

Consultation response form

Please use this form to respond to the consultation questions. Please return form to

HQDMailbox@wales.gsi.gov.uk

or by post to:

Natalie Harris
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Health and Social Services Group
Welsh Government
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Your name: Patrick McKenna - Policy and Public Affairs Officer, Together for Short Lives

Your address: Together for Short Lives, 2nd Floor, New Bond House, Bond Street, Bristol, BS2 9AG

Responding as (please tick one):

- Individual
- Local Government body
- University/academic body
- Political party/union
- Health professional representative body/advisory group/association
- NHS body
- Government department/agency
- Citizen voice/third sector organisation
- Social enterprise/business
- Legal or other professional

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here:

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Question 8: Do you have any comments in relation to the charging and collection of a fee which you feel we should take into account?

Your response to Question 8:

1. Together for Short Lives urges the Department of Health and Social Services to exempt child deaths from the new fees structure, for the reasons set out below. There are approximately 210 child deaths in Wales each year¹. Statistics for total deaths for all ages are collated together with England (529,655 deaths²), but the combined child death totals (210 in Wales, 3,565 in England³) represent less than 1% of all deaths. We therefore feel that this exemption would have a minimal impact on the new death certification scheme.

Additional costs of caring for a disabled child

2. 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.⁴ 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

3. 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'.⁵ 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

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<http://www.wales.nhs.uk/sitesplus/documents/888/CDR%20patterns%20%2B%20trends%20v1%20EN.pdf>

2

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2015>

3

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/537359/SFR24_2016_Text.pdf

⁴ <http://www.cafamily.org.uk/news-and-media/contact-a-family-launches-counting-the-costs-campaign/>

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

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.'⁶

4. 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

5. 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'.
6. 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.
7. 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.'⁷

Funeral costs

8. 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

9. 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.

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

⁷ <http://www.york.ac.uk/inst/spru/research/pdf/Financial.pdf>

10. We therefore call for the Department of Health and Social Services to exempt child deaths from the new fees structure. 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.

Please use the box below for any other comments you wish to make:

Thank you for taking the time to respond to the consultation.