

**Briefing for MPs:  
General Debate on Baby Loss awareness week  
10 October 2017**

**Request to MP**

**Please could you raise the following points with the Minister during this debate.**

**Along with other organisations backing Baby Loss Awareness Week, Rainbow Trust joins the call for:**

1. All UK hospitals to be required to offer excellent bereavement care to parents.
2. A member of staff appointed to lead on bereavement care in every hospital department where pregnancy loss and baby death occurs.
3. Bereavement rooms to be available and accessible in all hospitals
4. All health and social care professionals to receive the highest standard of bereavement care training.

Alongside this we call for:

- The value of bereavement support outside the hospital setting to be recognised and funded to ensure all families can receive the support they need when their baby dies, wherever they live, and for as long as required.

**A General Debate on Baby Loss Awareness Week will be held on the afternoon of Tuesday 10 October.**

This briefing sets out the role of tailored bereavement support in the community and its value alongside bereavement care in clinical settings.

**1. Supporting parents through uncertainty and bereavement**

Rainbow Trust Children's Charity provides emotional and practical support to families across England who have a baby or child with a life threatening or terminal illness. With 30 years of experience, we are the leading organisation providing children's social palliative care - which we define as the essential support that a family needs, alongside medical care, to face each day as it comes. This includes supporting parents through bereavement if a baby or child dies.

In light of the rise in the number of babies with palliative care needs, Rainbow Trust has offered tailored support to parents of babies in neonatal units since early 2015, beginning with the creation of a dedicated Neonatal Support Worker at the Chelsea and Westminster Hospital. More than 156 families have been referred to this post so far.

Rainbow Trust now provides neonatal support in each of the nine areas that we work in across England, and we run three neonatal support groups and sibling groups at neonatal units. More than 100 referrals were received in the last 12 months across all teams.

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## **2. Bereavement support in the community and at home**

Parents of a seriously ill baby may have to live with the knowledge their child has a terminal or a life threatening condition with all the uncertainty that means. Our aim is that babies' lives will have meaning and impact, no matter how short.

The death of a baby is a devastating event for all members of the family. It can seem like the death of much unfulfilled potential, and there can be an overwhelming sense of despair. This can lead to emotional and physical exhaustion, a deep longing for the baby, and conflicting emotions including anger and guilt.

A Rainbow Trust Neonatal Support Worker can provide:

- Someone independent to talk to, during a baby's time on a neonatal unit, including support during difficult appointments and conversations with doctors
- Focussed support around grief and loss for parents and siblings, including memory-making activities, delivered in the place of their choosing.

## **3. The new National Bereavement Pathway**

We warmly welcome the recent work on a new National Bereavement Pathway and its piloting in eleven sites in England to help improve the care bereaved parents receive.

However, it is notable that the new per-patient funding currency (non-mandated) for children's palliative care, published in spring 2017, includes pre-bereavement assessment, but not bereavement support. The NHS England guidance to the currency states:

*Bereavement counselling does not form part of the currency model, but commissioners should think about the excellent value that these services provide, especially in terms of impacts on the wider health system, in thinking about the way they commission services.*

We believe that providing high quality bereavement counselling and support is an important investment which will enable parents to manage their feelings more effectively and will create savings over time for the health system and wider society.<sup>1</sup> One way to ensure all parents can access the care and support that they need is for a National Bereavement Care Pathway to be included in the Government's Mandate to NHS England.

## **4. We know that appropriate neonatal bereavement care and support is often a postcode lottery. For this reason Rainbow Trust backs the coalition calls for:**

1. All UK hospitals to be required to offer excellent bereavement care to parents.
2. A member of staff appointed to lead on bereavement care in every hospital department where pregnancy loss and baby death occur.
3. Bereavement rooms to be available and accessible in all hospitals.
4. All health and social care professionals to receive the highest standard of bereavement care training.

### **Alongside this, we call for:**

- The value of bereavement support outside the hospital setting to be recognised and funded to ensure all families can receive the support they need when their baby dies, wherever they live, and for as long as required.

## 5. Examples

### **Example A: Lack of neonatal family support in Bradford**

A mother who did not have access to family support explains:

*'I was in hospital five days before our first beautiful boy arrived. Sadly he passed away after being born too early. A day later our other two baby boys were born and were taken straight to NICU [Neonatal Intensive Care Unit]. We have a 22 month old daughter, who was at home being cared for by my parents.'*

*This was a very difficult time for both my husband and myself. Not only was I recovering from surgery, we had to come to terms with the death of our son, worry if our other two boys would survive, and also try to keep things as normal as possible for our daughter.'*

The Muslim Chaplain at Bradford Teaching Hospital has spoken at length to Rainbow Trust Children's Charity about her experience of mothers in need of culturally and religiously sensitive emotional support after leaving the Neonatal Unit, but finding this very difficult to access.

### **Example B: Perspectives on compassionate care from a bereaved family**

*'A reflection from a bereaved mother of twins was that whilst both of her babies died, she felt like their deaths were treated differently. It was a shock when the first twin died as he was always described as the stronger, 'more well,' twin. The mother reported the doctors discouraged an autopsy, reflecting he had been through enough in his little life, and the parents agreed.'*

*When their other baby died, more than a month later, the mother found it confusing that the doctors were really encouraging them to have an autopsy, and were saying different things. This made her feel like they were treating her second baby like a science experiment, and in her eyes the autopsy was all about them finding out what they wanted to know, and had nothing to do with what they wanted as a family. She repeated the words they used the first time regarding her first baby and told them he has been through enough in his life. The hospital respected her wishes, but the different experience with each baby has left a negative impression for her about the processes in place following a baby's death.'*

*In terms of bereavement support, the mother was interested but slightly ambivalent about going back to the hospital to see the psychologist. The psychologist is only available two days a week and the times available were not convenient. The limited availability acted as an additional barrier to bereavement counselling and as a result she has not engaged further.'*

*There are parent groups on the neonatal unit but there are no bereaved parent groups. This is something this mother expressed to me she would participate in if it existed.'*

Rainbow Trust Neonatal Support Worker

## **Background**

### **a) The changing nature of neonatal deaths in England**

There is a rise in babies living with complex and life limiting conditions. Analysis of data for 2009-10 to produce estimated prevalence showed that life limiting conditions had their highest prevalence in children under one years old compared to all other age groups under 19.<sup>ii</sup> This rise can be attributed to:

- Rapid developments in medical science which mean that many more babies born prematurely and/ or with complex medical conditions now survive birth.
- Increasing maternal age at delivery, and older mothers being at greater risk of complications at birth.
- The rise in use of fertility treatment, leading to higher numbers of twins and triplets, with multiple pregnancies more likely to result in premature birth.

### **b) Rainbow Trust's neonatal service**

As well as offering emotional support and bereavement support, our neonatal service addresses practical challenges that families can face such as:

- Complicating factors such as twins receiving treatment in different hospitals
- Siblings being cared for by relatives due to parents needing to be at a unit with a very sick baby
- Parents who have poor natural support networks
- Parents who cannot drive.

A Rainbow Trust Neonatal Support Worker can provide:

- Help with transport to and from hospital – neonatal units can be miles away from the family home. As an example, our services enabled a mother to visit her baby in a level three neonatal unit when the alternative was a three-hour journey each way on public transport which would not be possible around school pick-ups for her older children
- Respite care - sitting with the baby if parents need some time to themselves
- Help with care of siblings – so that brothers and sisters feel less isolated and remain connected with their family. Parents can feel torn between the needs of their sick baby and the needs of existing children. 'Winter visiting' policies designed to avoid the spread of infections in some hospitals can mean that siblings under 12 years cannot visit their sick baby brother or sister for 5 months, for example

Our evaluation data suggests our services are much valued by both families and professionals.

### **c) Rainbow Trust's funding**

- Despite evidence of the good outcomes that we can enable for families, and the savings that we enable for the health and social care system, just 3 per cent of all Rainbow Trust costs are funded through the public purse.
- None of our neonatal support services receive any funding from NHS England, CCGs or local government. Funding criteria are narrowly defined to cover clinical palliative care services (such as hospice care provided by nursing staff or paid personal carers) or Short Breaks provision which Local Authorities often target at meeting the recurrent needs of families with a child with disabilities, rather than meeting the immediate needs suddenly arising for families with a seriously ill baby.

**For more information, please contact:**

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<sup>i</sup> See *Hidden Savings: How Rainbow Trust saves money for the health and social care system*, Rainbow Trust Children's Charity, 2017

[https://rainbowtrust.org.uk/uploads/other/pdfs/Hidden\\_Savings\\_Report\\_Final.pdf](https://rainbowtrust.org.uk/uploads/other/pdfs/Hidden_Savings_Report_Final.pdf)

<sup>ii</sup> See *Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity*, University of Leeds/ Together for Short Lives, 2011.

[www.togetherforshortlives.org.uk/assets/0000/1100/Leeds\\_University\\_Children\\_s\\_Hospices\\_UK\\_-\\_Ethnicity\\_Report.pdf](http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Children_s_Hospices_UK_-_Ethnicity_Report.pdf)