26 September 2018

Budget 2018

Representation from Together for Short Lives

About Together for Short Lives

- We are 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 – so that no family is left behind.

- We directly support children and families through our helpline and the information and resources on our website, which help ensure that families can find the right local services and make the right choices about their child's care.

- We support all the professionals, children's palliative care services and children's hospices that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers. By working together, we provide a strong and unified voice for the sector, and help services deliver the best quality care and support tailored to each family's needs.

- The Chancellor of the Exchequer's budget announcement on October 29 is an important opportunity for the government to show support for children with life-threatening and life-limiting conditions and their families. These children are some of the most vulnerable and disadvantaged in our society. Many parent carers are forced to juggle numerous responsibilities such as work and other childcare responsibilities on top of the challenges of providing round the clock care to their seriously ill child. Families caring for a child with a life-limiting or life-threatening condition often find themselves under immense emotional, physical and financial pressure; it's important that the government supports strategies that support these families and prevent them reaching crisis point.

- The targeted investments that we advocate in our representation would help the government to implement existing policies, improve outcomes for seriously ill children and their families and reduce some of the unjustified health inequalities that they currently experience. Crucially, they would also deliver cost-savings for the state by reducing the demand that children with life-limiting conditions and their families have for expensive, emergency and unplanned health and social care.

- Our representation outlines some of the steps an active government can take to empower broader civil society – through both the NHS and the Voluntary Community Sector (VCS) – to provide the care and support that these families deserve and need. Our representation doesn't just make the societal case for support, but also outlines the value for money that investment in children's palliative care services can represent for the NHS, particularly emergency services.

- Together for Short Lives is a member of the Disabled Children's Partnership, a coalition of more than 60 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 the UK.

The economic case for investing in children’s palliative care

- 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’.[1] **NICE calculate that by investing £12.7million in implementing the guidance, non-cash savings worth £34.7million would be released back into the NHS in England.[2]**

The societal case for investing in children’s palliative care

- Hearing the news that your child has a life-limiting or life-threatening condition and is likely to die young is completely devastating. For tens of thousands of families in the UK this is the reality. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week. There are 49,000 children and young people in the UK with life-limiting or life-threatening conditions, a number which is growing as a result of advances in medical technology and better care. Unfortunately, this small population is largely misunderstood and often don’t receive care and support that is appropriate to their age group, for both their quality of life and quality of death.

- We have found that the state’s total contribution to the total charitable expenditure of voluntary sector children’s palliative care providers, including children’s hospices, remained at 22% in 2016/17. This was the same as in 2015/16 and below the 23% recorded in 2014/15 and 27% in 2013/14. This is despite the fact that demand is increasing for children’s palliative care. It is estimated that more than 40,000 children (0–19 years) were living with a life-limiting or life-threatening condition in England in 2009/10 - compared to 30,000 in 2000/01. The highest rate of increase during this period was among those aged 16-19 years, who now account for 4,000, or one in ten, of 0-19-year-olds who need palliative care[3]. This is due to increasing life expectancy and improving quality of life resulting from advances in treatment and support. Children’s hospices are also experiencing an increase in demand for palliative care for very young babies.

- A 2015 report showed a 50% increase over a ten-year period in the number of children and young people with life-limiting or life-threatening conditions in Scotland[4]. This is a dramatic rise; if replicated across the UK then the number of children and young people with life-limiting or life-threatening conditions could be much greater than the current estimate of 49,000.

- On average, adult hospices in England receive 33% of their funding from statutory sources. We are calling on the Treasury to help bridge this funding gap and to ensure that funding parity is achieved between children’s and adult’s palliative care.

- The number of children and young people with life-limiting or life-threatening conditions is increasing. For example,

---

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

[2] 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.

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

[4] Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available to download from: http://bit.ly/1Krn2EU.

- There is overwhelming public support to make sure that children with short lives are not short-changed by the state. A survey commissioned by Together for Short Lives found that 81% of the public think that children's hospices receive too little funding from statutory sources. In September this year, Together for Short Lives delivered a petition to Downing Street, signed by 6,670 people, asking the government to fund, not fail children's palliative care.

Summary of our proposals

We are asking the Budget to invest in children's palliative care services

1. **Increase the Children's Hospice Grant to £25 million per year:** The Children's Hospice Grant has been steadily increasing since it was introduced in 2006/7, however it has not kept pace with the rise in demand. Initially the grant contributed an average of 14% towards the cost of providing clinical care in children's hospices, but in 2015/16, when it had risen to £11million, it contributed an average of just 8%. This represents an average fall of £182.65 (16%) per child. It is essential that the value of the grant is increased to £25million to reflect the growing demand and complexity of care required by children with life-limiting conditions and their families while also recognising any additional costs in developing reporting mechanisms and new services to meet growing demand.

2. **Provide parity of funding between children's and adult palliative care services:** Children's hospices currently receive only 22% of their funding from statutory sources, compared to 33% in adult hospices. This discrepancy must be addressed. The government should also address the post code lottery in funding and support and make sure that clinical commissioning groups and local authorities are transparent and are held to account in demonstrating how they fund children's palliative care.

3. **Introduce a funded children's palliative care strategy:** We would like the government to commit to a national inquiry, producing a children's palliative care strategy that takes a family-centred and holistic approach to health, social care and educational interventions.

We are asking the Budget to invest in support for families who have a child with a life-limiting or life-threating condition

1. **Provide the estimated £7,587,294 needed to make sure that families of children under the age of three who rely on bulky medical equipment receive mobility support to enable them to leave home or hospital:** Motability and Family Fund are currently piloting a scheme to provide vehicles to children under the age of three who are not eligible for the mobility component of child disability living allowance (DLA) but who rely on bulky medical equipment. We ask the Treasury to allocate funding to make sure that the scheme can be implemented for all of the 2,781 children in the UK under the age of three who depend on bulky medical equipment

2. **Children's social care, including short breaks for respite:** Research carried out by the Disabled Children's Partnership (DCP) and published in July 2018[5] found that there was a £1.5billion annual funding gap for disabled children's services. By committing £1.5billion per year, just 0.2% of total Government spending, the government can ensure disabled children and their families have the support in place when they need it. It will also enable local authorities and the NHS to meet their statutory duties and improve the availability and quality of services.

---

[5] https://disabledchildrenspartnership.org.uk/wp-content/uploads/2018/07/Case-for-a-Disabled-Childrens-Fund.pdf

3. **Bridging the cliff edge in care between children’s and adult services:** Young people face a cliff edge in care when they transition from children’s to adult services. We would like to see seed-funding for voluntary sector organisations with projects designed to ease this transition and prevent young people falling through gaps in care.

4. **Extensions in the regulations of the Parental Bereavement (Leave and Pay) Act 2018:** We welcome the Parental Bereavement (Leave and Pay) Act 2018 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 would now like to see funding allocated to make sure that the regulations associated with the act can ensure that parents have the flexibility and support they need to grieve the loss of a child in a way that is appropriate to them.

APPENDIX A – FUNDING CHILDREN'S PALLIATIVE CARE SERVICES

1. The contribution that VCS organisations can expect towards the cost of providing children's palliative care increasingly reflects a postcode lottery.

2. Children's hospices provide social value to a community and financial value to the NHS. They make a crucial contribution to local health economies. For example,

   - 92% of children's hospice charities provided end of life care to children and young people in 2015/16
   - 89% provided care which helped children manage their complex symptoms
   - 75% provided step down care.

   Without children's hospices, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS.

Increasing the Children's Hospice Grant to £25 million per year.

3. In 2011, a government-commissioned review of funding arrangements for palliative care found that the lack of a clearly defined funding model has led to a wide variation in the level of state funding provided to services, including children's hospices.[6] The only income that children's hospices receive which is committed to by NHS England is an annual £11million grant, which is split between 36 children's hospice charities.

4. As the children's hospice grant remains static at £11million and children's hospices face increasing costs to support children with life-limiting or life-threatening conditions, the grant is gradually diminishing as a proportion of children's hospices' charitable expenditure.

5. Over (59%) of VCS children's palliative care providers would be forced to reduce their services if the children's hospice grant was no longer available.[7] Over two thirds (70%) said that they would be most likely to cut short breaks, followed by bereavement support (41%), family support services, complementary therapies and day services/outpatient clinics (all 37%).

6. **We ask that the government increases the value of the children's hospice grant to reflect the fact that demand for this care is increasing and life-limiting and life-threatening conditions are becoming more complex. Without this support, responsibility for care would shift directly to the NHS.**

Provide parity of funding between children's and adult palliative care services.

7. On average, adult hospices in England receive 33% of their funding from statutory sources, while children's hospices receive just 22%.

8. Together for Short Lives' survey of voluntary sector children's palliative care providers shows that their average charitable expenditure increased by 9.7% in real terms between

---

[6] Hughes-Hallett T, Craft A and Davies C (2011). Palliative care funding review - creating a fair and transparent funding system; the final report of the palliative care funding review. Available to download from: http://bit.ly/XQBIE7.

[7] Together for Short Lives (2016). On the brink: a crisis in children's palliative care funding in England. Available to download from: http://bit.ly/2f7HowK.

2014/15 and 2015/16.[8] This increased spend reflects the growing complexity and demand for children's palliative care.

9. Together for Short Lives' survey of voluntary sector children's palliative care providers shows that the state's contribution to the cost of providing children's palliative care in the voluntary sector fell. It was 22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14.

10. If children's hospices did not exist, then the cost of care for these children would fall directly to the NHS with additional costs relating to 24/7 support and care and bed use.

11. **We call on the government to provide parity with funding for adult hospices.**

Introduce a funded children's palliative care strategy.

12. Together for Short Lives made a series of freedom of information requests of local authorities and clinical commissioning groups (CCGs) in England during April 2016, which sought to establish how well these organisations are planning, funding and monitoring care for children with life-limiting or life-threatening conditions.[9] Although we asked each CCG and local authorities how much they spend on short breaks, step-down care, end of life care and transition, very few were able to determine this spending.

13. Together for Short Lives would like the government to commit to a national inquiry, producing a children's palliative care strategy that takes a family-centred and holistic approach to health, social care and educational interventions.

14. This cross-departmental strategy should make funding available to CCGs and local authorities to commission essential services for families who have a child with a life-limiting or life-threatening condition. This includes vital out of hours support and a focus on training for children's palliative care professionals.

15. **We call on government to help build greater transparency, confidence and accountability by requiring CCGs and local authorities to report on the way they plan and fund children's palliative care.**

---

[8] Together for Short Lives (2016). On the brink: a crisis in children's palliative care funding in England. Available to download from: http://bit.ly/2f7HowK.

[9] Together for Short Lives (2016). Commissioning children's palliative care in England. Available to download from: http://bit.ly/2iAOH3z.

APPENDIX B – SUPPORTING FAMILIES

Improving access to mobility allowance in Disability Living Allowance.

16. The government's disability living allowance (DLA) benefit recognises that families of disabled children over the age of three may need financial support to access appropriate transport. Families can apply for the DLA 'mobility component', available at a higher and lower rate.

17. In setting the lower age limit for entitlement, the Department of Work and Pensions (DWP) considered views of medical advisors that the majority of children could walk at the age of 2½. 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.

18. However, babies and young children under the age of three with life-limiting or 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 they need to be fixed into a vehicle.

19. In January 2018, the Work and Pensions Secretary Rt Hon Esther McVey MP confirmed that after direction from her department, Motability is now piloting 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.

20. We are delighted that Family Fund and Motability are piloting this scheme, which we believe has the potential to help many of the babies and young children under the age of three – and their families – access the specialist vehicles they need to leave home or hospital. **We would like these specialist vehicles – or an equivalent mobility payment to those families who do not drive – to be made available to all 2,781 children in the UK under the age of three who depend on bulky medical equipment.** We are keen to work closely with DWP, Family Fund and Motability to understand the findings of the pilot

Table 1: The number of children that a new scheme would need to apply to and the cost of introducing it

Number of children/ cost	**Description**
2307	Number of children in England 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'
135	Number of children in Wales 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'
2442	England and Wales total
£59.75	Higher rate DLA mobility component for children

£145,910	**Per week** cost of extending mobility component to children under the age of three in England and Wales who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment
£7,587,294	**Per year** cost of extending mobility component to children under the age of three in England and Wales who are dependent upon bulky medical equipment, or need to be near their vehicle in case they need emergency medical treatment

Children's social care, including short breaks for respite

21. Together for Short Lives is a member of the Disabled Children's Partnership (DCP), a growing coalition of more than 60 charities who have joined forces, working in partnership with parents, to campaign for better health and social care for disabled children, young people and their families in England. In 2017 the DCP commissioned research by Development Economics to quantify the current funding gap for disabled children's services. They concluded that an estimated additional £433.9 million needs to be allocated to disabled children's social care services by local authorities and £1.1billion by the NHS.

22. The Disabled Children's Partnership is therefore calling on government to include in the Budget £1.5billion a year to a Disabled Children's Fund to plug the current funding gap. This equates to just 0.2% of total government spending.

23. By making this pledge, the government would:

    - ensure disabled children and their families have the support in place when they need it, which will in turn prevent them from reaching breaking point.
    - enable local authorities and the NHS to meet their statutory duties and improve the availability and quality of services
    - support parents and young disabled children to work and succeed at school

24. A government-commissioned review of funding arrangements for palliative care published in 2011[10] 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.[11]

25. **Together for Short Lives, along with the DCP, are also calling on the government to review the way in which short breaks are provided for disabled children and their families to identify and address national, regional and local funding gaps.**

---

[10] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

[11] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/245580/Short_Breaks_for_Carers_of_Disabled_Children.pdf

Bridging the cliff edge in care between children's and adult services

26. 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.[12] 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.

27. 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.

28. 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.

29. **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.**

Extensions in the regulations of the Parental Bereavement (Leave and Pay) Act 2018

30. Together for Short Lives welcomes the Parental Bereavement (Leave and Pay) Act 2018 and believes 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 welcome the government's support and thank Kevin Hollinrake MP for introducing it.

31. Now that the bill has received royal assent, we would like the government to allocate funds to make sure that the regulations of the bill provide greater flexibility for bereaved parents. Specifically, we would like money to be made available so that:
    - Leave is not restricted to parent carers, but is also available to legal guardians caring for the child, working grandparents, aunts and uncles who are significantly affected by the death;
    - 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;
    - Parent carers who are bereaved of young people with life-limiting conditions up to the age of 25 are able to access parental leave and payments.

---

[12] 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

For more information, please contact:

James Cooper
Public Affairs and Policy Manager
0117 989 7863
0741 522 7731
james.cooper@togetherforshortlives.org.uk

Lyndon Ashmore
Campaigns Officer
0117 989 7866
lyndon.ashmore@togetherforshortlives.org.uk