

FAMILIES FIRST

SPRING/SUMMER 2022



Inside:

Celebrating
**35 years of
supporting
families**

Family Support
Worker Ema
**helps James'
family to deal
with complex
needs**

**A week in
the life of**
a Family
Support
Worker

**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Dear Supporter

A huge thank you to all the generous organisations, volunteers and people like you that enable us to continue providing expert support to families with a life-threatening child.

I also want to give my heartfelt thanks to the newspaper the *i* for choosing us for their Christmas appeal. Thanks to this partnership and the generosity of the *i* readers we raised a phenomenal £146,000 from an initial target of £75,000. This could provide support for 82 families for an entire year – a truly amazing result.

This year we are marking 35 years of care – you can read more about how the charity began on page 11.

Our vision is that every family in the UK who has a child with a life-threatening illness receives the support they need. It has long been a strategic priority for us to grow our care services to reach more families, both in the regions where we already support and in new areas.

We have been extremely fortunate to secure funding to establish care teams in two new locations; one in Liverpool to expand coverage in the North West and into Wales; and one in Reading to boost care provision in the South. When the teams are in place later this year, it will take the total number of care team locations across the country to eight, enhancing our face-to-face support with capacity for up to 160 additional families per year. This, along with our new virtual support service, provides the opportunity to significantly increase our reach supporting families in need across the UK.



Cover photo: Jack is one and has complex heart and breathing difficulties. Between the age of seven weeks and nine months old he was in hospital. Jack and his family were supported by Family Support Worker Monica from the North East Care team until they moved to a new location. They are now supported by Family Support Worker Sophie from the North West Care team.



We know our support is more critical than ever: in January we asked families we support about their situation and in particular the impact of the COVID-19 pandemic. 58% of parents said their mental health was worse or much worse than before the pandemic, 30% said that Rainbow Trust is their **only** source of professional practical and emotional support, and a further 20% said they only have one other source of professional support.

Our snapshot audit at the end of 2021 asked families to rate our service provision and 92% of the families we support rated our overall service as good or excellent. Families face enormous strain when living with childhood illness and this makes the practical and emotional support that Family Support Workers deliver critical for families in crisis.

Thank you for all you do to help families with a seriously ill child.

Best wishes

Zillah Bingley, Chief Executive

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Rainbow Trust Family Support Workers help families practically and emotionally as they navigate the challenges of living with childhood illness. To many of us, family means everything so when serious illness affects a child, and family life is turned upside down, this tailored and expert support enables families to make the most of their time together.

STAY IN TOUCH

Call us: 01372 363438

Email us:

supportercare@rainbowtrust.org.uk

Visit us: rainbowtrust.org.uk

You can check our Privacy Policy at rainbowtrust.org.uk/cookieandprivacypolicy

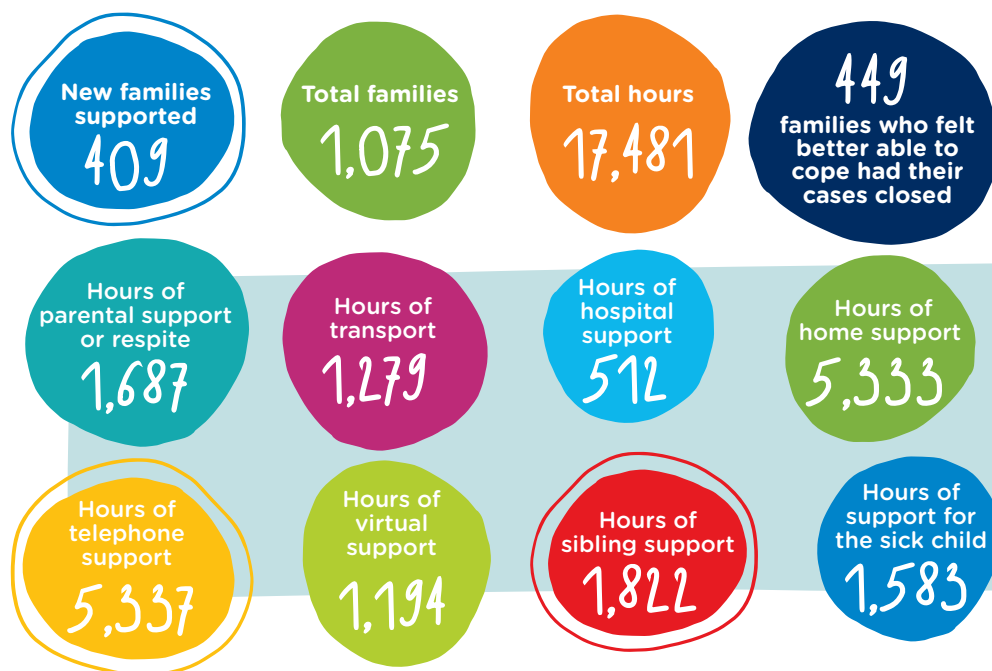
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Registered Charity No. 1070532.

OUR IMPACT 2020/2021

OUR SUPPORT IN NUMBERS



Figures from *Our Impact*, covering July 2020 to June 2021. You can download a full copy and watch our impact video here: rainbowtrust.org.uk/our-impact

WHAT PARENTS AND CARERS SAY

“ I love the support my family has received since my boys were born. I cannot fault the service as it has allowed me to visit my son in hospital as well as having the relationship with the Family Support Worker when I can rant or cry if I need to and it really does help so much. If I'm ever stressed or anxious, I always feel better after talking it through with my Family Support Worker on our way to the hospital - I don't think I would have been able to cope without Rainbow Trust. ”

“ My Family Support Worker's help to me has been massive, especially when I'm feeling low, unsure and stressed. Her presence is calming and gives the children support to grow within themselves. The help and support to go and do 'normal' activities that by myself I wouldn't be able to do. ”

“ My Family Support Worker is the best person to make all of us happy with ideas and lots of support for our family. She is loving, caring, kind and has lots of skills regarding children and professional family support. ”

When asked how much of a difference Rainbow Trust made to their lives **92% rated the positive difference** as eight, nine or 10 out of 10.

WHAT THE CHILDREN SAY

If I had a magic wand I would...

- ★ be better and be home in my own room - then fly to Disneyland with all my family and get fat eating lots of delicious food
- ★ turn my house into a pirate ship
- ★ have a million puppies and one horse
- ★ just eat a sweetie at school to make you learn all your education and can just stay and play with your friends
- ★ magic up a bunny that can walk and eat everything
- ★ change my Family Support Worker into a frog and she can eat flies
- ★ be able to eat everything I want and have a pink and purple shoe with glitter following me everywhere

79% of siblings who responded to our audit selected **'My Family Support Worker helps me spend more time with other children or people outside of the family'.**

FAMILY SUPPORT WORKER SHELLY HELPED TEISSY'S FAMILY IN THEIR GRIEF

Teissy tells us about the death of her daughter Ki Ki and the support her son Kingston needed

“

Ki Ki, Kingston's little sister, was born in October 2015. Aged almost three years she became really unwell in 2018. She was diagnosed with Leigh's disease (a progressive neurological disorder) and a severe type of scoliosis * in February 2019.

Whilst Ki Ki was seriously ill in hospital and we had this terrible diagnosis, the hospital team referred us to Rainbow Trust.

We didn't know how long Ki Ki would live. On top of the devastating news and having to learn how to look after Ki Ki being so ill, we decided to also focus on making her life the best it could possibly be and on creating memories for us all.

We wanted to make memories so we went on different holidays to enjoy as a family and Ki Ki's personality shone through, she was a real social butterfly.

The diagnosis and situation changed us all.

Rainbow Trust Family Support Worker Shelly started supporting our whole family, but focusing on Kingston. As my partner Adam and I spent more and more time with Ki Ki we had less time with Kingston, who was just six. He needed one-to-one time, moments when he could be himself and also have fun.

Shelly would spend time with Kingston to provide an outlet; in their sessions he was able to express how he was feeling and voice his worries and concerns. We started to see a real difference in him. It was evident that Shelly's support was very beneficial for him and made him feel special.

Shelly also took Kingston out with other siblings of very ill children. This helped him understand that he wasn't alone and also helped him make new friends.

Shelly made us all feel at ease. She is very inviting and conversations happen naturally with her. I didn't mind telling her how I was feeling. I didn't mind sharing thoughts or feelings that I would not even tell my family.

There was a unique difference from other organisations that provided some support: Shelly knew the whole family and what we were all going through. Other organisations didn't understand the whole situation. With Shelly it was different, she understood everything that we were going



Kingston and Ki Ki in Disneyland



Adam, Ki Ki, Kingston and Teissy enjoying a special family moment



Kingston painting a rock in memory of Ki Ki and one for his little sister Khailani

through. She really cared. Very quickly Shelly became our constant and stable support.

It pains me to say that in March 2020, two weeks before the country went into the first national lockdown, Ki Ki sadly died.

For us, things became very different. Relationships with people changed. On a normal school run, people would avoid me, look away and pretend they hadn't seen me.

People felt uncomfortable as they didn't know how to react to me. They didn't want to ask 'Are you all right?' because of course I wasn't all right and I will never be. Nothing will ever be the same.

Rainbow Trust was the only organisation that supported us throughout; Kingston's school offered some bereavement support but it wasn't constant and it only lasted for a couple of weeks.

Kingston and Ki Ki were just 14 months apart and were very close, they had a really good and special bond.

Ki Ki's death had a big impact on Kingston. He started having night terrors, was unable to sleep and was having a really difficult time. Kingston is so considerate that he didn't want to talk to us about what was happening with him and how he was feeling as he didn't want to upset us. He didn't want to worry us so he kept it all in and

only shared it with Shelly. While looking after Ki Ki Adam and I had a good routine. All this disappeared when Ki Ki died. Adam was very angry, very upset. I dealt with it in a different way. I felt sad and depressed. I was mad at Adam for shutting me out. Shelly also helped with these feelings. Shelly explained that there's no right or wrong way to grieve. His way of grieving was just as valid as mine.

18 months after Ki Ki died I gave birth to my daughter Khailani. She is 14 weeks old and Kingston is really good with her but, as he has gone through the trauma of losing Ki Ki, he also worries about Khailani.

Shelly's help felt like someone from outside our family cares and wants to help us get through this really difficult time, when we did not know how to deal with it all.

Losing a child is the worst experience a parent can go through and Shelly helped me to start accepting my loss and to grieve. Shelly gave Kingston the space he needed to learn to live with the pain of losing his little sister.



Ki Ki and her favourite doll, who had a nasal tube like her

Leigh's disease is a disorder that affects the central nervous system (brain, spinal cord and optic nerve) deteriorating movement, posture and mental abilities. Some signs may be poor sucking ability, the loss of head control, loss of motor skills and seizures. Some children may have a period of normal development before being affected by this disease. It is a progressive disorder that usually happens in early childhood and life expectancy is two or three years after diagnosis.

rainbowtrust.org.uk/donate-magazine

FAMILY SUPPORT WORKER EMA SUPPORTS JAMES' FAMILY AS THEY DEAL WITH HIS COMPLEX NEEDS

Nothing prepares parents to deal with childhood illness so Ema is helping to improve the family's quality of life

During a pre-eclampsia examination at 28 weeks, when Danielle was pregnant with her second child James, the doctors discovered that the baby's heart beat kept dropping to a dangerous level, unable to bring it back up. Danielle had to be induced, which meant James was born 12 weeks prematurely.

James was in hospital for the first four months of his life. When he was finally discharged, he needed home oxygen treatment and to be fed through a tube as his breathing is compromised due to suffering chronic lung disease.

Since birth James has had complex needs and requires looking after 24 hours a day. James is non-verbal, has low muscle tone and is unable to eat or drink anything. Nothing prepares a parent for this. Danielle says: *"The world stopped when James was born as we weren't expecting a child with such complex needs. He weighed just 1lb 4oz. James had a bleed on his brain at three days old which has caused cerebral palsy, developmental delay, visual impairment, hydrocephalous* and many other conditions."*

Danielle and her husband Chris heard about Rainbow Trust through their Community Nurse, and they have now been receiving support from Family Support Worker Ema for nearly three years. Ema met James when he was eight months old. Her support was originally mainly for James and his now nine-year-old sister Bella, who found it hard with James



Danielle, James and Ema enjoying the sunshine

being in and out of hospital. Ema has been helping them to have fun despite the day-to-day difficulties they face. These play sessions also provide an opportunity to give emotional support to both children. For Bella monthly one-to-one sessions give her focused "me" time. These sessions have boosted both children's confidence and social skills.

"Bella enjoys it when Ema comes over to see her, as she finds it hard to build relationships with other people. She has been diagnosed with autism, and without Ema's help we wouldn't have spotted the signs and pushed for an assessment and support at school, which she now has."

"Ema has made our life easier as we have been able to do things as a family. She has made our daughter feel special."

"James prefers to play on his own, but he is also building his social skills with Ema and will sometimes choose to play with her, he has started to initiate play."

Ema also helps to improve the family's overall quality of life by providing much needed emotional support for Danielle at home and over the phone. Danielle was diagnosed with Post Traumatic Stress Disorder (PTSD) due to the trauma of James' birth, the difficult first few days of his life and his numerous conditions. With

* A build-up of fluid in the brain.



James' sister, Bella, proudly shows biscuits baked with Ema



Ema plays with James, helping increase his social skills



James in an incubator in hospital

both counselling and Ema's help Danielle has started to overcome her PTSD. Ema's emotional support has focused on helping Danielle to have more confidence in general and specifically around looking after James, empower her to share more responsibilities with her husband, Chris, and to allow herself more time to heal emotionally.

Over the last three years, James has been in and out of hospital. This, together with the numerous medical appointments, presents many challenges for the whole family. As the family waits for a mobility vehicle Ema provides transport so they don't have to worry about booking and paying for taxis, traffic jams and delays and can just focus on James.

As James' brain is so fragile a fall on a hard floor could be very dangerous so Ema helped the family to secure funds to lay carpet throughout the whole house.

At the end of 2021 James started passing out, losing control of his limbs and body and, as he is non-verbal, he was pressing the back of his head with the palms of his hands. Unable to express what was happening to him this showed he was having pain and discomfort. This was due to a cyst on his brain. The cyst was causing a blockage and fluid was accumulating, increasing pressure in his brain.

Because of this, James recently

had to undergo two brain surgeries. The seriousness of the operations was made clear to Danielle and Chris when they were told that if anything went wrong James could end up paralysed or could have a stroke.

Ema picked them up from home at 6am and dropped them off at the hospital at 7:30am for the first operation. Two weeks later James was in pain again and the local hospital sent him in an ambulance, on a ventilator, to John Radcliffe hospital as an emergency. There was so much equipment that there was no room for Danielle in the ambulance. She was told to make her own way – so Danielle called Ema, who was able to help and took her immediately. Fortunately, the second operation went well and James went home later to continue his recovery.

"Rainbow Trust makes you realise that you're not alone and that there are many other families who are in the same situation. The Family Support Workers can guide you to a more positive outcome in your life."

“Ema has gone above and beyond to help us. Ema is our own Nanny McPhee!”

Family means everything.

Having a child with complex needs is tough on parents; the everyday workload may feel relentless and the whole family may feel isolated. The experience could become emotionally and physically draining. Rainbow Trust Family Support Workers like Ema help the whole family, tailoring the support to each family member, in the hope that we can make life a little easier, giving them time to focus on what matters the most to them.

→ Help families and **sponsor a Family Support Worker like Ema today.** Your sponsorship will enable families who have a child with a life-threatening illness to make the most of time together because family means everything.

rainbowtrust.org.uk/sponsor-us



YOUR SUPPORT REALLY MATTERS

Your support helps change lives

Some of the children and families you have helped us support during the past months.



↑ Musa, four, has recovered from a brain tumour but is still under treatment. Musa had a hospital appointment so Family Support Worker Monica took his siblings Eisa and Nooriya to soft play.



↑ Vanessa, who has sickle cell anaemia, having fun with her siblings and Family Support Worker Sabrina at the beach.



↑ Henry, seven, has been learning to lip read with Family Support Worker Mandy. Henry lost his hearing due to his Mitchell syndrome, a progressive disorder.



↑ Family Support Worker Sarah has supported Amelie's family for over six years doing school pick ups and holiday support for her and her three siblings. Amelie's brother, Mason, 17, has a brain tumour.



↑ Rachael and Thomas' brother suffers from a degenerative condition. Family Support Worker Sophie took them on an alpaca walk along the Keswick hills for a very different support session.



↑ Family Support Worker Ema and Max had a painting session together. Max's twin sister has a narrowing of the airway above her trachea and has a tracheostomy.



↑ Family Support Manager Sean went to see Mia, seven, and Maisie, nine, and baked a lovely cake. Mia had an acquired brain injury that lead to cerebral palsy and complex health needs.



↑ Sonny, 15, who has Duchenne Muscular Dystrophy, enjoyed carving and decorating his 'three-faced' pumpkin with his Family Support Worker Georgia.

→ Marrveen, eight, at the park with Family Support Worker Sarah. His brother Raynnav, three, has a serious condition that affects his development.



It is only thanks to your generosity and support that we can help families with a seriously ill child

The families we support face difficult and challenging circumstances whilst they care for their life-threatened child.

Family Support Workers tailor the support they provide to each family. From key practical and emotional support to the parents to giving the ill child and brothers and sisters a break with outdoor activities and fun, playing, doing arts and crafts, reading and providing a safe space to talk. These sessions give the parents some respite and help the children to have some normality, at the same time as they improve their wellbeing and increase their self-esteem.

Thank you for all your support.

A WEEK IN THE LIFE OF A FAMILY SUPPORT WORKER

Georgia is a Rainbow Trust Family Support Worker in the Southampton Care team and shares a typical week with us

By Georgia Cooper

Some names have been changed.



MONDAY:

I was in Bournemouth today visiting Tony and his family. Tony is 14 years old and has Sanfilippo Syndrome, a progressive disorder which means that he has very little mobility, is non-verbal and his mum is his full time carer. I collected Tony's sister Amelia, nine, from school and walked her home, we chatted about how her day was and all the amazing things she has been learning about.

Once home, I was able to talk with their mum about how the whole family had been since my last visit. Today's session with Amelia was more of a sensory experience, where we made some slime together – which she really enjoyed – and then we played with her Lego.

Sibling support is a really important part of our service. It can play a vital preventative role, helping children to learn coping mechanisms, find an outlet for their strong feelings and worries, build a support network – as well as having some much needed fun. My visits with Amelia are very much play and craft-based and allow her to talk openly to me about any worries that she may be feeling regarding school or her brother Tony, in a safe space while doing the things that she loves.

TUESDAY:

Today I was invited to a school in Southampton that Teddy, five, attends to be presented with a cheque. The school had raised money for Rainbow Trust over Christmas and wanted to donate it to a charity that supports Teddy and his family through his cancer diagnosis. I met the head teacher and spoke about what we could do to work together to continue to support the family.

Afterwards, I collected Teddy and drove him home from school. He

told me all about his day, and how excited he was that he got to see me today. At home, we played lots of board games together and his mum and dad joined us for some of them, which he seemed to really enjoy. I spent time with his mum, and she showed me some photos and videos of Teddy and his brother that she had captured over the last week which made her beam with pride.

WEDNESDAY:

Neonatal care has been especially difficult during the pandemic for parents of premature or seriously ill babies. Visiting can be complicated by the distance that parents may need to travel to see a seriously ill baby. Short and infrequent visits can create a barrier to caring and bonding activities which can assist in a baby's development.

We support many parents with seriously ill babies, and today I drove to Salisbury to collect a mum from her home and took her to Princess Anne Hospital in Southampton so that she could see her baby, who was born prematurely at 27 weeks.

Currently she can only see her baby twice a week, as travelling to and from the hospital is difficult without support. On the way there I provided some emotional support, I listened to her talk through her concerns as well as the positives surrounding her baby and home life. Once I had dropped her off, it allowed her to have a few much-needed hours with her baby. I then collected her from the hospital and drove her back home to Salisbury, where we chatted more about her baby's progress.

THURSDAY:

I drove to Fleet this morning to visit Ben, who is 12 years old and has been

diagnosed with a serious heart condition. His mum asked me if I could take him to watch the new Spider Man movie so that he could have some fun whilst she got on with some jobs around the house. We spent a few hours at the cinema, then we walked around town to browse in some shops. We chatted about all the new Marvel films that are coming out soon. On the drive home Ben said that he really enjoyed spending time with me today and that he cannot wait for my next visit. His mum was very appreciative and said that it allowed her to have some time to herself to do things that she wouldn't have been able to do while looking after Ben.

FRIDAY:

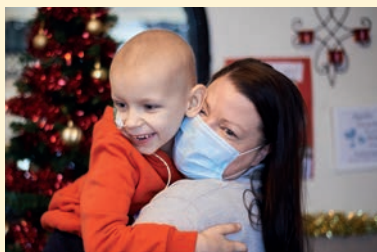
On Fridays we have a team meeting in our Southampton office, where we all come together and share any latest information within the team and Rainbow Trust. We also get the opportunity to share how our week has been, talk about the families that we have been able to support during that week and exchange ideas on how to improve or address anything that may seem difficult.

→ Family Support Workers like Georgia help families with a seriously or terminally ill child practically and emotionally.

It's only thanks to your donations that we can give life-threatened children and their families this expert support for as long as they need it. Sponsor a Family Support Worker like Georgia today. rainbowtrust.org.uk/sponsor-us



FUNDRAISING HEROES



THE **i** CHRISTMAS CHARITY APPEAL

Our **heartfelt thanks** to the **i** and its generous readers that helped raise over £146,000 with the **i**'s 2021 Christmas Appeal. When we first knew we had been selected for the appeal we thought £75,000 would be an impressive amount, so to have nearly doubled it is truly brilliant.

This is enough for Rainbow Trust to provide support to 82 families across the UK for a year to help them cope with the emotions and practicalities of having a seriously ill child. **Thank you.**



St James Group Ltd, part of the Berkeley Group, did a Santa relay run along the Thames river in London in December raising over £1,200.



Denise did a 10 mile walk throughout Durham in December (it was only 3 degrees) and raised £967.



The St Cuthbert's Society at Durham University raised £1,000 over two weeks of fundraising activities that included a bingo night, pub quiz, silent disco, karaoke and ice bucket challenge.



Coffee shop Bob & Berts in Lancaster raised over £1,038 during December by asking for charity donations at the tills.



Hook with Warsash C of E Academy's Head Teacher Sarah Willoughby hands a cheque for £410.05. The money was raised as Teddy is being supported by Family Support Worker Georgia.



V Cars Chippenham donated a generous £1,000.

To all our amazing
supporters
and fundraisers
thank you!



London's West One Shopping Centre staff raised £1,287 by holding a 'One Great Day' bucket collection.



Reed's School in Surrey held a Fun Santa Run in December and raised £1,108.

BERNADETTE CLEARY OBE: FOUNDING INSPIRATION

35 years later we keep going strong

In the autumn of 1981 a neighbour came to Bernadette's door and asked if she could help a young girl who had come home to die. It was a tragic case. Rachel had been diagnosed with cancer when she was six, successfully treated and then, when she was 12 years old, the cancer returned. When Rachel's father, an accountant who had been happily married to Maureen for 18 years, heard the news that his only child was dying he went to work one day and never returned home, leaving Maureen, a teaching assistant, to cope alone.

When Bernadette met Maureen and her daughter they were in a terrible state. Rachel had checked out of the hospital, against her doctors' wishes to die at home. Her local GP refused to treat her, she had no pain relief drugs and when Bernadette first saw Rachel she was in excruciating pain.

Bernadette's first action was to wait a whole day in hospital to see Rachel's consultant who was so shocked by the situation that he made his first ever home visit to give Rachel pain-controlling drugs.

Bernadette was there to help and support them, comforting both and consoling Maureen when Rachel died.

Word got around about how Bernadette had supported Rachel and Maureen and she started travelling round the country helping other families in a similar situation.

Bernadette is married to Dennis and they have three children. As well as that they have fostered over 50 children. Bernadette set up Rainbow Trust in 1986, working from a shed at the bottom of the garden. She and Dennis personally funded all of her travel to families with a seriously ill child while friends pitched in with coffee mornings.

Bernadette's vision was to make the movement bigger, to be able to reach more seriously ill children and their families.

35 years on, and supporting over 1,000 families each year, we are expanding our reach with two brand new teams, one in Liverpool and the other in Reading. We have continued to innovate and now also provide virtual support, allowing us to work with families where we may not have a care team on the ground.

Here's looking forward to the next 35 years.

Read more about the expansion at rainbowtrust.org.uk/news



Our new virtual support service

consists of play sessions which start after a support pack is delivered to the family. Each pack contains a puppet, paper, art materials and play dough, toys to relieve anxiety and boost concentration, and an emotions journal. With this, the children can be creative and play at the same time as they understand their worries and emotions. Virtual sessions enable children to have one to one support and parents to have some respite or some time to look after their other children.



A virtual support pack costs £60 and is sent to the family free of charge

Ways to fundraise



Skydive 35

We are looking for 35 brave people to sign up and jump for us between 6 and 12 June 2022.

Help us to celebrate our 35th year and tick off the experience of a lifetime. Imagine the rush as you free fall at 125mph from 10,000 feet above the ground, all whilst raising vital funds to help Rainbow Trust reach even more families with a seriously ill child in 2022 and beyond.



Do the Distance

Challenge yourself and take on this virtual challenge by running, walking, cycling or swimming the distance from Liverpool to Reading to help us reach more families in these new areas – an impressive 180 miles.

Do something amazing and go to rainbowtrust.org.uk/events

