

Spring Budget 2023

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's 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.
- The UK Government, NHS England and NHS Improvement (NHSE/I) and the National Institute for Health and Care Excellence (NICE) have published a number of clear policies which provide an imperative for providing palliative care to seriously ill children and their families.
- However, our evidence shows that children and families face a number of challenges in accessing the palliative care they need, when and where they need it.
- 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.
- Too few parents and families can access much-needed short breaks for respite.
- This means that too many children and families are missing out on the care and support they need, when and where they need it. This is having a negative impact on their physical and mental well-being and increases the risk of them needing unplanned emergency care and support.
- Families of seriously ill children also face a number of other serious challenges.
- The rising cost of living has left them anxious and exhausted. The cost of powering their children's life-saving equipment is disproportionately high: families of disabled children are paying on average £1596 extra a year to run disability equipment.
- A lack of access to high-quality, affordable and accessible childcare is having a negative impact on the education and social development of seriously ill and disabled children.
- Positive progress has been made in recent years, including NHSE/I's decision to ringfence and increase the Children's Hospice Grant to £25million by 2023/24 – and the commitment in the Long Term Plan to match fund CCG children's palliative care funding by up to £7million a year by 2023/24.

- However, NHS England will not commit to directly providing the grant to children's hospices beyond 2023/24. As inflation soars, children's hospices are spending more during 2022/23 meeting the increasingly complex needs of the children and families they care for.
- Together for Short Lives welcomes the recent energy price guarantee put in place by the government and the recent one-off payment for those receiving a disability allowance. But, the cost of living crisis is still threatening and stressful for families with disabled children.
- Action is needed now to make sure the NHS and local authorities have the resources to fund palliative care services that meet the needs of children and families. Several key areas of the children's palliative care sector need targeted government investment to ensure the sustainability of lifeline services for seriously ill children.
- This would help make sure more children and families could access palliative care when and where they need it. It could also reduce their demand for unplanned, emergency care and support.
- We ask the Chancellor to make the following commitments in at Budget 2023:

1. As a minimum, invest an additional £301 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 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.
- With patchy local NHS funding and the negative experience that some children's hospices have reported in trying to access the NHS Long Term Plan match funding and £25million non-recurring funding in 2019/20, it should also include maintaining the Children's Hospice Grant as a ringfenced, centrally distributed funding stream from NHS England. This will make sure that NHS funding meant for children's hospices reaches children's hospices. Ministers should also maintain the NHSE match funding for children's palliative care services.

2. When the government settles the health workforce education and training budget with the NHS, it should include funding to expand the children's palliative care workforce

- This should include an aspiration to increase spending on specialist paediatric palliative medicine GRID and SPIN training to £2.26million per year, proportionate to an expansion in the overall medical education and training budget.
- Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament include children's

nurses with the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.

3. Meet the annual £573 million funding gap in 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.

4. 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.

5. Make sure that seriously ill children and their families receive sustainable energy assistance payments, to recover from the impact the cost-of-living crisis has on their lives

- Provide an energy assistance payment for families of seriously ill children who are unable to access medical grants from the NHS.
- Double the £150 disability payment to reflect their higher household and energy costs.
- Uprate benefits urgently in line with current inflation rates.
- Exploring the idea of social tariffs as a long-term solution to reducing energy bills for households with high energy usage due to disability.

6. Make sure that families of seriously ill children have access to childcare

- Make additional resources available to local authorities to ensure disabled children can access childcare and early years education.

7. Give all bereaved parents who need it paid time away from work if their child dies

- Enable Her Majesty's Revenue and Customs (HMRC) to offer more flexible, daily payments so that parent carers are not forced to take bereavement leave in one-week blocks.
- Extend statutory parental leave and payments to self-employed people.
- Enable parent carers who are bereaved of young people with life-limiting conditions up to the age of 25 to be able to access parental leave and payments.

8. Reduce the financial cost to families when a child dies

- Make sure that parents who have been full-time carers of a child who has died automatically receive Limited Capability for Work and Work Related Activities (LCWRA) for the first 12 months following the child's death, if they are in receipt of Universal Credit.
- Increase the amount of money available for child funeral expenses through the funeral payment in line with funeral cost inflation.

Our representation

The cost of meeting children's palliative care standards

1. Based on the specialist and core professionals that the National Institute of Health and Care Excellent (NICE) state should comprise children's palliative care multidisciplinary teams – and the population that needs access to them – we estimate that the NHS in England should spend approximately **£385million every year**.

Positive action already taken by the UK Government and NHS England

2. Children's hospices in England have received a direct annual grant from the UK Government and subsequently NHS England (NHSE) since 2006/07. In July 2019, NHS England (NHSE) decided to increase the Children's Hospice Grant from £12million to £25million by 2023/24 and ringfence this money specifically for children's hospices. The planned Children's Hospice Grant amounts during this period were/are:
 - 2020/21: £15million
 - 2021/22: £17million
 - 2022/23: £21million
 - 2023/24: £25million.
3. In addition, the NHS Long Term Plan commits NHSE to match up to £7million of local NHS funding for children's palliative care, including children's hospice services, by 2023/24. The money is available to NHS and voluntary sector providers and is already being used to fund some new and existing specialist children's palliative care services. The funding amounts during this period were/are:
 - 2020/21: £2million
 - 2021/22: £3million
 - 2022/23: £5million
 - 2023/24: £7million.
4. In 2022/23, NHSE is funding a dedicated children and young people's palliative care lead in each of the seven palliative and end of life care strategic clinical network (SCN) regions in England.

5. In April 2020, the government's Emergency Coronavirus Fund for charities included a commitment of £200million for hospices, including children's hospices. In November 2020, the government announced that it would provide an additional £205million of support for the NHS for the winter 2020/21. This included up to £125million to secure additional hospice capacity and up to £148million for the period December 2021-March 2022 to secure and increase NHS capacity to enable hospital discharge.

The funding gap

6. Despite this progress – and the money which we estimate that the NHS is also spending through integrated care boards (ICBs) on funding specialist paediatric palliative medicine consultants, community children's nurses and children's hospices – we still approximate that the NHS will be spending only £84million every year on children's palliative care by 2023/24. We therefore estimate that there will be an **annual £301million gap** in NHS spending on children's palliative care in 2023/24.
7. Our mapping shows that, in some areas, standards are being met without commissioned service specifications being in place. This suggests that the costs of some children's palliative care services – particularly some specialist services provided by NHS acute trusts – are being absorbed by the NHS trusts themselves or funded from charitable sources without being fully reimbursed by CCGs.

Unsustainable statutory funding for children's hospices in England

8. Our 2022 survey shows a wide variation in funding for children's hospices from local NHS organisations. Until July 2022, clinical commissioning groups (CCGs) were responsible for funding local NHS services. They were then replaced by ICBs.
9. While average funding from CCGs represented one pound in every five spent by children's hospices in 2021/22 on the care and support they provided (an average of £689,000 for each children's hospice from CCGs, an increase of 38% compared to 2020/21), the amounts received by individual children's hospices varied greatly.
10. Half of children's hospices (50%) saw their CCG funding decrease between 2020/21 and 2021/22.
11. Nearly one in ten (9%) children's hospices received over half of their charitable expenditure from CCGs, while one in five (22%) received five per cent or less of their charitable expenditure from CCGs.

The impact of inflation

12. On average, children's hospices expected their charitable expenditure to grow by over one fifth (22%) between 2021/22 and 2022/23. However, as these figures were provided in April 2022, their actual costs may have been higher this year as a result of soaring prices and growing costs of recruiting and retaining care professionals.

The impact on children's hospices and the families they support

13. It is concerning that over a quarter (27%) of children's hospices were cutting short breaks for respite as a result of funding changes between 2020/21 and 2021/22. Despite average increases in overall income (including charitable sources), the high rate of vacant care professional posts was restricting many children's hospices' ability to expand their services for seriously ill children and young people.

The action we ask the UK Government to take

14. Together for Short Lives welcomes the planned increase in the NHS England (NHSE) grant to £21million in 2022/23 and then £25million in 2023/24. However, officials are refusing to commit to protecting and extending the grant as funding stream distributed centrally by NHS England after 2023/24.
15. Children's hospices are already warning that if they were unable to access the grant in 2024/25 and beyond, they would be forced to cut vital care and support for children and families:
 - nearly one in five (18%) would cut end of life care
 - over a quarter (27%) would cut symptom management services
 - nearly two thirds (64%) would cut short breaks for respite.
16. We believe the NHS should fund the lifeline 24/7 palliative care that children and families need in hospitals, at home and in children's hospices.
17. With patchy local NHS funding and the negative experience that some children's hospices have reported in trying to access the NHS Long Term Plan match funding and £25million non-recurring funding in 2019/20, we call on ministers and officials to maintain the Children's Hospice Grant as a ringfenced, centrally distributed funding stream from NHS England. This will make sure that NHS funding meant for children's hospices reaches children's hospices. Ministers should also maintain the NHSE match funding for children's palliative care services.
18. We also ask HM Treasury should meet the annual £573 million funding gap in social care for disabled children in England identified by the Disabled Children's Partnership; 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, are sustainable for the long-term.

Expanding the children's palliative care workforce

19. There are too few professionals with the skills and experience needed to provide children's palliative care in hospitals, children's hospices and in the community. In 2019, Together for Short Lives found that:
 - **There are too few community children's nurses (CCNs) employed by the NHS:** CCNs provide the bedrock of children's palliative care. 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 713 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 18 in England. This suggests a significant deficit of 22-42 consultants.

- **The growing vacancy rate in the non-medical care and support vacancy rate in children’s hospice charities is higher than in the NHS – and posts are increasingly difficult to fill:** In 2022, the average vacancy rate for roles equivalent to Agenda for Change bands 2-9 inclusive (including nurses) for children’s hospices charities in England is 18.4%. The average vacancy rate for roles equivalent to Agenda for Change bands 5-9 inclusive (which we have historical data for) is 18.6%, compared to 12.2% in 2019, 11% in 2016 and 10% in 2015. The NHS nursing vacancy rate in quarter three of 2021/22 was 10.5%¹, which is also worryingly high. Two thirds (67%) of vacant posts in children’s hospices were proving hard to fill (vacant for three months or more), which is unchanged from 2019. 65% reported that posts were hard to fill in 2016 and 57% in 2015. Just under a quarter (24%) of posts had been vacant for over 12 months, compared to 25% in 2019.
- **There are too few skilled professionals to fill vacant posts in children’s hospices:** 92% of children’s hospices cite an overall lack of professionals as a significant or very significant factor in the vacancy rates they are experiencing, compared to just over a half (58%) in 2019.
- **There are shortages among other health and care professionals who support seriously ill children and their families:** in England in 2021, the overall vacancy rate for children and family social workers in England was 17%².

20. Specific skills are needed when speaking to children and families about the choices available to them and developing advance care plans with them; there is no shortage in the number of people who have the desire to provide the complex palliative care and support that children need. However, there is a dearth of education and training places and shortages in children’s nurses and children’s palliative care consultants are particularly acute.
21. We are concerned by the low number of national GRID training posts available for paediatric palliative medicine consultants. There is currently one whole time equivalent (WTE) GRID post in the UK for 2022; because it takes two years for existing paediatric consultants to complete GRID training only one whole time specialist consultant is being produced every two years. This is not enough to fill the existing number of consultant posts available in the UK.
22. Opportunities for general paediatricians to undertake special interest (SPIN) training in children’s palliative care is also compromised by a lack of training posts. This is despite considerable interest to develop capability in this field. This is being caused by the lack of paediatric palliative medicine consultants and a dearth of funding for these posts from HEE.
23. This paucity of speciality palliative medicine consultants means that it is particularly challenging for NHS trusts to provide and maintain specialist children’s palliative care services within their organisations.
24. We estimate that a total of 10 GRID training posts and 12 SPIN training posts for consultant paediatricians could be provided by the existing specialist paediatric palliative medicine consultant workforce – if funding was available from HEE. We estimate that each training place would cost £113,000 per year; we have calculated this based on the

¹ Nuffield Trust. 2022. Vacancy rates for nurses and doctors. Available to download from:

<https://www.nuffieldtrust.org.uk/chart/vacancy-rate>

² HM Government. 2022. Children’s social work workforce. Available to download from: <https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce>

cost of the time of the specialist consultants and senior nurses who would need to provide the training, in addition to the salary cost of the consultant undertaking the training. These posts would cost a total of £2.48million per year to fund. However, we estimate that only £226,226 is being spent every year on providing GRID and SPIN training to consultant paediatricians, which leaves an **annual funding gap of £2.26million.**

25. We support the call from RCPCH that, to meet the challenges of making sure that there enough professionals who have the skills and experience to meet the needs and wishes of children and families, the existing workforce should be mapped to establish a baseline and service delivery assessed against required standards.
26. We welcome the work of 'Managing Complexity in Children's Healthcare: A Partnership for Change'³, 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.
27. We also welcome the Children's Palliative Care Education and Training UK and Ireland Action Group's Education Standard Framework⁴. This supports provides a sustainable, standardised approach to educating and training children's palliative care professionals in the UK. We ask NHSE/I, 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.
28. We recognise that the workforce challenges which limit the extent to which seriously ill children have access to 24/7 palliative care are part of wider shortages in the healthcare workforce in England. We acknowledge that the government has committed to an additional 50,000 nurses by the end of this parliament, in addition to five new medical schools. We also accept that specialist children's palliative care education and training places for health professionals, such as GRID and SPIN training, can only be expanded at a rate which is proportionate to an expansion to education and training for professionals in other areas of healthcare.
29. The government should make sure that, using NHSE/I's children's palliative care service specification, NHSE/I and HEE work with stakeholders to develop a plan to use the existing children's palliative care workforce as effectively as possible. This should include organising services into NHS-commissioned children's palliative care operational delivery networks (ODNs), as is the case for neonatal critical care⁵.
30. When the government settles the health workforce education and training budget with the NHS, it should include funding to expand the children's palliative care workforce. This should include an aspiration to increase spending on specialist paediatric palliative medicine GRID and SPIN training to £2.26million per year, proportionate to an expansion in the overall medical education and training budget. Ministers should also make sure that the additional 50,000 nurses that the government has committed to by the end of this parliament includes children's nurses with the skills and experience to provide palliative care to children in hospitals, children's hospices and at home.

³ Managing Complexity in Children's Healthcare: A Partnership for Change. 2019. <https://collaborative.whitefuse.net/>

⁴ Children's Palliative Care Education and Training UK and Ireland Action Group. 2020. Education Standard Framework. Available to download from: <http://www.icpcn.org/wp-content/uploads/2020/10/CPCET-Education-Standard-Framework.pdf>

⁵ NHS England. 2021. Operational Delivery Networks. Available to download from: <https://www.england.nhs.uk/ourwork/part-rel/odn/>

Meeting the gap in social care funding for disabled children in England

31. 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 social care is vitally important to relieve this stress, spend time as a family and do the things that other families do. However, too few NHS organisations and local authorities in England plan and fund short breaks for children who need palliative care – and many argue about who is responsible. We call on the UK Government to fill the £434 million disabled children’s social care funding gap in England.
32. The pressure on parents of having a child with a life-limiting condition is immense. Most relationships will suffer, with 36% experiencing a breakdown of the family.
33. 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 may live in poverty.
34. Many brothers and sisters will miss school or experience educational difficulties; many will be bullied or feel isolated at school.
35. Children with life-limiting conditions – and their families – rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do. Every family’s needs are different: some need overnight, residential short breaks either with or without their child; some need short breaks for only a few hours at a time, provided at home or in hospital. Some will need a mix of both.
36. Overnight short breaks for children and young people with life-limiting conditions usually include some element of clinical care to meet their often complex health needs, even if it is just an initial clinical assessment. Therefore, NHS organisations have a specific role in jointly planning and funding these services with local authorities.
37. As Together for Short Lives own freedom of information (FOI) requests have found (see report linked on the right-hand side of this page), too many clinical commissioning groups (CCGs) and local authorities in England are failing to plan and fund short breaks. 84% of CCGs reported that they commission short breaks for children who need palliative care, which is an increase from our 2016 research, when just 77% commissioned these services. However, more than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so. This figure has declined since 2016, when one in seven (14%) reported that they do not commission these short breaks.
38. A report from Together for Short Lives and Julia’s House Children’s Hospice called ‘Give Me a Break includes research by Pro Bono Economics, in association with volunteers from Compass Lexecon, which sets out the positive impact that short breaks have. The research has estimated that:
 - 11 per cent of parents of children who need respite delivered by children’s palliative care providers would experience significantly less stress as a result of receiving breaks – moving them out of the ‘most stressed’ category of society.
 - Reduced stress leads to improved physical health among carer parents, which in turn leads to reduced number of GP visits and cost-savings to the health system. Demand for GP services declines by 8 per cent as a result of an individual moving out of the most stressed category.

- Reduced stress leads to improved mental health among carer parents, which in turn reduces the use of mental health services and the associated costs. Demand for mental health services falls by 49 per cent as an individual moves out of the most stressed category.
 - 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.
39. Together for Short Lives and Julia's House Children's Hospice are calling on the government to create a ringfenced £434 million grant for local councils to fill the funding gap in social care services for disabled children. Local authorities would be able to use this money fund short breaks for seriously ill and disabled children equitably and sustainably.
40. UK-wide research conducted by Julia's House Children's Hospice and Bournemouth University has examined the impact that caring for a child with a life-limiting or life-threatening condition has had on parental relationships. 17 children's hospices from across England and Scotland took part. The research has found that:
- 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship
 - of those couples, 75% had no access to short breaks at that time
 - most parents (74%) rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family
 - couples whose relationships were identified as 'non-distressed' by the research were found to have received on average 43% more hours of short breaks from a children's hospice compared to those who were in distressed relationships.
41. A government-commissioned review of funding arrangements for palliative care published in 2011 recognises that "short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties", including the short breaks duty on local authorities in England.
42. In February 2022, we welcomed a government decision to allocate £30 million for additional short breaks for respite for families with disabled children in England. The Department of Education announced that the funding will be available for the following three years to set up more than 10,000 additional respite placements. It forms part of a wider package of reforms that ministers have launched to transform education and opportunities for most disadvantaged.
43. We call on HM Treasury to meet the annual £573 million funding gap in social care social care for disabled children in England identified by the Disabled Children's Partnership: 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.

Making 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

44. 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
45. 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.
46. 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.
47. 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.
48. 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](#)⁶.
49. 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

⁶ 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/>

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.

50. 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.

51. 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.

52. 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 targeted - and hopefully provide valuable insight to help inform future government policy.

53. 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 needs⁷. However, we note that the scheme is only open to families who meet Family Fund eligibility criteria (including income criteria).

54. In November 2020, the Social Security Advisory Committee [published a report](#)⁸ 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 take the following action:

55. 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.

56. To enable this, we ask the government to extend the higher rate DLA mobility component to all of these children.

⁷ Family Fund. 2020. Family Fund Mobility Support. Available online at: <https://www.familyfund.org.uk/mobilitysupport>

⁸ 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

Making sure families can afford the costs of caring for seriously ill children at home

57. Children with life-limiting illnesses who are being cared for at home often depend on vital life-saving equipment such as ventilators, oxygen and temperature control. An estimated 3,000 children require long-term ventilation to stay alive. Around 6,000 are dependent on assistive technology.
58. Essential equipment like ventilators, food pumps and hoists all add up to bigger bills.
59. Families often have to do extra washing due to their child's continence issues. Some disabled children are less mobile and get colder quicker, meaning that they need their home heated for longer. Others have health conditions that mean they cannot regulate their body temperature.
60. Families do not have a choice whether to use them less or switch them off. They are left with spiralling costs that they simply must meet if they want to keep this life-saving equipment switched on and helping their child.

The extra costs that families of seriously ill and disabled children face

61. Families often experience a drop in their income if their child needs palliative care. Contact, a charity with which we work closely, has found that nearly two thirds of disabled parents say that caring responsibilities mean they or their partner has given up paid work.
62. Contact has also recently surveyed of families of disabled children across the UK about their energy costs:
 - They are paying on average £1596 extra a year to run disability equipment – up almost £600 since April 2022.
 - More than a third (39%) have cut back or stopped using disability equipment due to rising energy costs, three times higher than before the higher energy price cap rose in April 2022.
 - 40% of those going without this vital equipment say it is making their child's condition worse.
 - In the last 12 months, 79% of families with disabled children have reduced the amount of energy they use because they cannot afford their bills
 - Almost half (45%) say they have not been able to keep their home warm enough for their child's needs.

Families will not be able to care for their children at home if their power is cut

63. Families of seriously ill children are also worried about the risk of power cuts and their potential to prevent them being able to care for their child at home this winter.
64. Families are often eligible for energy suppliers' priority services register. This provides advance notice of planned power cuts and priority support in an emergency. It does not, however, guarantee a supply to children who rely on electrical equipment to stay alive.

Children's hospice and palliative care charities are also paying more for their energy

65. Seriously ill children and families rely on children's hospice and palliative care charities for lifeline care including short breaks for respite, symptom management and end of life care. They provide them in homes and in children's hospices.
66. Combined, Hospice UK have found that children's and adult hospices are incurring £100million a year in additional costs resulting from the cost-of-living crisis, including heating buildings and running equipment.
67. Amid a growing workforce crisis, many children's hospices are spending more on recruiting care staff. In 2022, the average vacancy rate for children's hospice roles in the UK equivalent to Agenda for Change bands 5-9 inclusive is 18.6%, compared to 12.2% in 2019 and 10% in 2015. The NHS nursing vacancy rate in quarter three of 2021/22 was 10.5%.
68. Children's hospices are also experiencing a higher demand for the care and support they provide. On average, children's hospices' active caseloads increased by 11% from 262 in 2020/21 to 292 in 2022/23. This is 6% greater on average than the 276 reported in 2019/20.

UK Government action so far is welcome – but families need more help

69. A number of NHS service specifications state that local NHS Trusts can reimburse running costs of certain equipment such as oxygen concentrator and home dialysis machines used at home. But reimbursement (sometimes called a medical grants) is inconsistent across England and many patients receive none or very little financial support to pay for the additional energy costs of running medical equipment at home.
70. Information and awareness of grants and local reimbursement schemes is also poor among families, disabled people, advice charities and NHS providers themselves.
71. Contact's recent survey has found that those families that had managed to get a medical grant, usually after a long battle, said not all equipment is included, and grants rarely cover true running costs.
72. Together for Short Lives welcomes the support announced in the Autumn Statement, which will help families of seriously ill children and young people. The additional £900 to households on means-tested benefits and £150 to people on disability benefits are positive steps.
73. We also welcome the *Energy Price Guarantee*, which has frozen the unit cost of energy for domestic households. The guarantee is not a cap on overall bills, however. Households that use a lot of energy still pay more.
74. We welcome the government's plans to consult on the best ways to ensure that vulnerable high energy users, such as those with medical requirements, are not put at risk.
75. We also welcome the UK Government's cut non-domestic energy bills through the *Energy Bill Relief Scheme*. We are concerned, however, by the potential costs that voluntary sector children's hospice and palliative care charities will incur when the scheme ends in March.

Some seriously ill children may be admitted to hospital if help does not arrive soon

76. Much more is needed to help families of seriously ill children afford the extra energy they need to keep them alive. One-off payments help but are not enough to address the long-term challenges that seriously ill children and their families face.
77. No family should have to face difficult choices between feeding their family or heating their home. Families face unbearable decisions of whether they can continue to care for their child at home, or transfer them to hospital when their energy bills become unaffordable.
78. This means that many families could be denied the choice to care for their seriously ill child at home, undermining the principle of personalised care and support. It could also pile pressure on already overstretched emergency services.

Together for Short Lives is providing grants to families who need them most

79. Together for Short Lives is providing financial support this winter for the families most in need. These grants will make it possible for the most vulnerable families to continue to care for their child at home.
80. When a child is diagnosed with a life-limiting condition, parents suddenly need to navigate a complex world of medical and social services, and many will need to give up their job to care for their child full-time. Added to that the pressure of paying rising energy bills to keep their child alive, some parents are feeling overwhelmed and stressed about how they will make ends meet – when all they want to do is to spend time with the child they love so dearly.
81. Families desperately need financial support so that they can focus on making precious memories, as this Christmas may be their last together.
82. Together for Short Lives' Cost of Living Support Fund will help ease the burden of families' rising bills, so they can keep life-sustaining equipment running. We will begin by prioritising families that rely on equipment to help them to breathe, and who are facing financial hardship this winter.

But we cannot solve this alone. We need the UK Government to act now too

83. Together for Short Lives cannot provide a grant to every family caring for a seriously ill child. We know that many more are struggling with the soaring cost of living this winter. That's why we are urging the UK Government to go further by:
 - Providing an energy assistance payment for families of serious ill children who are unable to access medical grants from the NHS.
 - Doubling the £150 disability payment to reflect their higher household and energy costs.
 - Uprating benefits urgently in line with current inflation rates.
 - Exploring the idea of social tariffs as a long-term solution to reducing energy bills for household with high energy usage due to disability.
84. Together for Short Lives is also calling on the UK Government to take the following action:

- Work with the energy industry to make sure that families of seriously ill children, who rely on life-saving equipment at home, have access to a secure and constant supply of power – and are included energy suppliers' priority services register.
- Prioritise children's hospice and palliative care charities for targeted financial support when the non-domestic *Energy Bill Relief Scheme* ends in March 2023.
- Make sure children's hospice and palliative services, including those provided by the voluntary sector, are on the Protected Sites List (PSL) as part of the Electricity Emergency Supply Code; this is to make sure that, during an emergency, critical sites remain supplied.