

7 February 2020

Budget 2020

Representation from Together for Short Lives

Executive summary

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. Together for Short Lives is the secretariat for the [All-Party Parliamentary Group \(APPG\) for Children Who Need Palliative Care](#).

The challenges facing children who need palliative care and their families

- Time is short for seriously ill children. Some will not be alive when the next Budget 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.

How Budget 2020 can help

- Budget 2020 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. We ask the Chancellor of the Exchequer to make a series of targeted investments which help to make sure that:

- 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
- Children's palliative care is funded equitably and sustainably by the NHS, local authorities and voluntary sector providers
- 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
- Assessments, plans and services are joined up for seriously ill children and their families across health, social care and education
- Seriously ill children receive the financial support they need from the benefits system
- To achieve this, we ask the Chancellor to make the following eight commitments in Budget 2020:
 1. **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.
 2. **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.
 3. **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
 - develop a core skills education and training framework for children's palliative care
 - focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses
 4. **Boost overall nursing numbers in England** by taking the action recommended by the Royal College of Nursing 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.
5. **Invest £8.6 million per year to give children under the age of three who rely on bulky medical equipment access to benefits to meet their mobility needs** for the long-term which are equal in value to the higher rate mobility component of the disability living allowance (DLA).
 6. **Invest in seed funding to bridge the gap in care between children's and adult services.**
 7. **Provide funding to enable more flexibility to be built into Jack's Law.** At present, the law excludes parents who are self-employed and restricts the period of paid bereavement leave to week-long blocks. We are calling for the government to allow more flexibility with this.
- Together for Short Lives is a member of the Disabled Children's Partnership, a coalition of more than 70 charities campaigning for improved health and social care for disabled children and their families. In addition to our own submission, we support their representation outlining the main challenges faced by disabled children in England.
 - We also work closely with Hospice UK and fully support its Budget representation.

Our representation

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

1. NICE¹ 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 consultants². 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 4³. 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 never⁴:
 - 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.
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

¹ 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>

² 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).

³ 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).

⁴ 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>

hours. Although 64% of CCGs commission services to provide community paediatricians, only 29% commission them to provide out of hours care.

4. NICE states⁵ 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 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
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 guidance⁶. 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 responsible⁷:
 - 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
 - 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

⁵ 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>

⁶ 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>

⁷ Together for Short Lives. 2017. Commissioning children’s palliative care in England: 2017 edition. <http://bit.ly/2MbiE4O>

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](#)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.
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 patients⁹."
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.
12. 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%.
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 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 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

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>

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/>

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 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
20. However, across England, specialist children's palliative care teams are only sometimes led by Level 4 consultants¹³.
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. 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

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/2g9nlWA>.

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.

23.

Meet the annual £434 million gap in local authority funding for social care for disabled children in England

24. 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 councils¹⁶. 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.

Help end the children's palliative care workforce crisis

25. 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 crisis¹⁷:

- **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

¹⁶ 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/>

¹⁷ 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 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%

26. 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

27. 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.

28. 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

29. Overall, the RCPCH has identified what it considers to be an incoherent and inconsistent approach to planning for the child health workforce¹⁸. 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 care¹⁹.
30. Together for Short Lives welcomes the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'²⁰, 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.
31. 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.
32. 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:
- 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 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

¹⁸ Royal College of Paediatrics and Child Health. 2018. Workforce briefing. Available to download from: <https://www.rcpch.ac.uk/resources/workforce-briefing-2018>

¹⁹ 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>

²⁰ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

- 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
- 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
- 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

Give children under the age of three who rely on bulky medical equipment access to benefits to meet their mobility needs

33. 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.
34. 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.
35. 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
36. 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.
37. 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](#)²¹.
38. 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
39. If all were accessing the higher rate mobility component of £61.20, this would be an weekly investment of £170,197.20 - or £8,850,254 per year.
40. 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.
41. 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.
42. 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.

²¹ 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/>

43. 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.

Bridging the gap in care between children's and adult services

44. Medical advances mean more young people with a range of life-limiting or life-threatening conditions are living into adulthood. There are 56,000 young adults aged between 18 and 40 with life-limiting or life threatening conditions and this figure continues to grow.²² The transition from the comprehensive care offered by children's services to unfamiliar adults' services can be daunting as they must forge relationships with new agencies and professionals.

45. For many young people with life-limiting or life-threatening conditions, this transition coincides with a rapid decline of their condition and eventual death. As such, they have specific needs which differ from both younger children and older adults, yet there is a lack of age and developmentally-appropriate palliative care services for these young adults.

46. Specifically, there is a dearth of services which can offer short breaks to young people with the most complex health needs. This is a market failure, whereby the services available do not match the needs of these young people. We believe the government should intervene to correct this failure and step in where the market cannot deliver, by providing seed funding to stimulate voluntary sector services to provide age and developmentally appropriate services to this group of young people. This earlier investment will help avoid a 'cliff edge in care' and the associated wellbeing costs.

47. We would like the government to commit to providing seed-funding to stimulate voluntary sector organisations to provide age and developmentally appropriate services to young people with life-limiting or life-threatening conditions - and which bring about smooth transitions from children's to adult services.

Provide funding to enable more flexibility to be built into Jack's Law

48. We welcome the Parental Bereavement (Leave and Pay) Act 2018, recently renamed Jack's Law, and believe that it will introduce an important period of paid leave for parents to help them come to terms with the unbearable experience of losing a child. We are now calling for more flexibility to be built into the law. At present, the law excludes parents who are self-employed and restricts the period of paid leave to weeklong blocks. We are calling for the government to allow more flexibility with this.

²² Fraser LFK, Miller M, Aldridge J, PA, Parslow RC (2013). Prevalence of life-limiting conditions in young adults in England 2000-2010; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24VQQ>

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