

**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD



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

This report sets out the need to support the siblings of seriously ill children, and why this model of support should be valued and funded more highly, at a time when the prevalence of life threatening and life limiting conditions among children is known to be rising.

The names of children and parents have been changed throughout this report to protect their privacy.

ABOUT RAINBOW TRUST CHILDREN'S CHARITY

Rainbow Trust Children's Charity's vision is that every family who has a child with a life threatening or terminal illness has the support they need.

We believe that families with a seriously ill child should be fully supported in the way that suits them, from the moment their child becomes ill, during treatment, and if needed, through bereavement.

With more than 30 years' experience, Rainbow Trust provides essential practical and emotional support to families, filling in the gaps between hospital, hospice and home.

THANK YOU

Our thanks to Martin Edwards (Julia's House), Sarah Jasper (Acorns Children's Hospice) and Clare Kassa (Sibs) for their advice as this report was developed. We also thank all the parents and siblings who have generously shared their stories with us.

CONTENTS

EXECUTIVE SUMMARY	3
INTRODUCTION	6
SECTION 1 THE IMPACT OF HAVING A SERIOUSLY ILL BROTHER OR SISTER	7
The scale of the need	7
How are siblings recognised in policy?	8
What sources of support exist for brothers and sisters?	10
The impact on a sibling	11
Existing research	15
SECTION 2 HOW SIBLING SUPPORT CAN SAVE MONEY FOR THE EDUCATION, HEALTH AND SOCIAL CARE SYSTEM	19
Example 1: Enabling school attendance	21
Example 2: Support to a young person while her brother was receiving cancer treatment	23
Example 3: Rochdale sibling support group	25
Example 4: Supporting a bereaved sister at school	27
Estimated amount saved for the education, health and social care system	29
SECTION 3 HOW RAINBOW TRUST SUPPORTS SIBLINGS	30
Support groups and group activities	33
What do children value about sibling support?	36
CONCLUSION AND RECOMMENDATIONS	38
USEFUL ORGANISATIONS	40
END NOTES	40

EXECUTIVE SUMMARY

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 or wellbeing, are more seriously affected.



Support can help siblings keep up with school work

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.ⁱ
 - 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.
-

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 both the Rainbow Trust North West team and the Central London team.
- ➔ 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.*
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.

* The Disabled Children's Partnership is a coalition of more than 60 organisations campaigning for improved health and social care for disabled children, young people and their families.

INTRODUCTION

Supporting siblings is one of the most valued aspects of Rainbow Trust's service for parents, children and professionals, but this support remains under-valued by commissioners and decision-makers.

At a time when the prevalence of serious and complex illness among children is rising, this report seeks to build understanding of the needs of their siblings, who are also growing in number.

Sibling support can take many forms:

- looking after brothers and sisters along with the sick child, while parents take a much-needed break
- taking siblings to and from school or nursery
- talking to children who struggle to understand what is happening
- taking children on breaks or trips out of the family home for some precious time when they can be the centre of attention.

Section 1 sets out the potential impact of having a seriously ill sibling on a child or young person's wellbeing, mental health and educational attainment.

Section 2 uses four case studies to illustrate how this model is saving money for the education, health and social care system. It then makes a conservative estimate of the savings enabled for the public purse by Rainbow Trust's preventative support to siblings.

Section 3 sets out Rainbow Trust's model of sibling support.

Based on our experience, we believe that sibling support should be valued and funded more highly. We hope this report will prompt funding and policy decisions to ensure that the needs of the brothers and sisters of children with life threatening and terminal conditions start to be recognised and met, no matter where they live.

Rainbow Trust saw a
12%
increase in the number
of new families being
supported in 2017-18

SECTION 1: THE IMPACT OF HAVING A SERIOUSLY ILL BROTHER OR SISTER

OVERVIEW

No parent can predict how their healthy children would cope if they had a brother or sister who became seriously ill. Each family will have a differing capacity to respond to this, and the situation will vary according to the stage, and stability of the sick child's condition, and their prognosis.

A sibling's needs for support will be fluid and will change at different points in their childhood and later life.

- Some will have known no other experience of family life
- Some may not need in depth support. Perhaps the sick child is in a stable phase of illness, or there are existing strong family support networks
- Other children may have a sibling who suddenly becomes ill. For them, their world may be turned upside down in a matter of days
- The siblings of seriously ill babies may be unable to meet their new brother or sister in intensive care for some months
- A child's age and level of development will affect how they experience a bereavement.

THE SCALE OF NEED

Recent decades have seen a steady improvement in the life chances of seriously ill children. Medical advances now enable more premature babies to survive birth with complex medical conditions, and improved treatment and support enables more children to live longer with their conditions.

Many of these seriously ill children will have one or more siblings. There is no official data to record the number of families affected in this way. However, an annual service audit of a segment of Rainbow Trust service users in 2018 found that 79% of supported families have one or more siblings.

This is a small sample and may not be reflective of all families who are affected. However, in the absence of other data sources, if we were to assume that around 80% of families where a child has a life threatening or life limiting condition have more than one child, we might expect there to be at least 32,000 families in England who could benefit from sibling support, based on academic estimates into the prevalence of life limiting and life threatening conditions in 2009-10. ⁱⁱ

Indications that the need is growing

- **Rainbow Trust saw a 12% increase in the number of new families being supported by the service in 2017-18**
- **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 that they offer more hours of support than three years ago but only one third said that they can 'always' meet demand. ⁱ**



HOW ARE SIBLINGS RECOGNISED IN POLICY?

Family members, and professionals working closely with a family, usually recognise that siblings will benefit from support. However, it is only recently that health guidelines have directly referenced siblings' needs.

Recognising that there is often a gap in current practice, the NICE Guideline on *End of life care for infants, children and young people with life-limiting conditions*ⁱⁱⁱ states:

'Be aware that siblings will need support to cope with:

- their brother's or sister's condition and death*
- the effects of their parents' or carers' grieving.*

This may include social, practical, psychological and spiritual support.'

The Department of Health and Social Care's policy on end of life care for England, *'Choice at end of life: Our Commitment to You'* also references siblings briefly.^{iv} It states that a distinguishing feature in children's end of life care, compared to that of adults, is the impact on the whole family. It notes that the support of siblings is 'critically important' in bereavement.

Siblings as Young Carers

The sibling of a child with a life threatening or terminal condition will often meet the definition of being a 'young carer', because of the emotional and practical support they are likely to be providing. The NHS definition describes that, as a young carer,

'You may do extra jobs in and around the home, such as cooking, cleaning, or helping someone to get dressed and move around. You may also give a lot of physical help to a brother or sister who is disabled or ill. Along with doing things to help your brother or sister, you may be giving them and your parents emotional support too.'^v

Under the Children and Families Act 2014, all young carers have a right to an assessment from their Local Authority, to document the impact that caring is having on their wellbeing and education. The aim is to determine if the child and their family need additional support to provide care, and/or time away from caring through a Short Break.

Short Breaks: Local Authorities are legally obliged to provide breaks to parents and carers of children with serious health conditions or disabilities. These Short Breaks can take a variety of forms, lasting a few hours or a few days, depending on the child and family's needs.

However, many parents do not identify their healthy children as being young carers, and media profile and government attention has often profiled an older segment of young carers who look after parents with mental or physical health problems.

One parent, whose son died in 2017, reflects:

'The girls didn't have access to any young carer's support: maybe that was my fault. I tried to keep life at home as normal as possible and didn't consider them to be young carers, which was very wrong of me.'

Few of the siblings that Rainbow Trust supports have been formally assessed. At the same time, many local authorities have reduced their funding for Short Breaks because of sustained financial pressures (see Section 3).

**EXAMPLE:
ADJUSTING TO A NEW 'NORMAL'**

Parents often describe the struggle to maintain some sort of normality as they respond to the needs of their situation. Maya had twin daughters in 2012, one of whom, Vinita, has a complex condition and chronic lung disease.

As well as coping with frequent periods when Vinita was an in-patient and sometimes in a critical condition, Maya felt tremendous guilt that her well daughter, Nadia, could not have a 'normal' life. She describes how the family 'lived out of carrier bags' in hospital or cared round the clock for her sister at home.

As parents, the care of Vinita dominated their life. For instance, they often got up four or five times in a night to check on her or empty her catheter bag.

'It's a big step for families to acknowledge they need help,' explains Maya. *'There is a lot of pride.'* Maya describes Rainbow Trust as a *'godsend'* whose help eased the burden on the whole family.

After being put in touch with a Rainbow Trust Family Support Worker, the parents finally had two hours of respite each week. The Family Support Worker took Nadia to soft play or to feed animals in the park, sometimes with Vinita as well. The Family Support Worker fondly became known as the 'balls and slides woman' because of their time at soft play.



WHAT SOURCES OF SUPPORT EXIST FOR BROTHERS AND SISTERS?

Alongside the support provided by Rainbow Trust, described in Sections 2 and 3, almost all children's hospices provide sibling support as part of their services if a sick child is under their care.

Hospice provision can be one-to-one support, or group activities such as outings, residential trips, visits to theme parks, sleepovers, rock climbing, crafts, baking, or bowling. However, depending where a family lives, it may be up to 90 minutes to travel to their nearest children's hospice.

A 2018 Rainbow Trust survey of children's hospices in England found that, in line with the rise in demand experienced by Rainbow Trust, more than 70% of children's hospices, who responded, reported that demand for sibling support has increased over the last three years.

60% of children's hospices said that that they offer more hours of support than three years ago but only a third said that they can 'always' meet demand.¹

Hospices report that they can be flexible in the location and timing of the support they provide. Almost all participating hospices said that it can be provided in the community, in the hospice or in the home, and is available throughout the week and at weekends.

The two most common forms of support offered were named as 'one-to-one support as part of family support', and 'one-to-one post bereavement support'.

Should there be a bereavement, support is open ended from more than half of the hospices responding. Post bereavement counselling sessions of up to ten weeks are sometimes offered, and some hospices said they can provide a degree of support for up to five years.

“ From the national sibling interest group, there is an almost universal agreement that we are finding ourselves working with more complex families and bereavements. This may be as a result of the pressures on statutory services to support families and perhaps the increase in blended families, but I do think that the intensity of therapeutic support and skills needed to support siblings in palliative care has increased. ”

Sarah Jasper, Family Services Manager and Organisational lead for Sibling Support, Acorns Children's Hospice

“ Many siblings tell us that people do not understand just how far from 'normal' their life is. This is why Julia's House runs an extensive programme of sibling support, enabling them to get out of the house, to befriend other siblings who understand them, to be free of responsibilities, have fun and let off steam. More needs to be done to help children like these to have the same life chances as anyone else. ”

Martin Edwards, CEO, Julia's House, Dorset and Wiltshire Children's Hospices

Another source of sibling support can be through a special needs play scheme. One parent explained:

“ Our local special needs play scheme took siblings as well as children with Special Educational Needs and Disabilities. This was the only time that my children spent time all together without either my husband or myself being around. It was important to me that they had that time together as, if Cameron had been a mainstream child, they would have all been in school together. ”

THE IMPACT ON A SIBLING

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.

Sometimes parents may need to accompany a child to frequent appointments with a multitude of different professionals or to stay with them for in-patient treatment. For example, a child with cancer may need to undergo six weeks of radiotherapy treatment at some distance from the family home.

Dropping or collecting other children to or from nursery or school can be difficult, as well as keeping up their regular clubs or activities. As a result, a child may feel isolated socially. When friends visit, a sibling may feel embarrassment that their brother or sister looks different or needs equipment, or may, conversely, feel extra protective of them. Most express a wish they could enjoy a more 'normal' life.

School can be a welcome break from a pressured home environment, but for some, sleep disruption could affect their focus and concentration – for instance, if their ill sibling needs medicines administered at regular intervals overnight or relies on equipment that alerts the parents with an alarm if the child's condition deteriorates. Keeping up with homework can be difficult, with time and energy at a premium. Some siblings experience bullying and teasing at school because their family is different.^{vi}

Research by Action for Children and Carers Trust suggested that

72% of young carers find the summer holidays a lonely time, and more than two thirds feel more stressed or worried during the holidays.

School holidays can be a particularly hard time with many siblings unable to leave the house as much as they would like. Research by Action for Children and Carers Trust suggested that 72% of young carers find the summer holidays a lonely time, and more than two thirds feel more stressed or worried during the holidays.^{vii}



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. Children will make up their own understandings in the absence of other explanations. Some may worry that it was something they did which has caused the illness, but it may be difficult for them to share this anxiety.

One child thought it was his fault that his new baby sister was born prematurely - he had wished for her to arrive early because he was so excited to be a big brother.

Seeing their parents experiencing high levels of anxiety can lead many children to hide their own feelings, to protect their parents from additional worry. This can result in a child becoming withdrawn. It is common for a brother or sister to feel jealous of the attention that their sick sibling is receiving, and perhaps express anger as a result. A healthy sibling may change their behaviour as they look for new ways to gain attention. Relationships may be even more complicated for step- or half-siblings, depending on family dynamics.

Serious illness can bring hardship to a family, with one parent often giving up work to spend time with the sick child, while facing the extra costs of travelling to appointments and hospital car parking.^{viii} Aware of the financial strain, siblings may avoid asking their parents for things they would like.

Bereavement

If a sibling is bereaved, there can be overwhelming feelings of loss, and potentially feelings of guilt that they themselves survived. Seeing their parents grieve may be distressing, and children may hide their own feelings to protect their parents.

Childhood grief can start long before a death. Honest and clear communication is essential to avoid misunderstandings. Euphemisms must be avoided, and it is important to check what a child understands. An example is a boy who misheard "heaven" for "Devon" and could not understand why he could not visit his sister there. Likewise, a girl was told her brother had "gone to sleep" and so she became terrified of bedtime. There is great value in preparing a child as well as possible for the approaching death of a close relative.^{ix}



TIPS FROM SIBLINGS IN GREATER MANCHESTER

Learn about my whole family so you can talk to me about them.

Treat us equally, we know we are different but don't make us stand out.

Don't be angry if I don't act the way you expect when you tell me something.

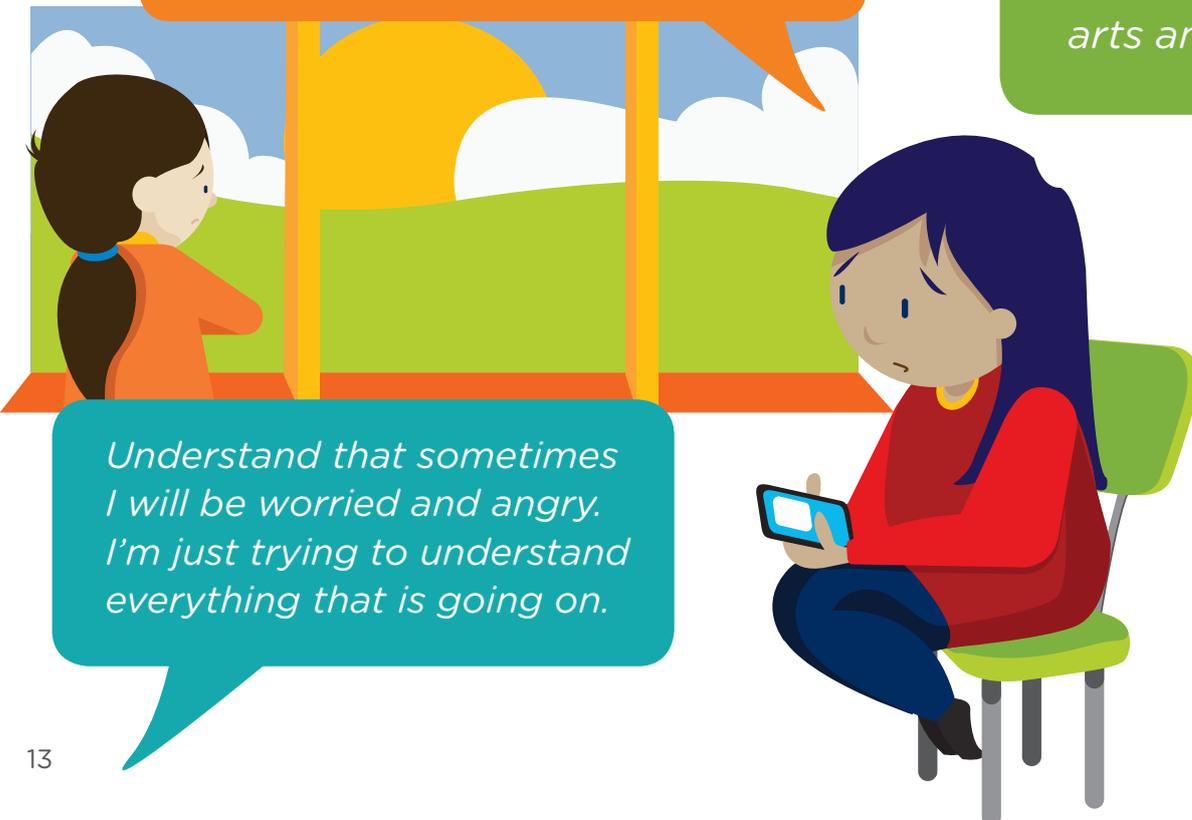
Let me say what I think, even if you don't agree with me.

Writing helps me to think about how I feel and talk about things I find difficult.

Listen to me. You don't always have to give me solutions, I just want someone to hear what I am saying.

Make things with me, using arts and crafts.

Understand that sometimes I will be worried and angry. I'm just trying to understand everything that is going on.



Don't forget about me!

Be honest with me, tell me what you can about my sibling's health and make sure I know what days appointments are on and what these appointments are for. Not knowing makes me worry.

Get to know me. Take time to talk to me and find out what I like and what's going on in my life.

The most annoying thing people say is "it's going to be okay". You can't guarantee this, so don't say it.

Take me out; I spend a lot of time in the house so getting out gives me a break.

Try to talk to me about the future, even if you can't give me answers.

Don't try to make me talk about what is going on. Subtle questions are ok, but I will talk when I am ready.

Don't lie to me.



EXISTING RESEARCH

Academic research has built a picture of the ways in which siblings are affected by a serious illness. This section presents a flavour of the studies available.

Studies of siblings

Now over 20 years old, *'In the Shadow of Illness: Parents and siblings of the chronically sick child'*, remains a ground-breaking study by Professor Bluebond-Langner.^x Using an ethnographic approach, she explored how parents find a 'new normal' for their families and balance the needs of different siblings. Her book draws out how siblings themselves see the illness and relate to the rest of their family.

Other research on the impact of critical illness on children and their families, has found that up to two thirds of children may have post-traumatic stress symptoms after being critically ill, and a third still have problems a year later.^{xi} One study, specifically looking at the experience of siblings whose brother or sister had a life limiting condition, identified that siblings often had feelings of guilt, worry, resentment, a sense of loss and isolation, embarrassment and responsibility.^{xii} A project looking at the experience of having a sibling with cancer found that there can be enduring sadness for the sibling, and feelings of 'a loss of self' within the family.^{xiii}

Studies of the much larger group of siblings whose brother or sister has a physical or learning disability, rather than a life threatening or terminal condition, are more common. Research by Family Fund and the University of Portsmouth identified thematic areas in which siblings themselves reported an impact on their lives: less time available from parents; aggression/violence (where their brother or sister exhibited behavioural problems); disrupted sleep; having to help out; impact on education; restrictions/staying at home/needing time away; emotional needs/wellbeing/upset.^{xiv}

Importantly, research has highlighted some positives in siblings' experiences, such as greater tolerance, patience, kindness, maturity, closer family relationships and independence. One study found that siblings taking on a valued role in the family as a care-giver can contribute to high feelings of self-worth. However, the study also highlighted that siblings may need support to broaden their personal development beyond the roles they feel they need to take on.^{xv}

The impact on education

Carers Trust Wales has reported that young carers in a pilot study of eight schools were, on average, missing or cutting short about 48 days of school a year, getting fewer GCSEs, and sometimes facing bullying.^{xvi}

One analysis found that young carers had on average significantly lower educational attainment at GCSE - the equivalent of nine grades lower overall than their peers. Young carers are also more likely than the national average not to be in education, employment or training between the ages of 16 and 19.^{xvii}

The Childhood Bereavement Network highlights evidence that while the GCSE scores of children bereaved of a parent are an average of half a grade lower than their non-bereaved peers, girls bereaved of a sibling scored almost a full grade below their matched controls in research in England.^{xviii}

The impact of bereavement

Grief is a normal response to death, and many children's reactions would not indicate any disorder. However, one study found that bereaved siblings had a greater probability to report self-assessed anxiety if they perceived that their need for social support was not satisfied prior to and following death. ^{xix}

A large-scale cohort study over more than three decades found that a sibling death in childhood was associated with a 71% rise in mortality risk in the short and long term for the surviving sibling, with higher risks found in the first year and among same-sex sibling pairs, or sibling pairs with a small age difference. ^{xx}



RACHEL'S STORY

There has been less research into the long-term impact on a sibling in cases where a life threatened brother or sister made a recovery. However, the potential death of their brother and sister, and many months or years of stress and uncertainty for the family, is likely to have a prolonged impact on family relationships and dynamics and on a child or young person's identity and character.

Rachel first knew that something was wrong when her grandparents collected her from school instead of her mother. Her four-year-old brother Alex had been diagnosed with Acute Lymphoblastic Leukaemia (ALL) and needed to start treatment immediately, 50 miles away in London.

Speaking 22 years later, Rachel remembers the family being thrown into panic. Her parents began to spend every day and night at the Royal Marsden hospital where Alex was being treated. She had to adjust from seeing him playing with cars on the track-mat to being gravely ill in hospital, where strict cleanliness control meant physical contact was not allowed.

'All I could do was play on my own with my dollies,' she explains. 'I couldn't be a sister to him. I couldn't make him better. You want to go and talk to him, reassure him, comfort him, but that was taken away from me. Even when I went to see him, I couldn't touch him... I couldn't give him a cuddle and that really affected me.'

“ I was worrying about whether my brother was going to die ”

Rachel's self-employed father had to reduce his workload to be at Alex's bedside, and to support his wife. Rachel remembers that her mother tried to put on a brave face to help her son cope with his intensive treatment. There was a lot of uncertainty. Holidays, for instance, would be cancelled at short notice depending on her brother's condition.

'I was petrified,' Rachel explains. 'I was fretting and worrying about whether my brother was going to die, crying every day, when I should have been a happy seven-year-old doing normal things, without a care in the world.'

Against this backdrop, a Rainbow Trust Family Support Worker was introduced to the family. Unlike wider family and friends who were unsure how to help, the Family Support Worker quickly got stuck in to doing whatever was needed and helped to 'keep things normal' at a very abnormal time.

The Family Support Worker became what Rachel describes as a 'second mum', picking her up from school and spending the evening with her on a regular basis. They had days out, did craft and pottery, and went trick or treating for Halloween. Rachel credits this support with giving her the attention and stability that she needed, while the Family Support Worker also provided vital emotional support for her mother.

**“ I couldn't be a sister to him.
I couldn't make him better ”**

Alex finally got the all clear in 2003 when he was 11, and when Rachel was 14, a long seven years after being diagnosed. Rachel reflects: *'If I hadn't had [my Family Support Worker], I think it would have coloured my future behaviour; having missed out on that essential parental closeness, I could have turned into a very difficult child. Instead I became a well-rounded young lady, who has excelled in education and work. The presence of Rainbow Trust in the long term really formed me as a person.'*

'As a child, instinct naturally made me become jealous of the sudden attention focused on my brother. I wanted my parents to be proud of me, but the focus was very much on my brother and I did struggle to understand this. As an adult that has shaped me as someone who wants to stand out.'

'I was off being well and living a healthy life and he was stuck inside in a hospital linked up to a machine.' Rachel adds, *'We hardly saw each other for four or five years. We couldn't go home and play in the garden like ordinary brothers and sisters...I do believe that not having that play time together affected our developing brother-sister relationship.'*

Many years on, the powerful memories of a traumatic period remain vivid, but above all Rachel feels gratitude that Alex survived. *'I'm just very grateful to have him, now I understand all he went through, I love him very much.'*

FAMILY SCHEDULE						
S	M	T	W	T	F	S
	Judo		Piano	Brownies	Playdate with Kevin	
	Judo	School Trip	Piano	Brownies		Sam's Birthday party?
	Judo?		Piano	Brownies	Playdate with Kevin	
	Judo		Piano	? Brownies		
	Judo		Piano	Brownies		

SECTION 2: HOW SIBLING SUPPORT CAN SAVE MONEY FOR THE EDUCATION, HEALTH AND SOCIAL CARE SYSTEM

It is impossible to know exactly how a sibling might cope in the absence of receiving support. What we do know is that failure to support the most vulnerable of these children and young people could result in much higher costs for the state in the medium to long term.

For example, the need for professional psychological support, greater reliance on the benefits system, and lower tax revenue because of potentially restricted life chances, may all result in costs for the education, health and social care system.

The 2017 report, *Hidden Savings: How Rainbow Trust saves money for the health and social care system*,^{xxi} set out a conservative estimate that Rainbow Trust Family Support Workers are saving at least £2 million each year by creating immediate and specific savings for public services, as well as potential longer term savings.

The following case studies look in more detail at the types of cost savings which can be enabled specifically by providing support to siblings of children with life threatening and terminal conditions.

The examples of support set out in this report seek to indicate the range of interventions provided by Rainbow Trust Sibling Support Workers and Family Support Workers in any given week.

HOW RAINBOW TRUST CURRENTLY FUNDS ITS SIBLING SUPPORT

Specific support for siblings has a very low profile among Local Authority Short Breaks managers, who often interpret their statutory duties as being to provide respite to the sick child and their parents/carers alone.

This is reflected in the fact that Local Authority Short Breaks funding is a declining source of income for Rainbow Trust's family support teams, comprising just 2.4% of the charity's income in 2017-18. Following years of budgetary pressures on Local Authorities, accessing Short Breaks funds has grown more difficult, with almost all Local Authorities putting out tenders for specific types of Short Breaks into which the Rainbow Trust model of tailored and flexible support does not fit.

As a result, Rainbow Trust's dedicated sibling support is mostly funded by general fundraising income from the public. One exception has been a sibling group and bespoke sibling support funded by Rochdale Council. A small number of other Local Authority funds enable Rainbow Trust to run group activities and outings which can include siblings alongside their sick brother or sister.

Rainbow Trust's ambition is to support more siblings and families by funding more Family Support Workers in existing teams and in new areas. But at times of high demand, some existing Family Support Teams are already forced to hold a waiting list, with priority given to supporting any family with a child approaching end of life.

**Just 2.4%
of Rainbow Trust's
income came from
statutory sources
in 2017-18**

CHALLENGES IN ACCESSING LOCAL AUTHORITY SHORT BREAKS FUNDS

Some Local Authorities state that the sick child or young person must have an Education, Health and Care Plan (EHCP) in order to qualify for Short Breaks provision. Most of the children that receive Rainbow Trust support do not have these. This may be because their family does not have time to apply for such a plan, or a child does not qualify for an EHCP because their health needs do not affect their education.

Some Local Authorities state that Short Breaks services must be open to children with all types of disability and not just children with palliative care needs.

Many Local Authorities increasingly stipulate that referrals must come through their Children with Disabilities Teams. However, most referrals to Rainbow Trust come from hospitals, community nursing teams or other health professionals.

Often, where Rainbow Trust does work with a Local Authority, it is through a Framework Agreement - a contract by which a provider can become a "preferred supplier". When a Local Authority receives a referral, providers may have to compete to provide support.

NO ACCESS TO NHS FUNDING

Rainbow Trust's provision of emotional and practical support, without nursing care, means that the service does not qualify for either the new NHS palliative care currency, or the NHS England Children's Hospice Grant Programme, and is not funded by any Clinical Commissioning Groups (CCGs).

Despite the prioritisation of bereavement care by NHS England, including the development of a bereavement care pathway, none of the charity's bereavement support is funded through statutory funds.

“ Siblings play a vital role in the lives of seriously ill and disabled children, providing care, fun and emotional support. But siblings have needs too. They have a lifelong need for information and support, but those needs are often overlooked by services and commissioners.

The right support at the right time, has a huge impact on the outcomes for siblings as children, but also on their long-term health and wellbeing as adult siblings. ”

Clare Kassa, CEO, Sibs, the UK charity for brothers and sisters of disabled children and adults

EXAMPLE 1: ENABLING SCHOOL ATTENDANCE

A family supported by Rainbow Trust has a three-year-old daughter with a terminal condition called Lissencephaly, and a healthy eight-year-old daughter called Mia.

The child's mother is her main carer, with the father working long hours at a considerable distance from home. Ensuring that Mia can regularly attend school has been difficult.

The family is entitled to a set number of hours from a carer. This includes an overnight carer for three nights a week because the seriously ill child can have seizures at night and is mostly on oxygen therapy. The child requires suction and medication overnight. Four nights a week, when there is no paid carer, the mother sleeps on a sofa downstairs next to her sick daughter and has disturbed sleep.

The mother suffers from migraines and ill health because of the burden of caring. It is particularly challenging when carers call in sick with no time for a replacement to be found. Family plans are frequently cancelled.

Due to regular hospital appointments and treatment, Mia was not sent to school on days when there was no practical way for either parent to collect her at the end of the day. While the school has tried to be supportive, there was a limit to what staff could do to assist.

However, the support of a Rainbow Trust Family Support Worker helped to address these logistical challenges. For eight months, the Family Support Worker collected Mia from school on one set day, enabling her to attend school more often than in the past.



A Family Support Worker takes a sibling to the park

Additional Rainbow Trust support was put in when the sick child was in hospital or when the paid carer was on sick leave. The mother needed to be in hospital with her daughter about 25 miles away from the family home, staying in parents' accommodation. In those periods, the Family Support Worker did the school drop off and pick up two to four times a week. The Family Support Worker explains: *'Mia is very good and understands the situation and doesn't often complain when plans get cancelled at the last minute, but I would say she requires a lot of attention when she is out with us, particularly in a group, as she sometimes displays some challenging behaviour.'*

Regular time with Mia was arranged in recognition that there was little opportunity for her to leave the house without Rainbow Trust support. The Family Support Worker and Mia spend time at the local park and go out for tea.

Mia also attends a 'closed' Rainbow Trust sibling group (where the same group meet at each session so they can get to know each other) and meets other siblings at Rainbow Trust activity days. Emotional support has been a natural part of their time together, without being an explicit focus. *'I'm an extra person for her to talk to when she needs someone,'* explains the Family Support Worker.

The potential costs to society can be significant. Government research found that, taking prior attainment and pupil characteristics into account, every extra school day missed was associated with a lower attainment outcome at Key Stages 2 and 4.^{xxii}

Feeling guilty about having less time for a healthy sibling adds to the stress and anxiety of caring for a seriously ill child. This stress can result in parental mental health problems, and sometimes family breakdown. A study has shown that parents who split up while caring for a seriously ill child were more likely not to have accessed respite care.^{xxiii} The annual cost of family breakdown to the Treasury is put at £48 million.^{xxiv}

RAINBOW TRUST INPUT:

64 hours of Rainbow Trust Family Support Worker's time required to support 32 pick-ups from school

Each hour of a Family Support Worker costs £23
Total cost of staff time = **£1,472**

Petrol costs = **£160**

Cost to Rainbow Trust **£1,632**

POSSIBLE STATUTORY SUPPORT IN ABSENCE OF RAINBOW TRUST

We are not aware of any Local Authority transport to school provided because of the logistical demands on parents who have a seriously ill child.

Significant potential costs to society in absence of support: life time cost of reduced educational attainment and potential cost of parental mental health problems or family breakdown.

EXAMPLE 2: SUPPORT TO A YOUNG PERSON WHILE HER BROTHER WAS RECEIVING CANCER TREATMENT

When James, aged eight, was diagnosed with a brain tumour and an aggressive brain and spinal cancer, life changed drastically for his family. Overnight, Alison, James' mother, needed to focus all her time on medical appointments and treatment for her son. As a single parent family, this was particularly hard and Alison was forced to stop work to become James' full time carer.

At the same time, Alison was deeply worried about the impact on Hannah, James' sister, who was 12 at that time. Alison was concerned that her daughter had to see her brother in great pain and had to cope with the panic and uncertainty that came with him being rushed to hospital in the middle of the night at times when his condition suddenly deteriorated and became life threatening. Hannah had to manage being apart from her brother, and it became necessary to move in with her grandparents while her mother spent long days in hospital at her brother's bedside.

Alison noticed that Hannah was becoming distant and closed off. She was trying to protect her mother by not sharing her feelings. At the same time, seeing her friends outside school became logistically difficult.

For these reasons, Alison sought help for Hannah from Rainbow Trust. A Sibling Support Worker started to meet with Hannah on a one-to-one basis for two hours a week. She also helped take the burden off both Alison and Hannah's grandparents, as the family juggled daily visits to hospital, and day to day tasks such as washing and cooking.

As they got to know each other, Hannah started to share her worries and anxiety, and her Sibling Support Worker was able to help liaise with her school on behalf of Alison. Hannah could start going to a book club and meeting up with friends outside school again.

'[The Sibling Support Worker] used to take me out for coffee or a hot chocolate and do an activity with me. This made me feel much better about feeling lonely and she made me feel as if I could talk to her. She had a very positive effect on me.'

'When James got ill, I felt isolated and like I couldn't talk to anyone, I didn't want to make mum worry more, so I didn't say anything. When [the Sibling Support Worker] came, she made me feel that I could open up to her and trust her. We also get to go on days and evenings out. It's really good seeing other brothers and sisters who are the same and understand.'

Hannah began to attend Rainbow Trust sibling days and youth groups. She felt less isolated and she developed some close friendships. Meanwhile Alison was relieved that she could spend time with her seriously ill son without worrying about Hannah.



A sibling on an outing with her Family Support Worker

As a result, Alison credits Rainbow Trust support for improving the health and wellbeing of the whole family by providing valuable 'breathing space'. She is confident that the support prevented Hannah from needing counselling.

James is now 11 years old and is in remission but continues to experience fatigue and stomach problems because of his treatment. Rainbow Trust continues to support the family.

Hannah still attends a Rainbow Trust youth group which meets three times a year and has received extra one-to-one support around exam time.

RAINBOW TRUST INPUT:

183 hours of staff time at £23 per hour
= **£4,209**

Petrol costs = **£500**

POSSIBLE STATUTORY SUPPORT IN ABSENCE OF RAINBOW TRUST

Mental health support: a spectrum of costs

£44-65 cost to CCG of GP consultation to make referral for specialist support.

£600 for six sessions of Cognitive Behavioural Therapy.^{xxv}

Support from a CAMHS (Child and Adolescent Mental Health Services) team: £4,549 -£4,937 average cost per case.^{xxvi}

Cost to Rainbow Trust **£4,709**

Potential costs in absence of support: spectrum of costs up to **£5,002**.
Additional lifetime cost of lower educational attainment and poorer mental health for Hannah in absence of support.

EXAMPLE 3: ROCHDALE SIBLING SUPPORT GROUP

A grant from Rochdale Council has enabled Rainbow Trust to run a monthly Sibling Support group at a church hall for six siblings, aged from five to 12 years old. Each sibling comes from a family which is receiving Rainbow Trust support.

Once established each year, the group is closed to new participants to make sure that children build relationships and gain trust in each other.

A typical meeting involves most of the children being collected from home by a Rainbow Trust Family Support worker and transported to the meeting place. The session then runs from 4.30-6pm, starting with some circle time. This allows each child to talk about what they remember from a previous session and to share anything that has happened, positive or negative, in their lives recently.

A Sibling Support Worker might then teach some therapeutic techniques that the children could find useful, and these will often incorporate a creative activity, such as making a Worry Box. This can then be a tool for the children identify their worries, and who they could share their worries with if they wish. Sessions end with a fun game or a light-hearted activity.

Asked for feedback in July 2018, two girls commented that they now understand that '*it is OK to be upset*'. They also said they now know that not everyone will understand their feelings, but that they know who they can talk to if they need support.



Brothers on a day out with Rainbow Trust

RAINBOW TRUST INPUT:

81 hours of staff time to deliver 9 meetings of sibling support group at £23 per hour (including preparation, transport, administration, delivery and evaluation)

= **£1,863**

Refreshments and materials = **£100**

Petrol costs = **£90**

POSSIBLE STATUTORY SUPPORT IN ABSENCE OF RAINBOW TRUST

The potential cost savings to public services of early intervention to assist siblings in managing their emotions and grief could be significant:

Six children receiving school-based social and emotional learning programmes to prevent conduct problems in childhood at £151 per child programme = £906 ^{xxvii}

If one of the six children required more specialist support:

Social care support for one child = £1,288 ^{xxviii}

£44-65 cost of GP consultation to make referral for one child requiring more in depth support

£600 for six sessions of Cognitive Behavioural support ^{xxv}

High level CAMHS support for one child = £4,937 ^{xxvi}

Cost to Rainbow Trust **£2,053**

Spectrum of costs up to **£5,908** for mental health or social care support. Additional potential lifetime cost of lower educational attainment for a child who does not receive support.

EXAMPLE 4: SUPPORTING A BEREAVED SISTER AT SCHOOL

A Rainbow Trust Family Support Worker supported a family with a terminally ill son. At the time of his death, his older sister, Charlotte, was three. The family was supported through bereavement and chose to cease receiving support when the mother returned to work and their daughter was starting school.

About three years later, Charlotte's grandmother rang the local Rainbow Trust office and explained that her granddaughter had been having problems at school for several months. Charlotte's parents did not know what was wrong and were getting increasingly worried, with their daughter being taken out of the classroom for disruptive behaviour. Various tactics had been tried and failed. As a last resort, the mother remembered their former Family Support Worker.

The Family Support Worker knew from her experience that a child's understanding of their bereavement can change as they get older. She offered to spend some more time with Charlotte, who was now seven. It was agreed that she would collect Charlotte from school a few times and take her to a soft play centre to re-establish a relationship.

After a few meetings, one day they travelled past the local cemetery. Charlotte started to share her thoughts, saying *'My brother was buried at the cemetery.'* The Family Support Worker took the opportunity to ask a few gentle questions. She asked if Charlotte took flowers with her family, and Charlotte said yes. The girl said, *'You were his friend, weren't you?'*, and the Family Support Worker said yes. Charlotte continued: *'I was his sister.'*

Charlotte then told the Family Support Worker that other girls at school were *'being mean'* to her. She explained that she had tried to tell the other children that she had a brother, but the other children said that they had never seen her mum at the school gate with a push chair or a spare car seat. They told Charlotte she must be a liar, and that they didn't want to be her friend.

The Family Support Worker later rang Charlotte's mother to explain what had come up in conversation. The mother was upset that her daughter had not felt able to tell her what was wrong. She asked the Family Support Worker if she could explain the situation to the school on her behalf.

School staff were shocked when they learnt about the bereavement. Although Charlotte's Reception teacher had been informed about a family bereavement, the current teacher knew nothing. The Family Support Worker suggested to the school that Charlotte be given the opportunity to bring in items from a memory box which held photographs of her brother and some special mementoes. Other ideas included identifying a member of staff that she could talk to when she wanted, and providing a notepad to write down any feelings she needed to express. Within a short period of time, Charlotte's behaviour had improved significantly and she started to make friends.



A sister enjoys some craft with her Family Support Worker

RAINBOW TRUST INPUT:

Family Support Worker time

16 hours at £23 per hour = **£368**

POSSIBLE STATUTORY SUPPORT IN ABSENCE OF RAINBOW TRUST

Mental health support: a spectrum of costs

School-based social and emotional learning programme to prevent conduct problems in childhood: £151 per child per year ^{xxvii}

If the child was referred for more specialised support:

£44-65 cost of GP consultation to make referral

Support from a CAMHS team: average cost of £4,549 to £4,937. ^{xxvi}

Cost to Rainbow Trust **£368**

Potential spectrum of costs up to **£5,002**

ESTIMATED AMOUNT SAVED FOR THE EDUCATION, HEALTH AND SOCIAL CARE SYSTEM

Rainbow Trust supports more than 1,230 siblings in various ways each year, ranging from occasional contact to intensive support once or twice a week. Estimating the amount of money that this, and other, preventative services are saving for the education, health and social care system is challenging.

The following calculations provide a conservative illustration of the types of annual savings that Rainbow Trust sibling support may be enabling, assuming that costs to the education, health and social care system are incurred within a 12 month period:

1. If 500 of these siblings received low level support through a school-based social and emotional learning programme at £151 per child

Cost saving of £ 75,500

2. If just 1 out of 20 of the 1,230 siblings supported each year by Rainbow Trust was prevented from needing in depth CAMHS support at some point in their life because of having an outlet for their feelings, the saving might be:

60 x £65 cost to CCG of GP consultation to make referral = £3,900

60 x £4,549 average cost per case with a CAMHS team = £272,940

Cost saving of £ 276,840

3. Further savings are enabled by reducing the strain on parents who often report feeling better able to cope with their situation because they are no longer so anxious about the needs of their other children.

If 100 parents are prevented from needing additional support because their well siblings are supported, the saving might be:

100 parents requiring GP appointment at cost of £65 per appointment = £6,500

100 parents referred to counselling could be 100 x £600 per parent = £60,000

Cost saving of £ 66,500

Grand total of £418,840 saved each year for the education, health and social care system.

Alongside these potential savings:

- A proportion of siblings supported by Rainbow Trust would otherwise be frequently missing days at school, with long term repercussions for their educational attainment.
- Parents whose families do not receive support and respite are more likely to experience family breakdown.^{xxiii}
- The annual cost to the taxpayer of family breakdown has been put at £48 million.^{xxiv}

SECTION 3: HOW RAINBOW TRUST SUPPORTS SIBLINGS

Rainbow Trust provides sibling support as part of its work with families where a child has a life threatening or terminal condition. Any family whose referral is accepted can receive sibling support. These referrals will commonly come from a nurse, a doctor, social worker or other professional who has contact with a family, but families can also self-refer.

Sibling support can include:

- One to one support – within family home, help with school or nursery drop offs or pick-ups, outings and activities. This can be both emotional and practical support.
- Group support – including holiday activities, closed groups for siblings (where the same group meet at each session so they can get to know each other), and drop in groups at hospitals for parents visiting neonates or children's wards.

At an initial assessment meeting, families are asked what sort of support would most benefit their situation. A tailored plan is drawn up and reviewed every six months to capture any changes in the family's needs. If sibling support is selected, children help to decide what activities they will do with their Family Support Worker.

Some siblings will receive support on a weekly basis, some fortnightly, and some more intermittently – such as in school holidays when it might otherwise be hard to get out of the house. Rainbow Trust teams are highly flexible, providing support at short notice or on varying days of the week if a family's circumstances require it.

In 2017-18, Rainbow Trust worked with 1,232 siblings



A Family Support Worker with siblings

Rainbow Trust support can be both practical and emotional. Importantly, siblings can enjoy time with someone who is there only for them, rather than for their sick brother or sister. As trust is built, a child will often start to express emotions that they may have hidden so as not to upset their parents. The friendship which can emerge between a sibling and a Family Support Worker can be an important source of support for a child.

The ability to talk freely about their situation is an element of support that families especially value. Children usually want to know what is happening to their sick sibling and may be faced with upsetting questions from classmates about whether their brother or sister is going to die.

As one parent explained,
“ Nobody really wants to talk about it, nobody knows how to talk about it. ”

This mother felt that their Family Support Worker had made their situation feel normal and could help the family have more open and honest conversations. *‘It wasn’t until afterwards that I realised that it really made a difference that [the well sibling] was able to have that support.’*



Brothers in a family supported by Rainbow Trust

**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.

SUPPORT GROUPS AND GROUP ACTIVITIES

To help reduce feelings of isolation and being different, Rainbow Trust's eight teams across England all run a range of sibling support groups and group activities or outings for siblings.

These can provide a much-needed change of scene for children whose lives are profoundly affected by the condition of their sick brother or sister. Valuable friendships can be formed, and the chance to try new activities can build their confidence and provide an opportunity to have fun and let off steam.

'I couldn't believe I met someone who had a brother just like mine. It really helps to talk to someone who knows what it's like,' said one child.

In one short survey, almost every child who took part in a Rainbow Trust sibling group held in Bury (spring 2018) reported that if they had not been there, they would have been either 'doing nothing/chilling' or playing video games at home.

Sibling drop-in groups are held at some neonatal units, so that parents can spend time visiting a seriously ill baby. This is particularly important if a unit has 'winter visiting restrictions' which prevent other children from visiting a unit to reduce risk of infections from cold or flu bugs.

While important for germ control, these rules can mean a brother or sister does not see, or even meet, a much-anticipated younger sibling for some months. The rules can create logistical problems for parents who otherwise need to find childcare to allow them to visit their seriously ill baby. A drop-in group can provide activities to keep siblings busy and occupied, and to help feel a bond with their seriously ill younger brother or sister through making a gift or card for them.

Feedback from siblings who attended neonatal sibling groups at St Thomas' Hospital run by Rainbow Trust's West London team:

'It's such fun coming to play here and I get to talk about my baby sister to you.'
- five-year-old boy

'I love this group because you have glitter.'
- nine-year-old boy

Feedback from siblings supported in summer 2018 by Rainbow Trust's North East team:

'It gives kids like us a break coming out with Rainbow Trust to forget about what's going on and feel normal like my friends.'

'I like how we make friends and see them at the hospital now - it makes it less boring.'

'Going out with you means I don't have to stay at the boring hospital all day!'

'I've been to so many cool places with you over the summer.'

'I've met lots of new friends through going out with Rainbow Trust.'

Specialist Sibling Support Workers

Two Sibling Support Worker roles exist in Rainbow Trust, one in the North West and one in Central London. The Sibling Support Workers work alongside a Family Support Worker as part of the whole support package provided to a family.

The roles were created with funding from the Big Lottery Fund in recognition of the lack of service provision for brothers and sisters of seriously ill children.

The Sibling Support Workers provide direct one-to-one support for siblings, and have the capacity to run regular sibling groups, sometimes in partnership with local authorities and other service providers, as well as a fuller programme of activities in the school holidays. The roles have also created additional tools and techniques for working with siblings which have been shared with other professionals.



A sister has fun with her Family Support Worker

Ongoing Support Through Recovery or Bereavement

Whether there is a recovery or bereavement, a Rainbow Trust Family Support Worker may be one of the only professionals continuing to work with a family when previously frequent contact with clinicians and nurses drops away.

Where a condition is terminal, memory-making activities in advance of the death can be an important way to prepare a brother or sister. Feeling grief is natural, and all children will cope with death in their own way. In bereavement, a Sibling Support Worker or Family Support Worker can provide important continuity, spending further time with siblings and other members of the family if requested. Often siblings want to have a 'normal' day out, or might be encouraged to talk about their feelings while doing arts and crafts or looking at a specialist children's book. At a time when life feels different and frightening, talking to a familiar face can help a sibling feel safe, secure and listened to.

“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.”

Clare, whose family receive support in Stockport.

**Rainbow Trust
supported
97
bereaved siblings
in 2017-18**

WHAT DO CHILDREN VALUE ABOUT SIBLING SUPPORT?

81 children, including 27 seriously ill children and 54 brothers and sisters, gave their views over two weeks in spring 2018.

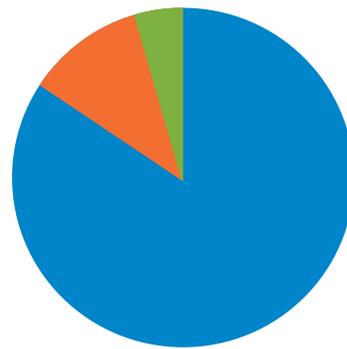
100% felt that their Rainbow Trust Support Worker listens all the time

100% feel safe with their Rainbow Trust Support Worker

94% (51 siblings) said they always liked Rainbow Trust visiting

6% (3 siblings) said they sometimes liked a visit.

Following a visit from their Family Support Worker, siblings were asked to describe their feelings:



87% described positive feelings, such as 'happy', 'excited', 'amazing'

9% felt sad that the Family Support Worker needed to leave

4% did not answer

Children chose the following reasons why they like a visit from Rainbow Trust:

- I get to do things/trips
- Play with me or read with me
- Fun
- Help us
- Ask about my feelings/easy to talk to
- Funny/make me laugh
- Bring us toys/teddies/games
- Nice and kind



WHAT DO PARENTS SAY?

“ The sibling support provided has made a massive difference to our house and home. [The sibling] has definitely flourished with the Family Support Worker, whereas previously he was in a state of neglect and ignorance. ”

“ The sibling support has been fabulous - helping her see she isn't alone in this. ”

“ Having access to Rainbow Trust makes a difference to our lives by spending time with the kids just by playing games - something as a parent I don't always have the time or energy to do. ”

CONCLUSION AND RECOMMENDATIONS

With growing numbers of children living longer with life threatening and terminal conditions, it is essential that the needs of their brothers and sisters are far better recognised and addressed.

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.

Rainbow Trust's conservative estimate is that its support for siblings is saving public services more than £418,000 each year. This is before considering the potential improvement to siblings' educational attainment and the protective value of such support for the whole family's ability to cope better with their situation, such as avoiding family breakdown.

However, existing sibling support services are highly dependent on charitable donations, and access is determined by where a family lives.



Twin brothers, supported by Rainbow Trust, with their Mother.

RECOMMENDATIONS:

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 or wellbeing, are more seriously affected.

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.^{xxix}

This guidance should:

- Highlight that the needs of siblings of children with life threatening or terminal conditions are often hidden from view, and this group of children may not be recognised as 'Young Carers' by their families or schools.
- Encourage the funding of sibling support services to reflect the reality of growing need across England.
- Ask Local Authorities to ensure that sibling support services are not excluded from their Short Breaks provision because of a narrow understanding of respite care being solely for the sick child or their parents.

- ➔ 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.

The aim of such a fund would be to:

- Increase the availability of early intervention services and prevent high-cost crisis intervention.
- Support Local Authorities and the NHS to meet their statutory duties to support seriously ill children and their families, including their siblings.

- ➔ 3. Support schools to play a fuller role in identifying and meeting the needs of siblings of seriously ill children. Whether or not a child is formally identified as a 'young carer', we recommend that all schools are resourced to support siblings, including:

- Systems to ensure good communication between parents and staff, and that information is shared in school transitions.
- Named staff with responsibility for understanding and addressing their needs.
- Knowledge of tools, strategies and other sources of support for siblings.

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.

As part of current moves to improve access to Child and Adolescent Mental Health Services (CAMHS), we urge commissioners to acknowledge this under-recognised group, and to implement a pathway to mental health support for siblings whose needs escalate.

USEFUL ORGANISATIONS

Sibs

The UK charity for brothers and sisters of disabled children and adults.

www.sibs.org.uk

Winston's Wish

Winston's Wish supports bereaved children, their families, and the professionals and the professionals who support them, and provides information and resources for schools.

www.winstonswish.org

ENDNOTES

- i Survey carried out by Rainbow Trust Children's Charity in July/August 2017. 22 children's hospices in England responded out of 35 invited to take part.
- ii Academic estimates for 2009-10 put the number of children (0-19) with a life-limiting or life threatening condition in England at 40,000. *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/ A new study, Make Every Child Count, will provide updated estimates and projections in late 2019. Information about the new project, funded by True Colours Trust, can be found here: www.togetherforshortlives.org.uk/making-every-seriously-ill-child-count/
- iii *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 - line 1.1.6.
- iv *Our commitment to you for end of life care*, Department of Health and Social Care, 2016, www.gov.uk/government/publications/choice-in-end-of-life-care-government-response - pages 36-37.
- v 'Being a young carer: your rights', www.nhs.uk/conditions/social-care-and-support/young-carers-rights/
- vi See Sibs UK website: www.sibs.org.uk/supporting-young-siblings/siblings-schools-project/top-tips-school-staff/
- vii Action for Children/ Carers Trust survey, August 2018 www.actionforchildren.org.uk/news-and-blogs/whats-new/2018/august/three-in-four-young-carers-feel-lonely-in-the-summer-holidays/
- viii See for instance, *Cancer Costs*, CLIC Sargent, 2016, www.clicsargent.org.uk/content/cancer-costs and *Are We Nearly There Yet? The financial impact of travel on young cancer patients and their families*, CLIC Sargent, 2018, www.clicsargent.org.uk/sites/files/clicsargent/field/field_document/NEW_Are_we_nearly_there_yet_A4_LR.pdf
- ix *Preparing the Way*, Penny, A., Child Bereavement Network, May 2018 www.childhoodbereavementnetwork.org.uk/media/91314/Preparing-the-way.pdf
- x *In the Shadow of Illness: Parents and siblings of the chronically sick child*, Bluebond-Langner, M., Princeton University Press, 1996.

- xi *Life After Critical Illness in Children – Toward an Understanding of pediatric Post-intensive Care Syndrome*, Scott Watson, R. et al, *The Journal of Pediatrics*, July 2018, Volume 198, pages 16-24, [www.jpeds.com/article/S0022-3476\(17\)31781-X/abstract](http://www.jpeds.com/article/S0022-3476(17)31781-X/abstract)
- xii *Meeting the Needs of Siblings of Children with Life-limiting Illnesses*, Lane, C. and Mason, J., *Nursing Children and Young People*, Volume 26, Number 3, April 2014. rcni.com/sites/rcn_nspace/files/ncyp2014.04.26.3.16.e349.pdf
- xiii *Siblings' Experiences With Childhood Cancer: A Different Way of Being in the Family*, Woodgate, R.L., *Cancer Nurs.* 2006;29(5):406-414. https://journals.lww.com/cancernursingonline/Abstract/2006/09000/Siblings__Experiences_With_Childhood_Cancer__A.10.aspxRef
- xiv *Do Siblings Matter Too?* Family Fund/University of Portsmouth, 2015. www.familyfund.org.uk/do-siblings-matter-too
- xv *Paediatric life-limiting conditions: Coping and adjustment in siblings*, Brennan, C., Hugh-Jones, S., Aldridge, J., *Journal of Health Psychology* 18(6) 813-824, 2012. <https://journals.sagepub.com/doi/10.1177/1359105312456324>
- xvi *'Young carers in Wales 'hidden' from schools'*, BBC News website, 31 May 2018. www.bbc.co.uk/news/uk-wales-44306700
- xvii *Hidden from View*, Children's Society, 2013, www.childrenssociety.org.uk/what-we-do/resources-and-publications/publications-library/hidden-view This uses data from the Longitudinal Survey of Young People in England and quotes research on young adults in education, employment and training in *Against the odds: Targeted briefing – Young carers*, Audit Commission, 2010. www.bl.uk/collection-items/against-the-odds-reengaging-young-people-in-education-employment-or-training-local-government
- xviii *A Road Less Lonely*, Scottish Partnership for Palliative Care, 2018 www.palliativecarescotland.org.uk/content/publications/A-Road-Less-Lonely-WEB.pdf
- xix *Impact of social support on bereaved siblings' anxiety: a nationwide follow-up*, Eilertsen ME1, Eilegård, A., Steineck, G., Nyberg, T., Kreicbergs, U., in *J Pediatr Oncol Nurs.* 2013 Nov-Dec;30(6):301-10. www.ncbi.nlm.nih.gov/pubmed/24326219 See also *Insufficient communication and anxiety in cancer-bereaved siblings: A nationwide long-term follow-up*, Wallin, A.E., Steineck G., Nyberg, T, Kreicbergs, U , 2016 in *Palliat Support Care*, 14(5):488-94 www.ncbi.nlm.nih.gov/pubmed/26515111
- xx *Association of Mortality With the Death of a Sibling in Childhood*, Yu, Y., Liew, Z., Cnattingius, S., Olsen, J., Vestergaard, M., Fu, B., Parner, E.T., Qin, G., Zhao, N., Li, J., *JAMA Pediatr.* 2017;171(6):538-545. <https://jamanetwork.com/journals/jamapediatrics/fullarticle/2617991>
This was a study of 55,818 participants who experienced sibling death and were followed up over a 37 year period.
- xxi *Hidden Savings: How Rainbow Trust saves money for the health and social care system*, Rainbow Trust, 2017. www.rainbowtrust.org.uk/hidden-savings
- xxii *The link between absence and attainment at KS2 and KS4, 2013/14 academic year, Research report, March 2016*, Department for Education. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/509679/The-link-between-absence-and-attainment-at-KS2-and-KS4-2013-to-2014-academic-year.pdf

- xxiii See, for instance, *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
- xxiv *Counting the Cost of Family Failure*, Relationship Foundation, 2016. www.relationshipsfoundation.org
- xxv *Unit Costs of Health and Social Care 2017*, Curtis, L. & Burns, A., Personal Social Services Research Unit, University of Kent, Canterbury, 2017. www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2017/, page 89.
- xxvi *Unit Costs of Health and Social Care 2017*, page 190-1.
- xxvii *Unit Costs of Health & Social Care 2017*, page 50.
- xxviii 'ongoing support as an open Child in Need case for 6 months at a low level' - *Unit Costs of Health & Social Care 2017*, page 96.
- xxix A comprehensive local children's palliative care service is described in detail in Appendix 1 of *End of life care: Strengthening choice*, a report by the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, 2018, page 49. www.togetherforshortlives.org.uk/wp-content/uploads/2018/10/PoI_Res_181019_APPG_Children_Who_Need_Palliative_Care_inquiry_report.pdf



SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

RAINBOW TRUST HAS EIGHT CARE TEAMS ACROSS ENGLAND. THEY ARE:

- **Central London** - covering certain central London boroughs
- **Essex** - covering Essex and North East London
- **North East** - covering Cleveland, Co. Durham, Northumberland, Redcar, Teesside and Tyne & Wear
- **North West** - covering Manchester, the wider Greater Manchester region, West Lancashire and Cumbria
- **Southampton** - covering Dorset, Hampshire, West Berkshire, West Sussex and South Wiltshire
- **South West** - covering Bath, Bristol, North East Somerset, South Oxfordshire and North Wiltshire
- **Surrey** - covering Kent, South East/South West London, Surrey and Sussex
- **West London** - covering West and North West London, Bedfordshire, Buckinghamshire, East Berkshire and Hertfordshire.

“ 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. ”

Clare, mother to Adam, Stockport

rainbowtrust.org.uk/seeushearus

#seeushearus

See us, Hear us, Notice us:

The case for supporting siblings of seriously ill children.

December 2018

© Rainbow Trust Children's Charity

Cassini Court
Randalls Way
Leatherhead
Surrey KT22 7TW