



Delivering high quality palliative care for seriously ill children in the next Parliament

General election 2019 manifesto priorities from Together for Short Lives

www.togetherforshortlives.org.uk

Executive summary

Time is short for seriously ill children. Many will not be alive when the next general election takes place. It is vital that the new Parliament acts urgently to make sure they can access the palliative care they need.

Seriously ill children can have complex and unpredictable conditions and often need round the clock care provided by their families, seven days a week. They may need palliative care from the point at which their condition is diagnosed or recognised until the end of their lives, in a mix of settings that include hospitals, their homes and children's hospices. However:

- too few children and families can choose to access palliative care at home out of hours and at weekends
- too few children's palliative care services are sustainably planned, funded or staffed
- assessments and plans are rarely joined up around children and families
- anomalies in the benefits system mean that some families miss out on crucial financial support.

This means that too many children and families are missing out on the care and support they need, when and where they need it. It also means that too many seriously ill children need unplanned, prolonged emergency hospital admissions, when their needs could potentially have been met elsewhere. As a result, the NHS is failing to achieve non-cash savings in the resources it spends on these children and their families.

The next government can help seriously ill children and their families to achieve the best possible quality of life – and make sure they receive the best possible end of life care. Together for Short Lives asks all the parties contesting the general election to commit to make sure that, by the end of the next Parliament:

1. Seriously ill children can access the palliative care services they and their families need, when and where they need it, including out of hours and at weekends.
2. Children's palliative care is funded equitably and sustainably by the NHS, local authorities and voluntary sector providers.
3. A workforce plan is in place to make sure seriously ill children can access professionals with the skills and experience needed to provide palliative care.
4. Assessments, plans and services are joined up for seriously ill children and their families across health, social care and education.
5. Seriously ill children receive the financial support they need from the benefits system.

We ask the parties to include the commitments we set out on pages 2-9 inclusive in their general election manifestos. Where we use the term seriously ill children, we refer to babies, children and young people up to the age of 25 who have life-limiting or life-threatening conditions. Background information about our suggested commitments is set out in the appendix.

As members of the Disabled Children's Partnership, we also support its manifesto asks and reflect them in this document.

The manifesto commitments we request

1. We will make sure seriously ill children can access the palliative care services they and their families need, including out of hours and at weekends.

In 2017 and 2018, the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care undertook an inquiry into the extent to which the government was meeting its end of life care choice commitment¹ to seriously ill children and their families.

Despite the commitment – which outlines six ways ministers believe that people approaching the end of their lives should be supported – the APPG heard evidence from young people, families, services and professionals that the quality of palliative care children and families could access was patchy and depended on where in England they lived. MPs and peers stated that this was unfair and represents a wholly unjustified health inequality.

The APPG's inquiry report, 'End of Life Care: Strengthening Choice'², highlighted five areas of particular concern, where many children and their families had limited access to:

- children's palliative care out of hours and at weekends
- short breaks for respite
- age-appropriate palliative care and smooth transitions to adult services
- specialist children's palliative care teams led by specialist paediatric palliative medicine consultants
- advance care planning.

We ask therefore parties to make the following manifesto commitments:

- Seriously ill children approaching the end of their lives and being cared for at home will have 24-hour access to both children's nurses skilled in providing palliative care and advice from a consultant in paediatric palliative medicine.
- Seriously ill children and their families will be involved in developing an advance care plan.
- Seriously ill children and their families will have a named medical specialist who leads and coordinates their care.
- Seriously ill children and their families will be given information about emotional and psychological support, including how to access it.
- Seriously ill children and their families will be cared for by a multidisciplinary team that includes members of a specialist children's palliative care team.

¹ Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOU5fj>

² All-Party Parliamentary Group for Children Who Need Palliative Care. 2018. End of life care: strengthening choice. Available from: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/Pol_Res_181019_APPG_Children_Who_Need_Palliative_Care_inquiry_report.pdf

- Seriously ill children and their families will be able to access regular short breaks for respite at home, in a children’s hospice or in another setting that meets their needs.
- Parents or carers of seriously ill children approaching the end of their lives will be offered support for grief and loss when their child is nearing the end of their life and after their death.
- Seriously ill young people will be able to access age-appropriate palliative care and smooth transitions to adult services.
- Seriously ill children will receive palliative care services in hospitals, homes and hospices which is planned, funded and provided by managed clinical networks (MCNs).
- To achieve these outcomes, NHS England will make it clear to local NHS organisations and local authorities what elements of children’s palliative care they are responsible for planning and funding – and how they should commission it jointly. NHS England will produce a new service specification and investment standard, making sure that commissioners are encouraged to implement them.

“Nine to five, my community nurses were amazing, but come five o’clock in the evening, you’re very alone. It’s a massively overwhelming responsibility keeping a child alive. When you’re out there on your own and you’ve got no support it’s hard – emotionally hard. If you were in hospital, it would be a consultant making those decisions. When you are at home, it’s you.”

Nikki Lancaster, mother to Lennon, who died in 2017, giving oral evidence to the All-Party Parliamentary Group for Children Who Need Palliative Care in 2018

2. We will fund children’s palliative care equitably and sustainably

On 20 June 2019, Together for Short Lives published a new report³ about the way in which children’s hospice and palliative care charities are funded by the state. It shows the money that children’s hospices must spend each year to meet the needs of seriously ill children and their families is increasing faster (4.5%) than the rate of inflation. Yet the NHS and local authorities’ overall contribution to children’s hospice charities in England fell by 3% between 2016/17 and 2018/19. It now represents just over a fifth (21%) of the money children’s hospices spend, down from 27% in 2013/14. Funding from NHS clinical commissioning groups (CCGs) fell by 2%. Funding is also very patchy and varies widely across local areas.

In addition to these challenges, NHS-provided children’s palliative care services are being funded neither equitably nor sustainably, from CCGs or directly from the NHS England specialised commissioning team. The Disabled Children’s Partnership has identified an annual £434 million deficit in the funding that local authorities in England need to meet the

3 Together for Short Lives. 2019. Statutory Funding for Children’s Hospice and Palliative Care Charities in England. Available to download from: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2019/06/190614-FINAL-Statutory-funding-for-children%E2%80%99s-hospice-and-palliative-care-charities-in-England-2019.pdf>

demand for social care for disabled children, including short breaks for respite for seriously ill children⁴.

We welcome NHS England's recent decision to ringfence and increase the Children's Hospice Grant to £25 million by 2023/24. We also welcome NHS England's commitment in the Long Term Plan to match fund the additional money that CCGs invest in children's palliative care services by up to £7 million per year. We ask the parties to make sure that these commitments are realised in the next Parliament – and go further by committing to develop a long-term, fully funded approach to planning, funding and providing palliative care to children in England in hospitals, homes and hospices.

We ask the parties to make the following manifesto commitments:

- Invest at least £200 million per year in making sure seriously ill children and families can access the palliative care they need out of hours and at weekends. This should include making sure:
 - The NHS England Children's Hospice Grant will increase to £25 million by 2023/24; it will be reallocated equitably to children's hospices.
 - All of the £7 million funding for children's palliative care committed in the NHS Long Term Plan will be matched by NHS clinical commissioning groups and fully allocated by 2023/24.
- Children with the most complex life-limiting conditions will receive specialised children's palliative care provided by the NHS and children's hospices which is funded equitably, sustainably and directly by NHS England.
- To meet the annual £434 million gap in local authority funding for social care for disabled children in England, including for short breaks for respite for seriously ill children.
- To develop a long-term, fully funded approach to planning, funding and providing palliative care to children in England in hospitals, homes and hospices; as a result, local NHS and council funding for children's hospice and palliative care charities will increase.
- To increase funding for health and social care for disabled children to meet the current funding gap; and to introduce a new innovation fund to support joined-up working and early intervention.

"I was shocked when I learnt how little Forget Me Not and other hospices like them receive from the NHS and local councils. They made sure that my family spent those years living as best we possibly could, focussed on enjoying the time we had together. Surely every family deserves the same?"

Gabriella Walker, mother to Thea, who died as a result of Niemann-Pick disease type A, in February 2019

⁴ Disabled Children's Partnership. 2019. Three 'Pillars' to deliver better support and care for disabled children and their families. Available to download at: <https://disabledchildrenspartnership.org.uk/three-pillars-to-deliver-better-support-and-care-for-disabled-children-and-their-families/>

3. We will put a workforce plan in place to make sure seriously ill children can access professionals with the skills and experience needed to provide palliative care.

As the APPG for Children Who Need Palliative Care identified in its inquiry report, there are too few professionals with the skills, knowledge and experience needed to provide children's palliative care in hospitals, children's hospices and in the community. Together for Short Lives has found the following⁵:

- There are too few community children's nurses (CCNs) employed by the NHS: CCNs provide the bedrock of children's palliative care in England. If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 5,500 CCNs would be working in England. Yet there are only 574 community children's nurses 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 this crucial part of the sector.
- There are too few specialist children's palliative care consultants: The Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 specialist children's palliative care consultants are needed in the UK. Worryingly, there are currently only 15. This suggests a significant deficit of 25-45 consultants.
- The growing nursing vacancy rate in children's hospice charities is higher than in the NHS – and posts are increasingly difficult to fill: The average vacancy rate for children's hospice charities in England is 12.2%, compared to just over 11% in 2016 and 10% in 2015. The NHS nursing vacancy rate is 11%, which is also worryingly high. Over two thirds (67%) of vacant posts are proving hard to fill (vacant for three months or more). This is an increase on the 65% who reported that posts were hard to fill in 2016, and the 57% who reported the same in 2015. A quarter (25%) of posts have been vacant for over 12 months.
- There are too few skilled children's nurses to fill vacant posts in children's hospices: Over half (58%) of children's hospices cite an overall lack of children's nurses as a significant factor in the vacancy rates they are experiencing.
- There are shortages among other health and care professionals who support seriously ill children and their families: in England, the vacancy rate for allied health professionals (AHPs, including physiotherapists, occupational therapists, and psychological therapists) is 14%. In 2018, the overall vacancy rate for children and family social workers in England was 16%.

We ask the parties to make sure that, by the end of the next Parliament, the rate of vacancies for doctors, nurses and other professionals needed to care for seriously ill children, in hospitals, children's hospices and the community, falls. We ask them to make the following manifesto commitments:

- We will urgently assess the gaps in the children's palliative care workforce.
- We will make sure there is a sustainable pathway for the training of paediatric palliative medicine specialist consultants and generalist paediatricians with an

⁵ Together for Short Lives. 2019. A workforce in crisis: children's palliative care in 2019. Available to download from: <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-palliative-care-workforce/>

interest in palliative care who have the appropriate capability to care for these complex children

- We will include the demand for professionals from children's hospice organisations and the independent sector in health workforce planning models
- We will develop a core skills education and training framework for children's palliative care; this could help employers to identify key skills for roles and teams, conduct training needs analysis and plan, design and commission appropriate levels of and systems for training. This could also ensure that robust peer review systems are established.
- We will focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.
- We will urgently fund NHS trusts to create specific medical training posts. This would help to make sure that paediatric palliative care special interest training (SPIN) can take place.
- We will make sure education providers embed children's palliative care in postgraduate medical and nursing courses; we will make sure children's palliative care is embedded in nursing courses in a way that is consistent with existing regulations.
- We will make sure that the UK's exit from the European Union does not have an adverse impact on the supply of children's palliative care professionals from across the world
- We will boost overall nursing numbers by taking the action recommended by the RCN to:
 - invest at least £1 billion a year into nursing higher education
 - invest at least £360m per year for nurses' continuing professional development
 - legislate for accountability for workforce supply and planning in England.

“My son has recently reached the continuing care threshold, so our local NHS clinical commissioning group is providing a care package for us for the next 6-8 weeks. It is a problem finding the right staff and making sure they turn up for day and night shifts.”

“We live in a rural area, and therefore it is difficult to recruit the right people to meet Fergus' needs and for him to mix with his peers and have any sort of social life. The carers we do have have to be trained by us to administer his medication and be able to feed him through his gastrostomy feeding tube.”

Gail Bedding, mother of 15 year-old Fergus, who has a condition called microcephaly

4. We will join up assessments, plans and services for seriously ill children and their families across health, education and social care

Single, joined-up education, health and care (EHC) assessments, plans and personal budgets for children and young people up to the age of 25 are only available to children and young people who have a special educational need. We are also unclear as to how the government's approach to personalising palliative care for children and young people, which is also underpinned by joint plans and budgets, correlates with the SEND system.

At both national and local level, responsibility for the support that disabled children need – including those with life-limiting conditions – sits with a range of organisations. All too often, the needs of disabled children and their families are not the priority within those services; and no-one sees it as their responsibility to ensure that services join-up and meet the needs of families.

The existing law related to disabled children and their families stems from over 10 different Acts of Parliament, regulations and guidance which have developed over the past 50 years. It is difficult for parents to navigate; and it leads to different services and agencies shifting responsibility between themselves, and with families falling between the gaps.

We ask the parties to make the following manifesto commitments:

- All seriously ill children in England will have the right to an integrated assessment, plan and personal budget.
- We will commission a review of health and social care law, to simplify and strengthen rights and entitlements for disabled children and their families, including seriously ill children.
- We will work with parents to clarify existing legal rights and entitlements.
- We will make disabled children a priority across government, at both national and local level
- We will appoint a Minister for Disabled Children.

“We’ve got four care plans...one for home, for our continuing care service. One for school and one for the community, when he goes on short breaks and working with social care. One in our hospice. If we put them all together to create a super care plan, it would be brilliant, but of course, we can’t do that because health must have theirs, education must have theirs, and that’s disappointing. We’ve been involved in writing all four of them and I just got great at cut and pasting, because I’m just giving them exactly the same information and just popping it into the forms. That’s if you can get an electronic form off them. ‘Can’t do that. Data sharing.’ Data sharing can get in the way, not only when you’re working with one service, but across services. It is used as a vehicle to act as a barrier, rather than an enabler sometimes. Absolutely recognise Data Protection Act, etc, but sometimes that can be a challenge.”

Doug Morris, father to Ben, a young man with Spinal Muscular Atrophy, giving oral evidence to the All-Party Parliamentary Group for Children Who Need Palliative Care in 2018

5. We will make sure that seriously ill children and their families receive the financial support they need from the benefits system

[Contact's 2018 'Counting the Costs' survey](#)⁶ found that families who provide long-term care for a disabled child face huge financial difficulties. This survey showed that in the preceding year, over a third of families have extra disability and care related costs of £300 or more per month. They also found that 7% of families had taken out more than five loans in the past year and that almost half (46%) the families had been threatened with court action for not paying bills. This is partly explained by the fact that 87% of families reported having caring responsibilities that mean they are unable to work as much as they would like.

Anomalies in the benefits system are preventing some seriously children and their families from accessing the financial support they deserve. We ask the parties to make the following manifesto commitments:

- Children under the age of three who rely on bulky medical equipment will have access to benefits to meet their mobility needs for the long-term.
- If a child has been diagnosed by a registered medical practitioner as being terminally ill, their application for benefits will be fast-tracked.
- We will change the way in which terminal illness is defined in the benefits system from “a progressive disease and their death as a consequence of that disease can be reasonably expected within six months” to a definition which is based on the clinical judgement of a registered medical professional – and which does not include a time limit.

“If we didn't have a wheelchair accessible vehicle for Stanley we'd be extremely limited in terms of what we could do. The vehicle helps us get out and about, giving Stanley the quality of life he deserves and helping us make amazing memories.”

Emma Murphy, mother to Stanley, who died as a result of Tay-Sachs disease in 2019, speaking before his death

About Together for Short Lives

- Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers. Together for Short Lives is the secretariat for the [All-Party Parliamentary Group \(APPG\) for Children Who Need Palliative Care](#).

Life-limiting conditions in children – and the palliative care they need

1. Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It is an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week. In 2010, there were 49,000 babies, children and young people in the UK with

⁶ Contact. 2018. Counting the costs: Research into the finances of more than 2,700 families across the UK in 2018. https://contact.org.uk/media/1395947/counting_the_costs_2018.pdf

life-limiting or life-threatening conditions⁷, including 40,000 in England. A new study is underway which will shortly provide an updated figure⁸.

2. Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services helping them, many families still have difficulties accessing the care and support they need.
3. Children with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including bereavement care after they have died. Palliative care for children includes, but is not limited to, end of life care, and the two terms should not be used interchangeably.
4. These children and their families rely on palliative care provided in hospital, children's hospices and in the community, by the statutory and voluntary sectors. Children's palliative care providers offer a range of services, including supporting families to manage their children's pain and distressing symptoms, providing children and their families with life-line short breaks and offering bereavement support both before and after the child has died.
5. Families want to be able to choose where they receive the lifeline children's palliative care services that they rely on, when they need and want them. They also want to choose who cares for their child and which treatments they receive.

For more information, please contact

James Cooper

Head of Public Affairs and Policy

0117 989 7863

07415 227 731

james.cooper@togetherforshortlives.org.uk

⁷ Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P. 2012. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24ZQw>

⁸ True Colours Trust. 2018. Making every seriously ill child count: UK-wide study to highlight the number of children with life-limiting or life-threatening conditions. Available to download from: <http://www.truecolourstrust.org.uk/making-every-seriously-ill-child-count-uk-wide-study-to-highlight-the-number-of-children-with-life-limiting-or-life-threatening-conditions/>

We will make sure seriously ill children can access the palliative care services they and their families need and want, including out of hours and at weekends.

1. NICE⁹ states that children with life-limiting conditions should be cared for by defined **multidisciplinary teams (MDT)** which include members of specialist children's palliative care teams. Children with life-limiting conditions usually receive coordinated care, provided by an MDT, which have access to medical advice provided by Level 3 children's palliative care consultants¹⁰. These consultants are able to provide elements of specialised children's palliative care, including prescribing alternative opioids and managing complex symptoms. However, NHS England states²⁰ that specialist children's palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4¹¹. We have found that, across England, this is sometimes, rarely or never the case.
2. Together for Short Lives has found that, sometimes, rarely or never¹²:
 - staff have 24/7 access to specialist advice on managing complex symptoms in children and young people
 - carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care
 - children have access to a 24-hour multi-disciplinary children's palliative care team for care within the home
 - services are delivered by a consultant-led, multi-professional specialist palliative care team across a children's palliative network or managed clinical network (MCN)
 - specialist children's palliative care teams provide clinical leadership in planning, delivering and evaluating children's palliative care services across a children's palliative network or MCN
 - care is led by a medical consultant working at Paediatric Palliative Care Competency Level 4.

⁹ The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

¹⁰ Level 3: a paediatrician (consultant or Staff or Associate Specialist (SAS) doctor) who has developed a special interest in paediatric palliative medicine, an established children's hospice doctor or GP with Special Interest (GPWSI) in paediatric palliative care. Likely to have a relevant postgraduate qualification such as the Cardiff Diploma in Palliative Medicine (paediatrics) (APPM/RCPCH, 2015).

¹¹ Level 4: a consultant paediatrician in paediatric palliative medicine, or a small number of children's hospice medical leaders (mainly leaders in sub-specialty formation and development, and with roles beyond their local hospice), and who have a substantive role in children's palliative medicine. Manage uncommon symptoms; understand principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine (APPM/RCPCH, 2015).

¹² Together for Short Lives. 2017. A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline. Available to download from: <http://bit.ly/2Kdzfnw>

3. There is a major discrepancy between services planned and funded ('commissioned') between 8am and 6:30pm Monday-Friday and services commissioned to provide care **out of hours**. 93% of clinical commissioning groups (CCGs) commission community children's nursing (CCN) teams, but just 67% commission them to provide care out of hours. Although 64% of CCGs commission services to provide community paediatricians, only 29% commission them to provide out of hours care.
4. NICE states¹³ that professionals should develop and record an **advance care plan (ACP)** at an appropriate time for the current and future care of each child or young person with a life-limiting condition. ACPs help to set out the needs and wishes of children and their families – and can help to make sure that their choices are realised.
5. The extent to which children and their families can make meaningful choices about how and where they receive palliative care – and record them on an advance care plan that all professionals who provide them with care and support plan can access – varies considerably across England. It depends on whether or not:
 - the complexity of the child's condition enables different options for how and where palliative care is provided to be offered
 - there is more than one way of meeting the child's best interests
 - a range of children's palliative care services provided in hospital, children's hospices and the community is planned, funded and delivered within a local area
 - there are enough professionals with the skills, knowledge and experience needed to provide these services in different settings and to speak to children and families about the choices available to them and develop an advance care plan with them
 - transport is available to take children from one setting to another at short notice and whether rapid discharge protocols are in place.
6. Children with life-limiting conditions and their families rely on frequent **short breaks** for respite, provided by skilled people who can meet their often complex needs. This may be for only a few hours – or overnight for a few days at a time. The 24/7 pressure on parents of having a child with a life-limiting condition is immense, so social care is vitally important to relieve this stress, catch up on sleep, spend time as a family and do the things that other families do. NICE recognises the need for short breaks in its guidance¹⁴. However, we have heard evidence from parents who have been unable to access short breaks when they needed them most. Too few CCGs and local authorities in England plan and fund short breaks for children who need palliative care and many argue about who is responsible¹⁵:
 - More than one in five (21%) local authorities are failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions

¹³ The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

¹⁴ The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

¹⁵ Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. <http://bit.ly/2MbiE4O>

- Only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities
 - Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs.
7. Where CCGs and local authorities fail to plan and fund short break services for children with life-limiting conditions, families have little alternative other than admitting their children to hospital when they reach breaking point
 8. Support for **grief and loss** can help parents or carers as well as siblings to cope before and after the death of their child. It can help with emotional and anxiety and depression, and relationship issues, and provide information on how to talk to other family members and tell them what has happened. Support for grief and loss can also provide advice on care following death, including information about post-mortems.
 9. The [NICE guideline on end of life care for infants, children and young people](#)¹⁶ recommends that children's palliative care services should be based on **managed clinical networks** (MCNs), which coordinate and the planning and provision of providing care in local areas.
 10. An MCN is "a linked group of health professionals and organisations from primary, secondary, and tertiary care, working in a coordinated way that is not constrained by existing organisational or professional boundaries to ensure equitable provision of high quality, clinically effective care . . . The emphasis . . . shifts from buildings and organisations towards services and patients¹⁷."
 11. MCNs help to build a strategic and joined-up approach to children's palliative care across health and social care services and bring together statutory and charitable providers.

We will fund children's palliative care equitably and sustainably

12. On 20 June 2019, Together for Short Lives published a new report¹⁸ about the way in which children's hospice and palliative care charities are funded by the state. It shows the money that children's hospices must spend each year to meet the needs of seriously ill children and their families is increasing faster (4.5%) than the rate of inflation. Yet the NHS and local authorities' overall contribution to children's hospice charities in England fell by 3% between 2016/17 and 2018/19. It now represents just over a fifth (21%) of the money children's hospices spend, down from 27% in 2013/14. Funding from **NHS clinical commissioning groups** (CCGs) fell by 2%.
13. Funding is also very patchy and varies widely across local areas: 15% of children's hospices receive nothing at all from their local NHS organisations. This is hitting our most vulnerable children and their families and a fifth (19%) of children's hospice

¹⁶ The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: <http://bit.ly/2ODg2hY>

¹⁷ Baker CD, Lorimer AR. Cardiology: the development of a managed clinical network. *MJ* 2000;321:1152–3

¹⁸ Together for Short Lives. 2019. Statutory Funding for Children's Hospice and Palliative Care Charities in England. Available to download from: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2019/06/190614-FINAL-Statutory-funding-for-children%E2%80%99s-hospice-and-palliative-care-charities-in-England-2019.pdf>

charities are cutting vital short breaks for respite. There is overwhelming public support for children's hospices to receive more money: a recent YouGov survey found that 78% of the public think that children's hospices receive too little funding from statutory sources.

14. Paragraph 3.41 of the NHS Long Term Plan¹⁹ states:

“Children’s palliative and end of life care is an important priority for the NHS. But local NHS funding has not kept pace with growth in clinical care costs or inflation, and NHS England’s children’s hospice grant programme currently provides an annual contribution of £11m. Over the next five years NHS England will increase its contribution by match-funding clinical commissioning groups (CCGs) who commit to increase their investment in local children’s palliative and end of life care services including children’s hospices. This should more than double the NHS support, from £11 million up to a combined total of £25 million a year by 2023/24.”

15. Together for Short Lives has welcomed NHS England’s subsequent decision to ring fence £25 million of NHS funding to support children’s hospices through the **Children’s Hospice Grant** by 2023/24, increasing annually from this year’s baseline of £12 million.
16. This welcome pledge will take the pressure of children’s hospices and better enable them to plan and deliver lifeline care and support to some of England’s most seriously ill children.
17. NHS England also says that it recognises that palliative care services provided by children’s hospices are currently not universally available. It plans to carry out a needs assessment to understand whether additional investment nationally or from CCGs is required where children’s palliative care is provided by other, non-hospice services.
18. The funding will provide much-needed confidence that will enable children’s hospices to maintain and deliver their services to seriously ill children, and in doing so help reduce pressure on the NHS, keeping children out of hospital longer and supporting the wider family.
19. Seriously ill children with the most complex symptoms need **specialised children’s palliative care**. NHS England states²⁰ that specialised children’s palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4. These consultants are vital because they:
- can manage uncommon symptoms
 - are able to advise on medical support for which there is no evidence base
 - lead and develop services within and beyond a local children’s hospice
 - support and teach other professionals who are not trained in palliative medicine.

19 NHS England. 2019. The NHS Long Term Plan. Available to download from: <https://www.longtermplan.nhs.uk/>

20 NHS England. 2013. E03/S/h – 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A – service specifications. Available to download from: bit.ly/11yjtVS

20. However, across England, specialist children's palliative care teams are only sometimes led by Level 4 consultants²¹.
21. Specialised children's palliative care services should be directly commissioned by NHS England. However, we do not believe that these services are being planned and funded equitably and sustainably, either in NHS tertiary centres or in children's hospices.
22. The Disabled Children's Partnership estimates that, every day, disabled children in England are missing out on £1.2 million of social care support from local councils²². This is preventing disabled children achieving positive outcomes that they can reasonably expect. It is also driving their families into the ground as they struggle to access the support they need, including lifeline **short breaks for respite**. In a recent survey, the Disabled Children's Partnership asked parents how this lack of support has had an impact on their lives. DCP found that only 4% of parent carers feel they get the right support to safely care for their disabled children and more than half of parent carers have been treated by a GP for depression, anxiety or stress. The DCP are now asking that £434 million of support owed to disabled children is given back; this presents a clear opportunity for the incoming Chancellor of the Exchequer to give this money to local councils so that they can properly fund social care for disabled children.

We will put a workforce plan in place to make sure seriously ill children can access professionals with the skills and experience needed to provide palliative care

23. The number of children with life-limiting conditions who are likely to need palliative care is growing. Worryingly, however, too few children's palliative care services in England are sustainably staffed. This means that too many children and families are missing out on the care and support they need, when and where they need it. There is a children's palliative care workforce crisis²³:
 - **There are too few community children's nurses (CCNs) employed by the NHS:** CCNs provide the bedrock of children's palliative care in England. If safe staffing levels recommended by the Royal College of Nursing (RCN) were being adhered to, 5,500 CCNs would be working in England. Yet there are only 574 community children's nurses 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 this crucial part of the sector.
 - **There are too few specialist children's palliative care consultants:** The Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 specialist children's palliative care consultants are needed in the UK. Worryingly, there are currently only 15. This suggests a significant deficit of 25-45 consultants.
 - **The growing nursing vacancy rate in children's hospice charities is higher than in the NHS – and posts are increasingly difficult to fill:** The average vacancy rate for children's hospices charities in England is 12.2%, compared to just over 11% in

²¹ Together for Short Lives. 2017. A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline. Available to download from: <http://bit.ly/2Kdzfnw>

²² Disabled Children's Partnership. 2018. £1.5 billion funding gap for services for disabled children. Available at: <https://disabledchildrenspartnership.org.uk/1-5-billion-funding-gap-for-services-for-disabled-children/>

²³ Together for Short Lives. 2019. A workforce in crisis: children's palliative care in 2019. Available to download from: <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-palliative-care-workforce/>

2016 and 10% in 2015. The NHS nursing vacancy rate is 11%, which is also worryingly high. Over two thirds (67%) of vacant posts are proving hard to fill (vacant for three months or more). This is an increase on the 65% who reported that posts were hard to fill in 2016, and the 57% who reported the same in 2015. A quarter (25%) of posts have been vacant for over 12 months.

- **There are too few skilled children's nurses to fill vacant posts in children's hospices:** Over half (58%) of children's hospices cite an overall lack of children's nurses as a significant factor in the vacancy rates they are experiencing.
- **There are shortages among other health and care professionals who support seriously ill children and their families:** in England, the vacancy rate for allied health professionals (AHPs, including physiotherapists, occupational therapists, and psychological therapists) is 14%. In 2018, the overall vacancy rate for children and family social workers in England was 16%.

24. These workforce shortages are having a negative impact on the palliative care that seriously ill children and families are able to access:

- Parents of seriously ill children with personal budgets have told us how difficult they find it to employ the staff their children need. Despite being assessed as needing 24-hour support by the NHS, some children and young people cannot access it because they cannot find carers to have the skills to provide it.
- Some parents of seriously ill children have told us that their access to vital short breaks for respite have been cut as a result of workforce shortages; some providers have confirmed this.
- The RCPCH has stated that a lack of access to fully trained specialists for advice and support is resulting in a lack of equitable and standardised clinical practice.

25. In September 2019, the Chancellor of the Exchequer announced a £210 million package of measures designed to better educate and train NHS staff. This included funding for a £1,000 personal development budget for every nurse, midwife and allied health professional to support their personal learning and development needs over three years.

26. Despite this, Together for Short Lives is concerned by the extent to which the government, NHS England and NHS Improvement, Health Education England and universities in England are taking the action needed to address the shortfall in children's palliative care professionals:

- There is no evidence to suggest that Health Education England (HEE) has made any strategic plans to address the current workforce crisis in children's palliative care across the NHS. Additionally there is no parallel assessment of the shortages in voluntary sector children's palliative care sector (medical and nursing) clinical workforce in modelling the demand for appropriately skilled professionals. While we welcome the competency framework for end of life care which HEE commissioned and which Skills for Health and Skills for Care published in 2017, we are concerned that it only relates to care for adults who are likely to die within the next 12 months.
- We are concerned that a paucity of education, learning and development opportunities specific to children's palliative care is hindering local access to quality training.

- There is a lack of training posts available for specialist paediatric palliative medicine consultants, nor is there additional training opportunity available to give general paediatricians specialist interest training in children's palliative care. This is being caused by a dearth of funding for these posts from NHS England and NHS Improvement's specialised commissioning team.
27. Overall, the RCPCH has identified what it considers to be an incoherent and inconsistent approach to planning for the child health workforce²⁴. The RCN has identified the lack of legislation on safe nurse staffing as a barrier to establishing in law who is accountable for safe patient care²⁵.
28. Together for Short Lives welcomes the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'²⁶, a group of individuals and organisations committed to working together and sharing good practice and resources. This collaborative aims to improve the healthcare of children with medical complexity and their families – and provide support and educational materials for the professionals looking after them.
29. We also welcome the work of the Children's Palliative Care Education and Training National Action Group. This is supporting work to design, develop and manage a sustainable, standardised approach to educating and training children's palliative care professionals in the UK. We ask HEE and the Council of Deans of Health to work with us to make sure that this approach becomes embedded in education and training for all children's palliative care professionals in England.
30. We believe that the government, HEE and others have a vital role to play helping to reduce the vacancy rates among key groups of children's palliative care professionals – and making it easier for providers to recruit the staff they need. To make sure that seriously ill children and their families are well supported by children's palliative care professionals, Together for Short Lives calls on ministers to end the children's palliative care workforce crisis by making sure the following measures are included in the NHS People Plan:
1. HEE to:
 - urgently assess the gaps in the children's palliative care workforce
 - make sure there is a sustainable pathway for the training of paediatric palliative medicine specialist consultants and generalist paediatricians with an interest in palliative care who have the appropriate capability to care for these complex children.
 - specifically include the demand for professionals from children's hospice organisations and the independent sector in their planning models
 - develop a core skills education and training framework for children's palliative care; this could help employers to identify key skills for roles and teams, conduct

²⁴ Royal College of Paediatrics and Child Health. 2018. Workforce briefing. Available to download from: <https://www.rcpch.ac.uk/resources/workforce-briefing-2018>

²⁵ Royal College of Nursing. 2019. Public urged to pressure government to fix the nursing workforce crisis. Available to download from: <https://www.rcn.org.uk/news-and-events/news/uk-safe-staffing-public-campaign-launch-170919>

²⁶ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

training needs analysis and plan, design and commission appropriate levels of and systems for training. This could also ensure that robust peer review systems are established.

- focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.
2. NHS England and NHS Improvement specialised commissioning team and Health Education England to urgently fund NHS trusts to create specific medical training posts. This would help to make sure that paediatric palliative care special interest training (SPIN) can take place.
 3. Education providers to make sure that children's palliative care is embedded in 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.
 4. The government to:
 - make sure that HEE has the resources to invest in the medical, nursing and allied health workforce and take the action we call for above
 - make sure that the UK's exit from the European Union does not have an adverse impact on the supply of children's palliative care professionals from across the world
 - boost overall nursing numbers by taking the action recommended by the RCN to:
 - invest at least £1 billion a year into nursing higher education
 - invest at least £360m per year for nurses' continuing professional development
 - legislate for accountability for workforce supply and planning in England.

We will join up assessments, plans and services for seriously ill children and their families across health, education and social care

31. Perhaps more so than for any other population group, joined-up care and support is crucial for children with life-limiting conditions and who need palliative care. We know from evidence that a disjointed system of care presents many challenges for families of children with life-limiting conditions. Because their conditions are often so complex, these families must typically liaise with around 30 different professionals from education, social care, health and other services.
32. All the evidence suggests that the best outcomes for children with life-limiting conditions and their families are achieved when there is effective partnership working between parents and services, with care co-ordinated around the needs of the family.
33. We support the aspirations of the special educational needs and disability (SEND) system in England; we believe it has great potential to join-up assessments, plans and services across education, health and social care for children with life-limiting conditions.

34. However, we are concerned that the government's vision for the SEND system is not being realised for children with life-limiting conditions. We note that children with life-limiting conditions – and professionals and services who provide palliative care – feel that the changes to SEND support have not substantially or adequately changed as a result of the reforms.
35. Families say they feel frustrated by the system. They have said that frequently they are not consulted early enough in the process and that when they disagree with the education, health and care (EHC) plan it is difficult to make the required changes. There is inconsistency in the way rules are applied between different areas, with families and children with life-limiting conditions experiencing different levels of engagement in assessment. There still seems to be pressure on parents to bridge these gaps themselves.
36. Some within the voluntary children's palliative care provider sector feel that EHC plans still do not contain enough insight from health and social care. They feel that, while some good assessments are being carried out, they are predominantly focused on educational need and do not reflect a holistic view of the young person's need.
37. There appears to be geographical variation in the success of joint working. We are seeing patchy provision between geographical areas and many members mentioned social care as being particularly challenging to integrate.
38. CCGs and local authorities have a legal duty to jointly commission services for disabled children, including those with life-limiting conditions, under the Children and Families Act 2014. Section three of the [SEND Code of Practice](#)²⁷ sets out in detail what local areas must and should do to jointly commission services for children and young people aged 0-25 with special educational needs and disabilities (SEND).
39. Despite this, in response to a series of freedom of information (FOI) requests issued by Together for Short Lives in 2017²⁸, only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities²⁸. Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs. Together for Short Lives has produced guidance for CCGs and local authorities on jointly commissioning palliative care for children and young people²⁸.
40. We are also concerned that local authorities are not meeting their statutory duty to assess the needs of parent carers (section 97 of the Children and Families Act).
41. The overall legal framework for health and social care for disabled children, including those with life-limiting conditions, is complex. It stems from more than ten different acts of Parliament, regulations and guidance which have developed over the past 50 years. While the 2014 Children and Families Act made important changes to the law which we welcome, it did not remove this complexity. The joint commissioning duties were intended to address this, by ensuring that arrangements are in place to resolve disputes between agencies. Instead, we are increasingly seeing parents forced to take legal action to protect services and clarify legal responsibilities.
42. We are also concerned that young people between the ages of 18 and 25 who may move in and out of education, or leave education altogether, will not have access to a single EHC plan and may lose access to support; this would include many young people

27 Department for Education. 2014. Special educational needs and disability code of practice: 0 to 25 years. Available to download from: <http://bit.ly/1kOCi5j>

28 Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. <http://bit.ly/2MbiE4O>

who need palliative care and, owing to the complexity of their conditions, do not continue in education.

We will make sure that seriously ill children and their families receive the financial support they need from the benefits system

Mobility payments for children under the age of three

43. Children with life-limiting and life-threatening conditions often depend on ventilators, large equipment or other types of technology to stay alive. This equipment is big and heavy. Some babies and young children have permanent wheelchairs and are not able to use buggies suitable for well children of the same age. These wheelchairs are heavy because of the equipment and need to be fixed to a vehicle
44. These children require specialist, adapted or broad base vehicles for transport which, without financial support, are often beyond the reach of their families. For families of children with life-limiting and life-threatening conditions 64% of mothers and 24% of fathers will need to give up work and this, combined with the extra costs of caring for a seriously ill child means that many families will live in poverty.
45. Children who depend on life-sustaining equipment must be attached to it at all times. It is extremely difficult to lift children who depend on this equipment in and out of car seats and there is a significant risk that they can be accidentally disconnected. For example, a child with a complex condition who is on high level ventilation must have the following equipment at all times:
 - A ventilator which is attached to them.
 - A spare ventilator nearby which includes a back-up battery.
 - A monitor to measure the child's oxygen saturation which provides alarms and vital monitoring.
 - An oxygen supply and mask in case the child suddenly collapses.
 - A tracheotomy emergency bag including spare tubes; this is vital in case one of the tubes in use becomes blocked, a scenario which can have catastrophic consequences for the child.
46. Disability living allowance (DLA) is available to all families who incur extra costs as a result of meeting the additional care and/or mobility needs of a disabled child.
47. However, children can only receive the higher rate mobility component of DLA from three years of age and the lower rate mobility component from five years of age. This is predicated on the views of medical advisors, [who advised DWP that the majority of children could walk at the age of 2½ and so by the age of 3 it was realistically possible in the majority of cases to make an informed decision as to whether an inability to walk was the result of disability](#)²⁹.
48. A freedom of information (FOI) request made of the Department for Transport in March 2017 showed that there are 2,307 children under the age of three who are dependent

²⁹ Written Question (13360) asked by Dr Sarah Wollaston MP on 26 October 2015. Answered by Justin Tomlinson MP. Available at: <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2015-10-26/13360/>

upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment' who have a blue parking in England. We made similar FOI requests of the Northern Ireland Department for Infrastructure, all Scottish local authorities and the Welsh Government. From these, we found that there are:

- 84 children in this category in Northern Ireland
- 255 in Scotland
- 135 in Wales.

49. If all were accessing the higher rate mobility component of £59.75, this would be an annual weekly investment of £166,164.75 - or £8,640,567 per year.
50. In January 2018, the former Work and Pensions Secretary Rt Hon Esther McVey MP confirmed that after direction from her department, Motability had begun now piloting a scheme to help children under the age of three who were not eligible for the mobility component of child disability living allowance but who relied on bulky medical equipment.
51. The scheme drew on the expertise and discretion of the Family Fund in order to determine which children were eligible. The Department of Work and Pensions stated that one of the key aspects of the pilot scheme will be to collect additional data to help officials better understand the extent and needs of this group of children. It would help to assess whether the scheme is was targeted - and hopefully provide valuable insight to help inform future government policy.
52. Together for Short Lives is delighted that Family Fund and Motability piloted this scheme, which helped some babies and young children under the age of three - and their families - access the specialist vehicles they needed to leave home or hospital.
53. As the pilot has now concluded, we would like these specialist vehicles - and an equivalent mobility payment to those families who do not drive - to be made available to all 2,768 children in the UK under the age of three who depend on bulky medical equipment. We call on the next government to make funding available to achieve this.

The way in which terminal illness is defined within the benefits system

54. We believe that the current legal definition of being terminally ill is unsuitable and obstructs children with life-limiting or life-threatening conditions from accessing financial support in a timely manner at the point they and their families most need it. We ask that the definition adopted by the Scottish Government, which allows fast-tracked benefit access without the requirement of a time-limit, should be similarly introduced in the rest of the UK.
55. Thanks to changes in medicine and clinical support, children with life-limiting and life-threatening conditions are living longer. However, conditions are still unpredictable and can worsen suddenly and unexpectedly.
56. It is important to acknowledge that following diagnosis or recognition, the trajectory of a child's illness or condition is unpredictable. Irreversible but non-progressive conditions causing severe disabilities can put children at a high risk of an unpredictable life-threatening event or episode, but may not fall within the current legal definition of a terminal illness.

57. Children with life-limiting or life-threatening conditions are likely to have a number of periods in which their health deteriorates, followed by a recovery. It is important that the variability and unpredictability of these conditions is recognised in the legal definition of terminal illness, as related to access to fast-track access to benefits, so that no families are left behind. A definition which includes a time-limit is therefore not appropriate for children.
58. Together for Short Lives supports the recent decision by the Scottish Government to remove any time-restriction from disability assistance applicants with a terminal illness. Under the Social Security (Scotland) Act 2018, the definition of terminal illness for the purpose of disability assistance will be based on the clinical judgement of a registered medical professional, removing any time restriction.
59. This clinical judgment will be based on guidance to be issued by the chief medical officer (CMO) and will enable registered medical practitioners to make a clinical judgement about whether an illness is regarded as terminal, for the purpose of accessing disability assistance.
60. Together for Short Lives would like to see a similar definition adopted in the rest of the UK so that families of children with life-limiting or life-threatening conditions are able to access crucial financial support. We recognise that guidance on the definition would need to be issued and would welcome the opportunity to respond to a consultation on the details of this.
61. Removing this time restriction will help protect families from building a 'debt legacy' when trying to meet the extra costs associated with care and would recognise the immediate financial pressures that families find themselves facing.
62. The extra costs and financial pressures faced by families caring for children with life-limiting or life-threatening conditions is significant, regardless of how long that child is expected to live.
63. [Contact's 2018 'Counting the Costs' survey³⁰](#) found that families who provide long-term care for a disabled child face huge financial difficulties. This survey showed that in the preceding year, over a third of families have extra disability and care related costs of £300 or more per month. They also found that 7% of families had taken out more than five loans in the past year and that almost half (46%) the families had been threatened with court action for not paying bills. This is partly explained by the fact that 87% of families reported having caring responsibilities that mean they are unable to work as much as they would like.
64. Additionally, the survey found that:
- 26% of parents said their child's condition has worsened due to going without basics
 - 33% have taken out a loan to pay for food
 - 26% of disabled children are going without essential therapies.
65. Delayed access to benefits and financial support is intolerable for any of these families, regardless of how long children are expected to live, and can contribute to a debt legacy which may remain for years following the death of a child.

³⁰ Contact. 2018. Counting the costs: Research into the finances of more than 2,700 families across the UK in 2018. https://contact.org.uk/media/1395947/counting_the_costs_2018.pdf

66. Together for Short Lives would like the definition of a terminal illness – for the sake of benefit applications – to be changed from “a progressive disease and their death as a consequence of that disease can be reasonably expected within six months” to one which is based on the clinical judgement of a registered medical professional – and which does not include a time limit.
67. Together for Short Lives would welcome an opportunity to work with the Department of Health and Social Care and the Department for Work and Pensions to help shape any guidance which is developed to help clinicians determine whether a child or young person is terminally ill.