

**Adjournment debate Wednesday 1 May 2019:
Children's Funeral Fund**

A briefing from Together for Short Lives

About us

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.
2. 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, the bulk of which is provided by families at home.
3. The 49,000 babies, children and young people with life-limiting or life-threatening conditions need palliative care from the point at which their conditions are diagnosed or recognised - often at birth - until the end of their lives. **In 2017 there were 2,351 deaths of children with known life-limiting or life-threatening conditions in England.¹**

The cost of caring for a child with a life-limiting condition

4. The extra costs associated with caring for a child with a life-limiting condition can be extremely challenging. [Contact's 2018 'Counting the Costs' survey²](#) found that families who provide long-term care for a disabled child face huge financial difficulties. The survey showed that in the past year, over a third of families have extra disability and care related costs of £300 or more per month.
5. The survey also found that 7% of families had taken out more than five loans in the past year and that almost half (46%) the families had been threatened with court action for non-payment of bills. This is partly explained by the fact that 87% of families reported having caring responsibilities that mean they are unable to work as much as they would like.
6. Additionally, the survey revealed that:
 - 26% of parents said their child's condition has worsened due to going without basics
 - 33% have taken out a loan to pay for food
 - 26% of disabled children are going without essential therapies.

¹ 'Child death reviews: year ending 31 March 2017', Department for Education,
<https://www.gov.uk/government/statistics/child-death-reviews-year-ending-31-march-2017>

² 'Counting the Costs: Research into the finances of more than 2,700 families across the UK in 2018', Contact,
https://contact.org.uk/media/1395947/counting_the_costs_2018.pdf

7. Research by [CLIC Sargent](#)³ has found that those caring for children and young people with cancer spend an average of £600 in additional expenses a month during their child's active treatment. It also found that:

- Three in five (61%) parents had accumulated some form of debt as a result of their child's cancer diagnosis, mostly owed to family and friends or to credit card companies. One in six (17%) had borrowed over £5,000.
- As a result of their child's cancer diagnosis, two in five (42%) parents stopped working, half (49%) experienced a loss of earnings, and almost a third (29%) felt they were able to do less at work.

The cost of funerals

8. Research by Royal London in 2018 found that the average funeral cost now stands at £3,757, with people taking on a record average debt of £1,744 to pay for it⁴.
9. The UK government's funeral payment was designed to cover the cost of a basic funeral for grieving families who would otherwise be unable to afford one. Spending on the fund has only increased by 4.5% between 2017 and 1988 – with 2017 expenditure the lowest for 10 years. The average funeral fund award only covers 40% of a basic funeral.
10. If a child dies with a long-term disability, parents 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.

Questions to ask the minister

- **Can the minister provide a specific date on which the children's funeral fund will be implemented?**
- **Will the government commit to providing backdated payments to families who have had to pay the local authority fees since the announcement that they would be scrapped in March 2018?**
- **Will the government commit to tapering benefits paid to families when their child dies, rather than ending them immediately, in acknowledgement of the significant 'debt legacy' families of children with life-limiting conditions may face?**
- **Will the government commit to increasing the Funeral Payment support so that it tracks in line with the retail price index?**
- **What other steps is the minister taking to ensure families whose child has died are given financial assistance for funeral costs, given that they will most likely be in a perilous financial situation because of care costs during their child's life?**

³ 'Cancer Costs: The financial impact of treatment on young cancer patients and their families', CLIC Sargent, 2016, <https://www.clicsargent.org.uk/wp-content/uploads/2018/08/Cancer-Costs-Report-2017.pdf>

⁴ 'Buried in debt', Royal London National Funeral Costs Index 2018, <https://www.royallondon.com/siteassets/site-docs/media-centre/national-funeral-costs-index-2018.pdf>

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