

# FAMILIES FIRST

SPRING/SUMMER 2024



## INSIDE:

- Adjusting to life with a child with special needs
- A week in the life of Family Support Worker Georgia
- How you can get involved

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

# Dear Supporter

**It has been an exciting few months since your last issue of *Families First*.**

Firstly, a very warm welcome to Jen Kenward, our new Director of Care Services following the retirement of Anne Harris after 17 years in the role. With a wealth of knowledge and experience in patient and care services, Jen leads Rainbow Trust's nine care teams across the country.

We welcomed the October publication of the 'Manifesto for palliative and end of life care' ahead of the next general election. The Manifesto calls upon all political parties to commit to ensuring that everyone affected by dying, death and bereavement receives the best possible support now and in the future.

We held our first match-funding fundraising campaign, 'No Family Alone Appeal', which helped us secure funds to support 100 newly referred families with a seriously ill child this year. A big thank you to all the champions and supporters who contributed over the four-day campaign.

We also celebrated a year of The Kentown Children's Palliative Care Programme, a community focussed children's palliative care service in North West England, which is going from strength to strength. It offers a unique model of care that ensures families can easily access all the support they need locally and at home by bringing together Nursing Care, Social Care, and Information and Awareness.

I would like to thank long-standing corporate supporters ILC, a network of insurance claims professionals, who hosted their annual lunch in aid of Rainbow Trust, and to extend a heartfelt thank you to the wonderful friends, volunteers and supporters like you who enable us to support more seriously ill children and their families, so they don't have to cope alone.

I can't finish without highlighting the continued impact of the cost-of-living crisis on many of the families we support. They are managing the challenging situation of their seriously ill child's needs with the additional worry about their financial situation.

As always, we want to do more to help and to reach families in desperate need of practical and emotional support. This will only be possible with your generous donations and support.

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



Zillah Bingley, Chief Executive



**Cover photo:** Five-year-old Kaitlyn, Ethan's sister, was taken to hospital with breathing difficulties. You can read about the support Family Support Worker Michelle gives to the family on page 10.

**Many families with a life-threatening child in the UK are coping alone, without support. Rainbow Trust Family Support Workers provide expert practical and emotional support, tailored to enable brothers and sisters to have a safe space to be like any regular child, parents to have some respite and the confidence that their seriously ill child is looked after by somebody they trust.**

1,141

Families  
received  
support

482

Newly  
referred  
families

1,173

Hours of online  
family support

3,876

Hours of  
sibling support

3,622

Hours of support  
for the sick child

1,467

Hours of  
telephone  
support

5,350

Hours of  
text message  
support

2,464

Hours of  
hospital  
support

1,608

Hours of  
neonatal  
support

569

Hours of  
bereavement  
support

## Financial year 2022/2023

Between July and December 2023 alone, Rainbow Trust **supported 953 families**. This would not have been possible without your support, which enables Rainbow Trust Family Support Workers to continue to give families with a seriously ill child a lifeline of essential help at a time when their life has been turned upside down.

Thanks to your support, between July 2022 and June 2023, Family Support Workers have been able to provide **3,876 hours of sibling support**, helping brothers and sisters to learn 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, as well as having some much needed fun. Sibling support ensures that loneliness is reduced and children do not fall behind.

Once a family starts to receive support, Rainbow Trust stays with them for as long as it is needed. Sometimes this includes bereavement, after the death of their child. With your support, Family Support Workers have been able to give **569 hours of support to families as they grieve**. They have been able to help with funeral plans, offer vital emotional support to family members, cook comforting meals, tidy up the house and take care of families who are struggling to cope.

These are just two of the many ways your support has impacted, and can continue to impact, families with a seriously ill child. Rainbow Trust is able to be there to help families whenever they need it, for as long as it is needed.

Wonderful supporters like you enable Rainbow Trust Family Support Workers to help in any way they can so families with a life-threatened child don't have to cope alone. They assist parents facing worry, anxiety and isolation, they help brothers and sisters to make sense of their new reality, drive to and from medical appointments and provide bereavement support when the unthinkable happens.

To help, simply scan the QR code to visit our secure online donation page.

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donate



# HELPING FAMILIES TO FEEL LESS ALONE

**When Teddy was one year old he was diagnosed with a severe immunodeficiency. Rachel, his mum, knew she could have the essential support she received from Family Support Worker Emma**



“

**I was supported by Rainbow Trust for the first time when my middle son Billy, now six, was in hospital with a condition which made him highly vulnerable to life-threatening infections.**

So when Teddy was also diagnosed with it a few years later I knew that there was support available. I attended a coffee morning organised by Rainbow Trust's North East Care team and, shortly after, Family Support Worker Emma began supporting us weekly.

### ***Bone marrow transplant***

Teddy's condition affects his immune system. He suffers frequent infections, viruses, and stomach bugs. If he gets the flu or a cold, it lasts for ages, can really affect his chest and, very worryingly, could be life-threatening. He can't even drink tap water because of the potential bugs in the water.

To treat the condition, Teddy needed a bone marrow transplant and to make sure his body would cope with this, he also had to have drug infusions to give him an artificial immune system.

In August 2023, when Teddy was only 18 months old, he had his bone marrow transplant. It was an incredibly stressful and isolating time for me.

“ ***We had to go to a hospital in Newcastle, 300 miles away from my older sons, Billy, six and eight-year-old Freddie, and our home.*** ”

I slept on a camp bed next to Teddy the whole time he was in hospital, and family and friends were not able to visit us due to Teddy's compromised immune system. Although we had a lot of virtual love, it was really hard because we were completely isolated and I was on my own for most of it.

### ***Difficult months in hospital***

After three and a half months in hospital following his transplant, Teddy and I spent a few weeks

at a hospital accommodation halfway house and then we were able to come back home.

Our Family Support Worker Emma was an absolute legend. I don't know how I would have managed without her. She was there for us throughout Teddy's treatment. She saw me cry many a time.

We always really looked forward to when Emma came round, we called it 'Rainbow Day'. She gave me much-needed respite while Teddy and I were at hospital or the halfway house. I knew that I could get away and just do normal things like go to a shop or for a walk.



**Family Support Worker Emma with Teddy after his bone marrow transplant**



### Practical and emotional support

Emma had had previous experience on the bone marrow transplant ward working as a play therapist, so I felt safe leaving Teddy with her. She understood and she knew all the staff and I felt Teddy was safe. That was really important for me. Those breaks she allowed me to have were so meaningful.

Emma helped feed Teddy and change his nappies. She also always had fun activities for him to do too, such as colouring, playing with toys, drawing, playing instruments and singing. He really loved it when he got to do messy play with paint or washing up liquid. It made him laugh and smile, which lit up the room.

Not only did Emma look after Teddy and make him laugh, she supported me emotionally too. That was so needed and very important. She listened to how I was doing and helped me to get rid of whatever weight I was feeling.

### Not 300 miles away

Being back at home, with things a bit calmer, all of the stress from the past few months has really hit me. Although Teddy

is quite well in himself, he still suffers with viruses and has a nasal gastric tube for feeding, fluids and medicines. He still gets stomach upsets that mean we can go through a whole pack of nappies in a day; he doesn't yet have a functioning immune system, so he just can't get rid of these illnesses.

### Feeling positive

Once he has fully recovered, I'll be able to take him swimming and to nursery and, most importantly, make sure he is vaccinated so that he is protected from bugs and infections, rather than having to isolate him away from everything. I am positive that Teddy will be able to live a normal life, just like his older brother Billy. We just need to get out of this bit we are in now.



**Teddy and Billy suffer from CD40 ligand deficiency. This is a very rare and severe impairment of the immune system which affects around two in one million males worldwide. Without a bone marrow transplant CD40 ligand deficiency can be life-limiting.**

*Teddy's happy smiles: with brothers Billy and Freddie; with mum, Rachel, ringing the bell to mark the end of treatment and getting some fresh air in Newcastle*

Rainbow Trust Family Support Workers help is tailored to each family so they don't have to cope alone.

Having a child with a life-limiting condition puts enormous pressure on the whole family. Some families, like Teddy's, are separated so their ill child is not alone in hospital.

Rainbow Trust Family Support Workers like Emma offer expert support, adapting to the particular needs of each family so they can focus on what matters the most.

Rainbow Trust Family Support Workers help with practical and emotional support so the family can adjust and face their challenging reality.

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# ADJUSTING TO LIFE WITH A CHILD WITH SPECIAL NEEDS

Michelle provides Ethan's mum, dad and older sister with a variety of support, offering them stability, trust and the chance to feel like themselves again.

In July 2022, Marie's 36-week scan showed that the size of her body was that of a 40-week pregnancy. This raised concern and a second scan confirmed that Ethan had hydrocephalus, a neurological disorder caused by a build-up of fluid in the brain. Ten days later, Marie had a caesarean section.

When Ethan was born, Marie and his dad, Wing, were allowed a quick cuddle before Ethan was taken to intensive care. At just two days old, Ethan had a tube implanted in the brain to drain away excess fluid.

Three days later Ethan was moved to Southampton Children's Hospital where he spent eight weeks.

*"There was a lot of back and forth visiting Ethan in hospital. He was on the neurology ward, but then he was struggling with his breathing, so they took him to the high dependency unit on the children's ward."*

Ethan's older sister, five-year-old Kaitlyn, was desperate to meet her new baby brother, but the hospital rules at the time made this difficult as siblings were not allowed in. The family struggled to help Kaitlyn adjust to having a new baby brother with complex special needs, while also attending Ethan's many appointments.

*"Kaitlyn is very protective of him. She has started to understand more about Ethan, and how he may be slower to learn things than she would like. She has now realised he won't go to the same school as her and things like that. But she is still determined to help him walk."*



*Michelle took Ethan to the park and listened to all the sounds around them. Ethan is visually impaired so recognising different sounds is really important*

Marie had to give up work to be Ethan's full-time carer as his special needs and the many appointments at different times of the day made working impossible.

*"It was tough at first, getting used to understanding Ethan's condition, and noticing if and when something is wrong. Now we have learnt and it is easier. We have adjusted well."*

Hydrocephalus runs in Marie's family, and she sometimes struggles with guilt that Ethan has inherited the condition:

*"To start with, I did blame myself a lot. Even though I know it is not my fault. But it is just the guilt that he has the condition. We have learnt to take every day as it comes and not get too ahead of ourselves."*

Ethan's family was referred to Rainbow Trust by their health visitor and started receiving support from Family Support Worker Michelle in June 2023. Michelle provides emotional, practical and sibling support for the family, visiting them twice a month at their home and taking them out on trips.

**Michelle takes Kaitlyn out during the holidays to give her a chance to have some fun, be a regular child and help with her emotional wellbeing and self-esteem.**



*Ethan and Michelle had their first painting session. He loved the feel of the paint but especially enjoyed hearing the word “splat” every time they patted their fingers on the paper*



*Family Support Worker Michelle accompanied Ethan and his family to Sea Life in Brighton and collected pebbles on the beach afterwards*



At Christmas, Michelle took Kaitlyn to a Snowdog Trail in Southampton. Kaitlyn had two hours where the focus was only on her, she was able to run around and chat, and she didn't have to wait for Ethan's feeds or any of his care.

The time she spends with Michelle offers Kaitlyn stability and an outlet for her to sit and chat with someone she trusts.

Alongside sibling support for Kaitlyn, Michelle also provides practical support, such as dropping Wing off at Ethan's eye appointments, picking Kaitlyn up from school, sourcing tickets for the family to be able to enjoy special days out and helping to fill in forms for housing.

However, Marie finds the emotional support she receives from Michelle to be the most valuable. She said: *“Michelle is such a good listener. It is good to have someone like Michelle to talk to.”*

Michelle looks after Ethan, taking him out to provide new stimulation and assist with his development, but also so that Marie can have

respite, some time for herself or to meet her friends.

Recently, Michelle joined Marie and Ethan when they went to visit a special nursery that Ethan will start at in September, giving Marie a chance to talk to the other mums.

The family also regularly attends drop-in groups run by the Southampton Care team, of which Michelle is a part. These offer a chance for the whole family to have some fun and receive support, to meet other families also dealing with challenging situations, for Wing to enjoy playing table tennis with Family Support Manager Matt and for Marie to relax and focus on her wellbeing and mindfulness.

*“I can talk to Michelle about anything, and Kaitlyn loves having her over too. Michelle also spends time with Ethan, and this helps me get stuff done, or do things that I normally wouldn't be able to do. Michelle is such a big help.”*

## → Sponsor a Family Support Worker like Michelle today

Adjusting to life with a seriously ill child can be challenging and very stressful. Parents may have to give up work, adding financial difficulties to an already complex situation. Parents, brothers and sisters may feel overwhelmed, isolated and lonely, unable to cope.

Rainbow Trust Family Support Workers help with practical and emotional support so the family can make the most of their time together.

Your sponsorship today will help families with a child with a life-threatening illness that need help right now.

[rainbowtrust.org.uk/sponsor-us](https://rainbowtrust.org.uk/sponsor-us)

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# A WEEK IN THE LIFE OF A FAMILY SUPPORT WORKER

Georgia joined Rainbow Trust in February 2022 as a Family Support Worker in the Greater Manchester Care team

*“I jumped at the chance to be a Family Support Worker to make a difference to families by providing whatever support I can through the difficult times they are experiencing. Helping to make a difference is a job I love doing!”*

*“Each week can look vastly different as we work to fit the needs of every family we support, but this is what a typical week can look like for me.”*



Family Support Worker Georgia

## MONDAY

I usually plan my week well in advance so on Mondays I look at my diary to double check what visits I have arranged and to make a note of anything additional I need to plan, organise or pick up for these sessions.

I picked Matthew and his mum, Sam, up from home to take them to Royal Manchester Children's Hospital for his regular MRI scan. Matthew is five years old and has a rare childhood cancer.

As the MRI scan is a long one, Matthew has to be sedated, so I stay to provide support throughout the appointment for both Sam and Matthew. It is usually a long and stressful day for them. The department was running late and Matthew ended up being taken for his scan three hours late. Sam and I tried to keep up with him and entertain him, as he is full of energy! I had a good chat with Sam while Matthew was in his scan. Talking to me helps her manage her emotions.

Afterwards, I drove them home, with the added bonus of saving a hedgehog we found in the road, much to Matthew's delight!

## TUESDAY

On Tuesday I provided school transportation for Lucy, 10, whose family have moved into an adapted house suitable for Lucy's six-year-old little sister, Sophie, who has a rare genetic disorder. Their new home is around 30 minutes away from her school. With me taking Lucy to school Mum can stay home to look after Sophie and to give her medication on time.

I then had a phone call where I provided much needed emotional support to a mum who is overwhelmed with her son's serious illness and all the challenges she is facing. She needed to talk. We had a good chat and developed a plan of action for moving forward. We also agreed a date for me to visit her in person next week.

I did some admin and then had an afterschool visit to Marley, four, whose 15-year-old-sister has Acute Myeloid Leukaemia. We went to the park, but it started to rain so we went to soft play for a while instead. This was just as much fun, a lot warmer, and most importantly... dry!



## WEDNESDAY

On Wednesdays we have the Greater Manchester Care team weekly meeting, so I travelled to our office an hour before the team meeting started to get some admin done.

Our team meetings are long enough to ensure that we save space for team wellbeing, for supporting each other if we experience any bereavements, sharing successes and special thank yous that we receive from families. We also discuss anything that needs to be done or important information that needs to be shared, such as new referrals. Once the team meeting finishes, I finish my admin and update case notes for the families I am supporting. If needed, I grab some supplies from our craft cupboard to take with me to family visits.

## THURSDAY

The day started with taking Elle to and from an appointment at Burnley General Hospital. Her two-year-old daughter, Delilah-Sky, suffers from an undiagnosed genetic condition. Once I had dropped them off, I headed to see another family in Bolton, where I have been helping mum Kelly de-clutter and taking things she would like to be donated to charity shops. Her little boy, JJ, is four and is receiving treatment for Acute Lymphoblastic Leukaemia. He has spent a lot of time as an in-patient at hospital, so they hadn't been home enough to sort through things until recently.

I then did an after-school visit with Mia who is seven and has an unnamed condition, and her little brother, eight-year-old Joe. I take lots of crafts to these visits as they love to get creative, and it usually ends in playing with some toys they want to show me when they have finished getting crafty.

## FRIDAY

Friday started with transport for Lucy again, as I have been providing school transport twice weekly to alleviate stress for her mum. Lucy didn't like my Abba playlist this morning!

I then headed to Bolton for a visit with Mohammed, a three-year-old little boy with an extremely rare genetic condition, Trichohepatoenteric Syndrome. Mohammed needs to be observed 24/7 as he has no sense of danger, so during my visits I take him out and about for a few hours to give his mum a chance for a break, and to catch up on jobs that she struggles to do when Mohammed is at home. Mohammed loves to go to the supermarket and walk up and down the aisles, so this is something we do often, especially during the cold weather. Mohammed and I have lots of fun on these visits, and his smiles brighten my day!

Once I have dropped Mohammed off, I head home to add the past few days admin notes to our database and to respond to emails before finalising my diary plan for the following week. I also had a meeting with the Rainbow Trust fundraising officer to give her some information for a report she is completing, which will be sent to a foundation in Manchester which funds my role. They like to keep up to date with the support I am providing to families in my area!



*To celebrate the first day of year one, Amy, six, and Family Support Worker Georgia had an ice cream at the park. Amy's nine-year-old brother, Bruno, has a rare neurodegenerative condition*



*Family Support Worker Georgia takes Mohammed to the supermarket, who loves going up and down the aisles*



*Family Support Worker Georgia taking Matthew to hospital*



## A gift in your Will ensures families don't have to cope alone

Writing a Will makes life easier for the people you love and gives you the confidence that they will be looked after as you protect your wishes for the future.

After remembering your loved ones, a gift in your Will to Rainbow Trust will make sure that Family Support Workers are there for families in crisis, giving them their expert support.

No matter how big or small, a gift in your Will is a wonderful act of kindness that will enable families with a seriously ill child to have the support they desperately need.

### Free Will-writing service

You can now write your simple Will online. Help is available in case you have any questions throughout the process and legal experts check over each Will. Or you may prefer to book to write your Will over the phone or face-to-face by calling 0800 773 4014.

Simply go to [rainbowtrust.org.uk/legacy](https://rainbowtrust.org.uk/legacy) for more information or to request your free Gift in Wills guide.



We will respect your wishes and decisions at all times and treat all enquiries and pledges in strictest confidence.

# JOIN THE RAINBOW TRUST COMMUNITY

## Do something amazing today

You can support and get involved in many ways: from marathons to skydives, a fundraiser in your local community or a sponsored challenge in your organisation. However you want to fundraise, we would love to welcome you to the team.

### Rainbow Adventure Trails

Tuesday 28 May, Syon Park, Brentford

Wednesday 29 May, Hatchlands Park, East Horsley

Join one of our two fun adventure trails with seven colourful checkpoints.

### Great North Run

Sunday 8 September, Newcastle-upon-Tyne

Be part of the incredible atmosphere at this iconic half marathon.

### Vitality London 10K

Sunday 22 September, The Mall, London

Run this 10K that guides you past some of London's most famous landmarks.

### Rainbow Day

Any time, any location

Hold a Rainbow Day in your school or company. Departments, teams, groups or classes choose a different colour to wear for the day and each person donates.

[rainbowtrust.org.uk/rainbowday](https://rainbowtrust.org.uk/rainbowday)

## sign up today at

[rainbowtrust.org.uk/events](https://rainbowtrust.org.uk/events)

## CarFest 2024

Friday 23 - Sunday 25 August,  
Laverstoke Park Farm, Hampshire



Come along for a fun action-packed weekend at CarFest, the UK's largest family festival.

The line up includes Beverley Knight, Olly Murs, Sam Ryder and The Feeling. There will also be celebrity chef demonstrations, impressive car stunts, wellness experts, amazing family activities and celebrity appearances. And we will be running our **seaside crazy golf course** again in RetroFest. There is something for the whole family.

Rainbow Trust is one of CarFest's nominated charities for a fifth year. Buy your tickets now by visiting [rainbowtrust.org.uk/carfest](https://rainbowtrust.org.uk/carfest)

# Thank you!

to all our amazing supporters  
and fundraisers



**Roger** raised £2,055 by painting and auctioning off his three rainbow-coloured sheep in Skipton. Genius fundraising!



**Helen and Heidi** dressed up to run the Disney World's Half Marathon in memory of George Michael, a past Rainbow Trust patron, raising a fantastic £1,228.



**Solent University Football** held a charity tournament in support of Rainbow Trust. They had a brilliant turnout and raised £230.



**Debbie**, Doncaster, trekked the Great Wall of China for Rainbow Trust and another charity raising £780!



**Kobi** and his friends smashed their fundraising target, raising £1,200 by running the Manchester Half Marathon.



Families had an amazing day exploring at Thames Valley Adventure Playground, thanks to the incredible team at **Investigo**.



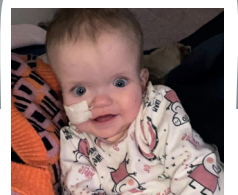
**Alresford Golf Club** chose Rainbow Trust as their 2023 Captain's Charity and raised £20,556.



**West One** shopping centre, London, raised £3,458 with a Christmas wrapping station.



**Paulton's Park** gifted tickets to the families we support to enjoy a special day out together. The families met Peppa Pig and went on lots of rides and everyone at the adventure park was soon covered in rainbows.



**Jason** braved a sky dive, raising £1,300. He said: *"It was amazing, I absolutely loved it!"* Jason's family are supported by Rainbow Trust due to their two-year-old-daughter Lola-Mae's rare syndrome.



**Hollie and Aaron** raised an incredible £1,148 by running the Oxford Half Marathon.



**Charles**, Rainbow Trust Trustee, completed the Richmond Half Marathon, raising £1,514 - enough to provide 50 hours of support to families with a seriously ill child.

# How **YOUR** support helps change lives

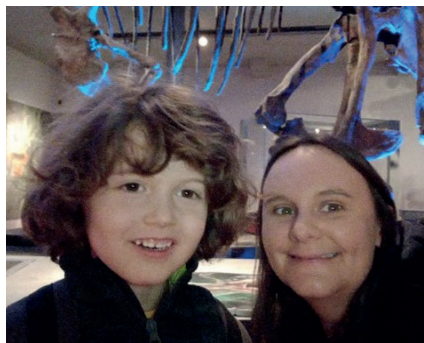


↑ Evie, three, who has a condition that causes tumours to grow along her nerves, and Family Support Worker Cindy had fun being doctors and playing dress-up.

→ Noah, four, and Family Support Worker Jen had fun exploring the Great North Museum. Noah, whose brother has complex health needs, has received sibling support for 18 months.



↑ Gabi, seven, invited Family Support Manager Natalie to attend her school nativity. Gabi's sister, Adriel, now 21 months old, just came out of hospital after six months of treatment.



↑ Eva, five, her sister Darcey, nine, and Family Support Worker Michelle visited Paulton's Park and got rainbows painted on their faces. Eva has stage three brittle bones disease.



↑ Logan-Ann, aged two, who has complex health needs, and Family Support Worker Laura had a trip to the park in Southampton. After two hours of fun, Logan-Ann slept in the car all the way home.



↑ After picking Louise, 14, who has sickle cell disease, and her brother Ethan, eight, up from school, Family Support Worker Jo played some drawing games with them. They couldn't stop laughing the whole time!



↑ Family Support Worker Shelly supports eight-months-old Louie, in-patient at the Great North Children's Hospital in Newcastle. He suffers from a severe immunodeficiency and just had a stem cell transplant.

## These are just some of the wonderful moments that your generosity and support are helping to create

Days out, playing, art and crafts are not just fun but allow the children to find ways to express their own feelings and to learn mechanisms to cope with their own or their brothers' and sisters' illness. This special time helps with their development, their communication and social skills, their wellbeing and self-esteem.

Family Support Workers can give the ill child and brothers and sisters some normality whilst providing parents with some respite.

*Thank you for all you do for seriously ill children and their families.*

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