Togetherforshortlives.org.uk
info@togetherforshortlives.org.uk
0117 989 7820

Spending Review 2024: A representation from Together for Short Lives

A summary of our representation

Thousands of families whose children need palliative care face a postcode lottery as to whether they receive it. This is reducing their choice and control and is causing unnecessary and unplanned emergency admissions to hospital among children and young people with life-limiting or life-threatening conditions, some of whom prefer to access palliative care at home:

Key Issues

- Only a third of local areas in England are meeting the required standard for 24/7 end of life care for children at home.
- There is an estimated £295 million funding gap for children's palliative care services; if NHS England does not commit to continuing £25 million ringfenced funding for children's hospices in 2025/26, they will be forced to cut lifeline services.
- There are significant shortages in the children's palliative care workforce.

Recommendations for the Spending Review

We call on HM Treasury to do the following:

1. Review the way in which children's palliative care is funded and fill the £295 million annual gap in NHS spending on children's palliative care in 2024/25.
2. Fill the £2.4 million annual funding gap in GRID and special interest (SPIN) training for palliative care for paediatric consultants – in addition to other funding gaps in educating and training other professionals, including community children's nurses.
3. Fund lifeline voluntary sector providers in England – including children's hospices – equitably and sustainably for the long-term as their costs increase. In England, this should include a commitment to maintaining £25 million as a ringfenced, centrally distributed NHS England grant for children's hospices beyond 2024/25 which increases by at least the rate of inflation.
4. 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.
5. Mobility benefits: 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.
6. Support with energy costs: make sure that seriously ill children and their families receive sustainable energy assistance payments. The government should explore

the idea of social tariffs as a long-term solution to reducing energy bills for household with high energy usage due to disability. We also ask for better access to rebate schemes so that families of children and young people who need palliative care are not paying for the cost of running medical devices.

7. Make sure that families of seriously ill children have access to childcare: the government should make additional resources available to local authorities to ensure disabled children can access childcare and early years education.
8. Give all bereaved parents who need it paid time away from work if their child dies.
9. Reduce the financial cost to families when a child dies: the government should 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. The government should also increase the amount of money available for child funeral expenses through the funeral payment in line with funeral cost inflation.

Our representation

Access to 24/7 end of life care at home

- Across England, and the wider UK, there are huge differences in the way children's palliative care is planned, funded and provided.

- In many places, children's palliative care which meets national standards is not available.

- Of particular concern is children and families' access to end of life care at home, 24 hours a day, seven days a week, provided by nurses and supported by advice from consultant paediatricians who have completed sub-specialty training in paediatric palliative medicine (also known as GRID training).

- This standard is met in just a third (30%) of integrated care board (ICB) areas in England, with nearly a half (47%) partially meeting it and almost one quarter (23%) not meeting it at all.

- Only 6 ICBs (14%) are funding and delivering services to provide 24-hour access to both children's nursing care and advice from a specialist consultant in paediatric palliative care. Two in five (41%) of ICBs do not commission this at all.

- The 24/7 end of life care at home standard is not met at all in Northern Ireland and only in a minority of areas in Scotland and Wales.

- We believe that key barriers in workforce, funding, leadership and accountability are preventing end of life care and wider symptom management for children with life-limiting conditions and their families being sustainably planned, funded and provided.

- Investment is therefore needed in the children's palliative care workforce and the sector as a whole to ensure seriously ill children, and their families can access the care and support they need.

Funding children's palliative care in England

- Funding is one of the most significant barriers to children and young people being able to access services capable of meeting national standards in England.

- Research has even highlighted the difficulty in obtaining consistent and sufficient funding, with leaders of children and young people's palliative care networks stressing the lack of NHS funding and reliance on the charitable sector in providing important services and key posts for their region.[1]

NHS funding shortfalls

- In England, we have estimated there to be a significant funding gap in the provision of children's palliative care.

- Based on the specialist and core professionals that NICE state should comprise children's palliative care multidisciplinary teams – and the population that needs access to them – we estimate that the NHS should spend approximately £376 million every year to meet this standard in 2024/25.

- We believe that the NHS will spend £81 million in 2024/25, which means that there will be a £295 million funding gap in 2024/25.

- You can view the model we have used for calculating the gap here.

NHS England funding for children's hospices

- Currently, on average, a third of children's hospices charitable expenditure is funded by the state. Of this expenditure, 16% is funded by the £25m NHS England funding for children's hospices (formerly known as the NHS Children's Hospice Grant).

- In July 2019, NHS England decided to increase the Children's Hospice Grant to £25 million by 2023/24 and ringfence this money specifically for children's hospices. The Children's Hospice Grant amounts during this period have been:

    - 2020/21: £15 million
    - 2021/22: £17 million
    - 2022/23: £21 million
    - 2023/24: £25 million

---

[1] **Papworth A, Hackett J, Beresford B, et al**. (2023). Regional perspectives on the coordination and delivery of paediatric end-of-life care in the UK: a qualitative study. BMC Palliative Care, 22. Available at: https://link.springer.com/article/10.1186/s12904-023-01238-w#Abs1.

- Following a campaign by Together for Short Lives, children's hospices and the public, the former Minister of State for Social Care, Helen Whately committed to renewing the grant for 2024/25.

- Whilst this commitment was welcome, we are deeply concerned that this funding stream is yet to be confirmed for years beyond 2024/25.

- Children's hospices have told us that if this funding was not available beyond 2024/25, the following action would have to be taken:[2]
    - 82% would cut or stop providing respite care or short breaks.
    - 70% would cut or stop providing emotional and/or psychological support.
    - 45% would cut the end of life care they provide.
    - 42% would cut their symptom management provision.
    - 64% would cut or stop providing hospice at home services.
    - 42% would cut or stop providing step down care.

- It is particularly concerning to see that the majority of children's hospices would be forced to cut or stop providing respite care or short breaks if this funding was not available from 2025/26 onwards.

- Respite care is invaluable to families of seriously ill children. According to one study published recently, the development of respite services can help reduce the risk of emotional exhaustion and mental health problems.[3]

- Cutting respite care would therefore have a profoundly negative impact on families.

- Research published in 2021 has shown that mothers of seriously ill children are significantly more likely to experience common and serious physical and mental health problems. It has also been shown that the risk of premature death is 50% higher for mothers of a child with a life-limiting condition than mothers of children with no long-term health conditions.[4]

- Cutting or stopping respite care could therefore further exacerbate these inequities.

- Not only would these cuts have an impact on families, but they would also negatively impact the NHS and wider health and social care system.

---

[2] **Together for Short Lives.** (2024). Short lives can't wait: Children's hospice funding in 2024. Available at: https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-hospice-funding-in-uk/.

[3] **Hizanu DM, Boeriu E, Tanasescu S, Balan A, Oprisoni LA, Popa MV, Gutu C, Vulcanescu DD, Bagiu IC, Bagiu RV, Dragomir TL, Boru C, Avram CR, Duceac LD**. (2024). Benefits of Respite Services on the Psycho-Emotional State of Families of Children Admitted to Hospice Palliative Care Unit: Preliminary Study on Parents' Perceptions. Healthcare (Basel), 12(7). Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11011478/.

[4] **Fraser LK, Murtagh FEM, Aldridge J, Sheldon T, Gilbody S and Hewitt C**. (2021). Health of mothers of children with a life-limiting condition: a comparative cohort study. Archives of Disease in Childhood, 106. Available at: https://adc.bmj.com/content/106/10/987.

- It is therefore vital that the UK Government commits as a matter or urgency to maintaining, ringfencing and increasing the £25 million NHS England funding for children's hospices by the rate of inflation – and returning it to being a centrally-distributed funding stream.

ICB funding for children's hospices

- The Health and Care Act 2022 imposed a legal duty on ICBs to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.

- In 2023/24, children's hospices received, on average, nearly 10% less funding from ICBs compared to 2022/23 and over a third (31%) less funding when compared to 2021/22.

- At the same time, children's hospices' charitable expenditure has increased by 15% since 2021/22 from an average of £3,633,197.

- Overall, this represents about 11% of the charitable expenditure incurred by children's hospices, down from 13% in 2022/23.

- From a series of freedom of information (FOI) requests, we have also found huge variance in local NHS funding for children's hospices from ICBs in England.

- On average, ICBs spent £149.15 for every case of a life-limiting or life-threatening condition among children and young people aged 0-24 in their local area.

- However, the amounts spent by each ICB varied by as much as £366.42. Whilst Bristol, North Somerset and South Gloucestershire ICB spent the most with an average of £397.01 per child or young person, Northamptonshire ICB spent the least with an average of £30.59 per case.

- Slight variation may be explained through differing levels of local need for care and support along with how local children's palliative care services are configured across hospital, community, and children's hospice services. We do not believe, however, that the extent to which funding varies between ICBs can be justified.

Local authority funding for children's social care

- Under the Children Act 1989, local authorities are required to provide services designed to assist family carers of disabled children 'to continue to provide care, or to do so more effectively, by giving them breaks from caring'.

- Despite this legal basis, we have found that the average amount children's hospices receive from local authorities has decreased by 26.1% over the past year.

- Whilst in 2022/23, on average, children's hospices received £149,939.92 from local authorities representing 3.65% of their charitable expenditure, 2023/24 has seen this funding figure fall to £110,767.56.

- Local authority funding now represents approximately 2.64% of children's hospices' charitable expenditure.

- 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 £573 million disabled children's social care funding gap in England.

- The pressure on parents of having a child with a life-limiting condition is immense. Most relationships will suffer.

- A high proportion of parents 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.

- Many brothers and sisters will miss school or experience educational difficulties; many will be bullied or feel isolated at school.

- 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.

- 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.

- 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.

- 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.

- 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.

- 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.

- 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.

Investing in the children's palliative care workforce in England

- Under the National Institute for Health and Care Excellence (NICE) quality standard, infants, children, and young people with a life-limiting condition should be cared for by a multi-disciplinary team that includes members of the specialist paediatric palliative care team.[5]
- According to NICE, this team should include the following as a minimum:
    - A paediatric palliative care consultant.
    - A nurse with expertise in paediatric palliative care.
    - A pharmacist with expertise in specialist paediatric palliative care.
    - Experts in child and family support who have experience in end-of-life care.
- However, in practice, children and young people do not always have access to specialist paediatric palliative care services due to a system-wide shortage in the number of professionals with the skills and experience needed to provide children's palliative care in hospitals, children's hospices and in the community.
- According to research published in 2023, only 35% of consultant led specialist paediatric palliative care teams in the UK have the minimum professional configuration as recommended by NICE.[6]
- As a result, this is impacting on patient access to symptom management, support with legal and ethical issues and leadership across services and systems.
- The government should **invest in education and training to increase the number of professionals** who have the skills, experience and competencies needed to care for children and young people with life-limiting and life-threatening conditions.

Specialist paediatric palliative care consultants across the UK

- NHS England state that the specialist paediatric palliative care teams should be led by specialist consultants in paediatric palliative care. These specialist consultants are

---

[5] **National Institute for Health and Care Excellence**. (2017). End of life care for infants, children and young people. Available at: https://www.nice.org.uk/guidance/qs160/resources/end-of-life-care-for-infants-children-and-young-people-pdf-75545593722565#:~:text=Statement%201%20Infants%2C%20children%20and,leads%20and%20coordinates%20their%20care.

[6] **Bedendo A, Hinde S, Beresford B, et al**. (2023). Consultant-led UK paediatric palliative care services: professional configuration, services, funding. BMJ Supportive & Palliative Care. Available at: https://spcare.bmj.com/content/early/2023/08/08/spcare-2023-004172.

vital because they:

  - Have specialist expertise in managing life-limiting and life-threatening conditions across the paediatric spectrum.
  - Have the ability to manage the full range of symptoms experienced as disease and illness progresses.
  - Can lead and develop services within their region.
  - Can enable, support, teach, and train other health care professionals.

- There are currently 21.4 WTE (whole time equivalent) GRID-trained specialist paediatric palliative medicine (PPM) consultants in the UK.[7]
- The Royal College of Paediatrics and Child Health (RCPCH) estimates that 40-60 are needed. There is therefore a significant deficit of 20-40 consultants.
- To qualify as a specialist consultant capable of leading a specialist paediatric palliative care team, a professional must complete their sub-speciality level 3 (GRID) training in paediatric palliative medicine.
- Alternatively, a professional may complete a special interest (SPIN) module if they are particularly interested in paediatric palliative care but wish to remain as a general paediatrician.
- We are concerned by the low number of national GRID and SPIN training posts available for paediatric palliative medicine consultants.
- While the total number of GRID training posts has increased from 1 WTE in 2022 to 7.2 WTE in 2024,[8] this is not enough to fill the number of consultant posts that are currently needed in the UK.
- 12 WTE SPIN training posts are currently being funded across the UK.
- We estimate that the number of these training posts could be doubled to 14.4 WTE GRID training posts and 24 SPIN training posts and could be provided by the existing specialist paediatric palliative medicine consultant workforce – if funding was available from NHS England.

---

[7] **Association of Paediatric Palliative Medicine**. (2023). Joint workforce statement from APPM and RCPCH CSAC for Paediatric Palliative Medicine: Workforce and Medical Training – October 2023. Available at: https://www.appm.org.uk/_webedit/uploaded-files/All%20Files/News/Joint%20workforce%20statement%20fro.

[8] **Royal College of Paediatrics and Child Health**. (2022). Sub-specialty Programme Information: Paediatric Palliative Medicine 2023. Available at: https://www.rcpch.ac.uk/sites/default/files/2022-10/paediatric_palliative_medicine_programme_2023.pdf.

- We estimate that each training place costs £124,924.64 per year; we have calculated this based on the 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. The training posts currently being funded cost a total of £2,398,553 per year to fund. To double these training places, we believe that NHS England should invest double this amount.

- You can view the model we have used to calculate this here.

Community children's nurses

- Community children's nurses (CCNs) provide the bedrock of children's palliative care in the community.

- According to safe staffing levels set out by the Royal College of Nursing (RCN), there should be 20 WTE CCNs per 50,000 children.

- If these safe staffing levels were to be met across England, there would need to be 4,963 CCNs employed by the NHS and working across the nation.

- There are currently 916 CCNs employed by the NHS in England.[9]

- Whilst progress has been made in increasing the number of CCNs employed by the NHS in England over the last few years, more still needs to be done to ensure sufficient community children's nurses are employed by the NHS.

Children's hospices' clinical workforce

- Children's hospices also play a pivotal role in providing children's palliative care. From the management of distressing symptoms to the provision of short breaks and end of life care, children's hospices provide vital care and support to children with life-limiting conditions and their families.

- However, a recent survey of the hospice workforce by Hospice UK has revealed an average vacancy rate of 14.5% in the clinical workforce of children's hospices across the UK. 22 of 38 children's hospice organisations (58%) across the UK responded.

- Nearly one in four (24%) posts for newly registered nurses or nurse practitioners within two years of qualification are vacant. One in five (20%) of healthcare assistant and support worker posts are vacant. 17% of other non-senior registered nursing posts are vacant.

- These rates are higher than in the NHS in England, which had a vacancy rate of 7.5% as of 31 March 2024 within the Registered Nursing staff group.35

---

[9] **NHS Digital.** (2024). NHS Workforce Statistics - April 2024**.** Available at: https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics/april-2024.

Social workers

- Alongside other health-related services, social workers can help families understand the services they are eligible for and advocate for the support they need. Taken together, social workers are a critical part of ensuring children and young people with life-limiting and life-threatening conditions and their families receive the care and support that caters for all their needs.

- According to recent research by the Disabled Children's Partnership (DCP), only a third of parent carers indicated that their disabled child had received social care support related to their disability or condition.[10]

- As of the 30 September 2023, 7,700 child and family social worker vacancies were recorded in England.[11]

- Furthermore, the overall vacancy rate stands at 19% with nearly three quarters (74.4%) of vacancies being covered by agency workers.[12]

- The number of posts being covered by agency workers has increased by 6.1% since 2022 to the point there are currently 7,200 agency social workers in post.[13]

- As a result, the Department for Education expect the shortfall of child and family social workers compared to demand to increase over the next decade.[14]

Making sure that children with life-limiting conditions and their families receive the financial support they need from the benefits system

- 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

- These children require specialist, adapted or broad base vehicles for transport which, without financial support, are often beyond the reach of their families.

---

[10] **Disabled Children's Partnership**. (2022). Failed and Forgotten. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCPreport-2023.pdf.

[11] **Department for Education.** (2023). Children's social work workforce. Available at: https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce.

[12] **Department for Education**. (2023). Children's social work workforce. Available at: https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce.

[13] **Department for Education**. (2023). Children's social work workforce. Available at: https://explore-education-statistics.service.gov.uk/find-statistics/children-s-social-work-workforce.

[14] **Department for Education**. (2024). Consolidated annual report and accounts: Year ended 31 March 2024. Available at: https://www.cypnow.co.uk/media/251793/dfe_consolidated_annual_report_and_accounts_2023_to_2024_-_web-optimised_version.pdf.

- 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.
- 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.
- 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.[15]
- Motability has piloted a scheme to help children under the age of three who are not eligible for the mobility component of child disability living allowance but who rely on bulky medical equipment.
- Together for Short Lives is delighted that Family Fund and Motability piloted the scheme, which has 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 needs[16]. However, we note that the scheme is only open to families who meet Family Fund eligibility criteria (including income criteria).

---

[15] 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/

[16] Family Fund. 2020. Family Fund Mobility Support. Available online at: https://www.familyfund.org.uk/mobilitysupport

- In November 2020, the Social Security Advisory Committee published a report[17] 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.

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

- 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.

- Essential equipment like ventilators, food pumps and hoists all add up to bigger bills.

- 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.

- 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.

- 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.

Giving bereaved parents paid time away from work if their child dies

- Together for Short Lives welcomed the Parental Bereavement (Leave and Pay) Act 2018, which introduced an important period of paid leave for parents to help them come to terms with the unbearable experience of losing a child.

- Looking after a child 24/7 in the knowledge that they will die young places the heaviest emotional, financial and social pressures upon families. Securing statutory bereavement leave for families who lose a child is one small but important way in which that some of that pressure can be relieved and societal understanding and support improved. Coming to terms with a child's death is unbearable for parents, siblings and all the family.

---

[17] 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

- There are many examples of employers showing fairness and compassion in the way they treat parents bereaved of a child; however, it should not be down to the discretion of individual employers as to whether parents should be allowed time off work to grieve for their child and make funeral arrangements.

- Payments such as the one provided for in legislation bill can only be taken in multiples of one-week blocks. This is because of the inflexible payment systems operated by Her Majesty's Revenue and Customs (HMRC). We would like the government to to consider what can be done to enable HMRC to offer more flexible, daily payments so that parent carers are not forced to take bereavement leave in one-week blocks.

- Self-employed people are not technically 'employees' and are outside the scope of the act. We would like the government to make sure that a financial benefit equivalent to the payment provided for in this bill can be offered to self-employed people who are bereaved of a child.

- As a result of advances in medical technology, many more young people with life-limiting conditions are living into adulthood. As such, we would like 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. There is a precedent for this age-range in another important piece of legislation, the Children and Families Act 2014.

Reducing the financial cost to families when a child dies

- When the worst happens, parents forced to come to terms with the impact of losing their child must also contend with a number of other issues. If the child dies with a long-term disability, they may also have to endure significant short-term financial hardship caused by the immediate loss of their income.

- This could be due to the end of benefits such as carer's allowance, disability living allowance and child benefit. This can often compound the debt legacy which families of children with life-limiting or life-threatening conditions may have incurred as a result of the additional costs of caring for their child over a long period of time.

- Families with disabled children faced significantly higher costs compared to other families.

- Research by Corden et al. shows that families caring for a child with a life-limiting or life-threatening condition face additional financial pressures as they are 'less likely to be in paid employment than other parents and may face financial hardship associated with lack of opportunity to work'. This is because parents may leave their employment, or not join the labour market so that they can care for their child – often 24/7.

- Because the trajectory of their child's condition is likely to be unstable, it is also difficult to plan time off work to attend medical appointments or to deal with long periods of acute illness. Corden et al. found that these factors, as well as difficulties finding appropriate substitute care to allow them to go to work, mean that 'during the period leading up to a child's death, both parents may therefore be depending on out-of-work income.'

- Typically, a parent of a seriously ill child will not be in employment and will solely rely on income from the child's disability living allowance (DLA), Carers' Allowance and Universal Credit top ups that include Child Benefit, Child Disability Allowance.

- When a child dies and one parent is the full-time carer, there is a 'run-off' period of 6-8 weeks for Child Benefit, Child Disability Allowance (UC) and Carers Allowance.

- However, the child's DLA stops the day the child dies, including the mobility component; this can mean that the family wheelchair adapted vehicle will need to be returned, in some cases leaving the family abruptly without a vehicle.

- Many children who seriously ill have a personal budget; if they choose to receive this as a direct payment, they can employ directly employ professionals to meet their child's needs. However, the personal budget stops the day the child dies, leaving the family to cover the costs of the notice period agreed.

- Parents are entitled to the two bedroom allowance on the universal credit rent component; however, when the child dies, this changes to the one bedroom allowance reducing parents' monthly income further.

- For a family already in enormous distress and grief from the loss of their child, this leaves them financially strained and places the parent, whom was the full time carer, in the process of having to prove that he or she is not fit for work or work related activity in a Work Capability Assessment. This can happen in the first six months of the bereavement.

- The full-time carer parent may have been a full-time carer for several years, making it more challenging for them to find work.

- We ask ministers to consider ensuring 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.

- Together for Short Lives is also asking the UK Government to go further by increasing the amount of money available for funeral expenses through a funeral payment which rises in line with funeral cost inflation.

How the government can use the Spending Review to ensure the sustainability of the children's palliative care sector for the long term

We call on the government to use the Spending Review to make sure that children with life-limiting conditions and their families can access high quality, sustainable palliative care when and where they need it, regardless of where they live. This would:

- give families greater choice and control
- help the NHS and local authorities to implement existing guidance and legislation
- reduce unnecessary and unplanned emergency admissions to hospital among children and families who would prefer to access palliative care at home.

To achieve this, we ask HM Treasury to focus on these key areas:

1. **NHS funding:** review the way in which children's palliative care is funded, fill the £295 million annual gap in NHS spending on children's palliative care in 2024/25 and commit to maintaining £25 million as a ringfenced, centrally distributed NHS England grant for children's hospices beyond 2024/25 which increases by at least the rate of inflation.
2. **Workforce:** fill the £2.4 million annual funding gap in GRID and special interest (SPIN) training for palliative care for paediatric consultants – in addition to other funding gaps in educating and training other professionals, including community children's nurses.
3. **Children's social care funding:** 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. **Mobility benefits:** 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. **Support with energy costs:** Make sure that seriously ill children and their families receive sustainable energy assistance payments. The government should explore the idea of social tariffs as a long-term solution to reducing energy bills for household with high energy usage due to disability. We also ask for better access to rebate schemes so that families of children and young people who need palliative care are not paying for the cost of running medical devices.
6. **Make sure that families of seriously ill children have access to childcare**: the government should 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:** the government should 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. The government should also increase the amount of money available for child funeral expenses through the funeral payment in line with funeral cost inflation.

For more information

Please contact:

Ben Dellow
Policy and Public Affairs Officer
07463 228 894
Ben.dellow@togetherforshortlives.org.uk