time for respite care and the number of children and young people with life-limiting and life-threatening conditions in their area, it was concerning to see a significant number of local authorities unable to provide a response.

The extent to which local authorities do not possess key information



Over half (nine, 50%) of local authorities that responded were unable to tell us what their average waiting time for respite care was. Meanwhile, two thirds of local authorities (12, 67%) were unable to say how many seriously ill children and young people there were in their area.

Given the statutory duty on local authorities to provide respite care, it is concerning to find that the majority do not hold this data, raising questions as to how respite can be planned and provided for their local population.

Nieve's story

Told by her mum Kristine.

"At the end of her life we were alone"

Nieve was born in July of 2007, a happy and content baby but it quickly became apparent in weeks that things weren't right: "Nieve didn't hit normal milestones like other babies and toddlers. She didn't develop the usual skills or hit the normal milestones. When she was about four she started to experience seizures."

When Nieve was only a couple of months old she was referred by her local paediatrician to the hospital for what resulted in a five year journey of investigations. Visiting multiple hospitals and undergoing many difficult tests, Nieve was eventually diagnosed with Rett syndrome at around age five.

Nieve required around the clock care at home. From moving to feeding, her mum and dad cared for her 24/7 throughout her short life.

Nieve had frequent admissions to hospital due to illness and her family had to quickly become experts in having to administer life saving interventions on a daily basis. As time went on they slowly adjusted to their new life and they became fluent in the medical world.

Nieve was a happy soul with a magnetic personality: "People were drawn to interact with her and despite her inability to communicate, her smile, facial expressions and sounds told us everything we needed to know about how Nieve was feeling and what she wanted at that precise moment. Those who were able to reach into Nieves world were rewarded with secret smiles, understanding and an ability to communicate without words."

As time progressed, Nieve's health slowly changed. She needed more medications, more treatments and underwent major spinal surgery to correct her debilitating spinal scoliosis.

In March 2024 Nieve was admitted to hospital with acute kidney injury. After several weeks she was discharged. Unfortunately, Nieve declined in the coming weeks. She was under the care of her local children's palliative care team, who kept in touch with Kristine.

At her last outpatients appointment with their renal team in April 2024, Nieve's parents were told that Nieve was unlikely to improve from her kidney failure: "We were told that Nieve was in the last few months of her life."

That night, Kristine and her husband Daniel planned out how they would spend the final months with Nieve, taking time off work and making precious memories with Nieve and her 11 year old sister Josie.

However a few days later, Nieve's condition changed: "She suddenly seemed quiet, less reactive, cool and noticeably more tired. I knew in my heart that she was dying. I was aware that the local palliative care team provided on-call cover over the weekend, 9-5pm and so I contacted the team. They came out to see us and sadly confirmed our feelings about what was going on."

The team immediately began arranging anticipatory medications although without having direct access to medications, this had to be done via the 111 service: "Both the consultant and ourselves felt frustrated at the arduous process whilst we sat with our daughter who was slowly dying."

The team returned in the week and the family discussed where they wanted Nieve to be during her final days and hours and what support they needed: "We felt strongly that Nieve should remain at home with her family around her."

Kristine and Daniel were provided with medication and a clear written plan on how to administer medications when the time came: "Neither us or the team anticipated Nieve's rate of decline and on Tuesday evening at 7pm, we knew that Nieve had only hours left."

"We sat with Nieve, administered the medications as per the plan, trying desperately to gauge whether she had enough pain relief, at what point to give her anti-sickness medications and whether she needed medications for seizure activity or agitation. I can't describe the pressure and stress we felt at this time. Alone as parents with a dying child, trying to make clinical decisions and do the right thing whilst facing the reality of our own daughters' death and wanting desperately 'just to be with her' without having to judge, draw up and administer medications. I still hold deep regret and sadness that I had to sacrifice precious moments holding Nieve's hand whilst I was taken away making phone calls to services pleading for help."

At midnight, they began to worry about Nieve's presentation: "She appeared a little unsettled and we had given her pain relief and other medications and didn't know what to do next. As per the management plan, our first call was to ring 111 and ask to speak to a doctor. I explained the urgency and the reason for why we were calling and were assured that we would get a phone call back quickly."

After 60 minutes and feeling increasingly anxious and worried, Kristine rang 999 and pleaded for help to ask if a medical professional could come out and review Nieve. 15 minutes later they received a call from the doctor who asked what they wanted them to do: "I explained the concerns we had and asked if they would call out to review Nieve to see if she required any further medications. The doctor agreed to come. At 1.55am the doctor arrived, at which point Nieve was in her final moments and we asked him to leave."

Nieve took her last breath at 2am.

Services making good progress

Despite challenging workforce and funding shortages, some encouraging progress is being made in parts of the UK. The following examples demonstrate how, with willingness and drive to join-up services, some areas are improving the children's palliative care that seriously ill children receive. With the right commitment and funding, they show how local systems can continue to strengthen support for families and improve outcomes.

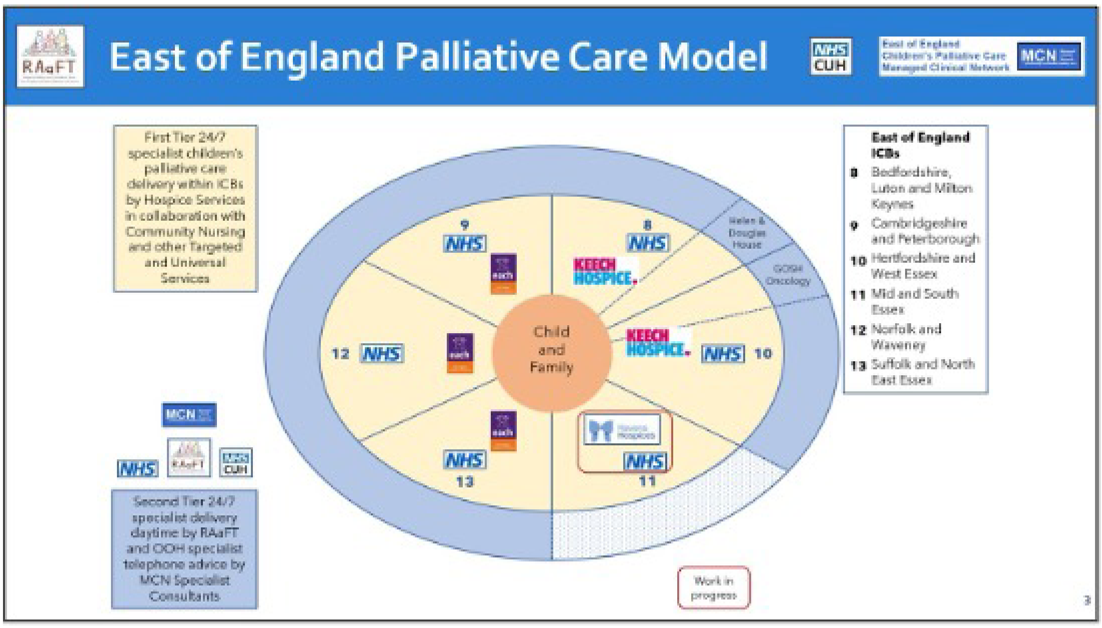
East of England Regional Advice and Facilitation Team (RAaFT)

The East of England Regional Advice and Facilitation Team (RAaFT) was established in 2022 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 NHSE.

RAaFT is spearheaded by Cambridge University Hospitals NHS Foundation Trust (CUH). The Regional service is delivered in partnership with other palliative care providers, East Anglia's Children's Hospices (EACH), Keech Hospice Care and Little Havens Hospice; as well as with the primary and secondary statutory health care organisations.

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 clinical model of service is outlined in the following diagram:



East of England Palliative Care Model

First Tier 24/7 specialist children's palliative care delivery within ICBs by Hospice Services in collaboration with Community Nursing and other Targeted and Universal Services

Second Tier 24/7 specialist delivery daytime by RAaFT and OOH specialist telephone advice by MCN Specialist Consultants

East of England ICBs
- 8 Bedfordshire, Luton and Milton Keynes
- 9 Cambridgeshire and Peterborough
- 10 Hertfordshire and West Essex
- 11 Mid and South Essex
- 12 Norfolk and Waveney
- 13 Suffolk and North East Essex

The highly specialist multi-disciplinary team consists of:

- Consultant in Paediatric Palliative Medicine (0.5 WTE) maternity leave from Sept 2024
- Consultant in Paediatric with Special Interest in PPM (0.2 WTE)
- Nurse Consultant (0.6 WTE from September 2024)
- Clinical Nurse Specialist (1.8 WTE)
- Consultant Clinical Psychologist (0.5 WTE)
- Senior Paediatric Pharmacist (0.5 WTE)
- Play Specialist (0.2 WTE)

The team supports Babies, children and young people with a full range of palliative care conditions, including:

- Cancer;
- Neuro-degenerative;
- those with extreme prematurity;
- severe congenital heart disease;
- life-limiting metabolic conditions; and
- those with highly complex health care needs often as a result of cerebral palsy or other brain injuries.

As the model diagram shows 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. Providing specialist clinical advice for BCYP and their families and support for professionals across the East of England 24/7.

The MCN mission statement matches key aims of RAaFT: For every life-limited baby, child or young person and their family to access the care they need in the right place at the right time, both before and after the death of the child. This means that the team offers support wherever babies, children and young people are being cared for, in hospital, hospice or at home and for those women and their partners who are making difficult decisions about their unborn, and acutely unwell, babies.

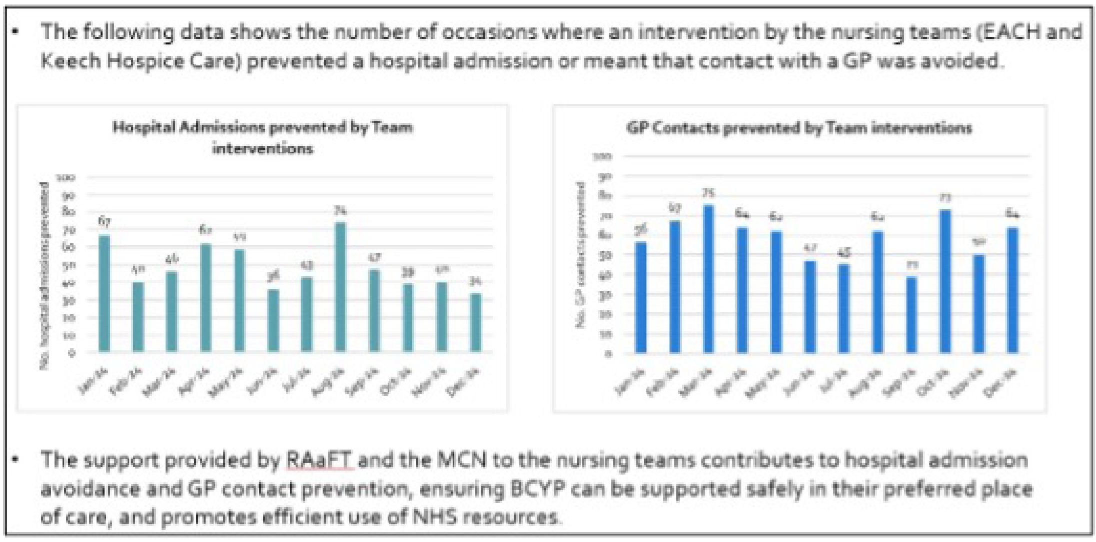
RAaFT also has an educational and research role, aiming to enable progress and development in palliative care through education and collaboration; sharing skills and knowledge to support professionals to act as advocates and provide high quality care. Scholarly activity by RAaFT team members included six publications and presentations achieved in 2024.

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 and end of life care according to need through a regular journal club and other specific activities. A regional conference was delivered and excellent feedback received in September 2024 which focused on various aspects of high-quality symptom management.

Support for children and young people's palliative and end of life 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 have been carried out over the last three years to provide information about the known number of children and young people who need palliative and end of life care in the region at any one time. An E poster was presented at the Rome Global Conference, October 2024 analysing this work: Who are the Children? Point Prevalence Survey to understand who needs Children's Palliative Care.

This diagram demonstrates a key RAaFT outcome and describes the reduction in avoidable high intensity care or in-patient stays as children, young people and their families are supported to manage the child of young person's condition safely in their own homes throughout 2024.



- The following data shows the number of occasions where an intervention by the nursing teams (EACH and Keech Hospice Care) prevented a hospital admission or meant that contact with a GP was avoided.

- The support provided by RAaFT and the MCN to the nursing teams contributes to hospital admission avoidance and GP contact prevention, ensuring BCYP can be supported safely in their preferred place of care, and promotes efficient use of NHS resources.

Rainbows' Single Point of Contact (SPOC) Project

The NHS Midlands Exemplar project led to the development of a single point of access (SPOC) for 24/7 specialist palliative and end of life care (PEOLC) advice for babies, children, and young people across the region delivered by specialist nurses at Rainbows Hospice for Children & Young People. Funded by the East Midlands children and young people (CYP) palliative and end of life care network, the pilot aimed to test whether a 24/7 SPOC service could reduce inequities, improve choice, and enhance the quality of care in the last months of life.

Launched on 18 December 2023, the service was delivered by a team of nine to 11 clinical nurse specialists and advanced clinical practitioners from Rainbows, all operating under a standard procedure.

Between December 2023 and October 2024, the service provided significant benefits to babies, children, young people and professionals across all ICBs in the East Midlands. Specifically, the service improved care experiences through greater choice of location, advance care planning and symptom management, and eased system pressures.

In particular, the service achieved the following:

- **Caseload and planning:** 46 babies, children, and young people (BCYP) were supported, including 10 not previously known to Rainbows. Of these, 30 BCYP deaths were supported, 29/30 died in their place of choice. Advance Care Plans were in place for 44 of 46 BCYP, and Symptom Management Plans for 34 of 39.

- **Service use:** 170 calls were recorded—49% during working hours, 51% out of hours, including 23% overnight.

- **Avoided admissions and callouts:** The service prevented 97 hospital admissions, 11 GP home callouts, 16 hospice GP callouts, and 46 ambulance callouts.

- **Coordination of care:** 13 calls facilitated 8 hospital discharges, three hospital transfers, and nine instances of post-death advice and care.

- **Specialist support:** 17 cases required additional specialist advice, which were escalated to a consultant.

- **Gaps in local services:** 39 calls came from parents in areas where no 24/7 community nursing was available.

Despite the strong evidence indicating the service to have improved family experience and led to greater efficiency within the local health system, ICB funding for the East Midlands CYP PEOLC Network has since been cut. As a result, funding is no longer available for the education programme and the SPOC service.

The loss of funding represents a significant setback for the region and could create numerous clinical risks. However, to ensure babies, children and young people remain supported, Rainbows have committed to entirely funding the service going forward.

Next steps for these services

These examples highlight the positive impact that well-funded, coordinated palliative care services can secure for babies, children and young people. They show how dedicated teams, innovative service models, and regional collaboration are making a real difference—helping to improve outcomes, reduce unnecessary hospital admissions, and enhance the quality of care and choice for families.

However, the discontinuation of funding for the Rainbows SPOC service highlights the pressing need for sustained investment. Without it, families risk losing access to the specialist support they depend on, undermining progress made in improving children's palliative care across the UK.

Barriers preventing equitable access

Despite the best efforts of professionals and service providers, significant gaps remain in the care and support being planned, funded and provided to children and families across the UK by NHS organisations and local authorities. As a result, the needs of seriously ill children and their families are far too often going unmet.

We believe that these gaps are the result of three key factors:

- Workforce shortages
- Funding shortfalls
- A lack of leadership and accountability

Workforce shortages

Specialist paediatric palliative care consultants

Given the increasingly complex clinical needs of children with life-limiting and life-threatening conditions, the in-depth expertise of a specialist palliative medicine consultant is required.

NHSE specifies that specialist paediatric palliative care teams should be led by consultants who specialise in paediatric palliative care. These consultants are crucial because they:

- Possess specialised expertise in managing life-limiting and life-threatening conditions across the paediatric age range,
- have the capability to manage the full spectrum of symptoms as diseases and illnesses progress,
- can lead and develop services within their respective regions; and
- can support, teach, and train other healthcare professionals.

Despite their importance, the Association for Paediatric Palliative Medicine (APPM) estimates that there is a shortage of consultants with GRID-equivalent qualifications across the UK. Currently, there are 24.4 WTE in the UK, while the Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 are needed, indicating a shortfall of 20-40 consultants. In Northern Ireland, there is no specialist GRID-trained paediatric palliative medicine consultant at all.

We are also concerned about the limited number of national GRID training posts available for paediatric palliative medicine consultants. Although the total number of these posts has increased from 1 WTE in 2022 to 7.2 WTE in 2024, this is still insufficient to meet the current demand for consultants in the UK.

12 WTE SPIN training posts are currently being funded across the UK.

We have estimated 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 as the training posts currently being funded cost a total of £2,459,854 per year to fund, to double these training places, NHSE should invest double this amount.[xviii]

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.

Nurses

According to our research with DJS, access to nurses with the skills and experience to meet their child's needs is critical for families to feel well supported. NHS community children's nurses (CCNs) and children's hospice at home nurses play a vital role in providing 24/7 end of life care at home.

Despite this, nursing shortages mean that this 24/7 care is unavailable in too many areas. Many parents are having to take on the role of nurses, inhibiting their ability to spend time making precious memories with their children.[47]

NHS community children's nurses

Despite providing the bedrock of children's palliative care, there is currently a lack of consistency and availability among community children's nursing services across the UK.

If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to,[48] there would be 4,963 community children's nurses in England.[49] Yet, despite progress in recent years, there are currently only 973 whole-time equivalent (WTE) CCNs employed by the NHS in England. 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.

Similar challenges are also present in other parts of the UK.

In Northern Ireland, despite the number of CCNs not being routinely published by the Department of Health, using the responses to our freedom of information request, we have estimated that a total of

---

[xviii] You can view the model we have used to calculate this here.

[xix] The total number of community children's nurses (CCNs) in Northern Ireland was estimated using FOI data provided by the five HSC Trusts. All five HSC Trusts were able to provide the total number of WTE CCNs employed by the Trust. Please see appendix 6 for individual HSC responses to the FOI request. For Belfast Health and Social Care Trust, although figures for other registered nurses and healthcare assistants were provided, the total number of CCNs has been calculated as 22.43, based on 1 WTE Band 7 CCN Team Leader, 10.98 WTE Band 6 CCN Sisters, and 10.45 WTE Band 5 CCN Staff Nurses.

We believe it is important that the Department of Health in Northern Ireland implements systems to gather data on CCN numbers. Doing so would enable greater transparency and help ensure workforce planning is based on accurate, up-to-date information.

In Scotland, there are currently 195.6 WTE CCNs employed by the NHS.[50] If the Royal College of Nursing's recommendation were to be met, there would need to be 455 WTE CCNs.

However, it is important to contextualise these figures within Scotland's unique situation:

- For a number of years, there has been no CCN Specialist Practitioner Qualification (CCN SPQ) available in Scotland; this means that some of the shortfall in CCN numbers could be explained by paediatric staff nurses working in the community who, despite not holding the formal CCN qualification, still provide essential care for children with complex health needs.

- Paediatric nurse specialists in fields such as neurology and renal care, Paediatric Oncology Outreach Nurse Specialists, Neonatal Nurse Practitioners, Diana Children's Nurses and CHAS at Home staff all play a vital role in supporting children, even if they are not captured by the CCN figures.

- Because of Scotland's geography, particularly in remote and rural areas, district nurses are sometimes trained to provide care for children, given the smaller population numbers.

While this multidisciplinary approach is valuable, we believe that there is a need to address gaps in the CCN workforce. We therefore welcome the action that has been taken to reinstate the CCN SPQ and are encouraged by signs that it is due to run again this year. By training more CCNs, we can ensure that children across Scotland receive specialised care from appropriately qualified nurses.

In Wales, there are currently 40 WTE CCNs employed by the NHS.[51] If safe staffing levels were to be met, 260 CCNs should be employed across Wales, meaning that 220 WTE additional CCNs are needed meet the RCN's recommendation.

Children's hospice 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, the most 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 to the survey.

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

These rates are higher than in the NHS in England, which had a vacancy rate of 7.5% as of 31 March 2024 within the Registered Nursing staff group.[52]

Social workers

As reported earlier, much of parents' and carers' time is often spent on researching advice, assessing what services are available to them, and then trying to secure access. By supporting families with all forms of personal care and practical support, social workers can play a pivotal role in helping parents to spend more time just being parents.

Social workers can help families understand the services they are eligible for and advocate for the support they need. They are critical in ensuring that children and young people with life-limiting and life-threatening conditions and their families receive the care and support they need.

Despite this, growing shortfalls mean that families will continue to struggle to access the social care they need, in many cases having to plug the gap themselves.

Recent research by the Disabled Children's Partnership (DCP) and the Law Commission has revealed the shocking extent to which children and young people are unable to access high quality social care support that they desperately need.

There is a critical shortage in child and family social workers: as of the 30 September 2024, 7,200 child and family social worker vacancies were recorded in England.[53] The overall vacancy rate stood at 17%, with over three quarters (76.2%) of vacancies being covered by agency workers.[54]

Despite this data demonstrating some improvements compared to 2023, we are concerned about the future projections for this workforce. According to the Department for Education, the shortfall of child and family social workers is expected to increase even further relative to the demand for social care over the course of the next decade.[55]

As a result, increases in vacancies coupled with agency and staff turnover could create even more significant challenges for local authorities in meeting statutory duties and achieving financial sustainability.[56]

Of further concern is analysis of workforce statistics conducted by the DCP, which has found that three in four local authorities have dedicated 10% or less of the children's social care workforce to disabled children.[57]

In Northern Ireland, high levels of staff vacancies have resulted in large numbers of unallocated cases. It is estimated there are over 4,000 children and their families currently waiting after having crossed an initial threshold for statutory children's social care involvement.[58]

In Scotland, the number of whole time equivalent social worker posts decreased by 7.5% between December 2022 and June 2023.[59] In Wales, difficulties with attracting people into the sector and retaining them has seen workforce challenges continue.[60]

Children with life-limiting and life-threatening conditions and their families deserve a support system that enables them to flourish at whatever stage of their life they are at.[61] However, in the absence of sufficient child and family social workers, it is difficult to see how such a support system can be achieved.

It is therefore essential that the UK's governments address these workforce shortages to ensure that families caring for children with life-limiting conditions can access a proactive and knowledgeable social worker capable of supporting families and meeting their needs.

Educational psychologists

When provided correctly with suitable support in place, being able to attend a good specialist school not only enables disabled children to access education in a setting that is capable of meeting their needs, but it can also help alleviate symptoms of emotional and social isolation being experienced by parents and carers.

Unfortunately, shortages in the specialist workforce, particularly among educational psychologists, has contributed to the significant delays faced by many disabled children when it comes to getting their needs assessed.[62] As a result, many are unable to attend the correct setting to meet their needs and the needs of their parents or carers.[63]

In response to the DCP's survey, one parent carer even mentioned waiting over 12 months for an appointment with an educational psychologist to assess their child's needs.[64]

This shortage of educational psychologists has been well documented by the Department for Education. According to a report published in 2023, the majority (88%) of local authorities reported difficulties in recruiting educational psychologists, while a third of local authorities reported difficulties in retaining educational psychologists.[65]

These difficulties have resulted in poorer outcomes for children and young people requiring support in nearly all of the local authority areas (96%) that reported recruitment and retention issues.[66]

With nearly half (48%) of local authorities citing pay as a key driver behind these issues, many local authorities (69%) lack confidence that they will be able to meet the demand for educational psychologist services.[67]

Educational psychologists are therefore being stretched to capacity. Recent years have seen the number of pupils with special educational needs and disabilities increase. As a result, the proportion of young people with an Education, Health and Care Plan (EHCP) has increased from around 2.8% of pupils in 2015 to 4.3% in 2023.[68]

The British Psychological Society have called on the Government to grow the educational psychologist workforce to ensure thousands of schoolchildren get the support they need.[69] It is vital that the UK Government takes this action. If left unaddressed, this problem has potential to only get worse in years to come, with more families' needs going unmet.

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.

Funding shortfalls

Funding is one of the most significant barriers to services being planned, funded and provided to meet national quality standards. Research has highlighted the difficulty in obtaining consistent and sufficient funding, with children's palliative care network chairs stressing the lack of NHS funding, and reliance on the charitable sector in providing important services and key posts for their region.[70]

England

In England, there is a significant gap in NHS funding for 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 £396.5 million in 2025/26 to meet this standard.

However, we believe that the NHS will spend £86.5 million in 2025/26, leaving a £310 million funding gap.[xx]

While £310 million may seem like a significant sum, it represents just 0.16% of the total NHS budget in England for 2025/26. The total budget is set to increase by £21 billion to £192 billion in 2025/26 compared to £171 billion in 2023/24.[71] This increase alone is nearly 70 times the size of the funding gap in children's palliative care.

Addressing this shortfall would ensure that seriously ill children can receive the care they need and require a fraction of this overall increase. Without additional investment, many will continue to struggle to access essential services, leading to unnecessary, unplanned and costly hospital admissions and less choice and control for families.

This funding shortfall is having a negative impact on children's hospices. In 2023/24, children's hospices received, on average, nearly 10% less funding from ICBs compared to 2022/23 and over a third (31%) less funding when compared to 2021/22. As a result, ICB funding now represents about 11% of the charitable expenditure incurred by children's hospices, down from 13% in 2022/23.[72]

Similarly, the average amount children's hospices receive from local authorities has decreased by 26.1% over the past year.[73] This is despite the statutory requirement for local authorities to provide services that give family carers of disabled children breaks from caring to help them continue their roles.[74]

Despite this legal requirement, our recent findings show that one third (27%) of children's hospices in England have had to cut respite care in 2023/24 due to changes in their funding.[75]

From a series of FOI requests published in June 2024, we have also found huge variance in the

---

[xx] You can view the model we used for calculating the gap here. Individual NHS Trust responses to our FOI request regarding specialised commissioning can be found in appendix 9.

average amounts spent on children's hospice care by ICBs.[76]

In 2023/24, on average, ICBs spent £149.15 for every case of a life-limiting or life-threatening condition among children and young people aged 0-24 in their local area. However, this amount varied widely. While Bristol, North Somerset and South Gloucestershire ICB spent the most with an average of £397.01 per child or young person, Northamptonshire ICB spent the least with an average of £30.59 per case.

Here it is important to note that, at any given time, some children and young people with life-limiting or life-threatening conditions may be relatively stable and not require active care from a children's hospice. However, children's hospices remain a vital part of the local palliative care system, providing essential support, crisis care, and respite for families.

While ICB funding decisions should reflect local needs and the way palliative care services are structured across hospital, community, and hospice settings, we do not believe that the extent to which funding varies between ICBs can be justified.

Encouragingly, the UK Government did announce in December 2024 that it would maintain the NHSE funding stream for children's hospices (formerly known as the Children's Hospice Grant) in 2025/26 and increase it to £26 million.[77]

Ministers also announced that they would provide an additional £100 million in capital funding for all children's and adults' hospices in England across 2024/25 and 2025/26, enabling improvements in facilities, IT systems, and outdoor spaces to enhance palliative and end of life care.

These policies will mean that, in 2025/26, thousands of families will continue to have the choice of accessing lifeline support at home or at a children's hospice. Access to the £100 million will also help children's hospices navigate a challenging funding environment and rising costs.

However, the £26 million and £100 million are only short-term solutions. The children's palliative care sector urgently needs a more equitable and sustainable statutory funding settlement from both the NHS and local authorities.

Northern Ireland

A significant factor contributing to the needs of families caring for children with life-limiting conditions in Northern Ireland being left unmet is the insufficient statutory funding for the Northern Ireland Children's Hospice.

In Northern Ireland, the children's hospice currently receives approximately 37% of its funding from statutory sources, down from 39% in 2023/24.

Although statutory funding for the hospice increased to £1,786,000 in 2023/24, this rise has not kept pace with inflationary pressures and the escalating costs of care. In 2023/24, this totalled £4,611,000.

In summer 2023, the department ended a temporary annual payment of £170,000, leading to an £85,000 reduction in the hospice's funding for the 2023/24 financial year. Although the former Northern Ireland Health Minister, Robin Swann reinstated this £85,000 payment and confirmed that a £420,000 component of the core funding would be made recurrent, the hospice advised that restoring the full £170,000 would not reverse the decision to reduce services.

This led the minister to acknowledge that the financial difficulties confronting the Northern Ireland Children's Hospice (NICH) extend beyond the recent reduction in departmental support.[78]

The minister also recognised the need for the hospice to develop longer-term solutions, indicating that the Executive would be willing to support such efforts.

However, in February 2024, the children's hospice announced a reduction in its services due to the loss of government funding for one of its beds. The hospice, which previously operated seven beds every night of the week, now plans to run only six beds from Monday to Friday and three beds on weekends.[79]

Furthermore, following the UK Government's decision to increase employer National Insurance Contributions, it is expected that costs incurred by the hospice in providing children's palliative care will experience a significant increase from April 2025. Alongside other significant financial challenges,[80] the hospice estimates that this tax rise will increase their costs by £89,000 per year.

As mentioned previously, Northern Ireland is also faced with a shortage of community children's nurses. This shortage is significantly limiting children and young people's access to 24/7 nursing care at home at the end of life.

Significant investment is therefore needed to recruit and fund the additional 90 CCNs required to meet safe staffing levels as advised by the Royal College of Nursing. Assuming these nurses are employed at Band 6 of Agenda for Change, we have estimated that an investment of £5,054,612.40 is required from the Executive to fill this gap.[xxi]

[xxi] The estimated additional investment of £5,054,612.40 is based on the requirement for 90 community children's nurses (CCNs) to meet the Royal College of Nursing's safe staffing levels. The Band 6 salary calculation incorporates standard NHS working hours (Monday–Friday, 8:00am – 6:30pm) and adjustments for out-of-hours and weekend shifts.

- Standard NHS hours: 8:00am – 6:30pm, Monday – Friday (excluding bank holidays), totalling 52.5 hours per week (31.25% of the week).
- Out-of-hours & Saturday shifts: 91.5 hours per week (54.46% of the week), paid at time + 30% for Band 6 nurses.
- Sunday shifts: 24 hours per week (14.29% of the week), paid at time + 60% for Band 6 nurses.

These weighting factors were applied to the Band 6 salary to estimate the total cost of employing 89 additional nurses.

Scotland

In Scotland, Children's Hospices Across Scotland (CHAS) operates as the single national provider of hospice care to children, with staff working across hospices, hospitals, and local communities.

Thanks to the backing of the Scottish Government, the Convention of Scottish Local Authorities (COSLA), and the generosity of the Scottish public, CHAS offers all care at no charge.

However, the growing number—and complexity—of children in Scotland with palliative care needs is putting increasing pressure on CHAS, and not every child and family who could benefit from its services is currently being reached.

While the Scottish Government has pledged to provide "high-quality child palliative care, regardless of location," supported by at least £7 million per year in sustainable funding through CHAS, this funding is no longer sufficient to meet the rising costs.[81]

Inflationary pressures, service change to meet increasing acuity (including in hospitals), and NHS pay awards have significantly raised CHAS's cost base. As a result, the £7 million of pledged annual funding from the Scottish Government now only covers about 30% of CHAS's total expenditure.

While the commitment to link hospice funding to NHS pay awards in the Scottish Budget is hugely welcome, detailed work is needed to get the baseline right.

Urgent help is also needed to address the underlying funding gap faced by hospices across Scotland, including CHAS.

CHAS is urgently calling for a renewed commitment from the Scottish Government to cover 50% of its agreed costs, including inflation-based increases, to ensure a sustainable long-term funding arrangement.

This investment would be highly beneficial, as the care provided by CHAS can prevent children from needing hospitalisation, enable earlier discharges, reduce the strain on the most expensive NHS beds, and help prevent families from reaching a crisis point – all of which have significant preventative spending implications.

Independent analysis has shown that for every £1 of statutory funding CHAS receives from the Scottish Government and COSLA, CHAS generates £6.24 in public value, demonstrating the substantial return on investment that supporting this essential service provides.[82]

We call on the Scottish Government to reaffirm its commitment to covering 50% of CHAS' agreed costs. Given that Scottish hospices are facing more than £2.5 million in additional National Insurance Contributions next year, action must be taken to avoid further financial strain on services supporting vulnerable children and families. Specifically, if the Scottish Government intends to cover these additional costs in the NHS using Barnett consequentials, they should do so in hospices too.

Wales

In Wales, a significant factor behind the postcode lottery and the unmet needs of families caring for children with life-limiting conditions is the lack of long term, sustainable and fair statutory funding provided to the two children's hospices, Tŷ Hafan and Tŷ Gobaith.

Currently, these hospices receive only about 12% of the total costs of delivering palliative care from statutory sources, with 67% of that funding coming from the Welsh Government and the remaining 33% from local health boards.

In 2022, the Welsh Government took a positive step by allocating an additional £2.2 million to hospices in Wales as part of the Lifeline Fund, with £888,000 specifically directed to the two children's hospices.[83] This was the first increase in statutory funding for these hospices since 2007, raising their coverage to approximately 21% of their palliative care costs.

This funding was instrumental in enabling the hospices to recruit more nurses, enhance their resilience both in hospices and in the community, expand their services, and provide more respite care to families in need. It also helped reduce the burden of unplanned and crisis admissions on the NHS.

However, the benefits of this funding have been reduced by inflationary pressures, particularly challenges in recruiting and retaining staff due to the need to align with increased Agenda for Change pay settlements. Consequently, the funding previously awarded no longer represents 21% of the hospices' care costs, making the current financial support unsustainable.

At the end of the 2023/24 financial year, the Welsh Government provided an additional £770,000 to the two children's hospices as part of its end-of-life care review.[84]

While the children's hospices welcomed this one-off payment, which brought the hospices closer to covering 21% of their care costs for that year, it was non-recurrent and came too late in the financial year to allow for effective long-term planning.

More recently in the Draft Budget, the Welsh Government committed to providing £3 million in recurring funding to the hospice sector. Despite this, we remain concerned that more will still be required to address the significant funding challenges faced by the children's hospices.

Specifically, both Tŷ Hafan and Tŷ Gobaith are in desperate need of additional support to mitigate the impact of the increase in employer National Insurance Contributions, which will place further financial strain on hospices. According to the children's hospices, this uplift will cost them an additional £550,000 to continue providing lifeline care to seriously ill children and their families.

Significant investment is also needed in NHS community services. As noted earlier, Wales faces a shortage of NHS community children's nurses, limiting access to 24-hour end of life nursing care at home for seriously ill children and young people. Assuming these nurses are employed at Band 6 of Agenda for Change, we estimate that an additional £12,355,719.20 is required to address this workforce gap.[xxii]

A fair and sustainable funding model is therefore essential to help hospices and community services plan for the long term and expand their support to reach more children and families. Reliance on sporadic, short-term funding leaves crucial services struggling to meet the growing demand and the increasing needs of children with life-limiting conditions in Wales.

[xxii] The required investment has been calculated using the same assumptions and salary weighting as previously described.

Lack of leadership and accountability

England

In England, significant progress has been made in recent years by both the UK Government and NHSE to develop a number of clear health policy imperatives that could help local systems achieve national standards and meet families' needs. These include:

- the legal obligation under the Health and Care Act 2022 for ICBs to commission palliative care as deemed appropriate for the needs of their communities;[85]

- NHSE's Palliative and End of Life Care Statutory Guidance for ICBs, outlining key actions that ICBs should consider to meet the palliative and end of life care duty;[86]

- the Ambitions for Palliative and End of Life Care Framework;[87]

- NHSE Service Specifications for Palliative and End of Life Care for Children and Young People (CYP);[88]

- the Government's end-of-life care choice commitment, which applies to individuals of all ages and ensures the right to pain management regardless of care setting;[89]

- the National Institute for Health and Care Excellence (NICE) guideline and quality standard for end-of-life care for children;[90] and

- the NHS Long Term Plan, which emphasises children's palliative care as a priority in paragraph 3.41.[91]

Despite these, our FOI requests have revealed significant disparities across England in the way these policies are being implemented. The proportions of ICBs with relevant children's palliative care service specifications and/or an Ambitions for Palliative and End of Life Care self-assessment have increased slightly. However, we remain concerned by the number of those that do not have these in place.

Previously, only 17 ICBs (40%) were able to provide data on how many children and young people with life-limiting or life-threatening conditions in their areas accessed hospice care in 2023/24.[92] Given the legal duty of ICBs to commission palliative care based on reasonable community needs, we question how this can be effectively achieved without comprehensive data.

We believe that this is partly due to a lack of oversight from the UK Government in holding ICBs to account for the way they commission children's palliative care.

Until now, the UK Government has held NHSE to account through the mandate to the NHS, which sets national priorities and requires the Secretary of State to oversee NHSE's progress.[93] However, there has been no clear mechanism to enable NHSE to apply the level of scrutiny needed to ensure ICBs' meet their legal duty on children's palliative care. While NHSE's regional performance managers have monitored ICBs' operational and financial performance,[94] specific expectations or reporting on children's palliative care have been lacking.

To support ICBs, NHSE has introduced a palliative and end of life care dashboard to help assess local palliative care needs and track progress in reducing disparities. However, without clear reporting requirements or a framework to ensure ICBs use this data to drive improvements, services will remain inconsistent, and too many families will continue to struggle to access the care they need.

On 13 March 2024, the UK Government announced that NHSE will be abolished as an arms-length body and brought back under the Department of Health and Social Care (DHSC) within the next two years. Given the Secretary of State's emphasis on greater autonomy for local systems, we believe clarity is needed on the extent to which DHSC will hold ICBs to account for meeting their legal duty and implementing policy guidance once the structural changes are complete.

With the UK Government preparing to publish its 10-Year Plan for the NHS, it is vital that ministers commit to addressing the significant variation in children's and families' access to high-quality palliative care. While we acknowledge the ambition to enhance local decision-making and reduce disparities in care, the plan must establish clear mechanisms for DHSC to hold ICBs to account for implementing policy guidance—especially given the potential impact of upcoming structural changes on DHSC capacity.

Doing so will be essential in translating national commitments into meaningful change for seriously ill children and their families.

There are also established policy directives for local authorities on children's social care.

Under the Children Act 1989, local authorities must provide services to support family carers of disabled children, including respite care. The Act also requires local authorities to maintain a register of disabled children in their areas. However, research and FOI requests from the DCP reveal that many local authorities are failing to meet these legal obligations.[95]

Northern Ireland

In 2016, the Department of Health in Northern Ireland released the strategy "Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life Care 2016-26," which outlines the strategic direction for the next decade. The strategy focuses on acute hospital services, the transition to adult services, and the integration of hospital and community care, using an outcomes-based approach.[96]

In 2020, the "New Decade, New Approach" deal promised increased investment to fully implement service improvements for palliative and end-of-life care, including enhanced support for hospices and palliative perinatal care.[97]

More recently, the Department of Health's "Health and Social Care Workforce Strategy 2026," published in June 2022, references the children's palliative care strategy with the goal of improving children's lives through a responsive nursing workforce.[98]

Despite these commitments, we have found that, too often, these policies are not being implemented. It is crucial that the Department of Health in Northern Ireland works with the HSC trusts to make sure that they are.

Scotland

Over the past year, the Scottish Government has made significant progress in developing its draft national strategy for palliative and end of life care, now published for consultation. Underpinned by a clear vision and an encouraging level of ambition, the new strategy presents a crucial opportunity to deliver meaningful change for seriously ill children and their families.

We welcome much of what has been proposed in the strategy, particularly the commitment to supporting CHAS and NHS partners to develop and embed a national 24/7 specialist paediatric palliative care service. However, achieving this ambition will require significant investment in the specialist workforce, including community children's nurses and paediatric palliative care consultants.

We also support the proposed development of paediatric palliative care standards to ensure equitable access to high quality services across Scotland. However, for these standards to be a success, they must be backed by clear accountability mechanisms to ensure health boards and local authorities fully implement them. Ultimately, for the strategy to succeed, it must go beyond setting a vision. It must provide the necessary funding, workforce development, and governance structures to drive real change at a local level.

At the same time, we strongly support Marie Curie's campaign for a legal right to palliative care in Scotland. Enshrining this right in law would help ensure that every child with a life-limiting condition and their family can access the care they need, when and where they need it. By embedding this principle into the new strategy, alongside clear commitments concerning implementation and funding, would represent a major step forward in achieving a truly comprehensive and equitable palliative care system.

This progress builds on previous commitments by the Scottish Government to improve children's palliative care. In 2012, the Scottish Government published a Framework for the Delivery of Palliative Care for Children and Young People, followed by a Strategic Framework for Action for Palliative and End-of-Life Care in 2015.

Furthermore, in its 2021/22 program, the government reinforced its commitment to providing the highest standards of palliative care, ensuring seamless, timely, and high quality support. It also pledged at least £7 million per year in sustainable funding through Children's Hospices Across Scotland.[99]

Despite these positive steps, many families are continuing to experience gaps in their care. It is therefore vital that the new strategy is not only ambitious but also backed by strong leadership and accountability. Only with clear implementation and oversight can it bridge these gaps and ensure that all children and families receive the palliative care they need, when and where they need it.

Wales

In Wales, the National Palliative and End of Life Care program provides leadership and guidance to drive improvements, aligning with the Welsh Government's goals for end of life care.[100]

Guided by the Quality Statement for Palliative and End of Life Care, the program aims to give people choice over where they die and ensure access to high-quality care, regardless of location or condition.[101] The statement outlines the vision for 24/7 access to coordinated care, medication, and advice about end-of-life care across Wales, aiming to reduce distress and prevent unnecessary hospital admissions. It also emphasises the need for seamless transitions from paediatric to adult services.[102]

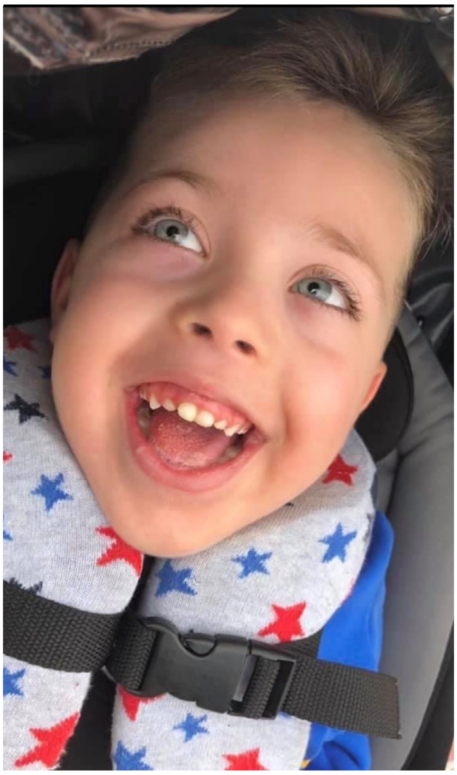
Despite these intentions, there is very limited scrutiny or holding to account of health boards and local authorities for the way in which they deliver existing quality standards. As such, a postcode lottery in accessing children's palliative care that meets national standards is persisting across Wales.

The Welsh Government's draft National Service Specification for Palliative and End of Life Care, currently under consultation, presents an opportunity to address these inconsistencies by setting out clearer expectations for service provision. However, for the specification to be effective, it must be backed by sustainable funding, workforce investment, and accountability measures to ensure its implementation across all Local Health Boards.

Overall, it is crucial that adequate funding and measures are in place to enable NHS Wales to achieve their vision, ensuring that children with life-limiting and life-threatening conditions, along with their families, can access the necessary care when and where they need it.

Frazer's story

Told by his Mum, Amy



"Frazer had a love for life, an energy unmatched and loved Paw Patrol, Peppa Pig, story books, riding his bike and swimming; they were his favourite things to watch and do. As soon as people met him, they literally fell in love with him; he was the most beautiful little boy with the cheekiest personality."

Early signs of change

Frazer was born by natural birth relatively quickly, in February 2013; "He developed in line with expectations and met all of his development goals until he was around three and a half. At this time, we noticed that there were regressions in his speech, and he seemed to be very clumsy." Amy soon discovered that Frazer was having seizures in the form of drop attacks, something that the family were completely unaware of at the time. He was put on medication for epilepsy but between the ages of four and five, the seizures were hard to control and not responding to medication.

A scan and genetic testing revealed CLN2 Battens Disease.

"We were sat in the room looking at his scans on the screen with a consultant. We were sent away with an A4 information leaflet and advised to contact our local Children's Hospice. It was completely and utterly devastating; we were just numb."

The challenge of care

Frazer deteriorated rapidly, he began to lose his speech further and then his mobility, his ability to swallow and started to have dystonic episodes: "Slowly we watched him lose all his abilities."

Amy and Dave, Frazer's dad, made the decision early on that it was vital to make as many memories as possible as they knew there was no cure and that time was crucial.

Amy gave up her job as a Primary School Teacher and cared for Frazer at home 24 hours a day: "I very much led on asking for the things that we needed. I provided every element that Frazer needed."

Amy struggled to access the overnight care she needed to allow her time to sleep at night: "I couldn't be awake through the night every night. But it was difficult to access consistent and high-quality overnight care through the only agency local to us."

Amy was approved to recruit and train the staff herself so that it was completely personalised to Frazer and his needs. Amy was fortunate to have great support from her husband Chris, Frazer's Dad, Dave and her family and friends. They were too a great support to Frazer's older brother, Alfie.

A peaceful farewell

Frazer died in September 2022, aged 9 and a half.

"We wanted him to die at home and I was certain that I would make that possible; so that he could be around all those that love him and the things he loved and was familiar with. He died quickly, comfortably and peacefully."

The family were supported by the hospital's Children's Palliative Care Team throughout the later months and at the end of Frazer's life: "They went above and beyond, for Frazer and for the rest of us."

Navigating grief

The family returned home to a very quiet house. "The telephone calls stopped; no more appointments or emails to write and reply to, no medication orders to place or 'stock' to refill; everything just instantly stops, it's overnight".

"It's only when you look back and begin to try and process everything, that you realise you were frightened and overwhelmingly terrified every single day, living on the edge of your nerves in flight or fight mode."

Amy was diagnosed with PTSD and chronic depression a year after Frazer died. 18 months after Frazer passed away, and into her grief journey, Amy suffered a carotid artery dissection and was admitted to hospital at critical risk of stroke at the age of 39. The cause of this was unknown but could have been due to extreme emotional distress which was not ruled out.

"I said to Frazer, at the end, that if at any time he wasn't too busy having lots of fun up in Heaven, I would be waiting, watching, looking and listening for his signs that he is with me, and he never fails to show me those precious signs, he is always with me."

Recommendations

We welcome the progress that has been made by the UK's governments since our Short Lives Can't Wait report in March 2024. However, there is still more to be done to ensure seriously ill children, and their families can access the care and support they need, when and where they need it.

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 and the Department of Health and Social Care:

- DHSC should make sure that, using NHSE's children's palliative care service specification and working in collaboration with Health Education England (HEE), a plan is developed to use the existing children's palliative care workforce as equitably 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.[103]

- We join the Royal College of Nursing in asking for:

  o The Government to set nurse-to-patient ratios for all health and care settings. These must be measured and reported on publicly.

  o 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 calling on the Government to ensure that a portion of the £1 billion increase in SEND and alternative provision funding is directed towards improving access to the specialist workforce. Workforce planning must take a broad and integrated approach across education, health and care to holistically support children and young people with SEND. Furthermore, the Government must work in partnership with the coalition, as well as children, young people and their families, to develop and implement solutions that address the significant challenges in recruiting, retaining, and investing in the specialist workforce.

- DHSC should 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.

- DHSC should assess the demand for nurses from children's hospice organisations and the independent sector and include it in their planning models.

- The UK Government should 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.[104]

- If it is found that there are too few children's nurses likely to fill posts across all types of healthcare providers, for example, universities should increase the number of places they offer to undergraduates.

Integrated Care Systems

- In carrying out their people function,[105] integrated care systems (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. 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

- The Department of Health should invest in GRID training for at least one paediatric consultant in Northern Ireland.

- As part of its work to implement Health and Social Care Workforce Strategy 2026, the Department of Health should put systems in place to routinely gather data on the number of community children's nurses employed by the Health and Social Care service.

- 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 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 CHAS, NHS territorial boards, NHS Education for Scotland 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 continue to support the Specialist Practitioner Qualification, at Masters level, for community children's nursing that launched in September 2024 in Scotland and ensure that this qualification includes palliative care as a core component.

- 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.[106]

- 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.

Addressing funding shortfalls

England

- As part of the NHS 10-Year Plan, the UK Government should commit to reviewing the way in which children's palliative care is planned and funded. This should lead to multi-year long term NHS funding for children's palliative care in England that fills the £310 million gap that we have identified and sustains lifeline services, including children's hospices.

- A review should examine whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale.

- DHSC should model how much it should be spending on children's palliative care – and then hold ICBs to account for the extent to which they spend money for this purpose.

- A funding review should set out a transition plan to bring about a shift to an equitable and sustainable model of commissioning children's palliative care. We would welcome further opportunities to engage with DHSC to create such a model together.

- As part of a transition, we call on the UK Government to commit to maintaining centrally distributed funding, formerly known as the Children's Hospice Grant, as a ringfenced fund for children's hospices. We call for it to be increased year on year to take account of inflation and returned to being a directly-distributed grant.

- In future, ICBs should be able to work together to equitably and sustainably fund children's hospices without the need for a central grant. However, it is vital that the ministers and officials do not remove the grant until ICBs have proven that they are able to do so for at least one financial year.

Northern Ireland

- The Northern Ireland Executive should commit to providing additional and sustainable statutory funding to Northern Ireland Children's Hospice for the long-term. This funding should be sufficient to cover 50% of the costs incurred in providing lifeline care and support to children and their families.

- The Executive should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

- To achieve the Department of Health's vision of improving children's lives through a responsive nursing workforce, as outlined in the "Health and Social Care Workforce Strategy 2026", the Northern Ireland Executive should fill the £5 million per year needed to fund the additional community children's nurses needed.

- 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.

Scotland

- The Scottish Government should re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long-term. This funding should be sufficient to cover 50% of agreed costs in providing lifeline care to children and their families, alongside additional costs associated with rising employer National Insurance Contributions and achieving pay parity with the NHS.

- The Scottish Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

- The Scottish Government should provide sustainable funding so that its new national strategy for palliative and end of life care can be implemented in full.

Wales

- We join Tŷ Hafan and Tŷ Gobaith in calling for all Welsh political parties to commit to sustainable, fair funding for both children's hospices. That means committing to 25% of care costs by Children's Hospice Week in June 2025, rising to 30% by 2030.

- The Welsh Government should ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

- The Welsh Government should fill the £12.3 million per year needed to fund the additional NHS community children's nurses needed in Wales.

Increasing leadership and accountability of relevant bodies

England

- In addition to filling funding gaps in ICB budgets, DHSC should hold ICBs to greater account for the way in which they commission children's palliative care.

- DHSC should direct ICBs to work with neighbouring ICBs in their region to plan and fund key services.

- DHSC should regularly monitor the extent to which ICBs are commissioning this care and hold them to account if they fail to do so.

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

- The Secretary of State for Health and Social Care should mandate the Care Quality Commission (CQC) to assess the extent to which ICBs are commissioning children's palliative care effectively.

Northern Ireland

- The Northern Ireland Executive should make sure sustainable funding is in place to implement Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and End-of-Life care 2016-26 in full.

- The Department of Health should commission children's palliative care services in a way which meets the NICE standards.

Scotland

- The Scottish Government should introduce legislation to establish a legal right to palliative care, ensuring that all children and young people with life-limiting and life-threatening conditions have timely access to high quality, person-centred support. This legal right should apply across all settings, including hospitals, hospices, and home-based care, and be underpinned by clear accountability mechanisms to guarantee equitable provision.

- The Scottish Government should make sure sustainable funding is in place to implement the new national strategy for palliative and end of life care in full.

- The Scottish Government should ensure that sufficient accountability mechanisms are in place to ensure effective implementation of the strategy at a local level.

- 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 focused 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.

- Within its forthcoming National Transitions to Adulthood strategy, the Scottish Government should include a specific focus on young people with life-limiting or complex medical conditions. Specifically, the strategy should adhere to the Principles of Good Transition,[107] and ensure multidisciplinary, age-appropriate support is available throughout the process, with an emphasis on continuity of care and integrated services.

Wales

- The new palliative and end of life care service specification should outline clear expectations for delivering services, ensuring that all children and young people with life-limiting and life-threatening conditions can access timely, equitable and high quality care across all settings, including 24/7 end of life care at home. Specifically, the specification should:

  - o Outline workforce requirements to address shortages and ensure sufficient staff across health, social care and education are trained to deliver high quality palliative care.

  - o Mandate sustainable funding commitments to support service availability and prevent reliance on short-term or charitable funding.

  - o Ensure sufficient accountability by requiring NHS bodies to demonstrate how they are delivering against the specification.

- The Welsh Government should 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.

- The Welsh Government should 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 hold local authorities to account for meeting their legal obligations under the Social Services and Well-being (Wales) Act 2014, and providing adequate respite care to seriously ill children and their families.

Appendices

Appendix 1: ICB responses to our FOI request

NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board
NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board
NHS Birmingham and Solihull Integrated Care Board
NHS Black Country Integrated Care Board
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board
NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board
NHS Cambridgeshire and Peterborough Integrated Care Board
NHS Cheshire and Merseyside Integrated Care Board
NHS Cornwall and The Isles of Scilly Integrated Care Board
NHS Coventry and Warwickshire Integrated Care Board
NHS Derby and Derbyshire Integrated Care Board
NHS Devon Integrated Care Board
NHS Dorset Integrated Care Board
NHS Frimley Integrated Care Board
NHS Gloucestershire Integrated Care Board
NHS Greater Manchester Integrated Care Board
NHS Hampshire and Isle of Wight Integrated Care Board
NHS Herefordshire and Worcestershire Integrated Care Board
NHS Hertfordshire and West Essex Integrated Care Board
NHS Humber and North Yorkshire Integrated Care Board
NHS Kent and Medway Integrated Care Board
NHS Lancashire and South Cumbria Integrated Care Board
NHS Leicester, Leicestershire and Rutland Integrated Care Board
NHS Lincolnshire Integrated Care Board
NHS Mid and South Essex Integrated Care Board
NHS Norfolk and Waveney Integrated Care Board
NHS North Central London Integrated Care Board
NHS North East and North Cumbria Integrated Care Board
NHS North East and North Cumbria Integrated Care Board clarification
NHS North East London Integrated Care Board
NHS North West London Integrated Care Board
NHS Northamptonshire Integrated Care Board
NHS Nottingham and Nottinghamshire Integrated Care Board
NHS Shropshire, Telford and Wrekin Integrated Care Board
NHS Somerset Integrated Care Board
NHS South East London Integrated Care Board
NHS South West London Integrated Care Board
NHS South Yorkshire Integrated Care Board
NHS Staffordshire and Stoke-On-Trent Integrated Care Board
NHS Suffolk and North East Essex Integrated Care Board
NHS Surrey Heartlands Integrated Care Board
NHS Sussex Integrated Care Board
NHS West Yorkshire Integrated Care Board

Appendix 2: ICB service specifications

NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board 1
NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board 2
NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board 3
NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board 1
NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board 2
NHS Black Country Integrated Care Board
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board 1
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board 2
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board CCN specification
NHS Cambridgeshire and Peterborough Integrated Care Board
NHS Cheshire and Merseyside Integrated Care Board
NHS Cornwall and The Isles of Scilly Integrated Care Board CCN specification
NHS Devon Integrated Care Board CCN specification
NHS Dorset Integrated Care Board
NHS Frimley Integrated Care Board 1
NHS Frimley Integrated Care Board 2
NHS Gloucestershire Integrated Care Board CCN specification
NHS Gloucestershire Integrated Care Board 1
NHS Gloucestershire Integrated Care Board 2
NHS Hampshire and Isle of Wight Integrated Care Board NHSE specialised commissioning specification
NHS Herefordshire and Worcestershire Integrated Care Board CCN specification
NHS Hertfordshire and West Essex Integrated Care Board 1
NHS Hertfordshire and West Essex Integrated Care Board 2
NHS Lancashire and South Cumbria Integrated Care Board children's palliative care framework
NHS Mid and South Essex Integrated Care Board CCN specification
NHS Mid and South Essex Integrated Care Board PCIN specification
NHS Norfolk and Waveney Integrated Care Board
NHS North East and North Cumbria Integrated Care Board 1
NHS North East and North Cumbria Integrated Care Board 2
NHS North East London Integrated Care Board
NHS North West London Integrated Care Board
NHS Nottingham and Nottinghamshire Integrated Care Board CCN specification
NHS Nottingham and Nottinghamshire Integrated Care Board CCN sub-service specification
NHS Nottingham and Nottinghamshire Integrated Care Board 1
NHS Nottingham and Nottinghamshire Integrated Care Board 2
NHS Shropshire, Telford and Wrekin Integrated Care Board
NHS Somerset Integrated Care Board
NHS South West London Integrated Care Board 1
NHS South West London Integrated Care Board 2
NHS South Yorkshire Integrated Care Board
NHS Suffolk and North East Essex Integrated Care Board

Appendix 3: ICB Ambitions for Palliative and End of Life Care self-assessments

NHS Black Country Integrated Care Board
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board
NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board
NHS Cambridgeshire and Peterborough Integrated Care Board
NHS Devon Integrated Care Board
NHS Hampshire and Isle of Wight Integrated Care Board
NHS Humber and North Yorkshire Integrated Care Board
NHS Kent and Medway Integrated Care Board
NHS Leicester, Leicestershire and Rutland Integrated Care Board
NHS Lincolnshire Integrated Care Board
NHS Mid and South Essex Integrated Care Board
NHS North Central London Integrated Care Board—Barnet
NHS North Central London Integrated Care Board—Camden
NHS North Central London Integrated Care Board—Enfield
NHS North Central London Integrated Care Board—Haringey
NHS North Central London Integrated Care Board—Islington
NHS North East London Integrated Care Board
NHS Northamptonshire Integrated Care Board
NHS Nottingham and Nottinghamshire Integrated Care Board
NHS Shropshire, Telford and Wrekin Integrated Care Board
NHS South East London Integrated Care Board
NHS South Yorkshire Integrated Care Board
NHS West Yorkshire Integrated Care Board

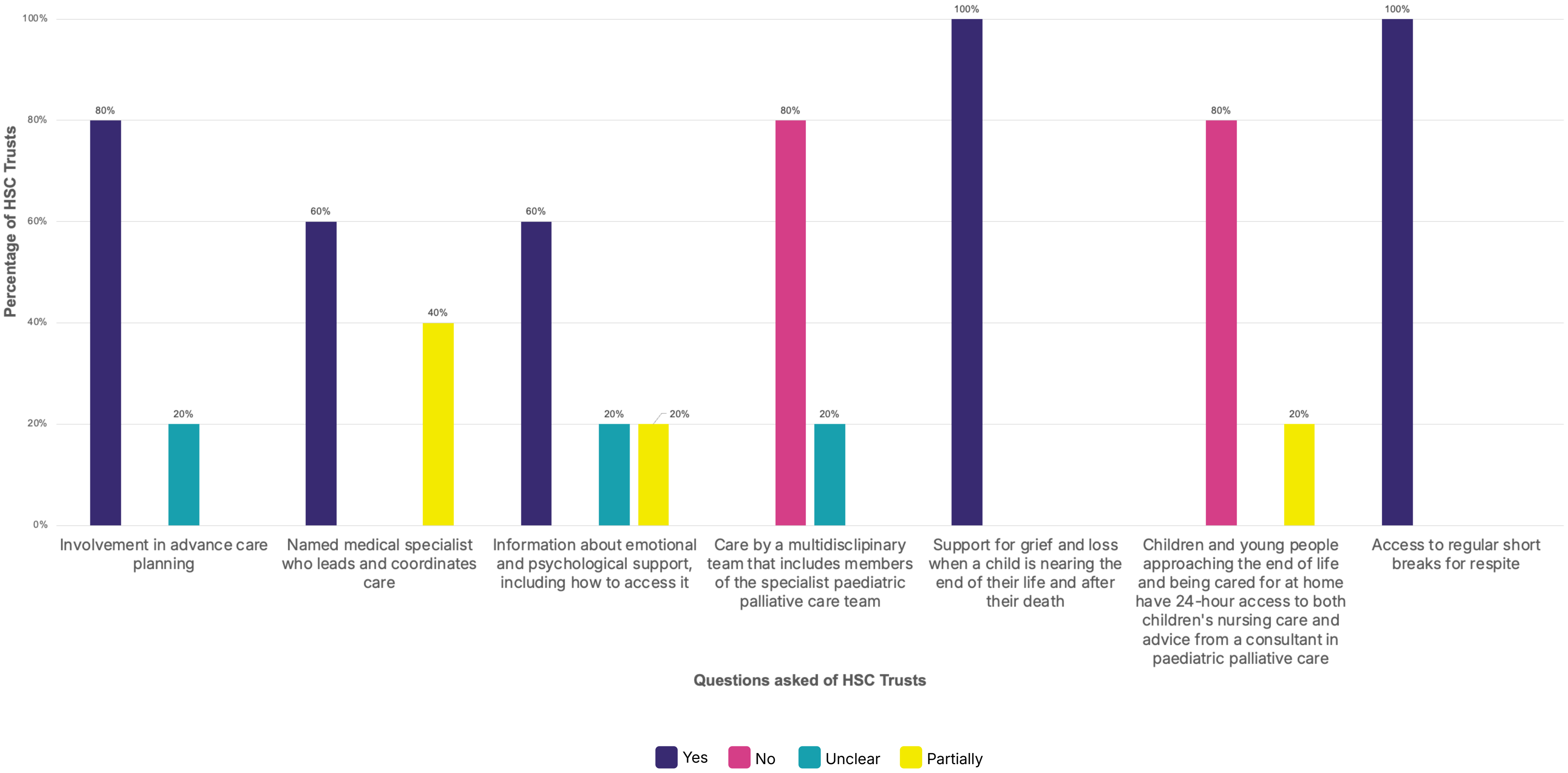
Appendix 4: Summary of ICB FOI responses to key questions

ICB	**Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in England**	**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**	**Question 1: Does the ICB possess a children's palliative care service specification?**	**Question 2: Has the ICB completed an Ambitions for Palliative and End of Live Care self-assessment?**	**Question 8: Does the ICB possess a relevant service specification which explicitly accounts for the provision of 24/7 end of life care at home, provided by nurses and supported by specialist advice from a consultant in paediatric palliative care**
Bath and North East Somerset, Swindon and Wiltshire	1456	258463	56.3	Yes	No	Partially
Bedfordshire, Luton and Milton Keynes	2101	278001	75.6	Yes	In progress	Partially
Birmingham and Solihull	2871	386491	74.3	Unable to respond	Unable to respond	Unable to respond
Black Country	3104	410934	75.5	Yes	Yes	Unclear / Maybe
Bristol, North Somerset and South Gloucestershire	1859	285263	65.2	Yes	Yes	Yes
Buckinghamshire, Oxfordshire and Berkshire West	2945	505501	58.3	Yes	Yes	Yes
Cambridgeshire and Peterborough	1540	255934	60.2	Yes	Yes	Partially

Cheshire and Merseyside	4856	721332	67.3	Yes	Partially	Yes
Cornwall and the Isles of Scilly	1076	147483	73.0	Yes	Yes	Yes
Coventry and Warwickshire	1596	266058	60.0	Specification in development	Yes	Specification in development
Derby and Derbyshire	1746	284652	61.3	Specification in development	No	Specification in development
Devon	2075	329179	63.0	No	Yes	No
Dorset	1251	200486	62.4	Yes	Partially	Partially
Frimley	1297	221132	58.7	Yes	No	Unclear / Maybe
Gloucestershire	1105	173823	63.6	Yes	Yes	Partially
Greater Manchester	6241	873958	71.4	No	No	No
Hampshire and the Isle of Wight	3373	523136	64.5	Specification in development	Partially	Specification in development
Herefordshire and Worcestershire	1257	203879	61.7	Partially	Partially	Partially
Hertfordshire and West Essex	2552	417811	61.1	Yes	No	Partially
Humber and North Yorkshire	2755	492490	55.9	No	Yes	No
Kent and Medway	3301	517431	63.8	No	Yes	No
Lancashire and South Cumbria	3437	502922	68.3	Specification in development	Yes	Specification in development
Leicester, Leicestershire and Rutland	1739	322329	54.0	Specification in development	Yes	Specification in development
Lincolnshire	1113	199737	55.7	No	Yes	No
Mid and South Essex	2079	335057	62.0	Partially	Yes	No
Norfolk and Waveney	1477	270388	54.6	Yes	In progress	Partially
North Central London	2719	399457	68.1	No	Yes	No

North East and North Cumbria	6019	880871	68.3	Partially	Unable to respond	No
North East London	4006	554599	72.2	Yes	Yes	Yes
North West London	4068	568841	71.5	Yes	Partially	Yes
Northamptonshire	1373	206193	66.6	No	Yes	No
Nottingham and Nottinghamshire	1926	311302	61.9	Yes	Yes	Partially
Shropshire and Telford and Wrekin	881	134598	65.5	Yes	Yes	No
Somerset	1011	147617	68.5	Yes	Partially	Partially
South East London	3400	490600	69.3	No	Yes	No
South West London	2860	411342	69.5	Yes	In progress	Yes
South Yorkshire	3270	454676	71.9	Yes	Yes	No
Staffordshire & Stoke on Trent	2027	316909	64.0	Specification in development	Yes	Specification in development
Suffolk and North East Essex	1553	267857	58.0	Yes	In progress	Partially
Surrey Heartlands	1744	288602	60.4	Yes	Partially	Yes
Sussex	2980	442427	67.4	No	Yes	No
West Yorkshire	5318	763423	69.7	No	Yes	No
TOTAL	105357	16023184				

Appendix 5: A graph illustrating the extent to which Health and Social Care Trusts in Northern Ireland are providing children's palliative care services that meet national quality standards



Appendix 6: Health and Social Care Trust (Northern Ireland) responses to our FOI request

Belfast Health and Social Care Trust
Northern Health and Social Care Trust
South Eastern Health and Social Care Trust
Southern Health and Social Care Trust
Western Health and Social Care Trust

Appendix 7: Local Health Board (Wales) responses to our FOI request

Aneurin Bevan University Health Board
Betsi Cadwaladr University Health Board
Cardiff & Vale University Health Board
Cwm Taf Morgannwg University Health Board
Hywel Dda University Health Board
Powys Teaching Health Board
Swansea Bay University Health Board

Appendix 8: Local authority (Wales) responses to our FOI request

Blaenau Gwent County Borough Council
Caerphilly County Borough Council
Cardiff Council
Carmarthenshire County Council
Ceredigion County Council
Conwy County Borough Council
Denbighshire County Council
Flintshire County Council
Gwynedd Council
Isle of Anglesey County Council
Merthyr Tydfil County Borough Council
Monmouthshire County Council
Neath Port Talbot County Borough Council
Powys County Council
Swansea Council
Torfaen County Borough Council
Vale of Glamorgan Council
Wrexham County Borough Council

Appendix 9: NHS Trust responses to our FOI request

Alder Hey Children’s Hospital Trust
Birmingham Women’s and Children’s NHS Foundation Trust
Great Ormond Street Hospital for Children NHS Foundation Trust
Guy’s and St Thomas’ NHS Foundation Trust
The Leeds Teaching Hospitals NHS Trust
The Royal Marsden NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust

References

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

[2] **Lotstein DS, Inkelas M, Hays RD, Halfon N and Brook R.** (2008). Access to Care for Youth with Special Health Care Needs in the Transition to Adulthood. Journal of Adolescent Health, 43(1). Available at: https://www.sciencedirect.com/science/article/abs/pii/S1054139X08000979.

[3] **Together for Short Lives.** (2024). Short lives can't wait: the state of children's palliative care in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/an-overview-of-childrens-palliative-care-in-the-uk-in-2024/.

[4] **National Institute for Health and Care Excellence**. (2017). End of life care for infants, children and young people. Available at: https://www.nice.org.uk/guidance/qs160/resources/end-of-life-care-for-infants-children-and-young-people-pdf-75545593722565#:~:text=Statement%201%20Infants%2C%20children%20and,leads%20and%20coordinates%20their%20care.

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

[6] **NHS England.** (2021). Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. Available at: https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/.

[7] **Welsh Government.** (2022). Quality statement for palliative and end of life care for Wales. Available at: https://www.gov.wales/quality-statement-palliative-and-end-life-care-wales-html.

[8] **Together for Short Lives.** (2018). A Guide to Children's Palliative Care (Fourth Edition). Available at: https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-FINAL-SINGLE-PAGES.pdf.

[9] **Together for Short Lives.** (2018). A Guide to Children's Palliative Care (Fourth Edition). Available at: https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-FINAL-SINGLE-PAGES.pdf.

[10] **Hizanu DM, Boeriu E, Tanasescu S, Balan A, Oprisoni LA, Popa MV, Gutu C, Vulcanescu DD, Bagiu IC, Bagiu RV, Dragomir TL, Boru C, Avram CR, Duceac LD**. (2024). Benefits of Respite Services on the Psycho-Emotional State of Families of Children Admitted to Hospice Palliative Care Unit: Preliminary Study on Parents' Perceptions. Healthcare (Basel), 12(7). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11011478/.

[11] **Fraser LK, Murtagh FEM, Aldridge J, Sheldon T, Gilbody S and Hewitt C**. (2021). Health of mothers of children with a life-limiting condition: a comparative cohort study. Archives of Disease in Childhood, 106. Available at: https://adc.bmj.com/content/106/10/987.

[12] **Lotstein DS, Inkelas M, Hays RD, Halfon N and Brook R.** (2008). Access to Care for Youth with Special Health Care Needs in the Transition to Adulthood. Journal of Adolescent Health, 43(1). Available at: https://www.sciencedirect.com/science/article/abs/pii/S1054139X08000979.

[13] **Mellor C and Hain R.** (2010). Paediatric palliative care: not so different from adult palliative care? British Journal of Hospital Medicine, 71(1). Available at: https://www.magonlinelibrary.com/doi/abs/10.12968/hmed.2010.71.1.45971.

[14] **Kerr H, Price J, Nicholl H and O'Halloran P.** (2018). Facilitating transition from children's to adult services for young adults with life-limiting conditions (TASYL). Programme theory developed from a mixed methods realist evalu-

ation. International Journal of Nursing Studies, 86. Available at: https://pubmed.ncbi.nlm.nih.gov/30005314/.

[15] **Kerr H, Price J, Nicholl H and O'Halloran P.** (2018). Facilitating transition from children's to adult services for young adults with life-limiting conditions (TASYL). Programme theory developed from a mixed methods realist evaluation. International Journal of Nursing Studies, 86. Available at: https://pubmed.ncbi.nlm.nih.gov/30005314/.

[16] **O'Dwyer ST, Sansom A, Mars B, Reakes L, Andrewartha C and Melluish J.** (2024). Suicidal Thoughts and Behaviors in Parents Caring for Children with Disabilities and Long-Term Illnesses. Archives of Suicide Research. Available at: https://www.tandfonline.com/doi/full/10.1080/13811118.2024.2363230?scroll=top&needAccess=true#abstract.

[17] **Barrett L, Fraser, L, Noyes J, Taylor, J, Hackett, J**. (2023). Understanding parent experiences of end-of-life care for children: A systematic review and qualitative evidence synthesis. Palliative Medicine, 37(2). Available at: https://pubmed.ncbi.nlm.nih.gov/36546591/.

[18] **Goudie A, Havercamp S, Jamieson B and Sahr T.** (2013). Assessing Functional Impairment in Siblings Living With Children With Disability. American Academy of Pediatrics, 132(2). Available at: https://publications.aap.org/pediatrics/article-abstract/132/2/e476/31441/Assessing-Functional-Impairment-in-Siblings-Living?redirectedFrom=fulltext.

[19] **Barrett L, Fraser, L, Noyes J, Taylor, J, Hackett, J**. (2023). Understanding parent experiences of end-of-life care for children: A systematic review and qualitative evidence synthesis. Palliative Medicine, 37(2). Available at: https://pubmed.ncbi.nlm.nih.gov/36546591/.

[20] **McDonagh JE and Kelly DA.** (2003). Transitioning care of the padiatric recipient to adult caregivers. Padiatric Clinics of North America, 50(6). Available at: https://www.sciencedirect.com/science/article/abs/pii/S0031395503001317.

[21] **Together for Short Lives.** (2018). A checklist to a good transition. Available at: https://www.togetherforshortlives.org.uk/get-support/information-about-your-childs-care/transition-to-adult-care/a-checklist-to-a-good-transition/.

[22] **National Confidential Enquiry into Patient Outcome and Death**. (2023). The Inbetweeners: A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services. Available at: https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf.

[23] **National Confidential Enquiry into Patient Outcome and Death**. (2023). The Inbetweeners: A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services. Available at: https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf.

[24] **National Confidential Enquiry into Patient Outcome and Death**. (2023). The Inbetweeners: A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services. Available at: https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf.

[25] **National Confidential Enquiry into Patient Outcome and Death**. (2023). The Inbetweeners: A review of the barriers and facilitators in the process of the transition of children and young people with complex chronic health conditions into adult health services. Available at: https://www.ncepod.org.uk/2023transition/The%20Inbetweeners_full%20report.pdf.

[26] **Health and Care Act 2022, s3(1) NHS Act 2006 (as amended)**. Available at: https://www.legislation.gov.uk/ukpga/2022/31/data.pdf.

[27] **Together for Short Lives.** (2024). Short lives can't wait: the state of children's palliative care in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/an-overview-of-childrens-palliative-care-in-the-uk-in-2024/.

[28] **NHS England**. Service specifications. Available at: https://www.england.nhs.uk/specialised-commissioning-docu-

ment-library/service-specifications/.

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

[30] **NHS England.** (2021). Ambitions self-assessment tool. Available at: https://learninghub.nhs.uk/Resource/2349/Item.

[31] **Disabled Children's Partnership**. (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCP-report-2023.pdf.

[32] **Disabled Children's Partnership**. (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCP-report-2023.pdf.

[33] **Law Commission**. (2024). Disabled Children's Social Care: Consultation Paper. Available at: https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/30/2024/10/Disabled_-Children_Social_Care_CP.pdf.

[34] **Law Commission**. (2024). Disabled Children's Social Care: Consultation Paper. Available at: https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/30/2024/10/Disabled_-Children_Social_Care_CP.pdf.

[35] **The Public Accounts Committee.** (2025). Support for children and young people with special educational needs. Available at: https://committees.parliament.uk/publications/46238/documents/231788/default/.

[36] **The Public Accounts Committee.** (2025). Support for children and young people with special educational needs. Available at: https://committees.parliament.uk/publications/46238/documents/231788/default/.

[37] **The Public Accounts Committee.** (2025). Support for children and young people with special educational needs. Available at: https://committees.parliament.uk/publications/46238/documents/231788/default/.

[38] **The Public Accounts Committee.** (2025). Support for children and young people with special educational needs. Available at: https://committees.parliament.uk/publications/46238/documents/231788/default/.

[39] **Scottish Government.** (2024). Palliative care strategy: Palliative Care Matters for All. Available at: https://www.gov.scot/publications/palliative-care-strategy-palliative-care-matters/pages/11/.

[40] **Scottish Government.** (2024). Palliative care strategy: Palliative Care Matters for All. Available at: https://www.gov.scot/publications/palliative-care-strategy-palliative-care-matters/pages/11/.

[41] **Scottish Government.** (2024). Palliative care strategy: Palliative Care Matters for All. Available at: https://www.gov.scot/publications/palliative-care-strategy-palliative-care-matters/pages/11/.

[42] **Fraser L, Bedendo A and Jarvis S.** (2023). Children with a life-limiting or life-threatening condition in Wales: Trends in prevalence and complexity final report May 2023. Available at: https://www.tyhafan.org/wp-content/uploads/2023/07/Prevalence-Complete-Report-2023.pdf.

[43] **Fraser L, Bedendo A and Jarvis S.** (2023). Children with a life-limiting or life-threatening condition in Wales: Trends in prevalence and complexity final report May 2023. Available at: https://www.tyhafan.org/wp-content/uploads/2023/07/Prevalence-Complete-Report-2023.pdf.

[44] **Fraser L, Bedendo A and Jarvis S.** (2023). Children with a life-limiting or life-threatening condition in Wales: Trends in prevalence and complexity final report May 2023. Available at: https://www.tyhafan.org/wp-content/uploads/2023/07/Prevalence-Complete-Report-2023.pdf.

[45] **Social Services and Well-being (Wales) Act 2014, s37.** Available at: https://www.legislation.gov.uk/anaw/2014/4/section/37.

[46] **Social Services and Well-being (Wales) Act 2014, s15.** Available at: https://www.legislation.gov.uk/anaw/2014/4/section/37.

[47] **Weaver MS, Wichman B, Bace S, Schroeder D, Vail C, Wichman C, and Macfadyen A.** (2018). Measuring the Impact of the Home Health Nursing Shortage on Family Caregivers of Children Receiving Palliative Care. Journal of Hospice & Palliative Nursing, 20(3). Available at: https://journals.lww.com/jhpn/fulltext/2018/06000/Measuring_the_Impact_of_the_Home_Health_Nursing.11.aspx.

[48] **Royal College of Nursing.** (2012). Mandatory Nurse Staffing Levels. Available at: https://www.rcn.org.uk/-/media/royal-college-of-nursing/documents/policies-and-briefings/uk-wide/policies/2012/0312.pdf.

[49] **NHS Digital.** (2025). NHS Workforce Statistics – October 2024**.** Available at: https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/october-2024.

[50] **TURAS: Data Intelligence.** (2023). NHS Scotland Workforce. Available at: https://turasdata.nes.nhs.scot/data-and-reports/official-workforce-statistics/all-official-statistics-publications/05-march-2024-workforce/dashboards/nhs-scotland-workforce/?pageid=11224.

[51] **Welsh Government.** (2024). Nursing, midwifery and health visiting staff, by grade and area of work. Available at: https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Staff/Non-Medical-Staff/nursingmidwiferyand-healthvisitingstaff-by-grade-areaofwork-year.

[52] **NHS Digital.** (2024). NHS Vacancy Statistics England, April 2015 - March 2024, Experimental Statistics. Available at: https://digital.nhs.uk/data-and-information/publications/statistical/nhs-vacancies-survey/april-2015---march-2024-experimental-statistics.

[53] **Department for Education.** (2025). Children's social work workforce. Available at: https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce.

[54] **Department for Education.** (2025). Children's social work workforce. Available at: https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce.

[55] **Department for Education.** (2024). Consolidated annual report and accounts: Year ended 31 March 2024. Available at: https://www.gov.uk/government/publications/department-for-education-consolidated-annual-report-and-accounts-2023-to-2024.

[56] **Department for Education.** (2024). Consolidated annual report and accounts: Year ended 31 March 2024. Available at: https://www.gov.uk/government/publications/department-for-education-consolidated-annual-report-and-accounts-2023-to-2024.

[57] **Disabled Children's Partnership.** (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf.

[58] **Jones R.** (2023). Children's Social Care Services Northern Ireland: An Independent Review. Available at: https://www.cscsreviewni.net/publications/report-independent-review-childrens-social-care-services-northern-ireland.

[59] **Scottish Social Services Council.** (2023). Social worker filled posts and vacancies six-monthly survey. Available at: https://data.sssc.uk.com/images/SixMonthSurveyReport/LA_SW_WTE_Vacancy_Report_June_2023.pdf.

[60] **Social Care Wales.** (2024). Social care workforce delivery plan 2024 to 2027. Available at: https://socialcare.wales/about-us/workforce-strategy/social-care-delivery-plan-2024-to-2027.

[61] **Disabled Children's Partnership.** (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf

[62] **Disabled Children's Partnership.** (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf.

[63] **Disabled Children's Partnership.** (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.

org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf.

[64] **Disabled Children's Partnership.** (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf.

[65] **Department for Education.** (2023). Educational psychology services: workforce insights and school perspectives on impact. Available at: https://assets.publishing.service.gov.uk/media/649c4a4406179b00113f7498/Educational_Psychology_services_-_Workforce_insights_and_school_perspectives_on_impact.pdf.

[66] **Department for Education.** (2023). Educational psychology services: workforce insights and school perspectives on impact. Available at: https://assets.publishing.service.gov.uk/media/649c4a4406179b00113f7498/Educational_Psychology_services_-_Workforce_insights_and_school_perspectives_on_impact.pdf.

[67] **Department for Education.** (2023). Educational psychology services: workforce insights and school perspectives on impact. Available at: https://assets.publishing.service.gov.uk/media/649c4a4406179b00113f7498/Educational_Psychology_services_-_Workforce_insights_and_school_perspectives_on_impact.pdf.

[68] **British Psychological Society.** (2024). The rise in Education Health and Care Needs Assessments and the current crisis in the educational psychology workforce. Available at: https://www.bps.org.uk/news/rise-education-health-and-care-needs-assessments-and-current-crisis-educational-psychology.

[69] **British Psychological Society**. (2024). Government must grow the educational psychological workforce or risk thousands of children being left behind, says BPS. Available at: https://www.bps.org.uk/news/government-must-grow-educational-psychological-workforce-or-risk-thousands-children-being-left.

[70] **Papworth A, Hackett J, Beresford B, et al**. (2023). Regional perspectives on the coordination and delivery of paediatric end-of-life care in the UK: a qualitative study. BMC Palliative Care, 22. Available at: https://link.springer.com/article/10.1186/s12904-023-01238-w#Abs1.

[71] **HM Treasury**. (2024). Autumn Budget 2024: Fixing the foundations to deliver change. Available at: https://www.gov.uk/government/publications/autumn-budget-2024.

[72] **Together for Short Lives.** (2024). Short Lives Can't Wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[73] **Together for Short Lives.** (2024). Short Lives Can't Wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[74] **Children Act 1989, Part III**. Available at: https:// www.legislation.gov.uk/ukpga/1989/41/part/**III**.

[75] **Together for Short Lives.** (2024). Short Lives Can't Wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[76] **Together for Short Lives.** (2024). Short Lives Can't Wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[77] **GOV.UK.** (2024). Biggest investment into hospices in a generation. Available at: https://www.gov.uk/government/news/biggest-investment-into-hospices-in-a-generation.

[78] **Department of Health**. (2024). Statement by Health Minister Robin Swann on NI Children's Hospice. Available at: https://www.health-ni.gov.uk/news/statement-by-health-minister-robin-swannni-childrens-hospice.

[79] **BBC News**. (2024). NI Children's Hospice: Families speak out at reduction in bed capacity. Available at: https://www.bbc.co.uk/news/uk-northern-ireland-68214768.

[80] **Together for Short Lives.** (2024). Short Lives Can't Wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[81] **Scottish Government**. (2021). Programme for Government 2021 to 2022. Available at: https://www.gov.scot/publications/fairer-greener-scotland-programme-government-2021-22.

[82] **York Health Economics Consortium**. (2021). Children's Hospices Across Scotland: Economic Evaluation of Hospice Services – Executive Summary. Available at: https://chas-assets.s3.eu-west1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/6042715c0f7d335888887167/YHECExecutive-Summary-CHAS-Economic-Evaluation.pdf.

[83] **Welsh Parliament**. (2022). Statement by the Minister for Health and Social Services: Reform of Hospice Funding. Available at: https://record.assembly.wales/Plenary/12592#A69800.

[84] **Welsh Government**. (2024). Vital funding to support Welsh hospices. Available at: https://www.gov.wales/vital-funding-support-welsh-hospices.

[85] **Health and Care Act 2022, s3(1) NHS Act 2006 (as amended)**. Available at: https://www.legislation.gov.uk/ukpga/2022/31/data.pdf.

[86] **NHS England**. (2022). Palliative and End of Life Care Statutory Guidance for Integrated Care Boards (ICBs). Available at: https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf.

[87] **NHS England**. (2021). Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. Available at: https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/.

[88] **NHS England**. (2023). Service specifications for palliative and end of life care: Children and young people (CYP). Available at: https://www.england.nhs.uk/publication/service-specifications-for-palliative-and-end-of-life-care-children-and-young-people-cyp/.

[89] **Department of Health**. (2016). Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf.

[90] **National Institute for Health and Care Excellence**. (2017). End of life care for infants, children and young people. Available at: https://www.nice.org.uk/guidance/qs160/resources/end-of-life-care-for-infants-children-and-young-people-pdf-75545593722565#:~:text=Statement%201%20Infants%2C%20children%20and,leads%20and%20coordinates%20their%20care.

[91] **NHS**. (2019). The NHS Long Term Plan. Available at: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf.

[92] **Together for Short Lives.** (2024). Short Lives Can't Wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[93] **Department of Health and Social Care.** (2025). Road to recovery: the government's 2025 mandate to NHS England. Available at: https://www.gov.uk/government/publications/road-to-recovery-the-governments-2025-mandate-to-nhs-england/road-to-recovery-the-governments-2025-mandate-to-nhs-england.

[94] **The King's Fund.** (2022). Where does the buck stop? Understanding accountabilities and structures in the national health and care system in England. Available at: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/understanding-accountabilities-structures-health-care#:~:text=Performance%20managers%20in%20NHS%20England's,8%2C000%20posts)%20expected%20to%20disappear.

[95] **Disabled Children's Partnership.** (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf.

[96] **Department of Health**. (2016). A Strategy for Children's Palliative and End-of-Life Care 2016-26. Available at: https://www.health-ni.gov.uk/publications/strategy-childrens-palliative-and-end-life-care-2016-26.

[97] **UK Government.** (2020). New Decade, New Approach. Available at: https://assets.publishing.service.gov.uk/media/5e178b56ed915d3b06f2b795/2020-01-08_a_new_decade__a_new_approach.pdf.

[98] **Department of Health.** (2016). Health and Social Care Workforce Strategy 2026. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/health/hsc-workforce-strategy-2016.pdf.

[99] **Scottish Government**. (2021). Programme for Government 2021 to 2022. Available at: https://www.gov.scot/publications/fairer-greener-scotland-programme-government-2021-22/.

[100] **NHS Wales**. National Palliative and End of Life Care Programme. Available at: https://executive.nhs.wales/networks/programmes/peolc/#:~:text=The%20National%20Palliative%20and%20End,of%20life%20care%20in%20Wales.

[101] **NHS Wales**. National Palliative and End of Life Care Programme. Available at: https://executive.nhs.wales/networks/programmes/peolc/#:~:text=The%20National%20Palliative%20and%20End,of%20life%20care%20in%20Wales.

[102] **Welsh Government**. (2022). Quality statement for palliative and end of life care for Wales. Available at: https://www.gov.wales/quality-statement-palliative-and-end-life-care-wales-html.

[103] **NHS England**. (2021). Operational Delivery Networks. Available at: https://www.england.nhs.uk/ourwork/part-rel/odn/.

[104] **Nursing and Midwifery Council**. (2019). Standards. Available at: https://www.nmc.org.uk/standards/.

[105] **NHS England**. (2021). Building strong integrated care systems everywhere: guidance on the ICS people function. Available at: https://www.england.nhs.uk/wp-content/uploads/2021/06/B0662_Building-strong-integrated-care-systems-everywhere-guidance-on-the-ICS-people-function-August-2021.pdf.

[106] **Welsh Government**. (2022). Quality statement for palliative and end of life care for Wales. Available at: https://www.gov.wales/quality-statement-palliative-and-end-life-care-wales-html.

[107] **Scottish Transitions Forum.** Principles of Good Transitions. Available at: https://scottishtransitions.org.uk/7-principles-of-good-transitions/.