

14 January 2021

How Budget 2021 can build back better for seriously ill children and their families

A representation from Together for Short Lives

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 families, children hospices, voluntary sector organisations and statutory service providers.

Executive summary

- 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. As a result of the pandemic, families of seriously ill children are exhausted after months of providing often complex care at home without access to many of the vital services they rely on. However:
 - too few parents and families can access much needed short breaks for respite due to a £434 million funding gap that exists for local authorities; the impact of losing regular care and support as a result of the pandemic on families of seriously ill children means that many are now at breaking point. Many need respite urgently.
 - too few children and families can choose to access palliative care at home out of hours and at weekends; too often, this depends on the areas where children and families live.
 - 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.
- Together for Short Lives welcomed the announcement from the Chancellor at Spending Review 2020 which enabled local authorities to access over £1 billion of spending for social care through £300 million of social care grant. However, the situation remains that several key areas of the children's palliative care sector are in need of targeted government investment in order to ensure the sustainability of these lifeline services for seriously ill children.

- Budget 2021 can level the system up for seriously ill children and their families. Ministers have an opportunity to improve the outcomes these families experience from public services – and deliver on existing commitments that this government has made to them. We ask the Chancellor of the Exchequer to make a series of targeted investments which help to make sure that:
 - children’s palliative care is funded equitably and sustainably by the NHS, local authorities and voluntary sector providers
 - 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
 - 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
 - seriously ill children receive the financial support they need from the benefits system.
- To achieve this, we ask the Chancellor to make the following commitments in the Budget 2021:
 1. **Meet the annual £434 million gap in local authority funding for social care for disabled children in England.** Local authorities could use this funding to make sure that short breaks for respite for families of seriously ill children, including those provided by children’s hospices, were sustainable for the long-term.
 2. **Establish a £41 million Disabled Children’s Innovation Fund.** An innovation fund model would provide financial backing to organisations delivering ground-breaking support and approaches in early intervention. The Fund would promote whole-family care, with a long-term view to ‘scaling up’ successful programmes into sustainable provision.
 3. **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 also include funding for core children’s palliative care provided by NHS and voluntary sector-provided community children’s nursing, community paediatrics and allied health professionals. It should also include making sure children with the most complex life-limiting conditions receive specialised, consultant-led children’s palliative care provided by the NHS and children’s hospices which is funded equitably, sustainably and directly by NHS England.
 4. **Give Health Education England the resources it needs to help end the children’s palliative care workforce crisis,** enabling it 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
 - focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children’s palliative care nurses.

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

- children under the age of three who rely on bulky medical equipment need access to benefits to meet their mobility needs for the long-term; in November 2020, the Social Security Advisory Committee recommended that the government consider extending the higher rate disability living allowance (DLA) mobility component to children under the age of three.
- 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.
- These initiatives would help the government to achieve the commitment that the Conservative Party made on page 11 of its 2019 general election manifesto to “support our precious hospices”. They would also help the government to deliver important elements of the NHS Long Term Plan; for example, paragraph 3.41 states that children’s palliative and end of life care is an important priority for the NHS.
- Time is short for seriously ill children; some will not live beyond the end of this pandemic, which has had a profound impact upon them and their families. It is vital that the government builds back better at Budget 2021 by investing in the palliative care they need.

Our representation

Meet the annual £434 million gap in local authority funding for social care for disabled children in England by creating an annual ringfenced grant – and establish a £41 million Disabled Children’s Innovation Fund

1. Children with life-limiting conditions – and their families – rely on frequent short breaks for respite. The pressure on parents of having a child with a life-limiting condition is immense, so short breaks which can meet their often complex physical, emotional, social and spiritual needs are vitally important to relieve this stress, spend time as a family and do the things that other families do. These are provided by a range of statutory and voluntary sector organisations, including children’s hospice and palliative care charities.
2. Short breaks for seriously ill children are proven to reduce the risk of their parents experiencing poor mental health. In October 2020 Together for Short Lives and Julia’s House Children’s Hospice published a report¹ with new evidence from Pro Bono Economics, in association with volunteers from Compass Lexecon. The evidence found that 11% of parents of children who need short breaks delivered by children’s palliative care providers would experience a significant reduction in stress if they received them.
3. This builds on prior research by Julia’s House Children’s Hospice and Bournemouth University which found that most parents (74%) rated short breaks provided by children’s hospices as having a direct, positive effect on their relationship with a partner. The other 26% all spent that time in other restorative ways.
4. The new research also finds that reduced stress leads to better physical health among parents, leading to fewer GP visits. Demand for GP services declines by 8% as a result of an individual moving out of the most stressed category.
5. Reduced stress also leads to better mental health among carer parents, which in turn reduces the use of mental health services. Demand for mental health services falls by 49% as an individual moves out of the most stressed category.
6. Improved work attendance can be measured in reduced number of sick days taken, which leads to increased productivity and tax revenue. For every working parent who experiences a reduction in stress, it is likely that this will reduce the number of days taken off work by around 2-3 days per year.
7. Pro Bono Economics have calculated the total potential benefits to taxpayers from delivering short breaks to all parents of seriously ill children in the UK who need them from children’s palliative care providers could be in the region of £5 million per year. However, they also found that this could be in the range of £3.7 million and £13.8 million depending on assumptions on the impact of short breaks on stress levels.
8. **These savings do not count the huge extra costs that the state incurs result of the breakdown of parental relationships, parents being unable to work and the impact on siblings associated with a lack of access to short breaks.**
9. Existing legislation and government policy is clear that local councils in England should ensure families can access short breaks. The NHS Long Term Plan sets out the need to

¹ Together for Short Lives and Julia’s House Children’s Hospice. 2020. Give Me A Break. Available to download from: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2020/10/Together-for-Short-Lives-and-Julias-House-Give-Me-a-Break-report.pdf>

maintain the mental health of both children and adults. Regulations set out how local councils in England must provide breaks from caring for carers of disabled children.

10. However, too few local authorities in England plan and fund short breaks for children who need palliative care. The Disabled Children's Partnership (DCP), which Together for Short Lives is part of, has found that even before the COVID-19 pandemic, the core services that families with disabled children relied on were being squeezed more than ever. Families struggling with the impact of cuts were often only being offered support once they reached crisis point. **Only 38% of families of disabled children were getting support from their local council or NHS such as a short break (respite) to help care for their child prior to the lockdown.** This is a serious health inequality.
11. The way in which short breaks for seriously ill children are planned, funded and provided is patchy and unsustainable. For example, average funding for children's hospices in England from local authorities was cut by 12% between 2018/19 and 2019/20. Children's hospices received an average of just £53,800 from their local authorities in 2019/20. This represented just 1% of their average charitable expenditure. More widely, there is a £434 million funding gap in social care services for disabled children. As Together for Short Lives has also previously found, there too few professionals with the skills, knowledge and experience needed to provide short breaks.
12. As the UK experiences the second wave of the COVID-19 pandemic, short breaks are more important than ever. Research by the Martin House Research Centre, Together for Short Lives and the University of Southampton² found that, during the first phase of the pandemic:
 - 93% of families of seriously ill children felt isolated
 - 59% had struggled to get nursing support during the pandemic
 - 66% struggled with in-home care
 - 86% had experienced difficulties accessing therapies like physio for their child.
 - 95% were worried about nurses or carers coming into their own home.
13. Parents remain anxious. Many are at breaking point having been forced to provide 24/7 care to their seriously ill child for several months without the support they previously relied on. Many children still cannot access education settings because too few professionals have the guidance they need to manage the infection risks created by undertaking complex aerosol generating procedures (AGPs) in schools and colleges.
14. It is vital that short break providers are given equitable and sustainable funding now. Only by doing so can we make sure that families are able to access the breaks they urgently need.

With our fellow members of the Disabled Children's Partnership, Together for Short Lives calls on the government to:

² Martin House Research Centre, Together for Short Lives and the University of Southampton. 2020. Forgotten families: Families feel more isolated than ever under lockdown. Available to download from: <https://www.togetherforshortlives.org.uk/forgotten-families-families-feel-more-isolated-than-ever-under-lockdown/>

- Fill the £434 million disabled children’s social care funding gap in England by creating an annual ringfenced disabled children’s grant. From this, local authorities would be able to make an equitable and sustainable funding contribution for short breaks for seriously ill children.
- Establish a £41 million Disabled Children’s Innovation Fund. This would provide financial backing to organisations delivering ground-breaking support and approaches in early intervention, such as short breaks for respite.

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

15. In England, 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.

16. NICE³ 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 consultants⁴. These consultants are able to provide elements of specialised children’s palliative care, including prescribing alternative opioids and managing complex symptoms. However, NHS England states¹² that specialist children’s palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4⁵. We have found that, across England, this is sometimes, rarely or never the case.

17. Together for Short Lives has found that, only sometimes, rarely or never⁶:

- 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

³ 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>

⁴ 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).

⁵ 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).

⁶ 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>

- 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.
18. NICE states⁷ 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.
19. 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 ACP 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
20. 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.
21. The [NICE guideline on end of life care for infants, children and young people](#)⁸ 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.
22. 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

⁷ 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>

⁸ 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>

quality, clinically effective care . . . The emphasis . . . shifts from buildings and organisations towards services and patients⁹.”

23. 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.
24. On 20 June 2019, Together for Short Lives published a new report¹⁰ 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%.
25. 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 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.
26. Paragraph 3.41 of the NHS Long Term Plan¹¹ 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.”
27. 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.
28. 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.
29. 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.
30. 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

⁹ Baker CD, Lorimer AR. Cardiology: the development of a managed clinical network. MJ 2000;321:1152–3

¹⁰ 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>

¹¹ NHS England. 2019. The NHS Long Term Plan. Available to download from: <https://www.longtermplan.nhs.uk/>

pressure on the NHS, keeping children out of hospital longer and supporting the wider family.

31. Seriously ill children with the most complex symptoms need **specialised children's palliative care**. NHS England states¹² 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
32. However, across England, specialist children's palliative care teams are only sometimes led by Level 4 consultants¹³.
33. 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.
34. In December 2016, the National Institute for Health and Care Excellence (NICE) published a clinical guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'.¹⁴ NICE calculate that by investing in implementing the guidance, net non-cash savings would be released back into the NHS in England.¹⁵

Together for Short Lives calls on the government to:

- Invest at least £200 million in order to make key improvements to the care of children with life-limiting and life-threatening conditions – therefore making sure children can access the care they need at weekends and out of hours.

Help end the children's palliative care workforce crisis

35. The number of children with life-limiting conditions are 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 crisis¹⁶:

¹² 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

¹³ 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>

¹⁴ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available to download from: <http://bit.ly/2g9nIWA>.

¹⁵ NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management 'Resource Template'. Available to download from <http://bit.ly/2k4V2jZ>. This figure for the whole of England was calculated using the 'Population & resource summary' tab.

¹⁶ 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/>

- **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 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%
36. 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
37. 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.
38. 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

39. Overall, the RCPCH has identified what it considers to be an incoherent and inconsistent approach to planning for the child health workforce¹⁷. 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 care¹⁸.

40. Together for Short Lives welcomed the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'¹⁹, 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.

41. We also welcomed 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.

42. 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

¹⁷ Royal College of Paediatrics and Child Health. 2018. Workforce briefing. Available to download from: <https://www.rcpch.ac.uk/resources/workforce-briefing-2018>

¹⁸ 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>

¹⁹ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

care workforce crisis by making sure the following measures are included in the NHS People Plan:

- 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
 - focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses
- NHS clinical commissioning groups (CCGs) 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
- 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

Together for Short Lives call on 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.

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 disability²⁰](#).
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 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.

²⁰ 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/>

49. If all were accessing the higher rate mobility component of £62.25, this would be an annual weekly investment of £173,117.25 - or £9,002,097 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 (DWP) 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. We are also pleased that an extended Family Fund Mobility Support pilot scheme, provided by Family Fund and Motability, is available to help families raising a disabled or seriously ill child under three years old meet their mobility needs²¹. However, we note that the scheme is only open to families who meet Family Fund eligibility criteria (including income criteria).
53. In November 2020, the Social Security Advisory Committee [published a report](#)²² of its study into the use of public funds in supporting the mobility needs of disabled people. The committee recommended that DWP consider extending the higher rate DLA mobility component to children under the age of three. The relevant passages are on pages 8 and 9 of the report.

Together for Short Lives calls on the government to:

- We would like 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, or need to be near their vehicle in case they need emergency medical treatment.
- To enable this, we ask the government to extend the higher rate DLA mobility component to all of these children.

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.

²¹ Family Fund. 2020. Family Fund Mobility Support. Available online at: <https://www.familyfund.org.uk/mobilitysupport>

²² Social Security Advisory Committee. 2020. The use of public funds in supporting the mobility needs of disabled people: a study by the Social Security Advisory Committee; Occasional Paper No. 23. Available online at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/935743/ssac-occasional-paper-23-mobility-needs-of-disabled-people.pdf

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 they 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 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' survey](#)²³ 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.

²³ 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

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.

Together for Short Lives calls on the government to:

- Change the definition of a terminal illness – for the sake of benefit applications – 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. 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.

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