

## Children's Palliative Care

Adjournment debate: Monday 1<sup>st</sup> July 2019

### Suggested questions to raise with the Minister for Care:

1. Will the Minister ensure that efforts to address the crisis in funding for children's palliative care will also encompass securing fair and sustainable funding for social care support for families with a life threatened or terminally ill child?
2. Will the Minister champion the social care needs of families with a seriously ill child in the next Spending Review?
3. What steps will the Minister take to encourage CCGs and Local Authorities to commission 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 raise the urgent issues facing children's palliative care providers which have been documented in Together for Short Lives' recent survey of statutory funding for hospice and palliative care charities.<sup>i</sup>
- As a member of Together for Short Lives, we share the grave concerns that children's hospice services are at serious risk of being cut, as a result of rising costs combined with the uncertainty regarding the continuation of the Children's Hospice Grant beyond 2020, and against a backdrop of decreasing funding from statutory sources.
- At the same time, we hope that this debate will consider the full range of child palliative care services, including emotional and practical support services for families, which are not currently funded by any Clinical Commissioning Groups (CCGs) or eligible for the Children's Hospice Grant.

**Rainbow Trust Children's Charity is calling for a fair and sustainable increase in statutory funding for the social care elements of child palliative care - in the community and in the home - as part of a joined up strategy to address the crisis in funding for children's palliative care.**

### The value of emotional and practical support

- Alongside access to a hospice, children and their families have needs every day, throughout the year, and they need support when they leave the hospital or hospice.
- Emotional and practical support can enable the whole family to cope better, providing parents with a much needed break, for instance, and regular opportunities to share their worries with a trusted Family Support Worker, or practical help to attend appointments or get siblings to school when the logistics are otherwise impossible.
- As recognised in Together for Short Lives' recent report<sup>ii</sup>, providers like Rainbow Trust Children's Charity are outside of the current funding models for child palliative care.
- We urge Government to ensure that social palliative care for families is not simply

recognised in theory, but is funded and commissioned in reality. Rainbow Trust backs the call from the Disabled Children's Partnership for the estimated £434m gap in social care support for seriously ill and disabled children to be funded by the Chancellor in the next Spending Review.

- This is not only about supporting families; it also makes economic sense. Emotional and practical support services are 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, and subsequently require more costly crisis interventions.

### **Meeting the needs of siblings**

- 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>iii</sup>
- NICE guidance recognises the importance of supporting siblings<sup>iv</sup> but at present there is little evidence of this support being translated into commissioning decisions. In fact, sources of funding are 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. Rainbow Trust estimates that there are at least 32,000 families in England with both a seriously ill child and one or more siblings.

### **Rising prevalence among 0-19 age group**

- The current funding crisis is of particular importance given the significant rise in prevalence of life limiting and life threatening conditions as a result of more seriously ill babies surviving birth, and more children and young people living longer with their serious and complex conditions as a result of advances in medical technology.
- Academic data put the figure of 0-19s with a life limiting and life threatening condition at 49,000 in the UK in 2009-2010.<sup>v</sup> Updated estimates to be published in spring 2020 are expected to show a sharp increase, as has been seen in research in Scotland.<sup>vi</sup>

### **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 has seen a 12 per cent rise in the number of new families being referred to its service in 2018-19 compared to 2017-2018.
- Rainbow Trust 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
  - run drop in groups for siblings



- help a family make memories and plan for end of life
- offer bereavement support.

### Declining statutory funding

- 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 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 – currently just two out of 152 Local Authorities in England. **This means Rainbow Trust must fundraise more than 97% of its income.**
- While the new match-funding commitment set out in the *NHS Long Term Plan* is in theory open to all providers of child palliative care, including those in the community, there is no evidence that CCGs or Integrated Commissioning Systems (ICS) will start commissioning emotional and practical support services given the enormous pressure to meet gaps in provision of clinical care in hospitals, hospices and community nursing.

### Parents' voices

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.’*

A 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>vii</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>viii</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

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<sup>i</sup> *Statutory funding for children's hospice and palliative care charities in England 2018/19*, Together for Short Lives, 2019. [www.togetherforshortlives.org.uk/wp-content/uploads/2019/06/190614-FINAL-Statutory-funding-for-children%E2%80%99s-hospice-and-palliative-care-charities-in-England-2019.pdf](http://www.togetherforshortlives.org.uk/wp-content/uploads/2019/06/190614-FINAL-Statutory-funding-for-children%E2%80%99s-hospice-and-palliative-care-charities-in-England-2019.pdf)

<sup>ii</sup> Ibid., page 6.

<sup>iii</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>iv</sup> *End of life care for infants, children and young people with life-limiting conditions: planning and management*, National Institute for Health and Care Excellence, 2016. [www.nice.org.uk/guidance/ng61](http://www.nice.org.uk/guidance/ng61)

<sup>v</sup> *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/resource/leeds-data-study/](http://www.togetherforshortlives.org.uk/resource/leeds-data-study/)

<sup>vi</sup> *Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)*, University of York, 2015. [https://chas-assets.s3-eu-west-](https://chas-assets.s3-eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5a0450190f7d3329ce4eeeb2/ChiSP_Report.pdf)

[1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5a0450190f7d3329ce4eeeb2/ChiSP\\_Report.pdf](https://chas-assets.s3-eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/5a0450190f7d3329ce4eeeb2/ChiSP_Report.pdf)

<sup>vii</sup> *Hidden Savings: How Rainbow Trust saves 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>viii</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)

