

FAMILIES FIRST

AUTUMN/WINTER 2026



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- Celebrating 40 years of care

**RAINBOW
TRUST**
CHILDREN'S
CHARITY



Dear Supporter

In this, our 40th Anniversary year, I want to thank you for your continued support for the work we do to help families facing the worst possible news that their child has a life threatening illness.

Just today I was reflecting on the origins of Rainbow Trust, the determination of 12 year old Rachel that she wanted to die at home and how things come full circle. Just recently a 15 year old young man made the decision that he did not want to undergo any further treatment and has sadly died. For Rachel, our founder, Bernadette Cleary, was there to support her and her family and for the young man, our Family Support Worker was there for him and remains there for his family for as long as they need. For families so desperately in need our Family Support Workers are a lifeline.

You can read on pages 6 and 7 how your support helped Lara's family when she needed a heart transplant. And on pages 8 and 9, Emily, mum to Alex, discusses how Rainbow Trust's support helped her to cope with guilt and exhaustion.

In one of her first newsletters Bernadette wrote *"We currently have our first domiciliary worker, working on a case in the locality and this is going very well indeed."*

Forty years on, we have 63 Family Support Workers who last year supported 1,650 seriously ill children and their families.

This growth would not have been possible without your support and generosity - you are the reason we are still going strong 40 years on.

Our 40th year also marks the start of our plans for transformational growth. We want to be there for twice as many families and ensure we are here for the next 40 years and beyond.

To do this we need your help and generosity like that highlighted on pages 4 and 5.

As costs continue to increase and even more families need our support, our aspiration that no family has to face childhood illness alone can only be fulfilled with your continued and immense generosity.

Thank you on behalf of all the families we currently support and those yet to come.



Zillah Bingley, Chief Executive



On the cover: Nieve is eight. Her brother Toby, 11, has complex health needs and the family is supported by Family Support Worker Gina from the Greater Manchester Care team.

Stay in touch

Call us: 01372 363438

Email us: supportercare@rainbowtrust.org.uk

Visit us: rainbowtrust.org.uk

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HEAR FROM THE EXPERTS

Kath Evans has been a children's nurse for more than 30 years. Now Director of Children's Nursing at Barts Health, she is passionate about family-centred care, listening to children and parents, and making sure services work around what matters most to them.

Kath is proud to support Rainbow Trust as a key member of its Care Committee and deeply values the difference the charity makes to families facing serious childhood illness.



“ As a children's nurse, you see that serious illness is never experienced by the child alone. It is experienced by parents, siblings and the wider family too.

It is not just a medical experience. Medical care is essential, but on its own it is not enough. Good outcomes for seriously ill children come from a wider network of support.

Families caring for children with life-limiting conditions are often trying to cope with fear, uncertainty, exhaustion, financial pressure, disruption to family life, the needs of siblings, practical issues around hospital admissions, and the emotional strain of trying to hold everything together.

Social palliative care, like that provided by Rainbow Trust, recognises that these families need help with living, caring, and coping.

It recognises that **children do best when families are supported too**, and that families need a kind of support which can be difficult for statutory services to provide consistently, particularly when health and care systems are under such pressure.

Rainbow Trust fills an important gap between services by providing something that many families would otherwise go without. It compliments the clinical services from the NHS by supporting families to cope better, which can reduce crisis and prevent some situations from escalating unnecessarily.

Rainbow Trust's support brings compassion, continuity and practical help into situations that are often frightening and exhausting. The support is humane, consistent and family-centred. It helps families feel less alone. At times of enormous uncertainty, that can make a profound difference.

For seriously ill children, it can mean greater stability, less distress and a stronger sense that they and their family are being supported, not just treated.

For parents, it can reduce isolation and help them feel more able to cope with the relentless demands of caring for a seriously ill child.

For siblings, it can mean they are seen and their needs are supported as well.

That kind of support is not an optional extra. For many families, it is a vital part of coping.”

“ *Support like this is not an optional extra; for many families it is a vital part of coping.* ”

Many seriously ill children and their families are struggling to cope alone. Through tailored support, Family Support Workers are helping to ease the stress, worry and challenges these families are facing.

To help us continue providing this vital support, simply scan to donate or go to rainbowtrust.org.uk/donate-magazine

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To all our amazing supporters and fundraisers,
Thank you for 40 years of support.



Amelia recently completed an incredible 100 miles in 100 days challenge alongside her mum, dad and brother Benji in Colchester. She finished the day before her 10th birthday and raised £642.

Amelia said: "We think the work you do helping poorly children and their families is really special and very important."



We are very grateful to **Pauline** (far right) and the **Harold Wood Friends** group in Essex, who have been volunteering for Rainbow Trust for over 35 years and have raised over £1.1 million in that time. Pictured the friends group at their annual beetle drive and garden party.

"This year was our 30th Garden Party and some of those attending have been coming every single year. We made £405 during a happy afternoon", said Pauline.



"As a NICU nurse I know how difficult and overwhelming caring for a seriously ill child can be as well as how much support is needed for the family as a whole. I appreciate that Rainbow Trust is able to help families in need and provide support during critical times. I think it's very much important and is needed." **Starlynn**, Rainbow Trust supporter.



Lovelies.help is a volunteer-led Facebook auction page dedicated to raising funds for charity in memory of George Michael.

They said: "We felt it was a fitting tribute to his legacy to support Rainbow Trust. George spoke movingly about his own reasons for supporting the charity: 'to lose any loved one is tragic, but to face the possibility of losing a child is unimaginable'.

"To know that we are helping Rainbow Trust to be there for more families facing such immeasurable adversities is a great privilege and honour."



- 1 **Deb** (right) is taking on the Sumatra Jungle Challenge. She has started her fundraising at a recent school fete in Leicestershire where she was joined by her granddaughter, Gracie.
- 2 A team of 13 supporters took on the **Arctic Adventure Challenge**. Together they raised a total of £82,000.
- 3 **Cubitt & West** has supported Rainbow Trust for nearly 20 years. They hosted their annual static cycling event at their offices across Surrey, Hampshire, East and West Sussex, raising over £2,800.
- 4 **Andy and Jo**, owners of Palmer-Lewis, recently hosted their second fundraising day. Showcasing a spectacular lineup of sports cars, the event in West Sussex brought their fundraising total to £1,300.
- 5 **Harriet and Elliot** both took on and completed the London Marathon, smashing their fundraising targets and raising over £6,000 each.
- 6 **Zak**, in a restored Morris Minor and who has recently completed treatment for leukaemia, is supported by Family Support Worker Janet. Ken, a family friend, is driving the car from West Sussex to France and back. So far he has raised £2,125, which will be split between Rainbow Trust and another charity.



At five years old Lara needed a heart transplant

Lara's family was seeking a safer life for their daughter after leaving war-torn Syria.

Since arriving in the UK they have had to face another life-threatening situation: they found out her heart was working at only 10%.

Lara crafting in hospital

Lara's dad, Mohamed, shared their story.

“ We had to leave Syria because of the war; it was unsafe. We moved to Lebanon where Lara was born. She was a beautiful, cheerful and vibrant child.

But Lebanon was also unsafe for us and offered no future. We came to the UK in 2021 for a better life for all of us, especially for Lara.

Lara went to nursery school and was a very happy child, especially when her brother Jude was born. She was so excited to play with him as they grew up.

At the beginning of 2023 Lara contracted a virus.

Lara stopped eating, she lost weight and she completely changed. She didn't want to play, just wanted to sleep, made strange noises, and preferred fluids to solid food.

We took her to the doctor several times and they told us everything was fine. They said it was just a virus, but we weren't comfortable with it. We started filming Lara every day.

In June 2023, we were preparing for Lara's fifth birthday. Lara got sick again. We went to the doctor and showed them everything we had filmed.

The doctor was silent and said she would have to go to the hospital.

At the hospital they did a chest x-ray, and something wasn't right. And then we got a shock that changed our lives completely.

The doctor told us that Lara had a problem on the left side of her heart. I started crying. How did that happen?

They told us Lara would need a heart transplant; her heart was only functioning at 10%.

Lara's heart was completely exhausted and she couldn't go to school. She stayed in intensive care for 15 days. They told us she wouldn't be coming home.

Although we live in Scotland we had to go to the Freeman Hospital in Newcastle where they assessed Lara's condition for a heart transplant. She was so ill that we feared she might have a heart attack during the journey.

They put her on a Berlin Heart. Finding a suitable heart was going to be very difficult. We were devastated and tired.

The Berlin heart also has risks so we feared bleeding or strokes that could end her life.

A Berlin Heart is an external mechanical heart pump that helps a child's when their own heart is too weak.



Family Support Worker Jen with Lara in hospital

Jude enjoying the sunshine

Then we met Jen, our Family Support Worker from Rainbow Trust.

She has helped us a lot with everything. She stayed with us throughout Lara's journey at the Freeman Hospital for sixteen months.

She was wonderful to all of us.

Every week, she offered support, stayed with Lara in hospital and played with her. They did lots of arts, crafts and played games. Lara looked forward to Jen's visits and spending time with her. She was so happy with her. It also gave me some time to take a break or to go shopping for essentials.

Jude has spent half of his life living in hospital accommodation and yet he is a healthy child. Jen has also supported him, spending time with him and taking him out when we were busy and trying

to juggle everything. He loves running around the park, playing and having time outside.

In April 2026, Lara received the gift of life, her new heart. We were so happy after all that waiting and fear. Hope returned to our lives.

Lara's recovery was difficult and tiring; she had many complications, but everyone at the hospital was wonderful. Jen, too. After Lara's heart transplant, Jen continued to support all of us and Lara through her recovery.

When we came back home, she provided online support every week. Initially Lara had to isolate, and we were afraid of infection and heart rejection.

Jen helped to keep her busy during this time. They did arts and crafts, drawing, colouring and chatted.

While our stay in Newcastle has ended, we were both happy and sad to be leaving. The people at the Freeman Hospital were like family to us and supported us in every way. Thank you to everyone, and especially to the wonderful Jen, who stayed with us even after we returned home.

Thank you so much Jen and thank you so much Rainbow Trust. **You are all amazing.** ”

Scan to donate to support more families, like Lara's, or go to rainbowtrust.org.uk/donate-magazine

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While coping with guilt and exhaustion, Rainbow Trust's support makes all the difference

Emily, mum to Alex and Roman, tells us about the invaluable support she has received over the last eight years and how it has helped her to cope as a single mother.



Alex in hospital

“ When I was pregnant with Alex, cysts were found in his cheek and face during a scan. He was diagnosed with severe cystic hygroma, a collection of fluid-filled sacs that result from a baby's lymphatic system not properly developing during pregnancy.

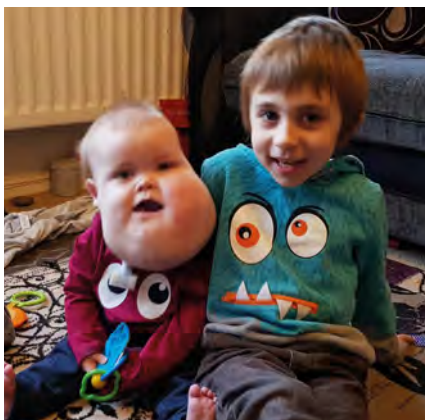
When he was born his airway was so squashed by the cysts that they put a tracheostomy in to help him to breathe better.

Being told my three-day-old child needed a tracheostomy was terrifying.

He had his first operation at three months old to remove some of the cysts and free up his airway. He was so tiny and I just cried. I remember them wheeling him off in this little cot. It was horrible.

I became a single mum two months before Alex was born. I didn't know how long Alex was going to be in hospital and it became tough looking after my other son, Roman, who was four at the time.

My parents looked after Roman for six months. I was with Alex during the week, came home on



Alex and Roman

Friday, looked after Roman for the weekend and went back to hospital to see Alex on Monday.

It was very hard. I felt guilty because I was not with Roman and then guilty because I was not with Alex.

It was exhausting. I was an emotional mess.

A community nurse told us about Rainbow Trust. Their South West Care team has now been supporting us for eight years.

When he was young, Alex needed to be looked after 24/7. He could pull the tracheostomy out and just stop breathing when he was

sleeping. It is really worrying seeing your child turn blue.

Our Family Support Worker would sit and play with Alex or she would watch him while he slept. I would be able to do housework that I had not done for ages, that I had no time for, knowing that Alex was being watched and was safe.

She spent time with Roman as well. It was nice for him to have someone who focused on him because, as much as I tried, I would still have to regularly check on Alex. Roman liked having that attention for himself.

When Roman was a little older, he struggled with feelings of anger and frustration. He didn't know how to deal with the emotions and needed additional support. Our Family Support Worker helped him to deal and cope with these emotions.

This was invaluable. He was always happy when she came.

Sometimes we had to rush Alex to hospital and she would pick Roman up from school and stay with him until we got home. Roman was so young, he couldn't



Alex and Roman on a day out with Family Support Worker Michelle

**“ I can’t leave Alex and I can’t leave Roman.
With Michelle, they are both looked after. ”**

walk home on his own and be left unsupervised. It was so helpful just to be able to ring her and ask.

We are now supported by Family Support Worker Michelle.

Michelle comes into the hospital and sits with Alex so I can grab something to eat. Going to hospital is stressful and to know someone is there and can help him when he needs it is reassuring.

She also visits after school, plays and does crafts with Alex, giving me a bit of quiet to sort things out around the house. She chats to me about what is happening. **It is nice to speak to someone who knows where you are coming from when you are talking about doctors, hospital appointments and medical issues.**

During the school holidays Michelle picks us up and takes us out for the day.

Recently we were able to go to Legoland in Windsor with her. It is such a long journey, very difficult with Alex and all his medical equipment. With Michelle we didn’t have to worry about the travel.

Because there is only me, trips out are always difficult. I can’t leave Alex and I can’t leave Roman. With Michelle, they are both looked after. We get to branch out a bit more and do stuff that wouldn’t be possible if Michelle wasn’t there.

Just knowing someone is there to help me, help Alex, and help Roman when we need it makes all the difference. **”**

The support of a Family Support Worker like Michelle can help a family cope as they juggle caring for their seriously ill child, hospital appointments, and the needs of their other children. By sponsoring a Family Support Worker today, you will be helping more families to receive this vital support.



Sponsor a Family Support Worker like Michelle today

**rainbowtrust.org.uk/
sponsor-us**



Events calendar



Rainbow Trust Carol Concerts

3 (London) and 14 (Liverpool) December 2026

Celebrate the magic of Christmas with us at one of our candlelit Carol Concerts at St Paul's Church, Knightsbridge, or Liverpool Cathedral.



Adriatic to Alps Cycle Challenge

5 - 10 June 2027

An unforgettable multi-country cycling adventure. Ride from the Adriatic coastline through Croatia and into the Julian Alps of Slovenia.



Prague Half Marathon 2027

3 April 2027

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Tour du Mont Blanc 3 countries 1 iconic route

July and September 2027

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From the frontline: the important role of a Family Support Coordinator

Crystal joined Rainbow Trust in January 2026 as a Family Support Coordinator in the Greater Manchester Care team.

“ My role works alongside Family Support Workers to connect families caring for a seriously ill child with the right opportunities, services and organisations at the right time. **Every conversation starts with one question: What would help this family most?**

One of the greatest privileges of my role has been supporting a bereaved family to plan a short break away together after two of their babies sadly died from the same condition.

We talked about what might bring them comfort and give their two other children something positive to look forward to. I was able to arrange a funded caravan holiday with tickets to a theme park.

It wasn't about taking away their grief but about creating an opportunity for them to spend time together, reconnect as a family and make new memories alongside those they will always treasure.

Not all of my support is about helping to create special experiences. Often, it is the practical things that make the biggest difference, that make an immediate and real impact on a family's daily life.

Recently a mum was moving from temporary to permanent accommodation. Moving has been quite a challenge. She had very limited furniture, no washing machine, no oven and no fridge.

Her child is three and has a condition where his body forgets to breathe. He needs constant oxygen, monitoring, suctioning. His medication needed to be refrigerated as soon as they arrived at their new house.

Alongside another organisation, we were able to arrange for a fridge to be delivered for free and on time, giving the mum one less worry at what was already an incredibly stressful time. For the other basic furniture, I have been helping her apply for crisis payments and welfare funds.

The families we support already have so much to think about and so much paperwork. Sometimes it is too much for them and sometimes they just don't know what is available to them.

Another family was struggling with rising household bills while caring for their nine-year-old son who has a genetic neurological condition. Financial pressures and reduced earnings meant every month felt like a balancing act. The mum told me that she was constantly worrying about how to pay for everyday essentials.

English is also her second language so she was really struggling. I sat down with her, helped her to set up payment plans, talked her through budgeting, sign-posted her to specialist advice and appropriate support and grants. Since then, she is beginning to regain control of her finances.



My role is about empowering families, alleviating those daily worries, practically making their lives easier and providing moments of joy. ”

Family Support Coordinators work alongside Family Support Workers, helping to ensure the families we support have access to what they need.

This includes sourcing practical goods and services, applying for grants and benefits and working with other charities or community organisations to obtain goods, equipment, or funds for families that Rainbow Trust does not provide directly.

With your kind help, more families can receive this crucial support.

Scan to donate



From the frontline: the impact of your support



Families supported by the South West Care team attended Dream Night at Cotswold Wildlife Park, a free evening for seriously ill children. Amongst the attendees was **Max**, 10, who has a rare neurological condition.



Connor, 12, has an aggressive type of bone cancer and is recovering from a leg amputation. Connor proudly showed Family Support Worker Cindy what he has been growing in the garden in Portsmouth.



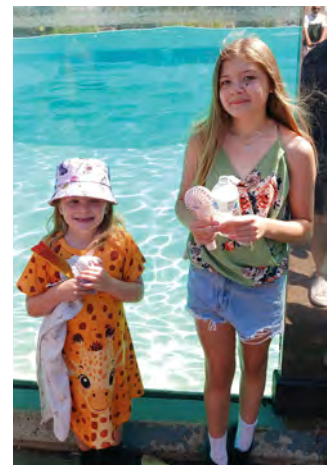
Aubrey (left) is seven and has leukaemia. She and her sister **Demi**, five, attended a day out at White Elm Petting Zoo with the Essex Care team. Their mum said: *"The trip gave my girls the chance to do something normal in such a difficult situation. They could just be kids and have no worries of hospitals. It made them so happy."*



18-month-old twins **Mya Mae** and **Myla Mae**, from Southampton, have chronic lung disease. Family Support Worker Carol spends time with them, giving their mum a chance to sleep and spend time with her three other children.



Family Support Worker Michelle helped apply for a dream trip to Disneyland for 12-year-old **Isla**, who has a rare brain tumour. Michelle helped the trip to start stress free by taking them to the airport.



Family Support Worker Hannah took **Alivia**, 13, and **Holly**, six, to Chester Zoo, providing their mum with some respite. Holly is now in remission following two years of treatment for leukaemia.

Supporters like you have helped seriously ill children and their families, like those on this page, receive vital support for 40 years. These wonderful moments and support are all because of you.

Thank you.

You can help us to be there for 40 more by scanning to donate.

