

Westminster Hall debate: Hospice funding and the NHS pay award

Wednesday 31 October, 9:30am – 11am, Westminster Hall

A briefing from Together for Short Lives

1. 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, so that no family is left behind. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers.
2. **[We work closely with Hospice UK and fully support its briefing for this debate which sets out the concerns we have about the impact of the recent pay award for NHS staff on hospices.](#)** In addition to the points in that briefing, we ask MPs to convey the issues we raise in this document, which focus on the actions which we ask ministers to take to make statutory funding for children's hospices fairer and more sustainable. The **[All-Party Parliamentary Group for Children Who Need Palliative Care has also highlighted these issues in its recent inquiry report.](#)**
3. 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.
4. There are 49,000 babies, 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. It is vital these children – and their families – have access to palliative care which meets their needs and wishes, manages pain and distressing symptoms and includes emotional and psychological support.
5. The government has committed to making sure that this is the case, and the standards that are set out in NICE guidance, quality standards and the Ambitions Framework for Palliative and End of Life Care are clear and welcome.
6. However, Together for Short Lives has found that the way in which palliative care for babies is planned, funded and provided represents a postcode lottery. This includes the care and support provided by children's hospices. On average, funding provided by NHS England, clinical commissioning groups (CCGs) and local authorities contributes only a fifth of the charitable costs that children's hospices incur. This funding is patchy and unsustainable and varies from area to area.
7. Without action now to make children's hospice funding more equitable and sustainable, the government risks failing to meet its end of life care choice commitment to babies, children and young people by 2020. We ask MPs to ask the following questions of the minister:
 - **Will the government increase the overall amount of funding available through the NHS England Children's Hospice Grant to £25million to reflect the growth in demand, costs and complexity of care needed by children and young people with life-limiting or life-threatening conditions?**
 - **Will the government bring about parity in the state's percentage contribution to the charitable costs incurred by children's and adult hospice and palliative care charities?** This would mean that children's organisations would receive at least

33% of their charitable costs, comprising contributions from NHS England, CCGs and local authorities. We note that the Scottish Government has committed to bring about parity and fund 50% of the agreed charitable costs of Children's Hospices Across Scotland.

- **Will the government undertake a review of the children's palliative care currently available to children with life-limiting conditions in England as a matter of urgency?** This should lead to a funded, cross-departmental children's palliative care strategy for achieving better outcomes for children and families across the statutory and voluntary sectors. It should bring about greater access to funding for services providing emotional and practical support for families in the community. It should also include a review of the way in which short breaks for disabled children, including those with life-limiting conditions, and families are funded.
- **Will the new NHS long-term plan commit to meeting the government's end of life care choice commitment for babies, children and young people – and ensure that funding is allocated to do this?**

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

Annex: Background information

1. The government's 2016 response¹ to a review of choice in end of life care in England states that to support high quality personalised care for children and young people, commissioners and providers of services **must** prioritise children's palliative care in their strategic planning; this is so that services can work together seamlessly and advance care planning can be shared and acted upon.
2. The government's commitment also sets out the range of services which children and young people with life-shortening conditions rely on from diagnosis until the end of their lives. It highlights the role of a range of services, including children's hospices; community children's nursing services; paediatric inpatient services, specialist palliative care consultant teams; GPs; and the wider network of supporting services such as school services.
3. 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.
4. Without children's hospices, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS.
5. Voluntary sector providers including children's hospices also bring social value to communities. When local NHS organisations remunerate these charities for the children's palliative care they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide children's palliative care which are part-funded from statutory sources, further adding value.
6. There is overwhelming public support to make sure that children with short lives are not short changed by the state: 81% of the public think that children's hospices receive too little funding from statutory sources. The public think that children's hospices receive 38% of their funding from statutory sources, when in reality they only receive 22%. The public also think that children's hospices should receive more statutory funding (73%, of their total funding).
7. The National Institute of Health and Care Excellence (NICE) published a resource impact template alongside the guideline on end of life care for infants, children and young people. This tool allows local areas to input their population data and it calculates the overall cost and savings of implementing the new guidelines. Using the total population of children in England, 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 England².
8. On average, the overall amount of statutory funding for charities providing children's palliative care continues on a downward trajectory, falling year on year (22% in 2015/16

¹ Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOUsfj>

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

compared to 23% in 2014/15 and 27% in 2013/14). Statutory funding remained at 22% in 2016/17.

9. When taking the NHS children's hospice grant and funding from CCGs and local authorities into account, there was a wide range in the state's contributions to VCS children's palliative care providers' charitable costs in 2015/16. The maximum contribution received by a charity in 2015/16 was over half (53%). The lowest was 2%. 30% of charities received a contribution of between 21% and 30%. 30% of organisations received between 11% and 20%.
10. Between November 2016 and January 2017, Together for Short Lives consulted children's hospice charities in England on a potential new future formula for allocating the Children's Hospice Grant. This is allocated annually to all children's hospices in England. The total grant amount has increased incrementally from £8,829,180 in 2006/07 (part of £27million awarded over three years) to £11,000,000 in 2015/16. We consulted all current recipients of the grant on behalf of NHS England, which is responsible for administering the grant.
11. From the evidence we received, the total amount of funding available through the Children's Hospice Grant is valued greatly but is also inadequate:
 - While this increase in the Children's Hospice Grant has been welcome, it has not kept pace with the growing cost of providing clinical palliative care incurred by children's hospice charities. In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children's hospices. In 2015/16, when it had risen to £11,000,000, it contributed an average of just 8%.
 - In 2006/07, the grant contributed an average of £1,129 per child cared for by a children's hospice charity. In 2015/16, that had fallen to £947 per child. This was a fall of £182.65 (16%) per child.

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

12. 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 hospices³. 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 in England.
13. 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.
14. 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.⁴ 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%).

³ 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>.

⁴ 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>.

15. 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.

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

16. On average, adult hospices in England receive 33% of their funding from statutory sources, while children's hospices receive just 22%.
17. 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 2014/15 and 2015/16⁵. This increased spend reflects the growing complexity and demand for children's palliative care.
18. 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.
19. 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.

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

Introduce a funded children's palliative care strategy.

21. 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.⁶ 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.
22. 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.
23. 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.
- 24. 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.**

⁵ 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>.

⁶ Together for Short Lives (2016). Commissioning children's palliative care in England. Available to download from: <http://bit.ly/2iAOH3z>.