

15 June 2016

## Introduction of Medical Examiners and Reforms to Death Certification: consultation



### A written submission 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.

#### Our submission

1. Together for Short Lives supports the principles behind these reforms and the introduction of the new medical examiner system, which will provide stronger safeguards for the public.
2. We are pleased that the new system supports urgent death certification for expected deaths of children in hospitals, so that families can move them home or closer to home – i.e. a children's hospice. We are pleased that feedback from the pilot sites shows that this urgent certification process is manageable and we urge the Department of Health to maintain this concession.
3. However, we share the concerns of the National Bereavement Alliance (of which Together for Short Lives is a member) in regards to the cost to families of the new system and we support their submission to this consultation.
4. In addition to the concerns raised by the National Bereavement Alliance submission to this consultation, **we are concerned that the new system as proposed will result in an additional cost for families whose child has died**, as they will be liable to pay the medical examiner fee, regardless of whether their child is buried or cremated.
5. Families who provide long-term care for their child suffer enormous financial pressures while their child is alive, in addition to further costs when their child has died and we believe this new fee will unfairly add to these pressures. Furthermore, there are fewer than 4,000 child deaths in England<sup>1</sup> each year and approximately 200 in Wales<sup>2</sup> and we believe that these deaths could be exempted from the new fees system with minimum financial implications.
6. These concerns are set out below.

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<sup>1</sup> <https://www.gov.uk/government/statistics/child-death-reviews-year-ending-31-march-2015>

<sup>2</sup> <https://www.childdeathreview.org/wp-content/uploads/Publications/WalesCDRAnnualReportJuly2015.pdf>

## **Additional costs of caring for a disabled child**

7. Contact a Family's 2014 'Counting the Costs' survey found that families who provide long-term care for a disabled child face huge financial difficulties.<sup>3</sup> This 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 1 in 7 families had taken out more than 5 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.

## **Additional costs of caring for a child with a life-limiting or life-threatening condition**

8. 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'.<sup>4</sup> 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.'<sup>5</sup>
9. Families face further financial pressures in the final months of their child's life, as identified by Corden et al., who found that household bills grew as a result of the cost of caring for a child with a life-limiting or life-threatening condition. 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 in areas like food purchasing. They may also require 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**

10. 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'.
11. 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.
12. 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 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 arrears.'<sup>6</sup>

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<sup>3</sup> <http://www.cafamily.org.uk/news-and-media/contact-a-family-launches-counting-the-costs-campaign/>

<sup>4</sup> <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

<sup>5</sup> <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

<sup>6</sup> <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

## Funeral costs

13. In addition to the extra financial pressures of caring for a child with a life-limiting or life-threatening condition, parents must also pay for a funeral for their child. Royal London found that funeral costs have increased above inflation for the past 35 years and in 2015 the average cost was £3,702 – up 3.9% from the year before.

## Concluding remarks

14. Under the present system, bereaved parents whose child is to be buried do not pay any death certification fees and, if they opt for cremation, doctors will often waive the cremation fees. We are concerned, therefore, that the new fees system will result in an additional cost for families at a time when they are already under huge financial pressures and have debts from caring for their child.
15. Together for Short Lives urges the Department of Health to exempt these deaths from the new fees structure. There are fewer than 4,000 child deaths per year in England<sup>7</sup> and approximately 200 in Wales.<sup>8</sup> and this exemption would therefore represent less than 1% of the approximately 500,000 deaths that are registered in England and Wales each year.<sup>9</sup> Though this would have minimal financial impact on the new death certification scheme, it would prevent the new fees structure from adding to the enormous financial pressures that families face when their child dies.

## For more information, please contact:

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<sup>7</sup> <https://www.gov.uk/government/statistics/child-death-reviews-year-ending-31-march-2015>

<sup>8</sup> <https://www.childdeathreview.org/wp-content/uploads/Publications/WalesCDRAnnualReportJuly2015.pdf>

<sup>9</sup>

<http://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015-07-15>