FAMILIES FIRST

SPRING/SUMMER 2025

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RAINBOW TRUST
SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Dear Supporter

It has been a busy few months since the last edition of *Families First* with many of you getting involved through fundraising challenges, events and other initiatives which is fantastic to see.

At Christmas, we took part in the Big Give, a week-long match-funded fundraising challenge, for the first time. A huge thank you to everyone who donated and to the generous match-funder, helping us to provide essential support to families who are struggling to cope.

With many more events just around the corner, I want to wish the very best of luck to everyone representing Rainbow Trust.

If you are inspired and want to get involved, we have some exciting new fundraising challenges coming up: you can take on the Adventure Triple Challenge, a team challenge of cycling, canoeing and trekking in the Lake District; or join us in Finland next year for the Arctic Adventure Challenge, a once in a lifetime experience where you will learn essential skills to survive in this extreme environment.

We are delighted that Anne Harris, our recently retired Director of Care Services, received her MBE from the Princess Royal in January. It is wonderful to see her recognised in this way and it shines a light on the importance of social care for seriously ill children and their families.

Sadly, the Government's recent decision to rule out funding for children's social palliative care outside hospices leaves many families without the care they desperately need. There continues to be an alarming lack of understanding that palliative care is not purely clinical and that organisations, such as Rainbow Trust, providing social palliative care alongside clinical-based hospices and the NHS, are vital. We continue to hope the Government will acknowledge our concerns and take meaningful action.

I would like to finish by thanking you for your support, generosity and kindness, helping us to ensure that families caring for a seriously ill child do not have to struggle alone.

Thank you.

Zillah Bingley, Chief Executive

Cover photo:
Artem, eight-years-old, was diagnosed with acute lymphoblastic leukaemia. Read about the support Family Support Worker Lilia gives to the family on page 6.

Last year Rainbow Trust supported 1,274 seriously ill children and their families by pairing them with an expert, dedicated Family Support Worker.

This enables families to make the most of their time together, giving them practical and emotional support, whenever and for as long as they need it.

However, there are still thousands of families with a child with a life-threatening illness who desperately need support today, who are struggling to cope alone.

STAY IN TOUCH

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You can check our Privacy Policy at rainbowtrust.org.uk/privacy-policy

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Hear from the experts

Lorna Fraser, Professor of Palliative Care and Child Health, and National Institute for Health and Care Research Professor, tells us about the importance of the social palliative care which Rainbow Trust provides for seriously ill children and their families.

Professor Lorna Fraser

> ***"From a parent's point of view, they should not really need to know where the funding comes from. They should just know that their child's needs will be met."***

"Children with life-limiting conditions should have the same rights as every other child: the right to live, the right to education and the right to participate and socialise.

In order to meet these basic needs, social palliative care support is required and that is where charities such as Rainbow Trust come in. Rainbow Trust helps fill the gaps where statutory services are not there or are not able to.

When I first became aware of Rainbow Trust's services, I was very pleased to see that their emotional and practical support was being provided for seriously ill children and their families, especially at home, and that the social care aspects of caring for a child with a life threatening illness were both understood and focused on.

Families caring for children with a serious or life-threatening illness have to cope with the cumulative effects of complex childhood illness, such as the impact on the family's daily life, having to attend hospital appointments, long stays in hospital, being unable to do the school run and, sometimes, having to stop work. There is also a higher-than-expected number of children with life-limiting conditions living in areas of higher deprivation.

Due to advances in medicine, seriously ill children's needs have become more complex over the years; with government funding for social care not being protected and sustained, care has had to be largely clinically focused. Additionally, the state statutory social care system is designed for older adults and therefore is a system which is very difficult for parents of seriously ill children to navigate.

From a parent's point of view, they should not really need to know where the funding comes from. They should just know that their child's needs will be met.

Rainbow Trust's support is really important because it responds and reacts to the needs of families caring for a seriously ill child in a timely manner and in a timeframe that suits them, tailoring to each individual family, which many medical services cannot offer.

There are times when families prefer to have the social care they need for their seriously ill child at home or in the community and Rainbow Trust's support plays an important part in that jigsaw.

Rainbow Trust gives crucial support to families whenever they need it during incredibly difficult times.

They continue to demonstrate the critical role of social palliative care for families, alongside the clinical care provided by healthcare services and hospices."

Families with a seriously ill child often struggle to cope as they balance uncertainty, stress and the challenges that childhood illness brings. Rainbow Trust Family Support Workers help to ease some of these pressures by offering tailored practical and emotional support.

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

Whenever I feel overwhelmed, I can rely on Georgia

With an uncertain future ahead, Sonia, Mohammed's mum, tells us how Family Support Worker Georgia helps the family with the challenges of caring for a seriously ill child.

"My son Mohammed is five years old and was born with a rare genetic condition called trichohepatoenteric syndrome which affects his liver, intestines and immune system.

Mohammed catches infections easily and often, sometimes leading to long hospital stays. He needs a Hickman line, an intravenous catheter, for nutrition; eats very little by mouth, tires easily, and experiences flare-ups of his condition, which can be life-threatening.

In the future he will need a liver transplant.

Family Support Worker Georgia with Mohammed

Mohammed also has a severe autism diagnosis, is non-verbal and has no sense of danger. We have to monitor him 24/7 to ensure that he does not pull out his Hickman line and stays safe.

Life is very difficult. I do struggle sometimes.

My husband works long hours, and I care for Mohammed full time. Trying to attend to Mohammed's needs and also be there for our three other children is demanding and incredibly overwhelming.

In May 2023, a local community nurse referred us to Rainbow Trust and we were paired with Family Support Worker Georgia from the Greater Manchester Care team.

Georgia's support has been essential for the whole family, helping us to navigate the challenges of caring for Mohammed, allowing me to have some much-needed respite. As our two other sons are older, Georgia focuses her support on Amal, our seven-year-old daughter, ensuring she gets the quality time she needs.

Georgia has helped me with paperwork when applying for benefits and Mohammed's disability badge, helps me with shopping, school pick up and running errands; she supports me by monitoring Mohammed and she helps me to understand medical jargon. This practical support alleviates some of my feelings of being overwhelmed while allowing me to have some respite and to focus on spending time with my family.

Due to his autism Mohammed struggles to connect with people but has developed a strong bond with Georgia. He is generally uncomfortable with people outside his immediate family; however, he gives Georgia a big hug when he sees her. This means so much to me.

When Mohammed catches an infection, it often means an urgent trip to hospital, sometimes for an extended period of time. These are usually unexpected and Georgia supports us by going to our house to collect the essential things we need and brings them to the hospital. It is one less thing to think about, and it helps so much.

Mohammed enjoying a supermarket visit with Family Support Worker Georgia

Amal at the farm during a Rainbow Trust sibling day

> ***Life is very difficult. I do struggle sometimes.***

Georgia will also sit with me in hospital, either to chat about how I am coping or to give us a break by spending time with Mohammed. Knowing someone is there to support us, listen to our worries and ease some of my stress is such a relief.

If we have to rush to the hospital with Mohammed, it is also a relief to know that Georgia will pick Amal up from school and talk to her about how she is feeling. Amal struggles when Mohammed is in hospital as me and her dad are not around as much but having Georgia's support has really helped give Amal the one-to-one time she needs.

Amal also attends the Greater Manchester Care team's sibling days, allowing her to connect with other children going through similar experiences and to create a support network outside the home. Most recently they visited a farm, she fed the animals and went on a tractor ride to see the donkeys – she absolutely loved it.

Georgia often takes Mohammed and Amal for days out to give them time to be like any other children and so neither feels overlooked. They get so excited to see her and love spending time with her. These days out give them a chance to have some fun and be in a non-medical environment. They go to the library, aquarium, farm, museum and even the supermarket, where Mohammed loves people watching and sensory activities, like smelling candles.

The time Georgia spends with Amal and Mohammed is very important to me as I can have some respite, time to myself and the chance to do jobs around the house that I cannot get done while monitoring Mohammed. I often feel overwhelmed balancing Mohammed's needs with those of my other children. On the occasions when Georgia takes Mohammed out by himself, I am able to spend quality time with Amal, while knowing that Mohammed is safe and happy.

Because of Mohammed's complex medical needs and the likelihood of him needing a liver transplant, our future remains uncertain. However, he recently started at a special educational needs school and is thriving. Alongside this, I know that whenever I need support or feel overwhelmed, I can rely on Georgia. She has supported and helped our family so much, we would struggle without her. ”

We want to ensure that no family has to face the uncertainty of their child's serious illness alone.

The support from a Rainbow Trust Family Support Worker like Georgia can make a huge difference to families who are struggling to cope. Family Support Workers are a stable presence for them, offering tailored support, helping to ease the overwhelming stress and challenges that caring for a seriously ill child brings.

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

Dealing with loss and grief far from home

How Family Support Worker Lilia supported Artem's family when the unthinkable happened.

In loving memory of Artem

Artem, a six-year-old boy from Ukraine, was evacuated to the UK when the hospital he was being treated in for acute lymphoblastic leukaemia was bombed.

Family Support Worker Lilia from the London and South East Care team began to support his family in June 2022. Due to being evacuated the family had to leave their home, family and friends under traumatic circumstances, they did not speak English, had very little other support in the UK and were completely isolated.

Originally, Lilia supported the family with whatever they needed, whether it was supporting Artem with schoolwork, signposting the family to resources, giving them a space to offload their feelings, or helping them to set up bank accounts. As Lilia speaks Russian, which is similar to Ukrainian, she was also able to translate for the family during essential hospital appointments.

Lilia's support helped to ease some of the stress Artem's mum, Alina, and his grandma, Natalie, were feeling, whilst they struggled to cope with caring for and managing Artem's serious condition in a foreign country, trying to understand a different language and customs, navigating complex situations away from their home and their support network.

Lilia also helped the family to create many long-lasting memories by planning special day trips. Artem became blind at age three. He loves trains so on one occasion Lilia took him to the London Transport Museum. There she guided Artem round, explaining and bringing to life what he was touching and his surroundings. On other occasions Lilia filled in applications and sourced opportunities that will allow the family to make precious memories together.

Lilia supported Alina and Natalie intensively, to help them come to terms with the devastating news that Artem's treatment had been unsuccessful and that he would die.

In November 2023, Artem began to deteriorate, getting worse each week. He started to need more medical care as his body was weak and struggling to fight. Artem fell into a coma and was intubated, a procedure that supports breathing, several times. His family was told that he might not wake up.

When he awoke in December, he was very distressed, confused and unable to understand the medical staff's instructions, so Lilia translated for Artem, explaining and guiding him through what was happening.

"It is so important for families to have support to help them keep going when the worst thing imaginable happens. For this to be from someone like me, who knew their child, makes a real difference and is a comfort to them. Alina has said to me 'I would be lost without you'.

"To have a child who is dying, to be away from home and not able to speak the language or communicate with doctors, it is a whole world of confusion and uncertainty. I am glad to have been able to be there to help them navigate and to have that flexibility to be able to do whatever was needed."

Lilia

< Artem having a lovely time at a farm

Artem having a fun day out

Alina was heartbroken and bewildered by the situation but Lilia encouraged her to sit at Artem's bedside, to hold his hand and to talk to him, reminiscing about happy memories. For Natalie, Lilia gave her the time to cry as much as she needed and to offload and talk about how she was feeling.

Artem died in January 2024, aged eight, with his family beside him.

Alina desperately wanted Artem's body to be taken home and buried in Ukraine. Lilia supported with the repatriation of his body for the funeral in Ukraine, helping to fill out paperwork and managing communications between the parties involved. Throughout their time in Ukraine for the funeral, Lilia remained in touch with Alina who was struggling.

Through regular phone calls and communication, Lilia was able to encourage Alina to focus on her positive memories of Artem, ensuring she knew there was nothing more she could have done. The family is now back in the UK and have begun to sort through and donate Artem's belongings. Lilia has been helping them to hold on to precious items and talk about their memories of Artem, remembering him as the lovely boy he was.

Support continues to be vital for the family as they come to terms with their grief. Lilia provides regular bereavement support for Alina and Natalie as they discuss their feelings and talk about what happened. Lilia offers them a safe, non-judgmental space to offload and cry if they need to.

King's College Hospital, where Artem received treatment, invited Alina to an event for bereaved parents. Alina did not want to go alone; she couldn't face going back to the hospital where Artem had died. Lilia accompanied Alina, comforting and reassuring her, offering her the chance to grieve with other parents while knowing she was supported.

Lilia has also sourced further bereavement support for the family in their native language while continuing to provide support for Alina and Natalie as they grieve for Artem.

Sponsor a Family Support Worker like Lilia today

Rainbow Trust's support does not end when a child dies. Family Support Workers like Lilia continue to support a family through bereavement, helping them to navigate their grief. Your donations allow us to give families caring for a life-threated child this essential support. By sponsoring a Family Support Worker like Lilia today, you will be helping to ensure that no family has to face this alone.

rainbowtrust.org.uk/sponsor-us

A career in the life of a Family Support Worker

Abi first joined Rainbow Trust as a volunteer. Nearly a decade later, she is now the Deputy Family Support Manager in the Essex Care team.

After gaining my qualification in childhood studies I worked with children and families as a private nanny. I also have a passion for travel and spent years both travelling and working in several countries.

Eventually I knew that I wanted to do something different, so I hung up my backpack and moved to Essex. I wanted to have a new challenge but continue to work with children and families and Rainbow Trust sounded like the perfect place for me.

In 2015, I began volunteering as a Family Support Volunteer for one day a week with the Essex Care team, and I haven't looked back since. Being able to volunteer gave me the opportunity to gain hands-on experience as well as get to know the role on a deeper level.

As a volunteer, I supported three families and each session was unique, whether it was giving seriously ill children and their siblings the chance to have some much-needed fun, supporting a child going through cancer treatment, spending time with brothers and sisters who are sometimes overlooked, or helping to minimise stress for families by driving them to hospital appointments.

After a year as a volunteer, I realised how rewarding this work was and applied to become a Family Support Worker.

My favourite thing about being a Family Support Worker, and the thing that truly highlights how essential Rainbow Trust's support is for seriously ill children and their families, is the time we can give. We can dedicate time to families, meaning we can properly support them with whatever they need, whenever they need it. It is so impactful.

> *“I don't know how I would have coped on this often tumultuous journey without Family Support Worker Abi.”*
>
> **A parent supported by Abi**

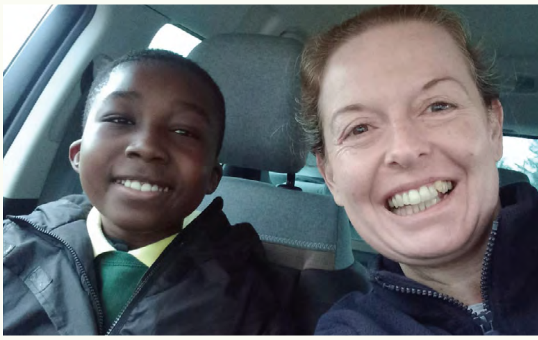
There are so many small moments that stand out from my time at Rainbow Trust. Seeing the excited face of a sibling when I come through the door and they know that they are going to have some time where the focus is on them. Watching a seriously ill child smile because they are going to get to be like any other child and play. Hearing a parent tell me how much my support has helped. These moments are all so special.

Each day is different, depending on what a family needs at that moment. Recently, for example, I provided school transport for a sibling as his mum cannot leave his seriously ill sibling at home. On the way we had a chat about how he was doing and how school was. This transport to and from school alleviates some stress on his mum and gives him some one-to-one time with me. After dropping him off, I collected a food shop for a family unable to leave their house and spent time chatting with the mum while unloading groceries and helping with some ironing.

This alleviates some stress on the parents as the family do not have the time to do these simple things. I then had some phone calls with families to arrange visits and check in on them before I finished the day by picking up the sibling from school.

Even one day of support can make a huge difference to a family who is struggling.

Now, after nearly a decade with Rainbow Trust, I have progressed to Deputy Family Support Manager in the Essex Care team. I am looking forward to the new challenges and I am excited for what the role will bring, particularly working in the local community to spread awareness of what Rainbow Trust does so that we can reach more seriously ill children and their families who desperately need support.



Abi and Moses in the car

Focus on volunteering

Volunteers are a huge part of everything we do at Rainbow Trust

Abi and Angelica, who is seriously ill

Oliver and Abi during a support session

Abi taking Emily out

Sophie, a volunteer with the London and South East Care team, tells us about her experience of volunteering with Rainbow Trust.

“Hello everyone. My name is Sophie and I am a volunteer in the Care team. I have worked for 10 years in different childcare settings and I am committed to supporting children who have additional needs as I was a premature baby myself. I enjoy swimming, doing arts and crafts and learning Makaton, a way for non-verbal children to communicate using signs and symbols.

Typically, my volunteering role involves helping to manage sibling groups and events, and to deliver arts and crafts drop-in sessions for the siblings of seriously ill children at the Evelina Children’s Hospital and St Thomas’ Hospital in London. These sessions allow parents to have some respite and siblings to have fun while building a support network away from the home.

I also attend the Neonatal Intensive Care Unit with the Family Support Workers, providing support for families with a seriously ill child.

When I first started volunteering with Rainbow Trust, I remember helping at a summer funfair and craft day for siblings. I was on the dodgems with one of the siblings, we were both having a great time, and the sibling told me that this was their first time going to a funfair. They said it was the best day as they could finally be like their friends at school.

Events like these allow siblings to have some time just for them, a chance to talk about how they are feeling, and just to be a regular child.

The most challenging experience has been seeing the effect that caring for a seriously ill child has on families. However, I know I am helping and doing something positive by giving my time to them, so it is a rewarding experience for me as well.

Volunteering is a great way to meet new people, gain life skills and practical experience. I like knowing I am supporting siblings and families by giving them someone to talk to at such a stressful time.”

Sophie

Join our friendly volunteer team today and help make a difference to seriously ill children and their families.

Find out more at **rainbowtrust.org.uk/volunteer**

Thank you!

to all our amazing supporters and fundraisers

Alex bravely took on the week-long Arctic Adventure Challenge in January, raising £5,500. While there she learned essential Arctic survival skills, and cross-country skiing, snowshoeing and campcraft.

Nuneaton Golf Club held a Disney-themed Ladies Charity Day that raised £1,400. It included colourful decorations and wonderful costumes.

13 **Invesco** employees took on an adventure, travelling from their Henley office to their London office by bike and on foot, covering 90km! They raised £13,572 which was kindly matched by the Invesco Foundation.

Barry ran the Great North Run which he enjoyed so much that he signed up to do it again in 2025, and also enrolled his grandson in the Mini Great North Run.

A team of runners from **Reeds School** in Surrey took part in the Vitality London 10K and raised just over £1,500.

Rory took on the challenge of running one mile a day for ten days, asking friends and family to sponsor his challenge! In total he raised an amazing £670.

Colchester Angling Preservation Society held a charity fishing match, raising £2,257. The fundraising was boosted by Rosie and Mia, who sold paracord bracelets to members.

Healthcode smashed their fundraising target with their staff taking part in many fundraising challenges, including Claire and Caitlyn who completed the Thames Bridge Trek.

Procurement Hub supported us as one of their Charities of the Month, raising £20,934. They visited our Greater Manchester team to meet the Family Support Workers.

Datapharm, neighbours in our Leatherhead head office, took on a 10-mile sponsored walk around Surrey, raising over £800.

There are many ways you can support Rainbow Trust and get involved, from taking part in an event or planning your own fundraising.

Join the Rainbow Trust community today at rainbowtrust.org.uk/events

The impact of your support

In our latest Impact Report 2023 - 24 three families talked about the imprints and impressions Rainbow Trust leaves on their lives and how these will last forever.

For 13-year-old Luke, who was diagnosed with acute lymphoblastic leukaemia and is supported by Family Support Worker Monica, Rainbow Trust meant he was less isolated after not socialising for 10 months.

For two-year-old Elodie's parents, Family Support Worker Laura provided essential respite and support. And for Louie's family, Family Support Worker Shelly helped them to spend precious moments together.

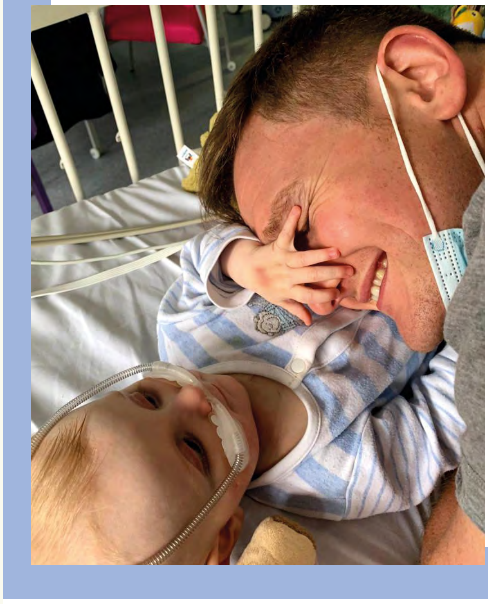
This impact is only made possible by your support.

Scan to read the latest Impact Report or go to **rainbowtrust.org.uk/impact**

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 Family Support Workers can continue helping seriously ill children and their families, giving them expert support.



Write your Will online for free

We have partnered with Octopus Legacy and are delighted to be able to offer you the opportunity to write your simple Will online for free.

Help is available in case you have any questions throughout the process and legal experts check over each Will. Or, if you prefer to write your Will over the phone or face-to-face, please call 020 4525 3605.

For more information or to request your free Gift in Wills guide, simply go to

rainbowtrust.org.uk/legacy

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

Do something amazing today: fundraise at your special occasion

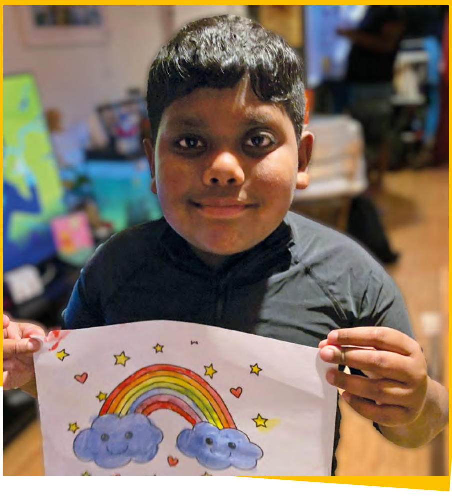
If you have a special occasion coming up, such as a wedding, anniversary, baby shower or birthday, make your celebration even more special by fundraising to give a family with a seriously ill child precious time together.

Scan the QR code or go to
rainbowtrust.org.uk/special-occasion
to make a difference on your special day.

How your support helps seriously ill children

↑ Family Support Worker Laura took three-year-old Logan-Ann, who has complex health needs, for a walk to the park where they found lots of different leaves and went on the swings.

↑ William and other seriously ill children supported by the South West Care team visited Hicks Gate Fire Station in Bristol where they had a blast using the hoses.



↑ During an online support session, Family Support Worker Anna and eight-year-old Nithin painted pictures of rainbows. Nithin's sister is two and has a complex heart defect.

↑ Eight-year-old Zainab's brother, who has a genetic condition, and mum had to go to the hospital so Family Support Worker Ellen took her to a light trail in Swindon. She had a great time and went home with a smile on her face.

← Six-year-old Jesse is recovering from major heart surgery. Family Support Manager Natalie took some arts and crafts, kindly donated by University of Reading, to the hospital. This gave his mum the chance to have some respite.

↓ To give mum some respite, Family Support Worker Emma took five-year-old Arthur, who has leukaemia, to Whitley Bay where they had a fun time at the arcades and eating ice cream.

↓ Sisters Alisha and Maria went pottery painting and to Grimsbury Farm to feed animals with Family Support Worker Wendy. Their sister Aqsa is two and has a complex diagnosis.

It is only thanks to your generosity and support that we can help seriously ill children and their families. Thank you.

Scan to donate

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