

The NHS 10-Year Plan

A response from Together for Short Lives

1. What does your organisation want to see included in the 10-Year Health Plan and why?

Whilst prevention is rightly a key part of the government's Health Mission, the needs of children and young people with life-limiting or life-threatening conditions, many of whom will not live into adulthood, must be reflected in the plan.

These conditions in children are rarely caused by preventable factors and come with unique, specific needs that differ from those of adults. However, conditions can be prevented from escalating to crisis by ensuring the right support is in place as early as possible. Palliative care plays a crucial role in enabling children and young people with life-limiting or life-threatening conditions to live as well as possible until they die.

Lord Darzi's independent investigation of the NHS in England highlighted that between 2001 and 2018, there was a 250 per cent increase in the prevalence of life-limiting and life-threatening conditions in children and young people.¹

Palliative care for children and young people may be considered as soon as a life-limiting condition is diagnosed or recognised. For those with a life-threatening condition, palliative care may be considered when it is recognised that curative treatment is no longer an option. However, access to palliative and end of life care is dependent upon individual need rather than diagnosis.

Some children need palliative and end of life care from birth; others only as their condition deteriorates or becomes unstable. Palliative and end of life care may be needed when it is recognised that the child or young person is likely to die within the next 12 months.

As members of the Children and Young People's Health Policy Influencing Group, Together for Short Lives' fully supports the group's call for the 10-Year Plan to reflect the recommendations made in 'The healthiest generation of children ever: a roadmap for the health system' document.²

What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Shift 1: moving more care from hospitals to communities

This means delivering more tests, scans, treatments and therapies nearer to where people live. This could help people lead healthier and more independent lives, reducing the likelihood of serious illness and long hospital stays. This would allow hospitals to focus on the most serious illnesses and emergencies.

More health services would be provided at places like GP clinics, pharmacies, local health centres, and in people's homes. This may involve adapting or extending clinics, surgeries

and other facilities in our neighbourhoods, so that they can provide things that are mostly delivered in hospitals at the moment. Examples might include:

- *urgent treatment for minor emergencies,*
- *diagnostic scans and tests,*
- *ongoing treatments and therapies.*

Our response

The ambition to shift more care from hospitals to communities has the potential to transform the way in which children's palliative care is delivered, improving outcomes and reducing pressures on acute care. However, for this shift to be successful, key barriers preventing children with life-limiting and life-threatening conditions and their families from being able to access high quality children's palliative care at home must be addressed.

Whilst progress has been made in some areas, significant variance across England remains, particularly in children and families' access to 24/7 end of life care at home, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training).

Currently, this standard is met in only a third of integrated care board (ICB) areas, and just six ICBs explicitly state that this level of care should be provided in service specifications.

This is a serious health inequality. When families wish to be cared for at home – and it is in the best interests of the child to be there – keeping them in hospital because of a failure to invest in community-based children's palliative care represents an ineffective use of NHS resources.

The NHS 10-Year Plan offers a vital opportunity to address these disparities by tackling the challenges in funding, workforce and accountability that are causing them.

Key challenges to address

i. Workforce shortages

- Providing the bedrock of children's palliative care in the community, community children's nurses (CCNs) will be key to delivering this shift. However, there is currently a severe shortage in the number of whole-time equivalent (WTE) CCNs employed by the NHS. According to NHS Digital data in April 2024, there were 916 CCNs employed in England. Whilst this figure has increased, it still falls significantly short of the 4,963 CCNs required to meet safe staffing levels recommended by the Royal College of Nursing (RCN).
- Specialist paediatric palliative care teams will also be crucial in shifting care closer to home. With expertise in managing life-limiting and life-threatening conditions, research by Mitchell et al (2017) has found specialist paediatric palliative care to deliver many benefits such as improved quality of life, improved symptom control and an increased likelihood that a preferred place of death will be achieved.³

- However, according to research published in 2023, only 35% of consultant led specialist paediatric palliative care teams in the UK have the minimum professional configuration as recommended by NICE.⁴ Furthermore, we have estimated there are only 21.1 whole-time equivalent 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.
- Children's hospices are also facing everlasting challenges in recruiting and retaining skilled and experienced clinical staff. As we set out above, according to a recent survey by Hospice UK, children's hospices have an average vacancy rate of 14.5% in the clinical workforce. This is higher than that of the NHS in England, which had a vacancy rate of 7.5% as of 31 March 2024 within the Registered Nursing staff group.⁵

ii. **Inconsistent funding for children's palliative care from integrated care boards (ICBs)**

- According to a recent statement by a Department of Health and Social Care (DHSC) spokesperson, it is an ambition of the Department for everyone to have access to high quality end of life care. Furthermore, in recognising the importance of shifting healthcare in the community, the Department has highlighted that 'hospices will have a big role to play in this shift'.⁶
- Despite the big role envisaged for children's hospices, we are deeply concerned about the reductions and inconsistencies in ICB funding that has been witnessed over recent years.
- 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. In 2022/23, each children's hospice received an average of £524,278 from their local ICBs. However, in 2023/24, they received an average of £477,677.⁷
- As a result, ICB funding now represents about 11% of the charitable expenditure incurred by children's hospices in 2023/24, down from 13% in 2022/23.⁸
- Additionally, the amounts spent by each ICB are continuing to vary significantly. 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, the amounts spent by each ICB varied by as much as £366.42. Whilst 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.⁹
- As a result of a lack of long-term and sustainable statutory funding coupled with the increasing costs incurred when providing lifeline care to seriously ill children and their families, over a half (51%) of children's hospices ended the 2023/24 financial year with a net deficit.

iii. **Lack of accountability among integrated care boards**

- Under the Health and Care Act 2022, ICBs are legally required to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.
- Despite this statutory duty and numerous other policy imperatives, we are concerned many ICBs are falling short of meeting this legal requirement.
- From a series of freedom of information (FOI) requests, we have recently found that only 17 (41%) of ICBs have a service specification for children's palliative care. 13 (31%) ICBs do not have one at all which a further 9 have indicated that their specification is currently in development.¹⁰
- Service specifications define the standards of care expected from organisations funded to provide specialised care. It is therefore concerning to see that the majority of ICBs do not currently have a published service specification for children's palliative care. In the absence of a specific service specification, there is no guarantee providers will deliver services capable of meeting the standards of care that are required.
- Of the ICBs that did have relevant service specifications, the extent to which they met individual quality standards varied drastically. Only six (14%) ICBs had a service specification explicitly mandating that 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care should be provided. Similarly, only four (10%) ICB specifications stated that infants, children, and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care.¹¹
- The Ambitions for Palliative and End of Life Care self-assessment tool supports localities to determine the extent to which their current level of service provision aligns with the six Ambitions for Palliative and End of Life Care.
- Yet only 22 (52%) ICBs have completed an Ambitions for Palliative and End of Life Care self-assessment.¹²
- Given the role ICBs will play in helping move care from hospitals to communities, it is vital service specifications for children's palliative care are not only developed but also made to include key components of NHSE's model. Doing so would help eliminate the extent to which a child or young person's access to high quality palliative care is dependent on their postcode.

Key enablers

i. Investing in the children's palliative care workforce

- Expanding and adequately funding the children's palliative care workforce including specialist paediatric palliative care teams and CCNs, is essential to ensuring high-quality care can be delivered in community settings.

- To address shortages in the workforce, the 10-Year Plan should include the following recommendations:
 - 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.
 - Make sure that, using NHSE's children's palliative care service specification, NHSE and HEE work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible. This should include organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs), as is the case for neonatal critical care.
 - Fund education providers to implement the NHSE qualification in specialism standard for palliative and end of life care practice, career pathway and core capabilities in practice for nursing and allied health professions in full.
 - Urgently assess the gaps in the children's palliative care workforce across the range of professions who care for children with life-limiting conditions, across hospitals, children's hospices, and community services.
 - Assess the demand for nurses from children's hospice organisations and the independent sector and include it in their planning models.
 - Fund NHS trusts to create more specialist medical training posts. This would help to make sure that paediatric palliative medicine GRID and SPIN training can take place.
 - Instruct ICSs to develop action plans to make sure children with life-limiting conditions and their families are well supported by children's palliative care professionals. The NHS Long Term Plan states that children's palliative care is a priority. Statutory, voluntary, and independent sector providers will all be crucial in making sure that children with life-limiting conditions are able to access the palliative care they need. On this basis, it is vital that ICSs secure sustainable children's palliative care workforces across all of these sectors.
- We also join the Royal College of Nursing in asking for:
 - The Secretary of State for Health and Social Care to have accountability for workforce planning and supply, as part of service and financial planning.
 - The Secretary of State for Health and Social Care to undertake and publish a detailed assessment and analysis of future workforce demand and supply requirements for all health and care services across England.
 - An expansion in the number of nursing students and full financial support including abolition of self-funded tuition fees, and grants that reflect the real cost of living.

ii. Sustainable funding for children's palliative care

- In England, we have estimated there to be a significant funding gap in the provision of children's palliative care.
- Based on the specialist and core professionals that NICE state should comprise children's palliative care multidisciplinary teams – and the population that needs access to them – we estimate that the NHS should spend approximately £376 million every year to meet this standard in 2024/25.
- We believe that the NHS will spend £81 million in 2024/25, which means that there will be a £295 million funding gap in 2024/25.
- Voluntary sector providers, including children's hospices, play a critical role in delivering care within communities. However, with vacancy rates in their clinical workforce higher than those in the NHS, children's hospices are in urgent need of long term, sustainable funding.
- Only a third of children's hospices' charitable expenditure is covered by statutory funding, with the £25 million of NHSE funding accounting for 16% of that figure. This funding is therefore critical to the sustainability of children's hospices.
- It is encouraging to hear the Secretary of State for Health and Social Care confirm the grant will continue. However, with rising costs and delays in accessing funding this year, it is vital the Government confirms this funding will be:
 - Ringfenced to protect it from being diverted to other areas.
 - Centrally distributed by NHS England to avoid delays. This year, the funding was disseminated via Integrated Care Boards (ICBs) as part of a wider move to a devolved NHS, leading to significant delays for many children's hospices in accessing their 2024/25 funding.
 - Increased in line with inflation and rising costs, including the increase in employer National Insurance Contributions set to come into force next year.
- Recognising and adequately funding children's palliative care providers, including children's hospices will be essential to the success of shifting care from hospitals to communities.
- To address the systematic challenges confronting the sector, the 10-Year Plan should include the following action:
 - Commit to reviewing the way in which children's palliative care is planned and funded, including:
 - Whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of

scale.

- How the £295 million annual gap in NHS spending on children's palliative care can be filled.
 - How NHS and voluntary sector providers in England, including children's hospices, can be funded equitably and sustainably for the long-term.
- Mandate that NHSE model for each ICB how much it should be spending on children's palliative care – and then hold them to account for the extent to which they spend money for this purpose.

iii. **Utilising the Ambitions self-assessment framework to monitor progress**

- To ensure local accountability and consistency in care delivery, we call on the government to ensure that ICBs complete annual self-assessments against the Ambitions for Palliative and End of Life Care framework.
- When completed correctly, this tool can support ICBs to determine the extent to which their current level of service provision aligns with key national quality standards. This would therefore help ICBs to evaluate how well their services align against these standards and identify areas for improvement.
- By requiring ICBs to complete a self-assessment on an annual basis, we could ensure that services are continuously improving and meeting the needs of children and young people, ensuring seamless, high quality care in community settings.

2. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Shift 2: Analogue to Digital

Improving how we use technology across health and care could have a big impact on our health and care services in the future.

Examples might include better computer systems so patients only have to tell their story once; video appointments; AI scanners that can identify disease more quickly and accurately; and more advanced robotics enabling ever more effective surgery.

Our response

Together for Short Lives welcomes the NHS' commitment to digital transformation. Digital technology has the potential to enhance care coordination, reduce administrative burdens and improve access to healthcare for families caring for children with life-limiting and life-threatening conditions. However, if we are to achieve this vision, there are a number of significant barriers that will need to be addressed first.

Key challenges to address

i. Equity of access

- Families caring for disabled children face significantly higher costs compared to other families. Research by Contact has found nearly two thirds of families have had to reduce or cease work due to caregiving responsibilities, losing an average of £21,270 per year.
- These financial strains have been compounded even further by the cost of living crisis, with nearly a third reporting debt or borrowing to manage expenses between 2020 and 2021.
- Furthermore, digital exclusion remains a critical issue, particularly for low-income families. In 2023, the House of Lords Communications and Digital Committee highlighted affordability of internet access as a key barrier to greater digital inclusion.
- We are concerned some families caring for seriously ill children may be unable to afford reliable broadband, devices or assistive software, consequently limiting their ability to access remote consultations or digital health tools.

ii. Fragmented IT systems

- As an active and dynamic approach to care, children's palliative care encompasses a wide variety of care and support, consequently involving a range of services from health, social care, and education, both in the statutory and voluntary sector.
- It is therefore crucial that information about children's needs is shared between professionals and services, so that care and support is joined up around families, and so families are asked to share their story as few times as possible.
- Worryingly, this does not happen frequently enough.

iii. Unsustainable and inequitable funding for voluntary sector providers

- Voluntary sector providers, such as children's hospices, are an essential part of the health and social care system. However, a lack of equitable and sustainable funding – and a lack of clarity and consistency over the data they should collect about the volume and activity of the children's palliative care they provide – is a barrier to providers implementing digital systems that could enable effective information sharing.

Key enablers

i. Investment in digital inclusion initiatives

- To address digital exclusion, the NHS 10-Year Plan could adopt recommendations from the House of Lords Communications and Digital Committee, such as cutting

VAT on social tariffs and expanding internet voucher schemes.

- By committing to provide subsidised broadband and devices for low-income families, the 10-Year Plan would be able to address digital exclusion among families caring for seriously ill children directly.
- This would be particularly important for families relying on remote health consultations or accessing digital support services.

ii. Investing in digital infrastructure

- Developing unified, integrated digital health records, accessible across NHS and social care providers in the statutory and voluntary sectors, would streamline care and reduce the administrative burden on families.

iii. Sustainable funding for the voluntary sector

- Secure and sustainable funding for voluntary sector providers is critical for enabling digital innovation.
- Investment would allow children's hospices and similar organisations to adopt advanced technologies, integrate with NHS systems, and contribute to a more connected and efficient health and care system.
- Maintaining the children's hospice grant for years beyond 2024/25 and increasing it to reflect rising costs, including increases in employer national insurance contributions, is a key step in supporting these essential services.

3. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Shift 3: Sickness to Prevention

Spotting illness earlier and tackling the causes of ill health could help people stay healthy and independent for longer, and take pressure off health and care services.

Our response

- Parents are under increasing pressure when caring for their child with a life-limiting diagnosis, and the impact on the whole family is huge.
- Evidence shows mothers of a life-limited child are much more likely to develop serious physical and mental health problems and have a premature death, compared to mothers caring for children with no long-term health condition.¹³

- They also have a significantly higher incidence of depression, anxiety and serious mental illness, and physical conditions such as cardiovascular disease, type 2 diabetes, hypertension, and obesity.¹⁴
- Siblings are similarly impacted, and healthy children who have a terminally ill sibling, live in an environment likely to entail considerable stress, and one which has the potential to impact on the well-siblings' psychological, social, and school functioning (70% of brothers and sisters say they feel bullied and isolated).¹⁵
- Moreover, many siblings take on the role of young carer for their sibling brother or sister and, like their parents, they also live with the uncertainty of when and how their sibling will die.
- Children with life-limiting illnesses who are being cared for at home are often dependent on vital life-saving equipment such as ventilators, oxygen, and temperature control - essential medical equipment like this, and food pumps and hoists, all add up to bigger energy bills.
- Families don't have a choice and are left with spiralling costs that they simply must meet if they want to keep this life-saving equipment switched on and their child alive. 40% of families with disabled children have been forced to cut back on life-saving medical equipment for their disabled children, with 40% stating that this is making their child's condition worse.¹⁶
- For families, managing the physical, cognitive, and emotional work generated by caring for an ill child too often takes up all their energy. More and more families with terminally ill children are finding themselves in financial and emotional hardship (84% of families and carers say they feel isolated),¹⁷ and it has now become necessary for Together for Short Lives' Family Support Hub to undertake suicide awareness training given the nature of the calls they are receiving.
- Parents often have little time for themselves or for their other children and a 2023 report 'Failed and Forgotten' from the Disabled Children's Partnership highlights the impact that the lack of support is having on families of disabled children. Levels of isolation are worryingly high with 87% of parents saying their mental health has been negatively affected and 82% their physical health.
- The detrimental impact is also evident across the wider family with the same report highlighting that sibling anxiety and isolation levels are at an all-time high (69% and 67% respectively), with more than half experiencing deteriorating levels of confidence.
- The total number of young adults (aged 14-25 years) with life-limiting conditions in England grew from 27,316 in 2009/10 to 38,261 in 2017/18 – an increase of 40%.¹⁸ Despite this, there is no clear pathway for the transition from healthcare services for children and young people to adult healthcare services. Moreover, the process of transition and the subsequent transfer is often fragmented, both within and across specialties.

Key enablers

By implementing the enablers we set out in the above question 'What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?', the government and NHS England can better support preventative approaches for children with life-limiting and life-threatening conditions.

Early access to specialist care and consistent respite services can improve quality of life, reduce hospital admissions, and prevent health crises for families. Tackling these challenges and implementing these enablers will be critical in realising the NHS's vision of shifting from sickness to prevention for this vulnerable population.

4. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

- **Quick to do, that is in the next year or so.**
- **In the middle, that is in the next 2 to 5 years.**
- **Long term change, that will take more than 5 years**

Ideas for change

We're inviting everyone to share their ideas on what needs to change across the health and care system. These could be:

- *Ideas about how the NHS could change to deliver high quality care more effectively.*
- *Ideas about how other parts of the health and care system and other organisations in society could change to promote better health and/or improve the way health and care services work together.*
- *Ideas about how individuals and communities could do things differently in the future to improve people's health.*

Our response

To improve the health and care system for children with life-limiting and life-threatening conditions, targeted policy changes are needed. These must address urgent funding gaps, severe workforce shortages, and ensure accountability of integrated care boards in the commissioning of children's palliative care.

Quick to do (1-2 years)

- 1. Close the £2.4 million funding gap in in GRID and SPIN training for paediatric consultants and address shortfalls in other workforces including NHS community children's nurses.**

- By closing this funding gap, more children and young people will be able to access specialist paediatric palliative care support, thus enabling the delivery of the third shift.
 - By addressing the shortfall in the number of community children's nurses, more palliative care will be able to be delivered in the community thus facilitating the success of the first shift.
- 2. Return the £25 million for children's hospices to being a centrally-distributed, ringfenced grant and increase it to reflect rising costs and the increase in employer National Insurance contributions**
- Whilst we are encouraged by the Secretary of State's announcement that the grant will continue,¹⁹ it is vital that it reverts to being a centrally distributed funding stream. Not only is this the preference of children's hospices but it will also avoid delays, similar to those experienced this year, in distributing the funding.
 - It is also critical the grant increases to reflect rising costs. Since 2021/22, children's hospices' charitable expenditure has increased by 15%. At the same time, the statutory funding children's hospices have received has decreased significantly leaving over half of hospices with a net deficit in 2023/24.
 - The recent decision to increase employer national insurance contributions will only worsen this financial strain.
 - It is critical the Children's Hospice Grant accounts for these funding pressures and acts as a means to alleviate them.
- 3. Hold integrated care boards to greater account for implementing existing policy frameworks relating to children's palliative care. This would include requiring ICBs to complete an Ambitions for Palliative and End of Life Care self-assessment and to report on progress annually.**
- Despite numerous policy imperatives being in place to help ICBs meet their legal duty to commission palliative care that meets the needs of their local population, many are falling short. Only 17 (41%) ICBs have a service specification for children's palliative care.
 - The Ambitions for Palliative and End of Life Care self-assessment tool supports localities to determine the extent to which their current level of service provision aligns with the six Ambitions for Palliative and End of Life Care. Despite this, only 22 ICBs (52.38%) have completed an Ambitions for Palliative and End of Life Care self-assessment.
 - ICBs therefore need to be held to greater account for the way in which they implement existing policy frameworks and the Ambitions self-assessment tool offers a means to do this.

In the middle (2-5 years)

1. Review the way in which children's palliative care is planned and funded.

- By conducting a comprehensive review to examine how children's palliative care is currently planned and funded, an investigation in whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale could occur.
- Furthermore, plans should be developed for how the £295 million annual gap in NHS spending on children's palliative care can be filled, and how NHS and voluntary sector provider, including children's hospices, can be funded equitably and sustainably for the long-term.

2. Optimise the way in which the current children's palliative care workforce is used.

- Whilst additional year on year investment is required to meet the increasing demand, action can be taken to optimise and develop the existing workforce.
- By encouraging ICBs to work with neighbouring ICBs in their region to plan and fund key services, the existing children's palliative care workforce could then be used more effectively.
- Furthermore, the 10-Year Plan offers an opportunity to ensure professionals from different roles have the skills and experience to care for children and young people with life-limiting or life-threatening conditions.

Long term (5+ years)

1. Continue to invest in the children's palliative care workforce

- Even if ministers and officials take the action above, as the volume and complexity of needs of children with life-limiting conditions increases, we believe it could take years for sufficient numbers of professionals with the skills and experience needed to provide children's palliative care to be educated and recruited.
- We therefore call on the government and NHS England to continue to invest in educating and training the range of professionals needed to provide children's palliative care.

2. Continue to implement and oversee sustainable children's palliative care funding

- If ministers and officials take the actions above, children and families should be able to access children's palliative care services which are equitably and sustainably funded – and commissioned effectively across the most appropriate geographical footprints.
- If this is achieved, it is possible that the Children's Hospice Grant may no longer be needed.

3. Continue to hold ICBs to account

- The government and NHS England should make sure that ICBs conduct Ambitions self-assessments on a regular basis to show the extent to which they are meeting national guidance.

These policy changes represent a phased approach to transforming children's palliative care. Immediate funding stability, mid-term system reviews, and long-term investment in infrastructure and workforce will ensure every child with a life-limiting condition and their family receives the care they need.

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- ¹¹ **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/app/uploads/2024/06/Short-Lives-Cant-Wait-Full-Report-Updated-19-June.pdf>.
- ¹² **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/app/uploads/2024/06/Short-Lives-Cant-Wait-Full-Report-Updated-19-June.pdf>.

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