

## **Support for children with life-limiting and life-threatening conditions and their families**

**Westminster Hall debate  
9.30am on Tuesday 29<sup>th</sup> January 2019**

### **Suggested questions for MPs to ask the Minister for Care:**

- 1. Will the minister clarify whether the increase in funding for child palliative care from £11 million to £25 million, announced in the NHS Long Term Plan, is intended also to be open to providers of emotional and practical support who are not children's hospices?**

**If not, will the minister set out what steps will be taken to make funding available for services providing emotional and practical support for families in the community?**

- 2. What steps will the minister take to encourage local authorities and CCGs to increase their commissioning of sibling support for the brothers and sisters of children with life threatening and life limiting conditions?**

Rainbow Trust warmly welcomes this opportunity for MPs to discuss support for children with life-limiting and life-threatening conditions and their families.

- The statement that child palliative care is a priority for the NHS in the recently published Long Term Plan is a significant step forward. It builds on valuable developments in recent years, including the 2016 Government End of Life Choice Commitment<sup>i</sup> (which recognised that end of life care for children must encompass the whole family), and the 2016 NICE Guideline on Care for the Dying Infant, Child or Young Person.<sup>ii</sup>
- Rainbow Trust strongly welcomes this growing focus on the particular needs of these children and their families. We endorse the recommendations of the recent APPG report<sup>iii</sup> and we encourage MPs to call upon the minister to set out the steps being taken to respond to them.
- We hope that this debate will consider the full range of palliative care services including those that provide emotional and practical support for children and families in their homes and in the community.
- For the families who use a hospice for a set number of nights per year, the increase in NHS England funding for child palliative care announced in the NHS Long Term Plan, from £11 million to £25 million, to match-fund CCG contributions, is extremely welcome.
- Alongside this it must be noted that children and their families have needs every day, throughout the year, and they need support when they leave the hospital or hospice. A parallel increase in funding for other types of care is now overdue.
- Emotional and practical support is a worthwhile investment to avoid longer term costs to the health, care and education system when children and families are not supported to cope with the demands of their situation. Failure to fund these preventative support

services may result in far more costly crisis interventions over time.

- The diverse ways in which a service like Rainbow Trust can support families can enable them to cope more effectively with their situation, yet the very same diversity makes it harder for the charity to meet the narrowly defined criteria for statutory funding or contracts.
- Statutory funding comprised just 2.4% of the charity's income last year. This was Short Breaks funding from a small and declining number of Local Authorities.

**Rainbow Trust suggests the following questions for MPs to raise with the Minister:**

- 1. Will the minister clarify whether the increase in funding for child palliative care from £11 million to £25 million, announced in the NHS Long Term Plan, is intended to be open to providers of emotional and practical support?**

**If not, will the minister set out what steps will be taken to improve access to funding for services providing emotional and practical support for families in the community?**

As a non-clinical service, Rainbow Trust does not qualify for the existing NHS England Children's Hospice Grant Programme, and receives no funding from CCGs for the emotional and practical support which it provides to families.

- 2. What steps will the minister take to encourage local authorities and CCGs to commission sibling support?**

Supporting the siblings of babies or children with life-threatening and life-limiting conditions can enable children and young people to learn important coping mechanisms, find an outlet for their strong feelings and worries, and keep up their school work.<sup>iv</sup> NICE guidance recognises the importance of this<sup>v</sup> but at present there is little evidence of this support being translated into commissioning decisions.

In fact, sources of funding for such support are small and declining, and it is likely that many siblings in this situation are not being recognised as young carers by either their parents or their schools.

**About Rainbow Trust Children's Charity**

- Rainbow Trust provides emotional and practical support to families where a child has a life-threatening or terminal illness, including undiagnosed conditions.
- It supported more than 2,500 families last year through eight teams of Family Support Workers across England.
- The charity saw a 12 per cent rise in the number of new families being supported by the service in 2017-18.
- Rainbow Trust is a member of Together for Short Lives, and was represented on the Expert Panel for the APPG for Children Who Need Palliative Care during its 2018 inquiry.
- Families are paired with an expert Rainbow Trust Family Support Worker who becomes a trusted and constant person in family life. Family Support Workers can tailor support depending on a family's needs.



- A Family Support Worker may:
  - help families at home with practical tasks
  - assist with transport to and from hospital appointments or neonatal units (which may be at some distance from family home)
  - offer emotional support
  - attend important medical appointments with parents
  - play with the sick child or their siblings
  - talk to brothers and sisters who struggle to understand what is happening
  - help siblings to attend school or nursery
  - help a family make memories and plan for end of life
  - run drop in groups for siblings
  - bereavement support.

One parent of a child with a life-threatening condition said, *“Practical support is really important to me. I don’t need help every day or every week but it makes a huge difference when someone else can make a phone call for me or sort something out so I can be with my son and don’t need to sit down at a computer to sort something out.”*

Clare, mother to Adam, who is now in remission from cancer, said: *‘At any other time, if we, as a family, were met with this level of trauma we would be there for our kids. The nature of sudden, life threatening illness in children means that we [parents] cannot practically be there for all of them...’*

*... The continual support from Rainbow Trust through to recovery and beyond is something very unique. Many services stop once the children leave hospital but the needs and pressure on the families can increase and, as a parent, you can feel very isolated and alone, no longer fitting into the pattern of your old life and struggling to find a new way of moving forward.’*

Another parent who particularly valued access to sibling support explained *“There’s only one of you and I found it was one of the hardest things to juggle, I felt a lot of guilt towards the other siblings, I felt they were very much missing out, whether it was due to hospital stays or the strict routine I had at home.”*

### **Saving money for the health and social care system**

Providing emotional and practical support can enable significant savings for the health and social care system, as set out in two reports by Rainbow Trust: <sup>vi</sup> Examples include:

- Freeing up hospital beds more quickly, when families feel better able to manage their baby or child’s condition at home with Rainbow Trust support.
- Reducing the number of missed appointments when Family Support Workers assist in helping a family to cope with the large number of appointments their child may have and by providing transport.
- Helping parents to stay together despite raised stress levels and enabling all family members to manage their feelings better and potentially avoid long term mental health problems, which can be difficult and costly to address. <sup>vii</sup>
- Enabling siblings to attend nursery or school when parents would otherwise not be able to do drop offs and pick-ups, and providing an outlet for siblings to open up about their worries and to feel less isolated.



## Contact information

Sophie Dodgeon, Policy & Campaigns Manager

[sophie.dodgeon@rainbowtrust.org.uk](mailto:sophie.dodgeon@rainbowtrust.org.uk)

---

<sup>i</sup> *Our Commitment to you for end of life care: The Government Response to the Review of Choice*, Department of Health 2016.

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/536326/choice-response.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf)

<sup>ii</sup> *End of life care for infants, children and young people with life-limiting conditions: planning and management*, NICE guideline NG61, 2016. [www.nice.org.uk/guidance/ng61](http://www.nice.org.uk/guidance/ng61)

<sup>iii</sup> *End of life care: Strengthening choice – an inquiry published by the All-Party Parliamentary Group for Children Who Need Palliative Care*, 2018. [www.togetherforshortlives.org.uk/appg](http://www.togetherforshortlives.org.uk/appg)

<sup>iv</sup> *See Us, Hear Us, Notice Us: The case for supporting siblings of seriously ill children*, Rainbow Trust Children's Charity, 2018. [www.rainbowtrust.org.uk/seeushearus](http://www.rainbowtrust.org.uk/seeushearus)

<sup>v</sup> *End of life care for infants, children and young people with life-limiting conditions: planning and management*, *ibid.*

<sup>vi</sup> *Hidden Savings: How Rainbow Trust is saving money for the health and care system*, 2017.

[www.rainbowtrust.org.uk/hidden-savings](http://www.rainbowtrust.org.uk/hidden-savings) This estimated that the service is saving at least £2 million per year for the health and care system. *See Us, Hear Us, Notice Us* (*ibid.*) estimates that current Rainbow Trust sibling support for 1,230 siblings across one year may be saving at least £418,000 for the health, education and social care system.

<sup>vii</sup> *See A national study of the impact on parental relationships of short breaks provided by children's hospices*, Julia's House/ University of Bournemouth, 2017, [www.juliashouse.org/keeping-families-together](http://www.juliashouse.org/keeping-families-together) and *Hidden Lives*, Together for Short Lives, 2018 [www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/180312-Report-on-Family-Survey-and-Misconceptions.pdf](http://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/180312-Report-on-Family-Survey-and-Misconceptions.pdf)

