

EXECUTIVE SUMMARY

SEE US, HEAR US, NOTICE US: THE CASE FOR SUPPORTING SIBLINGS OF SERIOUSLY ILL CHILDREN

**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Supporting the brothers and sisters of seriously ill children is central to the service provided by Rainbow Trust Children's Charity. This support is one of the most valued aspects of the service for parents, children and professionals.

Sibling support can play a vital preventative role. It can enable children and young people to learn important coping mechanisms, find an outlet for their strong feelings and worries, keep up with their school work, and build a support network for themselves outside the home before their needs escalate.

The consequences of a child not receiving support could be long-lasting, with an enduring emotional impact and possible negative consequences for their education and overall life chances. For these reasons, funding sibling support is a worthwhile investment to prevent avoidable future costs for public services.

Despite this, such support has a low profile among decision-makers, including Local Authority Short Breaks managers and budget holders, and among ministers and officials at the Department for Health and Social Care and the Department for Education.

Rainbow Trust urges decision-makers and commissioners to make sure that children and young people in all parts of England have access to high quality sibling support, as and when required, before their education, mental health and wellbeing, are more seriously affected.



KEY FINDINGS:

- 1. At least 32,000 families in England with a seriously ill child have one or more siblings** according to our best estimate. Some will have little or no access to sibling support depending on where they live.
 - 2. The need for support appears to be growing**, based on the experience of both Rainbow Trust and of children's hospices in England. More than 70% of children's hospices, who responded to a 2018 Rainbow Trust survey of sibling support in England, said that demand for sibling support has increased over the last three years. 60% of children's hospices said that they offer more hours of support than three years ago but only one third said that they can 'always' meet demand.
 - 3. Many parents do not identify their healthy siblings as young carers.** This means that many are likely to be hidden from official data on young carers, and yet this is what they are.
 - 4. Recent recognition of the value of supporting siblings has not been translated into increased funding.** In fact, many Local Authorities have reduced funding for services such as Short Breaks because of budgetary pressures, and the criteria for Short Breaks funds are often too narrow for charities to secure funding for sibling support.
 - 5. The emotional and practical impact on siblings can have enduring consequences for a child's wellbeing and life chances.** A parent will often have less time to focus on the healthy sibling(s) and routines have to change to fit around the needs of the seriously ill child.
 - 6. Emotionally, the healthy child may struggle to understand what is happening, depending on their age and level of development.** Explaining the full gravity of their sibling's situation can be frightening but concealing it might damage their trust in their parents or carers.
 - 7. While some studies show positives such as a raised sense of self-worth, a sibling may experience feelings of isolation, anger, jealousy, guilt and anxiety.** A sibling can become withdrawn as they try to protect their parents from additional worry. If not addressed, a sibling's mental health could be affected.
 - 8. School can be a welcome break** from a pressured home environment, but for some, sleep disruption could affect their focus and concentration. Keeping up with homework can be difficult, with time and energy at a premium.
 - 9. A sibling's education can be affected** by difficulties in maintaining school attendance, because their parents are focussed on their brother or sister's care. Siblings can be at greater risk of being teased or bullied than other children. School holidays can be a particularly hard time with many siblings unable to leave the house as much as they would like.
 - 10. If a sibling is bereaved,** there can be overwhelming feelings of loss, and potentially feelings of guilt that they themselves survived.
 - 11. Rainbow Trust conservatively estimates that its sibling support alone saves around £418,000** each year for the education, health and social care system.
 - 12. There are many examples of how sibling support can reduce costs to the public purse.** These include enabling children to attend school when both parents are in hospital or at work, and helping siblings to cope emotionally with their brother or sister's illness or to manage feelings in bereavement.
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**EXAMPLE:
PRACTICAL SUPPORT TO PREVENT SIBLINGS MISSING GCSE LESSONS**

Rainbow Trust support can be scaled up or down according to need, with extra support put in place should there be a medical crisis, or if the sick child appears to be entering end of life.

A family with seven children were supported by Rainbow Trust in London. One of the children had Lennox-Gastaut syndrome, a severe form of epilepsy, and was having frequent seizures. Contact with his father was limited, and the mother was unable to collect her younger children from school every day. Although the family had a care package in place for the son, this was only available when in the home. Social services could not provide any practical support out of the home. Whenever there was a hospital admission the two older siblings had to help collect their younger siblings from school.

With their GCSEs approaching, it was becoming a problem for the older siblings to have to leave school early once or twice a week to pick up their two younger siblings from primary school.

When Rainbow Trust got involved, a Family Support Worker was able to meet the younger siblings, meaning that important lessons were not missed by the older children. The Family Support Worker could also provide additional emergency school pick-ups when the sick child's condition deteriorated and plans suddenly changed.



ABOUT RAINBOW TRUST SIBLING SUPPORT

- Rainbow Trust currently supports more than 1,230 siblings each year. Support includes:
 - One-to-one support – within the family home, help with school or nursery attendance, outings and activities. This can vary from intensive support once or twice a week to less frequent support depending on the family’s situation.
 - Group support – including holiday activities, regular sibling groups, or drop-in groups at hospitals.
- Rainbow Trust teams are unique in their flexibility, seeking to provide support at short notice, or on varying days of the week if a family’s circumstances require it.
- A specialist Sibling Support Worker role exists in each of Rainbow Trust’s North West and Central London teams.
- In our 2018 annual service audit of seriously ill children and their brothers and sisters:
 - 100% of children said they feel that their Rainbow Trust Support Worker listens all the time.
 - 100% of children said they feel safe with their Rainbow Trust Support Worker.

RECOMMENDATIONS

The Department for Health and Social Care and the Department for Education should:

1. Jointly provide guidance to Clinical Commissioning Groups and Local Authorities to highlight the need to commission local sibling support, as part of a comprehensive local children’s palliative care service.
2. Champion the creation of an early intervention and family resilience fund to increase the availability of family services such as sibling support, in line with proposals from the Disabled Children’s Partnership (a coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people and their families.)
3. Support schools to play a fuller role in identifying and meeting the needs of siblings of seriously ill children.

Local healthcare commissioners should:

- Implement a clear referral pathway for mental health support for siblings if their needs escalate, with mechanisms to provide rapid support in crisis situations.

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See us, Hear us, Notice us:

The case for supporting siblings of seriously ill children.

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