

## Briefing for Adjournment Debate on Children's Funeral Fund: 1<sup>st</sup> May 2019

### Questions to government

- Will the Minister set a date to make the fund a reality?
- Will the Minister provide full details of the Children's Funeral Fund such as how parents might make a claim, and what the eligibility criteria will be?
- Will the government backdate any payments to families who have paid local authority funeral fees since the March 2018 announcement?

### About Rainbow Trust Children's Charity

Rainbow Trust was established in 1986. We provided emotional and practical support to more than 2,500 families with a child with a life threatening or terminal condition across England last year, through eight teams of Family Support Workers.

Support is offered in the home, community or hospital as required. We pair each family with a Family Support Worker who becomes a trusted and constant person in family life. Our support enables parents with a seriously ill child, and their siblings, to make the most of time together; providing expert practical and emotional support, where they need it, for as long as it is needed, including during bereavement when other forms of support may end.

### Children's Funeral Fund

Rainbow Trust strongly supports the creation of this fund and is deeply disappointed by the delay in its establishment. In our experience a bereaved parent will often be in shock and can be in a highly vulnerable state when considering options for their child's funeral. A child with a life threatening or terminal illness will often have had an uneven trajectory of illness, and may have appeared to be at end of life several times before making a recovery. For this reason, when a seriously child dies, the loss may still be sudden and unexpected. At the same time, families have usually experienced a drop in earnings while one parent is the full time carer of a child with a terminal or life threatening condition.

12 children in families supported by Rainbow Trust have died in the first quarter of 2019 alone.

The following examples are from just two of our eight teams of Family Support Workers, and illustrate how often the cost of a child's funeral causes both financial and emotional distress at the most difficult of times:

#### Example 1

A four year old boy, whose family had received support from Rainbow Trust for three years, died in December 2018. He had complex needs and a hole in his heart, but his death was sudden and unexpected. The stress of coping with their son's condition had contributed to the parents splitting up.

After her son's death, and while in a vulnerable state of mind, the mother went to an undertakers and started to make decisions about his funeral. She found that communication about the options and costs was unclear and misleading. The mother chose a cremation for her son in the hope of keeping the cost down, but the total bill was more than £4,000 which in hindsight may have been enough to pay for her preferred option of a burial.

Unusually, the undertaker's bill was issued for full payment two weeks before the funeral. The costs were met by family members taking on personal debts. The mother is still supported by Rainbow Trust. Her mental health continues to be poor, and has been worsened by the financial impact of her son's sudden death.

### **Example 2**

A young couple from Eastern Europe had their first son in October 2018. He was born with life-limiting neurological problems, and despite a prognosis of potentially living up to 18 months, he died in April 2019, aged six months. This was an enormous shock for his parents. As Orthodox Christians, the couple wished to arrange a quick burial for their son in line with their religious beliefs.

Both parents work but are on low incomes and have no other family in the UK. The child's funeral cost a total of £1,800, which could only be paid by borrowing £1,000 for the deposit from family abroad. There was no money for flowers at his funeral, so their Rainbow Trust Family Support Worker made sure that there was a bouquet. The parents are still working out how to pay the remaining £800 owed to the undertakers.

### **Example 3**

A family supported by Rainbow Trust had a child who died in 2018. The parents waited three and a half weeks for a funeral in order to minimise costs. This saved money, but meant they did not have a burial when, where or how they would have wished. For instance, the plot where their child was buried is not in a location that they would have chosen had they had the opportunity to select it.

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