

Briefing for MPs: Thursday 13 October 2016

Parliamentary Debate on Baby Loss

Request to MP

Please could you consider raising the following two questions during this debate:

1. How will government, NHS England, and local commissioners, make funding available so that tailored social care support services for families with high levels of need are available on all neonatal units?
2. How will the model of bereavement care for families affected by the death of a baby, currently under development by the Department of Health, work with existing voluntary sector providers?

A Backbench Business debate on Baby Loss will be held on the morning of Thursday 13 October.

Rainbow Trust Children's Charity urges MPs to attend this debate and to ask two questions relating to support for families whose baby is seriously ill or has died.

Rainbow Trust (rainbowtrust.org.uk) provides emotional and practical support to families across England who have a child with a life threatening or terminal illness. With 30 years of experience, we are the leading organisation providing children's social palliative care - the essential support that a family needs, alongside medical care, to face each day as it comes.

Overall just 3 per cent of all Rainbow Trust costs are funded through the public purse, and none of our neonatal support services receive any funding from NHS England, CCGs or local government.

Context: The changing nature of neonatal deaths in England

Providing neonatal support is an area in which our services are expanding owing to the rise in babies surviving 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.ⁱ 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.

Rainbow Trust's Neonatal Support Service

In the knowledge that there is a rising number of babies with palliative care needs, we have expanded our services to offer support to parents of babies in neonatal units, beginning with the creation of a dedicated Neonatal Support Worker at the Chelsea and Westminster Hospital in 2015. This post supported 37 families in the first year.

We now provide neonatal support in all the areas that we support, and we run three neonatal support groups. In the 12 months to August 2016, Rainbow Trust received 86 referrals for neonatal support.

Our aim is that babies' lives will have meaning and impact, no matter how short. Through our support we aim to facilitate improved bonding and attachment between parents and their baby, however short the baby's life.

Part 1: The role of social care support for families with a seriously ill baby

The report of the National Maternity Review highlights the importance of keeping premature and sick babies together with their parents and ensuring parents are 'actively encouraged' to participate in their baby's care on the neonatal unit and in discussions and decision-making with the neonatal team'.ⁱⁱ Early social care intervention can play an important part in this.

However, none of our neonatal support services receive any funding from NHS England, CCGs or local government, and there are many parts of the country in which our organisation cannot yet provide support on neonatal units because of a lack of funding. Overall just 3 per cent of all Rainbow Trust costs are funded through the public purse.

Being present and involved in the care of a terminally ill baby can be a particular challenge for families with:

- 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.

Tailored, flexible social care services such as ours 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
- 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
- Focussed support around grief and loss for parents and siblings, including memory-making activities.

Initial evaluative data suggest our services are much valued by both families and professionals.

However, funding criteria are often 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 more immediate social care needs suddenly arising for families with a seriously ill baby.

The need to join up health and social care is repeatedly emphasised by NHS England and the Department of Health. Improving social care provision for families whose baby is on a neonatal unit could be an important test of how this might be done more effectively.

Question 1: How will government, NHS England and local commissioners make funding available so that tailored social care support services for families with high levels of need are available on all neonatal units?

Example: 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.

Part 2: Bereavement support

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.

We are therefore pleased that the need for improved bereavement care has been recognised by DH.ⁱⁱⁱ The recent mapping of bereavement provision in England and the development of a National Bereavement Care Pathway by charities supported by the Department for Health is to be applauded.

However, the way in which improved services will be delivered and funded remains unclear. The new per-patient funding currency (non-mandated) for children's palliative care, which is due for commissioners to use from April 2017, includes pre-bereavement assessment, but not bereavement support. The national Maternity Review published by NHS England acknowledged the need for good-quality bereavement care,^{iv} but provided little detail on how such improved bereavement services might be implemented.

The provision of high quality bereavement care requires:

- Making enough staff time available to provide support
- Using a multidisciplinary approach
- Ensuring parents' experiences are heard and listened to.

Rainbow Trust Children's Charity recommends that any new initiatives by the Department of Health work closely with existing voluntary sector services in order to draw fully upon the expertise and reach of these providers.

Question 2: How will the model of bereavement care for families affected by the death of a baby, currently under development by the Department of Health, work with existing voluntary sector providers?

Example: 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.'

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ⁱ 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, http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Children_s_Hospices_UK_-_Ethnicity_Report.pdf

ⁱⁱ National Maternity Review, *Better births: improving outcomes of maternity services in England: A Five Year Forward View of Maternity care*, Feb 2016. <https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf> p.65, section 4.57

ⁱⁱⁱ George Freeman, then Parliamentary Under Secretary of State for Life Sciences, speaking in Commons debate on Still Birth on 9th June 2016, said *'We are committed and believe that good bereavement care should consider the needs of the whole family; mother, father and children. The Government are absolutely committed to improving bereavement care. We are working actively on setting out the next steps in due course.'*

^{iv} National Maternity Review, *ibid*, pages 67-69.