



RAINBOW TRUST CHILDREN'S CHARITY BRIEFING:

Isolation and loneliness amongst families who have a child with a life-threatening or terminal illness: The impact on children and young people: education and friendships.

SUMMARY

- Seriously ill children and their siblings experience high levels of loneliness and isolation, often due to time away from school, bullying, and changes to their family life.
- Friendships are disrupted as children are off school, miss social activities, or find their peers don't understand what they're going through.
- Schools often don't know how to support either the ill child or their siblings, and parents frequently have to fight for adjustments or access to emotional support.
- Siblings face additional challenges, including parental attention being diverted, emotional stress, and a lack of tailored support in schools or healthcare settings.
- The right support from schools, the NHS and charities like Rainbow Trust helps children stay connected, feel less alone, and experience greater emotional wellbeing.

INTRODUCTION

When a child is diagnosed with a life-threatening or terminal illness, the impact reaches far beyond their physical health. Rainbow Trust Children's Charity understands the emotional and practical toll this takes on the whole family, including the child themselves and their siblings.

Children and young people in these families often experience significant isolation and loneliness. Seriously ill children can be separated from their friends and school life for long periods, while their siblings may find their lives turned upside down - facing reduced attention from parents, disruption to routines, and challenges in school and social settings.

Despite the scale of these challenges, the loneliness experienced by children and young people in these circumstances has not been meaningfully recognised in loneliness policy or by education, health and care systems. These children are often hidden from view - coping with enormous emotional strain, often without the right support in place.

On behalf of the children and young people we support, we urge the Government to take this issue seriously and act on the recommendations we set out in this briefing.

“ *Both my ill child and his brother feel lonely and isolated as life has changed and we don't see many people as much or it's not the same if we do.* ”

“ *My daughter is being bullied due to her brother's disability. She is very lonely.* ”

“ *He has been off school for some time. His physical limitations mean he cannot play as enthusiastically as his friends which often leads to him being left behind.* ”

THE ISSUES FOR CHILDREN AND YOUNG PEOPLE:

- Children and young people facing a life-threatening or terminal illness, and their siblings, experience a range of emotional issues, as well as practical difficulties in accessing normal parts of childhood, adolescence, and early adulthood, such as education, social activities and friendships.
- Siblings may find that their parents are less available for them, due to the pressures and trauma of dealing with a child's diagnosis. A sibling's life may be turned upside down, with their ill sibling suddenly in hospital, or with extended family or friends having to play an increased part in their upbringing. Their family may see a loss in income with parents who do not get enough support being forced to give up work entirely or reduce their hours.
- If a child's illness is not curable, experiencing the bereavement of a sibling in childhood or adolescence is a traumatic life event.

OUR FINDINGS

Education

Attendance and attainment at school plays a critical part in enabling children to achieve their educational goals for the lives they want to lead. It also provides invaluable development support and social support - to see their friends, have fun, and participate in activities with them. School helps to maintain a sense of normality, helping with stability and reducing anxiety.

Due to the demands associated with their condition, seriously ill children are often at an educational and social disadvantage, having to be off school for significant periods at a time to receive specialist treatments or undergo operations. Even with home or hospital schooling, there is inevitably a knock-on effect on the child's education and social development.

“My child hasn't attended school since her diagnosis.”

“School friends literally dropped my child.”

“He has been off school for some time. His physical limitations mean he cannot play as enthusiastically as his friends which often leads to him being left behind.”

Many of the families we support may have had to manage their child's condition since birth and may have long-term support in place. But for others, their child's illness can be of sudden onset and focus is on immediate health needs. Equally, serious illnesses can be degenerative and unpredictable, and may lead to unexpected and repeated periods of time off school.

Individual support plans may need to be updated rapidly to meet changing needs and reduce isolation.

Siblings' education must not be compromised by their sibling's illness, and - where appropriate for them and their family - every opportunity must be given for them to engage with education, so that they have the qualifications and skills needed to thrive. This also provides them with opportunities to make friends and take part in extra-curricular activities.

“My ill child does not have any understanding of his condition yet - it's his sibling who suffers.”

“School friends literally dropped my child.”

“Yes I think my older kids do [feel lonely and isolated] as everything has to revolve around my sick child with her complex needs.”

For those children whose prognosis means they are likely to reach adulthood, education provides a sense of normality, and opportunities to play, learn and make friends. Whatever a child's prognosis, they deserve to be supported to enjoy learning and fulfil their potential.

Education settings, in partnership with the NHS, local authorities and the voluntary sector, need to consider the social and emotional needs of seriously ill children and their siblings, including bereavement support.

Support in education settings is mixed. Our survey found:

35% of parents
said their child's school
had a policy for serious
medical conditions.

33%
were unaware whether
their school had a
policy.

3%
believed their
school did not

56%
said reasonable
adjustments had
been made by the
school.

Parents told us of mixed support:

*“Both schools were
very supportive”*

*“I'm unsure of any
official policy, however
they couldn't be more
supportive and nothing is
too much trouble.”*

*“Only when I pushed
for it and I'm not sure it
was consistent.”*

*“This required a lot
of fight from us and
took a long time... it's
the thing we struggled
with the most.”*

*“Sibling's school attempts
to help but I don't think they
understand or know how to
support her properly.”*

*“Schools need to
provide an outlet for
children to talk about their
feelings. They need to be
given the time to come out
of themselves and through
[the use of] activities and
play therapy.”*

The Department for Education should:

- Monitor the implementation of its guidance “Arranging education for children who cannot attend school because of health needs” (December 2023).
- Expand this guidance so schools, local authorities and the NHS are clear how they meet the social and emotional needs of a seriously ill child and their siblings — including through staff training and better communication with parents.

Schools should also consider if a sibling is a young carer, and make referrals as needed. This could include working with the local authority, local young carers services and using the Young Carers in Schools programme resources.

“Given everything that is going on for parents when they have a child with a life-threatening or terminal illness, having to further advocate for their sick child or their sibling is another battle they have to face.”

Friendships:

Friendships are a hugely important part of childhood and adolescence. They play a significant role in development and in having fun — but for children with a life-threatening or terminal illness, and their siblings, making and keeping friends is often compromised.

School plays a huge part in facilitating these friendships. But when children are absent for long periods, or unable to participate fully, relationships with peers can break down.

“My daughter is being bullied due to her brother’s disability. She is very lonely.”

“School friends literally dropped my child.”

“My ill child does not have any understanding of his condition yet, it’s his sibling who suffers.”

“His friends don’t understand what he’s going through.”

Hospital treatment schedules, infection risks, and disrupted routines all exacerbate feelings of loneliness. But these aren’t the only reasons children feel isolated — many also struggle with the emotional impact of their family’s circumstances, and the social disconnection that follows.

“Whilst my little one on cancer treatment is too young to really feel isolated, she is aware that other children can hang out together and she can’t, which makes her sad.”

“Yes I think my older kids do [feel lonely and isolated] as everything has to revolve around my sick child with her complex needs.”

In our survey, most parents said their child felt
Isolated or lonely

Fewer than
20% of
parents said
their child
did not.

Voluntary sector services can play a vital role in helping children reconnect. Some siblings supported by Rainbow Trust go out on joint activities with their Family Support Worker, giving them the chance to play and spend time with others in similar circumstances.

20% of parents said
Rainbow Trust enabled their child to
have fun and meet other children.

“They have been a lifeline for so many years... our support worker is an amazing source of comfort for the whole family.”

There is a strong case for targeted loneliness support. Campaigns led by the Department for Culture, Media and Sport could be extended to cover the siblings of seriously ill or terminally ill children. Given their increased risk of loneliness, they should be considered as a priority sub-group in existing initiatives aimed at young people aged 16–24.

OUR POLICY RECOMMENDATIONS:

- Policies that support adults will directly benefit children, for example, policies to support parents to stay in work, and with income replacement benefits.

The Government should ensure that there are appropriate levels of funding for local authorities and the NHS, so that everyone in a family where this a child with a life-threatening illness can access the health and social care they need. This includes short breaks, and children's palliative and end of life care.

Integrated Care Boards must recognise that children's palliative and end of life care goes beyond building-based care, and commission fairly, so that all local providers, including charities, can benefit.

The government should ensure there is accessible mental health support and emotional support to siblings of children with a life-threatening or terminal illness, including bereaved siblings. The voluntary sector is an excellent source of support, and could be effectively commissioned via local authorities and the NHS.

Siblings are usually our longest relationships, facing the prospect of a sibling's death has the potential to be profoundly distressing and life-altering for children and young people. While bereavement is never something that we "get over", with the right support at the right time, children and young people living with a lifelong loss can be helped to integrate that loss into their lives and do well in life.

The Department for Education should monitor the implementation of guidance to provide children and young people with an accessible education across all educational establishments, local authorities and the NHS. This should be disaggregated so that it is clear how siblings or the ill child are being helped, whether they are living at home or staying in hospital.

The Department should also expand this Guidance so that schools, local authorities and the NHS are clear how they need to support siblings of a seriously ill child, as well as make children and young people an offer of emotional and pastoral support, and encourage their friendships in and out of school. Working in commissioned, active partnerships with the voluntary sector, who are ideally placed to offer this support, would help too.

Parents and children alike should be able to contact one key person with any concerns about education, who can coordinate across settings.

The Department for Culture, Media and Sport should extend their targeted loneliness campaign aimed at young people aged 16-24, to older siblings of life-threatened or terminally ill children.

Signposting to support, as well as encouraging schools and other organisations who work with young people to think about how they can work with this group of young people.

SOLUTIONS AND CONCLUSION:

- Rainbow Trust believe that some of the solutions to the issues children and young people face can be easily implemented, as outlined in our policy recommendations above. Some of our recommendations do require a more comprehensive solution, but are, nevertheless, achievable by the new government, and we are ready to offer our support to them, education, local authorities and the local NHS to enable this to happen.
- The good news is that the right support can make a difference to children, including reducing loneliness and staying in education. Commissioning support that focuses on reducing children's isolation and their ability to stay in education, would pay dividends. Parents report that Rainbow Trust's support has helped their ill child and/or siblings feel less isolated and lonely:

20% said
*"enabling my child to have
fun and meet other children"*

**“ They have been a lifeline for so many
years...our support worker is an amazing
source of comfort for the whole family.”**

- In conclusion, a child's serious ill health is a profound challenge that significantly impacts the emotional and psychological well-being of children and their siblings, including isolation. The right support systems at home and in school can play a huge part in alleviating this isolation, and by working together with government, councils and the NHS, Rainbow Trust can make a truly tangible difference in the lives of these children.
- Our policy recommendations are deliberately targeted across government departments and a range of structures, so that children's needs can be addressed holistically. While some of what we advocate for is increased funding for family support, both financial and practical, small things like schools facilitating a call so that pupils can keep in touch, would make a difference.
- By implementing these recommendations, we can create a more supportive environment that not only addresses the immediate challenges faced by children during their or their sibling's serious ill health, but also contributes to long-term resilience and wellbeing. It is our hope that these efforts will lead to a society where no seriously ill child or their sibling feels alone in their journey, and that every family can access the support they need to navigate these difficult times.

ABOUT RAINBOW TRUST CHILDREN'S CHARITY

- Rainbow Trust Children's Charity is a UK charity who provide tailored practical and emotional support for families caring for a child who has been diagnosed with a life-threatening or terminal illness. Last year, Rainbow Trust supported over 1,274 families.
- The type of care Rainbow Trust provides, social palliative care, is unique. We match families with a Family Support Worker, who provide a wide variety of emotional and practical support to parents, the unwell child, siblings and the wider family. Our support extends into bereavement.
- Rainbow Trust provides support to families across the UK. We support families physically via our face-to-face services in nine areas of England (Essex, Greater Manchester, Lancashire & South Cumbria, Liverpool, London & the South East, North East, Southampton, South West, and Thames Valley,) as well as digitally via our Online Support Team.
- Rainbow Trust receives no central Government funding, and despite providing palliative and end of life care and support, we are not widely commissioned by local authorities and the NHS as part of local end of life commissioning. We are proud of our record and would love to be able to support more families at diagnosis and beyond with the unique care and support we provide.

Methodology:

- In 2023, Rainbow Trust conducted a small survey of parents we supported, and this briefing is based on their voices.
- While our research was based on a small sample size, the findings still provide invaluable insights into families' experiences and views.

FOR MORE INFORMATION:

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