

Response from Together for Short Lives

About Us

Together for Short Lives is the UK charity that, together with our members, speaks out for children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families, we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Life-limiting and life-threatening conditions in babies, children and young people

Life-limiting conditions are those for which there is no reasonable hope of cure and from which babies, children and young people are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail. Children and young people with life-limiting and life-threatening conditions need continuing palliative care throughout the trajectory of their illness.

Question 1

Do you agree that we should allow recipients of Funeral Payments to receive additional contributions towards the cost of a funeral from charities, friends and relatives without us deducting these contributions from the value of the Funeral Payment we award them?

1. Yes. The cost of a basic funeral already far exceeds the amount paid out by the Funeral Payment. The average Funeral Payment award in 2015-16 was around £1,400¹, whereas the average cost of a funeral was £3,897². This means that the Funeral Payment award represents approximately 36% of the total cost of the average funeral.
2. From 1980 to 2015, funeral costs increased by an average of 6.1% per year, compared to an average inflation rate of 4.0% (RPI).³ Despite a slight fall (0.7%) in average funeral costs between 2015-16, which followed a 3.9% rise the previous year, the average level of funeral debt among those who struggle increased in the same year from £1,318 to £1,601⁴. One in seven (15%) say that they struggle with funeral costs⁵. Therefore, many families will require additional contributions towards the cost of a funeral from charities,

¹ House of Commons Library (2016). Briefing paper number 01419: Social Fund Funeral Payments. Available to download from:

<http://researchbriefings.files.parliament.uk/documents/SN01419/SN01419.pdf>

² Sun Life (2016). Cost of Dying Report 2016. Available to download from:

<https://www.sunlife.co.uk/press-office/funeral-costs-soar-by-10-times-the-increase-in-the-cost-of-living-in-a-year-%E2%80%93-forcing-families-to-cut-corners-on-their-loved-ones--send-off/#>

³ Royal London (2015). The Royal London National Funeral Cost Index Report 2015. Available to download from: <https://www.royallondon.com/Documents/PDFs/2015/10299-Funeral%20Report%2052pp%20FINAL.pdf/>

⁴ Royal London (2016). The Royal London National Funeral Cost Index Report 2016. Available to download from:

<https://www.royallondon.com/Documents/PDFs/2016/Royal%20London%20National%20Funeral%20Cost%20Index%202016.pdf>

⁵ Ibid.

friends and relatives on top of their Funeral Payment. Without these, they may not be able to pay for the funeral without being pushed into unaffordable debts.

3. Families whose child dies as a result of a life-limiting or life-threatening condition will face huge financial pressures during their child's life, as well as immediately following their death.

Financial pressures for families caring for a child with a life-limiting or life-threatening condition

4. Contact a Family's 2014 'Counting the Costs' survey found that families who provide long-term care for a disabled child face huge financial difficulties⁶. Their survey showed that in the past year, over a third of families took out a loan and half of these were to pay off other debts. They also found that one in seven families had taken out more than five loans in the past year and that over half the families had been threatened with court action for non-payment of bills. This is partly explained by the fact that 88% of families reported having caring responsibilities that mean they are unable to work as much as they would like.
5. 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'.⁷ 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'⁸.
6. Families face further financial pressures in the final months of their child's life, as identified by Corden et al. Heating costs increase as a result of using more rooms for longer parts of the day and for maintaining a constant temperature in the home. There are also additional costs due to time shortages as families are unable to economise when they buy food, for example. They may need new equipment, such as a larger washing machine, to enable them to care for their child.

Financial pressures for families following a child's death

7. Corden et al. found that, for parents, 'the period immediately following the death of their child is one in which they face significant financial problems, with serious implications for the healing and adjustment process on which the surviving family must embark'.
8. Most families suffer from an immediate loss of income after the death of their child due to the cessation of benefits including Carer's Allowance, Disability Living Allowance, and Child Benefit. This causes difficulties for families as they usually have a 'debt legacy' from the costs of caring for their child.
9. Interviews with families who use Martin House Children's Hospice found that families owed money to a 'variety of creditors, including fuel boards, banks, commercial credit

⁶ Contact a Family (2014). Counting the Costs 2014. Available to download from: https://www.cafamily.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf

⁷ A.Corden, R. Sainsbury & P. Sloper (2001). Financial Implications for parents of the death of a child. Available to download from: <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

⁸ Ibid.

companies, building societies, retail outlets, garages, travel and holiday firms, relatives and friends. Some bereaved families were believed to be in danger of repossession of their home as a result of mortgage arrears⁹.

10. Many applicants will however receive no financial contributions from charities, friends or families. For the reasons set out above, many of these families may already be in a perilous financial situation. Often these applicants will be the most vulnerable and isolated, without supportive social networks or skills to advocate for themselves. We ask that DWP proposes solutions for how these people can make up the shortfall between funeral costs and the Funeral Payment. Although Budgeting Loans are accessible for some to help cover funeral costs, because they must be paid back they do not represent an adequate solution for people already on very low incomes or those who have existing debts from caring for their child.

Question 2

Do you agree that we should not assign the responsible person status to people living in care establishments who receive income-assessed help from their local authority with their care fees, in place of an applicant who would otherwise be eligible for a Funeral Payment?

11. Yes. But the definition of care establishments must include older people's care homes and nursing homes, homes for people with disabilities, hospices and hospitals.
12. We welcome the acknowledgment that people living in a care home, whilst not on a qualifying benefit, are unlikely to be able pay for a funeral. However, this is not restricted to people living in care homes. Several other groups are not on a qualifying benefit but would be included as a responsible person, would thus disqualify relations from eligibility.

Question 3

Do you agree that we should extend the application period to claim Funeral Payments from 3 to 6 months?

13. Yes. Extending the application period rightly takes into consideration that the time following a bereavement can be overwhelming, and families may need longer than usual to complete tasks.

Question 4

Do you support the launch of a shorter application form for claims relating to children's funerals?

14. Yes. The application form should be shorter as the financial position of a child is much less complex than that of an adult.
15. Crucially, the DWP must also commit to shortening the processing time for the Funeral Payment for all applicants, as they are claiming for a payment to reimburse them for money that has already been spent on the funeral.
16. Shortening the overly long application form for grieving parents will not tackle the specific problems they face in applying to the Funeral Payment. Many funeral directors waive

⁹ A.Corden, R. Sainsbury & P. Sloper (2001). Financial Implications for parents of the death of a child. Available to download from: <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

their fees for children's funerals. But parents are still left trying to raise money for the deposit, required by most funeral directors before the funeral will go ahead. In most cases the deposit is the value of the cremation or burial plus any additional fees owing to third parties. Because parents are often much more financially ill-prepared for a funeral, they can find it incredibly difficult to raise this deposit. This leaves them in the incredibly distressing situation of not knowing how they will arrange the funeral for their child. Grieving parents would be far better served by a reform which addresses the delays in application processing times, to enable them to use a Funeral Payment to help cover the deposit and thus allow the funeral to go ahead.

Question 5

Do you agree that we should clarify that Funeral Payments will pay for the necessary costs of a burial with or without exclusive rights of burial?

17. Yes

Question 6

Do you agree that applicants and funeral directors should be able to submit evidence electronically to support a claim for Funeral Payments?

18. Yes. In addition to this, the government should explore other reforms which would speed up the processing of applications, for instance processing applications on the receipt of a final, agreed estimate from the funeral director, or providing a 'payment in kind' notification once an applicant has been deemed eligible. If such a system were to be considered, the DWP would need to consider how to build in safeguarding measures, so that the bereaved person(s) cannot be targeted by unscrupulous individuals or services.
19. Long processing times cause added distress, uncertainty and financial pressure for applicants, especially those whose religion or culture requires a funeral soon after death.
20. Because the DWP doesn't process forms until after the funeral has taken place and most funeral directors require a deposit before they will go ahead with the funeral, applicants are obliged to commit to funeral costs before they know if they'll receive financial support. In so doing, they are forced to make poorly informed financial decisions that may result in substantial debt.
21. The Scottish Government have sought to address the problem of delays in processing time within their devolved Funeral Payment system. They've committed to processing applications within a 10-day period. In contrast, data from clients at *Down to Earth* suggests it takes on average four weeks for the DWP to process claims¹⁰.
22. We ask that the UK Government seeks to learn from best practice in Scotland and match the commitment to a 10-day processing time.
23. We ask DWP to initiate up a working group with representatives from the funeral industry to propose and agree practical solutions for speeding up processing times.

Question 7

Do you agree that we should cover the proposed medical examiner fees, if adopted in

¹⁰ Fair Funerals Campaign (2017). Government taking action to fix the broken funeral fund. Available at: <http://fairfuneralscampaign.org.uk/content/government-taking-action-fix-broken-funeral-fund>

the future, as a necessary cost, as we currently cover them as necessary for cremations?

24. Yes. For the reasons set out in our response to question 1, families already face huge financial pressures when their child has died. As we are still awaiting the government's response to the consultation on 'Introduction of Medical Examiners and Reforms to Death Certification', it remains uncertain as to whether child deaths will be exempted from the new medical examiner fee, which Together for Short Lives has called for. If child deaths are not exempted from medical examiner fees, the Funeral Payments award should cover this cost.