FAMILIES FIRST

AUTUMN/
WINTER
2025

- Meet Ellis and Emily: find out why your support matters
- Fundraising heroes and ways you can get involved
- How you can leave a lasting legacy

RAINBOW TRUST
SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Dear Supporter

At Rainbow Trust we marked the beginning of our new financial year on 1 July. As our systems reset and we closed one chapter to begin another, we reflected on all that has been made possible thanks to the compassion and generosity of supporters like you.

With no central Government funding, we begin each new year facing the daunting challenge of starting from zero. It is your kindness and commitment that means we can continue to support seriously ill children and their families when they need it most.

I want to take this opportunity to thank each and every one of you for your incredible support in making this happen over the past year. You can see some of the wonderful ways supporters like you have fundraised on the opposite page.

On pages 4 and 6 you can read the difference your support has made to Ellis' family following his terrifying cancer diagnosis, and how Family Support Worker Abi is helping Emily's family navigate an uncertain future and countless hospital appointments.

Earlier in the year we welcomed a new report from the Commission on Palliative and End of Life Care. I was pleased to have the chance to give oral evidence to the Commission, reflecting what we consistently hear from families: that care for children with a life-threatening illness is too often unfair and inadequate.

We also published two briefings, showing the levels of isolation and loneliness amongst the families, parents, siblings and seriously ill children that we support. The briefings highlighted how serious childhood illness disrupts education, work, and relationships, leaving families feeling overwhelmed and alone.

With your help, we know we can continue to make a meaningful and lasting difference to seriously ill children and their families.

Thank you for your kindness.

Zillah Bingley, Chief Executive

Cover photo:
Ellis with Family Support Worker Jayne. Ellis was diagnosed with neuroblastoma when he was two. Read about the support Jayne provides on page 4.

Every day, families caring for a seriously ill child urgently need support as they juggle relentless hospital appointments, fear for their child's future and the emotional and practical toll this takes. At Rainbow Trust, we believe that no family should face this alone.

With your support, in the past year our Family Support Workers provided support to 1,532 seriously ill children and their families, **a 20% increase** from the year before, helping them when they need it most.

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/privacy-policy

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Registered Charity No. 1070532.

Fundraising Heroes

A very big **thank you** to all our amazing supporters

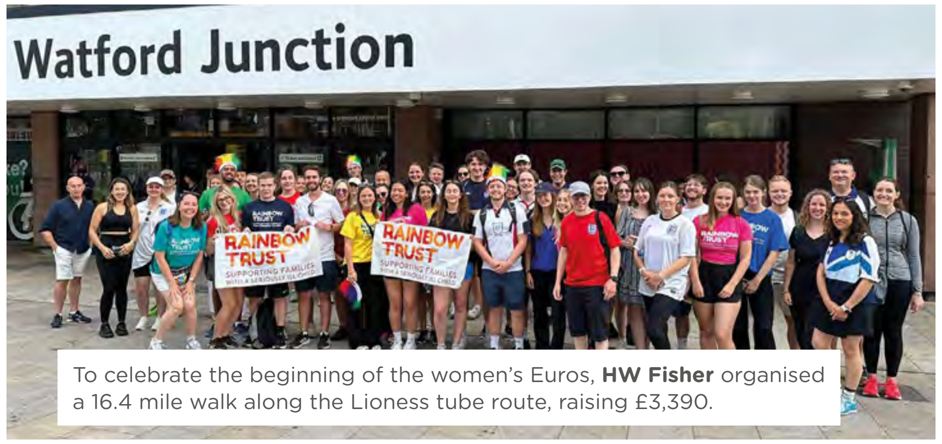
The Old Station Nursery team got together in Slough to host a bake sale and fun-filled afternoon of sports day games, raising £561.

47 fundraisers took part in Rainbow Trust's first **Adventure Triple Challenge**, raising £28,215. The challenge consisted of cycling, canoeing and trekking.

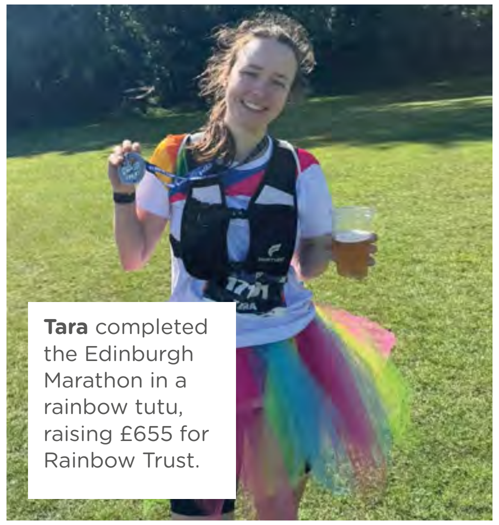
Fruit Loops, a student football team from **Newcastle University**, raised £2,172 after running 95km along the Tyne and Wear Metro line.

MCR Autorepair in Andover raised £965 after driving 1,621 miles in three cars they fixed up and saved from being scraped.

On the longest day of the year, Club Captain Karen and Vice-Captain Jo, from **Oakland Park Golf Club** in Buckinghamshire, took on the challenge of playing four rounds of golf, raising £2,186.



To celebrate the beginning of the women's Euros, **HW Fisher** organised a 16.4 mile walk along the Lioness tube route, raising £3,390.



Tara completed the Edinburgh Marathon in a rainbow tutu, raising £655 for Rainbow Trust.

Rokeby School in southwest London raised £4,935 through activities across the year, including taking on the Knight Frank Schools Triathlon.

Inspired? Get involved

From taking part in an event or planning your own fundraising, there are so many ways to get involved. Join team Rainbow Trust today: **rainbowtrust.org.uk/fundraise**

“When we had our babies, we never imagined we might not see them grow old”

Family Support Worker Jayne provides stability and crucial support for Chloe and her family, following her son Ellis’ terrifying cancer diagnosis.

> *“Your life can just change in one instant. This new life terrifies us and is so far from our everyday ‘normal’ life.”*

Pure heartbreak and desperation

“On Tuesday 18 July 2023 our world collapsed as we were told our baby Ellis had a tumour. I cannot describe the feeling of devastation, terror and shock. A feeling of pure heartbreak and desperation. I could hardly breathe.”

At the start of 2023, aged two, Ellis was admitted to hospital on several occasions with seizures. He was frequently unwell, went off his food, and wasn’t sleeping well, often waking in pain. He was diagnosed with stage four neuroblastoma, a rare type of cancer, and was given a 44% chance of recovery.

“‘Please just help our baby’ I said [to the consultants]. It was so difficult to see Ellis in pain.”

Before Ellis was diagnosed, Chloe had her own business but due to Ellis’ condition she had to stop. This had a big financial impact on the family and took an emotional toll on Chloe as she had to pause the business that had become a part of her life.

In March 2024, after being referred to Rainbow Trust, Family Support Worker Jayne from the London and South East Care team started supporting the family at home and in hospital.


Ellis during treatment in hospital

Endless hospital appointments

Ellis’ treatment was aggressive. To prepare for each session, Ellis had to stay in hospital overnight, to go for scans and to have a cannula put in his arm. These days were long and distressing for Ellis.

“He was terrified of everyone and everything, he became withdrawn. One minute he was playing with friends, the next he was being pinned down for cannulation and tubes down his throat.”

Jayne’s support was vital during these long days in hospital. She provided emotional support, listening to the family’s worries and concerns; respite, allowing Chloe and her husband Neil time to get some fresh air; and arts and crafts for Ellis, giving him a distraction from his treatment.

After many rounds of chemotherapy, stem cell harvest, a 6-hour surgery to remove his tumour and kidney, a nine week long hospital admission, and countless other procedures, Ellis is now in remission.

A safe space

“Your life can just change in one instant. This new life terrifies us and is so far from our everyday ‘normal’ life.”


Ellis giving big sister Lily a hug

Neuroblastoma is an aggressive and rare type of cancer that usually affects children under the age of five.

Each year around 100 children are diagnosed with neuroblastoma in the UK. With your donation, we can give these seriously ill children and their families vital practical and emotional support for as long as they need it.

For Chloe, Jayne’s support has been crucial as she struggled to come to terms and cope with Ellis’ diagnosis, the huge change that this brought, and his future. Jayne provides a safe space for Chloe, giving her the chance to offload. These moments encourage Chloe to spend time processing her emotions, something which she struggles to make time for.

Time to be a mum and a family

With the countless hospital appointments and treatments, Chloe has found trying to remain present for her six-year-old daughter Lily very hard.

> *“Overnight I have become a full-time medical carer. But I’m still a mummy to a little girl who needs me, and I’m trying to keep family life as normal as we can.”*

Jayne helps Chloe and Lily to have more one-to-one time by supporting with after school activities. When Ellis has been unwell, Jayne has picked him up from school and taken him home. Having Jayne’s support means that Chloe can spend meaningful one-to-one time with Lily, without worrying about Ellis. This support also ensures Lily can maintain her routines and not miss out on childhood moments with her mum.


Me with Ellis and Lily

Jayne has also helped around the house, taking the strain off Choe and Neil and offering them respite and time to make memories with Ellis and Lily.

“Home time has been few and far between so every day we have had is precious to us.”

Jayne provides reassurance and a sense of stability for the family at what continues to be an uncertain time.

→ Scan to donate or go to **rainbowtrust.org.uk/donate-magazine**

When Emily had her first seizure, our lives changed forever.

Remila, Emily's mum, shares the difference Family Support Worker Abi's support made to her family as they struggled mentally, physically and financially with Emily's diagnosis.

“Emily had her first seizure when she was six months old.

That moment changed our lives forever.

When Emily was two, she was referred to Great Ormond Street Hospital (GOSH). That is when we were told she had a very rare neurological condition. It is called de-novo-heterozygote variant gene SCN8A and it causes really bad seizures and global development delay.

There is no cure.

Hearing that broke us. We were very scared. We didn't know what to expect for our daughter, for her future.

Now Emily is eight. She still has seizures every week, she is non-verbal, and she uses a wheelchair and a walking frame. My husband Bujar and I have to be with her all the time, day and night. We give her medicine, monitor her, and if her seizures go on too long, we have to call an ambulance and rush to hospital.

It has been a very hard few years. We have had to learn how to live in this scary new world of hospitals, medication and uncertainty.

We even had to leave our home suddenly, with nowhere to go.

At one point, we thought we were going to be homeless. We ended up in emergency accommodation in a tiny two-bedroom flat that wasn't right at all for Emily or our newborn baby, Bjorn.

In September 2023, a social worker referred us to Rainbow Trust. Not long after, we met Family Support Worker Abi. She is such a lovely person and has been so supportive.

Abi helps us get to appointments at GOSH and Addenbrooke's Hospital in Cambridge. I have only just passed my driving test, and I am scared to drive alone with Emily because of her seizures.

It is just too much pressure and I feel very anxious. Abi picks us up and drives us, which takes away that stress of driving with Emily alone, traffic jams and finding parking. We would have really struggled without this support.

Before Abi, my husband Bujar had to take time off work to drive us to hospital, and he would lose a day's wage. We were really struggling financially because it is only him working, providing for the family. Abi's support has helped ease that burden and has given Bujar peace of mind.

Abi also stays with us in hospital. She plays with Emily so I have the time and energy to focus on the appointment and to talk to the doctors. She looks after Emily if I need a comfort break or to grab a coffee. This might sound small, but on those days it means everything. It means I can take better care of myself and of Emily. Abi is very kind and caring with Emily and with me.

One of my favourite photos of Emily

Family Support Worker Abi supporting Emily in hospital

A lovely day out for the family

> *“Abi and Rainbow Trust have changed our lives”*

Abi has helped with so many things, like applying for sensory toys and a special car seat for Emily. I didn't have the time or energy to do those things on my own.

Emily's condition is a lot to manage and some days it feels like I just can't cope. When it gets too much, having Abi to talk to makes a big difference.

It has helped me to feel less alone. Abi also spends time playing with both Emily and Bjorn, who is now three. They have such a special bond with her. She makes them laugh and smile and they have fun. And, for a little while, I can breathe, I can catch up on things or just have time to myself.

We don't know what the future holds for Emily. That is scary. But I do know that without Abi and Rainbow Trust we would still be like we were three years ago, struggling.

Abi and Rainbow Trust have changed our lives.”

→ Will you sponsor a Family Support Worker like Abi today?

Many more parents like Remila and Bujar are struggling with the impact of their child's life-threatening illness. They face emotional distress, relentless practical challenges and often financial hardship, with little relief. These families need support today.

By sponsoring a Family Support Worker like Abi, you will be helping Rainbow Trust give vital support to these families at a time when they are struggling to cope and need it most.

Sponsor a Family Support Worker today

Some names have been changed.

A day in the life of a Family Support Worker

Sarah joined Rainbow Trust in January 2024 as a Family Support Worker in Rainbow Trust's Lancaster-based Care team.

Family Support Worker Sarah

In the morning, I picked up five-year-old Amelia and her granny, Lizzy, from their home. Amelia was diagnosed with a neurological disorder last September. She needed brain surgery and spent a month in Liverpool's Alder Hey hospital - it was a frightening and uncertain time for her family.

I visited her after surgery and sat with her to give her dad, Paul, and Lizzy some respite. The difference this respite made was huge, especially for Lizzy who was exhausted. Just having the chance to sleep and shower gave her a refresh and time to begin to process everything.

Today I drove them to a hospital appointment in Lancaster. Appointments are already draining and stressful so not having to worry about how they are going to get there, parking, and traffic was a huge weight off Lizzy's shoulders.

These appointments are also usually unsettling for Amelia due to how busy and clinical hospitals are so I brought along some sensory toys to keep her occupied and so Lizzy could focus on what the doctors were saying.

To give the family time to decompress afterwards, I took them to a soft play where Amelia had the chance to have some fun. While she played, Lizzy and I took some time out to talk about the appointment.

For families, just having someone to talk to about their thoughts and be with them at appointments is so important. They are trying to manage their own emotions and the needs of their child while everything is coming at them: updates on test results, changes to treatment plans, new medical terminology, and future procedures to prepare for.

After dropping Amelia and Lizzy at home, I picked up two-year-old Rio and his mum Jahmilla. Rio, who has chronic lung disease, was born 24 weeks early and spent the first eight months of his life in Alston Community Hospital. He is on oxygen and has a nasogastric tube fitted for feeding.

Jahmilla cannot drive and, due to Rio's needs and oxygen tank, she struggles to get out. They often have to take expensive taxis. I support by taking them out to do food shopping or on trips to sensory rooms, which Rio absolutely loves.

> *"Every day is so different in this job due to the one-to-one nature of the support we provide for families. It is very specific support that is tailored to them and their needs. It is very unique."*

He is regularly in hospital, seeing medical professionals, so these trips give him a chance to be in a non-clinical and less scary environment. Having the non-medical side of support that Rainbow Trust provides is important, it gives him some fun and helps his development.

Rio enjoying the sensory room

Ruby and her sisters doing arts and crafts

Today's trip out was to the multi-sensory Creative Space Centre in Preston where we were holding an event for families we support. Rio was so excited - he especially loved the bubble tube. The event gave parents of seriously ill children, like Jahmilla, time to talk to others in similar situations. It also provided them with respite and a chance to relax as they know their children are in a safe, supportive environment.

On the way home we stopped at a shop so that Jahmilla could pick up some essential food items. While she was shopping, I entertained Rio, giving her time to focus on what she was doing without worrying about Rio and the complexities of moving his oxygen tank.

I ended my day with a visit to Ruby's family after receiving a text from her mum, Nikki, who thought it would be beneficial for Ruby and her sisters to have some support. Ruby is four and has a rare condition that affects bone marrow and the pancreas.

The family is getting ready to go on their first holiday since Ruby's diagnosis. Nikki is very worried about going as, due to her illness, Ruby falls ill easily and can end up in hospital.

I brought along some holiday themed arts and crafts for Ruby and her sisters and provided some emotional support for Nikki. We discussed how she was feeling and a plan of action for what to do if Ruby fell ill.

After that I headed home for the evening to catch up on my admin from the day.

Sponsor a Family Support Worker like Sarah today

The unique support Rainbow Trust provides means that Family Support Workers like Sarah can be a lifeline for a family, tailoring their support to what the family needs at that moment, offering stability and continuity when everything else feels uncertain.

With your help, more families can receive this vital support. Sponsor a Family Support Worker today and help ensure no family has to face their child's serious illness alone.

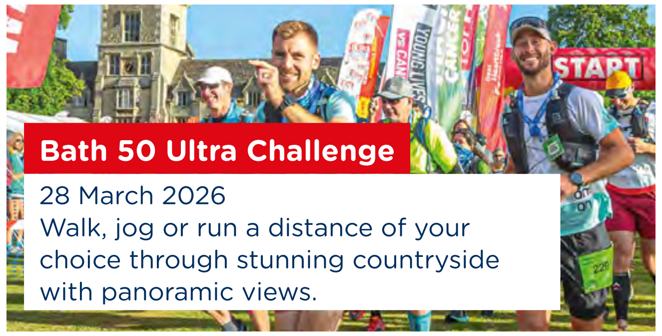
Sponsor a Family Support Worker today

Events calendar

Show your support and join us, or create your own event or challenge in your community or at work.

London Carol Concert

4 December 2025
Celebrate the magic of Christmas at our candlelit Carol Concert.



Bath 50 Ultra Challenge

28 March 2026
Walk, jog or run a distance of your choice through stunning countryside with panoramic views.

London Landmarks Half Marathon

12 April 2026
Not your typical half marathon, it is a sightseeing adventure on the run!

Brighton Marathon

12 April 2026
Take on one of the UK's biggest and best marathons in the beautiful coastal city of Brighton.

Other challenge events

Dates throughout the year in a number of world-famous marathons and half marathon events.

Join team Rainbow Trust!
Find out more and sign up:
rainbowtrust.org.uk/events

RAINBOW TRUST
SUPPORTING FAMILIES WITH A SERIOUSLY ILL CHILD

JOIN Rainbow Trust's Weekly LOTTERY

Don't miss out on winning up to

£25,000

every week!

Scan the QR code or go to rainbowtrust.org.uk/lottery

18+

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Celebrate with us!

If you have a special occasion coming up, a wedding, anniversary, baby shower or birthday, make your celebration even more special by fundraising to support seriously ill children and their families.

Scan the QR code or go to rainbowtrust.org.uk/special-occasion

YOUR support matters

These rare moments are only possible because of your generosity and kindness.

After supporting Lara, seven, for 13 months while she awaited a heart transplant, Family Support Manager Jen had her last in-person visit with the family. Jen regularly provided respite by doing play sessions on the ward with Lara and taking her brother Jude, aged two, out on trips.

While her mum attended a session about talking to your child about their diagnosis, Cora, two, played with Family Support Worker Laura. Cora has recently been given the all clear after receiving treatment for neuroblastoma.

Family Support Worker Gina took two-year-old twins Ellis, who has a rare condition, and Ava out for a sunny walk and picnic in Manchester, allowing mum to attend an important meeting.

During an online support session with Family Support Worker Anna, Nithin, aged nine, wanted to create a pop-up card. Nithin's sister is three and has a complex heart defect.

Evie, four, has a genetic condition that causes tumours to grow on her nerves. She enjoyed a walk with Family Support Worker Cindy, searching for plants to make a gift for her parents.

Oscar, aged three, attended a Family Fun Day organised by the Southampton Care team at Paulton's Park. His nine-year-old sister Alice was diagnosed with neuroblastoma.

For seriously ill children and their brothers and sisters, this special time, whether it be days out, doing arts and crafts or playing games, helps with their development, communication and social skills, wellbeing and self-esteem.

Thank you

Scan to donate

“My gift is a promise for the future”

Stacey and her partner Adam are leaving a gift to Rainbow Trust in their Wills.

Adam and Stacey

“I have been a Rainbow Trust supporter for four years now, I am 41 and I live with my five-year-old son Freddie and my partner Adam. I work in market research and I love running.

When Freddie was born, he spent a week in hospital with breathing difficulties. It was the start of the Covid pandemic and I was in Manchester on my own, away from my family and friends.

Adam could only be at the hospital during the day so it was just me with Freddie at night. It was terrifying.

Stacey enjoying a nice run in the sunshine

As a new parent, this was a really anxious time. Finding out that your newborn is unwell and you can’t take it away from them is so scary and overwhelming.

We are lucky that Freddie made a full recovery. But it made me realise how tough it is for families with seriously ill children, because some of them may never get that moment of “we are past that now”.

That is why Adam and I decided to leave a gift in our Wills to Rainbow Trust.

What I find particularly special is Rainbow Trust’s holistic approach. Family Support Workers care for the sick child and also help the family, driving to appointments, giving them some respite or looking after brothers and sisters.

I had been thinking for a year that I needed to write a Will and when I read about the free Will offer in Rainbow Trust’s Families First magazine, it encouraged me to write one.

Writing a Will may appear confusing and overwhelming but the process was very simple as Rainbow Trust has partnered with Octopus Legacy, a user-friendly and easy to understand Will writing service. It is not a scary form or a huge document. It took me just 20 minutes.

If you need to write a Will, this is a win-win: a free service and it is going to support seriously ill children should you decide to include a gift to Rainbow Trust.

It is nice knowing that something good is going to happen and I am going to leave a legacy.”

Stacey

Free Will offer

Writing a Will gives you the confidence that your loved ones 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 ensure that seriously ill children and their families continue to receive the support they need.

With our partner, Octopus Legacy, you can write a simple Will online, over the phone or in person for FREE.

octopuslegacy

Help is available if you have any questions and legal experts check over each Will. If you would prefer to write your Will over the phone or face-to-face, then please call 020 4525 3605.

For more information or to request your free Gift in Wills guide, simply scan the QR code or go to **rainbowtrust.org.uk/legacy**