

# FAMILIES FIRST

AUTUMN/WINTER 2023



## INSIDE:

- Helping Teddy's family cope with cancer
- A career in the life of Family Support Worker Marlene
- How you can get involved

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

# Dear Supporter

**We know that there are challenging times ahead with the ongoing cost of living crisis which is affecting us all, but more so families with a seriously ill child.**

Families may be struggling to pay higher bills for electricity to run life-saving equipment at home, cover additional cost of transport needed to attend medical appointments and the increasing costs of their rent or mortgage.

This enormous financial pressure is pushing families to their absolute limits. They are trying to cope with all the challenges that serious illness throws at them and, in some cases, are unable to work as they look after their life-threatened child. We anticipate an increase in demand from families as they struggle to manage alone.

Thanks to the generosity of trusts, foundations, organisations, volunteers and supporters like you 582 newly referred families started receiving support in our financial year July 2022-June 2023, with an increase of 7% in referrals against the previous year. We also saw a 5% increase in the number of families supported, with a total of 1,141. My thanks to all the wonderful supporters and to the care team who help us achieve this.

The analysis of last year's snapshot audit that seeks input from the families we support and professionals we work with is now complete. One quote from a parent really stood out and makes us more committed than ever to support as many families as we can: *"Rainbow Trust is a light in what can feel a very dark world."*

Best wishes



Zillah Bingley, Chief Executive



**Cover photo:**

Seven-year-old Alicja was diagnosed with leukaemia in 2022. She spent five months in hospital. The family is supported by Rainbow Trust Family Support Worker Sammi.

Families with a life-threatened child may feel they are in a really dark place. Rainbow Trust Family Support Workers help them practically and emotionally as they adapt to and navigate their new worrying and difficult reality. This tailored support enables parents to have some respite, some help with their children and some emotional support when they may be feeling completely overwhelmed.

## How your support helps

July 2022 to June 2023



**3,622**

hours supporting the seriously ill child



**3,876**

hours of sibling support



**2,464**

hours supporting families in hospital, of which **1,608** hours were neonatal support



**2,327**

hours of transport to and from medical appointments, hospital and care



**569**

hours of bereavement support

# HEAR FROM THE EXPERTS

**Professor John-Paul Kilday, Consultant in Paediatric Neuro-oncology at Manchester University NHS Foundation Trust, tells us about the positive impact that the support of Family Support Workers has on families with a life-threatened child.**



Rainbow Trust Children's Charity is an exceptional professional organisation that provides timely practical and emotional support to families of children with life-threatening or life-limiting illnesses.

As a medical specialist, I see first-hand the impact such life events have on a family's journey through diagnosis, therapy and aftercare.

I wholeheartedly endorse Rainbow Trust for the consideration they give to each family member and their specific needs, catering to their individual circumstances. Rainbow Trust Family Support Workers take the open hands of families and walk by their side through the most difficult of paths.

For the child, they can help sustain loving relationships with their siblings, support transition back into school if this is a source of anxiety and can spend time on trips with teenagers who are looking for some brief independent thinking time.

We have witnessed Family Support Workers support with end-of-life patient care, helping to create beautiful memories for the family, such as weekly reading sessions from a child's favourite book.

Individual days out and support sessions with siblings also prove incredibly helpful, as this is often an area of great need that is not typically highlighted.

Parental support, in the form of respite care, helping with practical tasks, assistance with everyday chores or even helping parents regain the confidence to leave the house and face the community again, all prove invaluable.

And when a seriously ill child dies, bereavement support is also provided and is a source of comfort to families due to the relationship already in place.

I have been amazed at the impact Rainbow Trust can have on families to enable them to remain exactly that, a family. Their involvement is always considered by my team when we meet new families and I champion the charity to my colleagues whenever the opportunity arises.

On behalf of all the care teams and families that you work alongside, thank you Rainbow Trust for everything you do.



*"I have been amazed at the impact Rainbow Trust can have on families to enable them to remain exactly that, a family."*

Families with a life-threatened child may be dealing with considerable worries, stress and anxiety. But thanks to supporters like you they are not alone.

Be a part of this important and valuable support to families by donating today. Simply scan the QR code to visit our secure online donation page.

Scan to donate



Unable to work, no income, living in temporary accommodation with a seriously ill child and no support network. What a difficult and lonely place to be.



↑ Antonio at home with mum Wahyuni

## Rainbow Trust Family Support Workers continue helping families experiencing isolation and loneliness so they don't have to cope alone

Wahyuni is mum to Antonio, who is nearly two years old and was born with Down's syndrome. Because of his Down's syndrome diagnosis Antonio was at a higher risk of having leukaemia so he had regular blood tests. Unfortunately, in September 2022, something unusual was found in his blood and Antonio was diagnosed with Acute Myeloid Leukaemia (AML), a type of blood cancer.

Wahyuni is a single parent with no family, friends nor social network in England.



↑ Antonio receiving treatment in hospital

Initially Wahyuni was on compassionate leave to care for Antonio, but it became impossible for her to work so she had to give up her job to be by Antonio's side, living at the hospital for six weeks. Wahyuni has described how lonely she felt without having anyone to talk to until Rainbow Trust stepped in.

*"There was very little human interaction. I was looking after Antonio changing nappies, feeding him, watching him have his chemotherapy, cuddling him when he felt unwell and playing with him to entertain him.*

*"I didn't really talk to anyone because it was just Antonio and me in the room. The nurses came in to give him the chemotherapy and chatted for a few minutes now and then. That's how terrible it was. I couldn't talk to Antonio, he was too little and wouldn't understand. I felt very sad during the hospital stay but put on a brave face. I didn't want to show that to my son, I wanted to shield him, so I tried to keep myself happy all the time."*

Wahyuni was referred to Rainbow Trust by a Young Lives vs Cancer Social Worker at John Radcliffe Hospital and Family Support Worker Tanya started supporting them, helping alleviate the isolation and loneliness that gripped Wahyuni during this daunting time. It helped her regain a sense of normality amongst the sterile and lonely medical setting in which she was living.

Tanya visited them regularly in hospital and spent time with them, talking, giving Wahyuni a break to grab a cup of tea, to take a short walk, or a period of much-needed respite.

*"We talked about different things, not just about Antonio. Sometimes, **when you are dealing with illness you don't want to talk about it all of the time because it is so sad**", Wahyuni said.*

Tanya helped take Wahyuni's mind off Antonio's illness and provided a break and a distraction from her daily reality.



This proved critical to Wahyuni's and Antonio's emotional wellbeing.

Antonio was discharged from hospital in March and both he and his mum are back living in accommodation at her previous employers. They live in the country, where there is no public transport, and Wahyuni doesn't drive so Tanya drove them to some of Antonio's hospital check-ups, which was of great help and made them feel less cut off.

*"He is doing really well after chemotherapy. The side effects were quite scary for me. But it is only me, so working is impossible as Antonio is not in nursery yet", Wahyuni said.*

Wahyuni and Antonio are on the housing list waiting for permanent accommodation. Antonio still gets very tired and they just take things slowly. He is a cheeky, happy little boy who enjoys singing and cuddles.

### **Rainbow Trust Family Support Workers help is tailored to the needs of each family living with childhood illness.**

Having a seriously ill child is tough on parents; everyday tasks may feel relentless; work may have to stop to look after the seriously ill child; and they may feel isolated and lonely. The whole experience could become emotionally and physically draining. Rainbow Trust Family Support Workers help by tailoring the support to each family member, giving them time to focus on what matters the most to them.



**A 2023 survey completed by families supported by Rainbow Trust found that almost two thirds of respondents, 64%, said Rainbow Trust had helped them feel less isolated by providing someone for them to talk to.**

**Wahyuni's struggles are an all too familiar story. A staggering 43% of survey respondents said they had to leave their employment to meet the needs associated with having a seriously ill child.**

**With your support we can ensure parents and their children don't have to face their worst nightmares alone.**



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# “I CAN’T TAKE THE PAIN FROM HIM. ALL I CAN DO IS SUPPORT HIM”.

Kat tells us of her experience dealing with Teddy’s rare cancer and about the support the family has from Family Support Worker Jayne

→ Silly faces in hospital



My son, Teddy, began to feel constantly unwell just after his third birthday.

Back and forth to the GP every week with viral infections that he never seemed to recover from, Teddy started complaining of pain in his sides. Worried it could be a kidney infection or appendicitis, I took Teddy to A&E and we were sent home with antibiotics. Teddy stabilised for a few days, but the pain quickly returned. Back in A&E, doctors did an ultrasound which showed that Teddy had an 11cm mass on his kidneys.



↑ Teddy, wearing Brighton and Hove Albion FC, his favourite team’s, top.

Blood tests confirmed that it was cancer, and an MRI scan that it had spread all over his body.

Teddy was diagnosed with the rare cancer, Neuroblastoma.

**We went from thinking he had appendicitis to finding out he had stage 4 cancer. It completely turned our world upside down. My heart broke in two.** It was all very scary and stressful. We had a tiny baby, Rupert, and a very ill three-year-old in hospital.

My husband, Alastair, and I then had to endure an agonising wait for Teddy to begin his treatment, whilst undergoing a list of endless scans, biopsies, blood tests and more.

It seemed to take forever, and he was becoming sicker and sicker, to the point of him lying in a darkened room all day crying or sleeping.

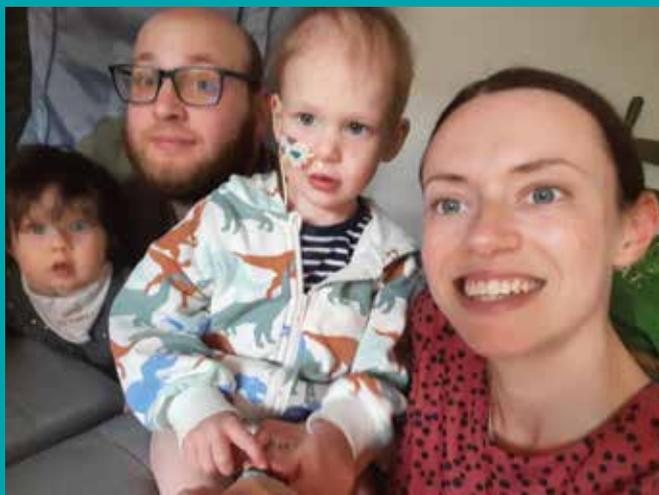
Teddy was in hospital for six weeks for his first round of chemo. I was living away from home, near the hospital, so I could be with Teddy every day. We were not able to spend any time together as a family, and even when Teddy did come home in between treatment, with constant check-ups, scans and unplanned hospital admissions, we barely had a day together for four months.

**It was completely relentless. There were awful, awful times.**

We were in complete survival mode for around seven months after Teddy’s diagnosis. It was just about getting through each day. Our family life completely turned upside down. I missed Rupert’s first Christmas because I was in intensive care with Teddy. And Alastair missed Rupert’s first birthday because Teddy was having his second bone marrow transplant.

At the time we were relying on hospital transportation to and from appointments because we don’t drive and we couldn’t use public transport because Teddy’s immune system was too weak. Living an hour away from The Royal Marsden, where Teddy was receiving treatment, and 40 minutes from the local hospital, complicated our situation further.

Using hospital transport made things more difficult. It was a lot of work to book it and they would often be late collecting us or be so early that we would have to wait hours in hospital prior to our appointment. In fact, we have had to wait for collection up to four hours after our appointment, to the point where the unit Teddy was on had closed before we had been picked up: all the nurses went home, and we were just left wandering around this empty unit waiting for transport to



← Rupert,  
Alastair,  
Teddy and  
Kat

come and get us with a child who had just woken up from a general anaesthetic, who was weak, tired and just wanted to go home.

Our community nurse referred us to Rainbow Trust. I remember feeling like other people must need this more than us. Then we thought 'if we don't need help then who does?'

Family Support Worker Jayne has been supporting us since January 2023, mainly with transport to and from hospital appointments.

The first time Jayne came to take us to a scan I felt a huge weight lifted off. I hadn't really realised how much extra stress the travel had added to our lives.

Teddy had radiotherapy recently and we stayed near the hospital. If we had still been using hospital transport, we couldn't have brought four weeks' worth of luggage. Jayne came to our house at 6am in the morning, helped us load up the car, she dropped us at the hospital, she collected the keys to the flat for us, she collected a supermarket shop for us, she came back and helped us unpack and make the beds. It's all help that you don't get from transport.

Alastair and I currently take it in turns to be at the hospital when Teddy is an in-patient and Jayne's transport support saves us train ticket fares and an immense amount of time. Jayne would drop Alastair off, we can then spend four or five hours together with Teddy, and a Rainbow Trust volunteer driver would take Alastair back home.

But is not just the time and money saving. We can actually rely on Jayne. We trust her. And I benefit from emotional support from her too.

Jayne is always on time and Teddy loves her because when Jayne comes, she doesn't take bloods, nor do any medical tests, she's there just to see Teddy, and Rupert loves her too.

Teddy's treatment has been harsh for all of us. We have our heads down and wake up in the morning not quite knowing how to get the strength to get up and face the day and knowing that we can count on Jayne really helps.



***“Knowing what the family is going through I can see what amazing strength they have”***  
**Family Support Worker Jayne**

→ **Will you sponsor a Family Support Worker like Jayne today?**

Having a child with a life-threatening condition puts pressure on the whole family. They may all feel that they can't cope, they can't carry on. Rainbow Trust Family Support Workers like Jayne tailor their support to the needs of each family, helping to make it a little easier, alleviating the load.

Your sponsorship will enable families who have a child with a life-threatening illness to make the most of time together because family is everything.

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

**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.**

Scan to donate



## MAKE YOUR MARK ON THE WORLD



People usually think of a legacy as organising finances to look after their loved ones. What we normally don't think about is that a legacy is also the impact we have on people lives, the wonderful memories we create over our lifetimes and what we write.

### Will you write a gift in your Will to Rainbow Trust?

Many families we support face the reality that their seriously ill child may die before them. Many families are trying to cope alone with the strain, disruption and stressful worry that a serious diagnosis carries.

After remembering your loved ones, a gift in your Will to Rainbow Trust will make sure that, for families in crisis during their darkest days, we are there so they have the best possible support.

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

### Take advantage of our Free Will-writing Service

You can now write your simple Will online. 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

You can support and get involved in many ways: from marathons to climbs or treks, being a fundraiser in your local community or doing a sponsored challenge in your organisation, however you want to fundraise, we would love you to join in.

### London Carol Concert

St Paul's Church, Knightsbridge  
Thursday 7 December 2023  
Save the date for a magical, candlelight evening to celebrate the beginning of the festive season.

### Ford Ride London-Essex 100

Sunday 26 May 2024  
Your chance to enjoy cycling through the closed roads of London and Essex, whilst taking in the sights of the capital and the beautiful Essex countryside.



### Fun First Newspaper

Grab some pencils and pens and get creative, share your Fun First inspired creations on our gallery and have the chance to win a fantastic prize every month.

Order your copy now!



### 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 £2.  
[rainbowtrust.org.uk/rainbowday](https://rainbowtrust.org.uk/rainbowday)

Do something amazing today, sign up online at

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



# A big, wholehearted Thank you! to all our amazing supporters and fundraisers



**K2 Corporate Mobility** volunteered at a family fun day at Bocketts Farm with the London and South East Care team.



**Hurst Dance Studios** in Hindley, near Wigan, run by Phil Hurst, held a Strictly Come Dancing fundraising and raised an amazing £4,707 in sponsorship from family and friends.



A fantastic team from **JPC by Samsic** played 16 hours of back-to-back golf at Lingfield Park Resort, in their Longest Day Golf Challenge raising over £8,500.



Four-year-old **Joshua** was six weeks premature, weighed just 4lb 14oz, and needed neonatal care for the first two weeks of his life. His local councillor invited him to join a litter pick and Joshua raised almost £200.

## LONDON MARATHON



**Debbie** ran the London Marathon 2023 in memory of her niece Eloise, who was supported by Rainbow Trust, raising an amazing £2,606.



**David** ran the London Marathon 2023 raising a fantastic £4,482. Rainbow Trust supports one of David's close friend's family.

## RAISING MONEY IN MEMORY OF ERIN

Erin died aged nine in December 2022 due to multiple long-term life-threatening conditions. She was supported from 15 months old by Family Support Manager Sarah, who is now giving bereavement support to her mum, Helen, and her grandad.

Wonderful supporters that knew Erin are now fundraising in her memory.



**Kenny** ran the Grand Union Canal Race 2023, a 145 miles long ultra-marathon from the centre of Birmingham to the centre of London, raising £6,348.



Nine members of **Bupa Dental Practice Colchester** did a pier to pier 14 miles walk raising £1,839, plus BUPA's contribution of £1,750, in aid of 'For the Love of Erin Campaign'.

## SPOTLIGHT ON



**Natasha** is doing a sporting challenge every month to raise money for Rainbow Trust, including Farnborough Half Marathon, Hankley 10km and a fancy-dress race where she ran as Wilma. So far Natasha has raised over £1,000.

# A 21 YEAR CAREER AS A RAINBOW TRUST FAMILY SUPPORT WORKER

We caught up with Marlene, from the Northwest Care team, who is retiring in December and has been a Rainbow Trust Family Support Worker for 21 years.

## WHAT AREA DO YOU NORMALLY COVER?

The Northwest Care team covers, more or less, North of Carlisle to Stockport.

For the last two years I have been working part time, covering mainly the South Lakeland area.

## HAS THE JOB CHANGED IN THE PAST 21 YEARS?

Absolutely! Initially Family Support Workers used to work Monday to Friday and would be on call every third weekend, visiting families to provide emergency response if they needed. Now we work weekdays only and there is an emergency line that families can contact if they need urgent support at weekends.

Also, when I started at Rainbow Trust we all had mobile phones, but no calls could be made directly to us. All calls had to go to the manager who would forward the messages. The manager would also assess and review the families supported every six months. This changed over time and it seems more efficient that families can contact their Family Support Worker directly, and can be assessed and reviewed by the same professional.

## HAS THE NATURE OF SUPPORT ALSO CHANGED?

No, the nature of support hasn't changed. Our commitment to support families with a life-threatening child hasn't changed.

But there are some differences in the serious illnesses we now see. At the beginning we were mainly supporting children with a cancer diagnosis. This has changed dramatically and we see more children with disabilities, more children with syndromes with names rather than 'complex needs' description. Having named syndromes helps the families because it gives them access to specific organisations and health professionals, while we support them.

## SO HOW DO YOU SUPPORT FAMILIES WITH A SERIOUSLY ILL CHILD?

I support them at home, in hospital, and in the hospice if the family needs me to. I provide transport to and from medical appointments and treatment, as well as sibling and emotional support to any family member that may need it.

Working so closely with families we build relationships. We see and support families as they are going through very tough times. We understand the difficulties and challenges they face and we know what they have been through.

If the worst happens, if a child dies, we are there to provide bereavement support too.

This is really important to families; when a child dies everybody else leaves, medical help is no longer needed so the families are left alone. But we continue supporting them for as long as they need us.

## WHAT HAS BEEN THE HIGHLIGHT OF WORKING WITH FAMILIES AT RAINBOW TRUST?

Something I am really proud of is setting up and organising a Tribute Day that has been going for eight years now. Every year, in September, families come together to remember their children who have died. We do a memorial craft, like decorating a candle holder; we have conversations, read some verses and light candles in memory of the children.



↑ Family Support Worker Marlene



→ Marlene abseiling Liverpool Cathedral in 2012 to fundraise for Rainbow Trust.



# Good luck in your retirement Marlene

## WHAT HAS BEEN THE SADDEST TIME?

Oh, there's been lots of really sad times. Some families you really connect with and those hit me very hard when there is a bereavement.

But the first child that died was probably the saddest. He was five years old, had leukaemia and I supported the family through treatment. He was in remission and the family was doing really well so we stopped support, until his mum called me. They took him to a routine check-up and doctors sent the boy home to die. The cancer had come back so aggressively that there was nothing else they could do. I started supporting them again straight away, looking after him and helping the family every other day. After he died I provided bereavement support to the family for about a year.

This was a long time ago, but I have never forgotten that.

## HOW DO YOU COPE WITH THE EMOTIONAL IMPACT THIS MAY HAVE ON YOU?

Sometimes is difficult to deal with these emotions, but my husband gets it. I also have both managerial and non-managerial supervision, and our team meetings. I find that just talking to the team helps as we've all been through it.

Because of the distances I travel I have time alone in the car, when I can reflect on what's happening. In some ways driving helps me disconnect.

## HOW DO YOU THINK YOUR WORK IMPACTS THE FAMILIES YOU SUPPORT?

From experience I know it makes a huge impact, I help make their life a bit easier: from tackling a pile of ironing, taking the ill child for a couple of hours, to keeping a mum company while they wait for test results or an operation. Every aspect helps the family at the hardest of times.

One mum said to me **'You're my angel without wings'.**

→ Marlene with Alan Titchmarsh OBE in 2013, who was a Rainbow Trust patron at the time and did a garden make-over for one of the families we supported for his TV show.



A Family Support Worker like Marlene sometimes is a lifeline, a connection to normality, a person who understands the family and knows what they are going through, a translator for medical terms, a companion to difficult hospital appointments, an entertainer of healthy brothers and sisters to give time to the parents to look after their seriously ill child.



**Family means everything. Sponsor a Family Support Worker like Marlene today**

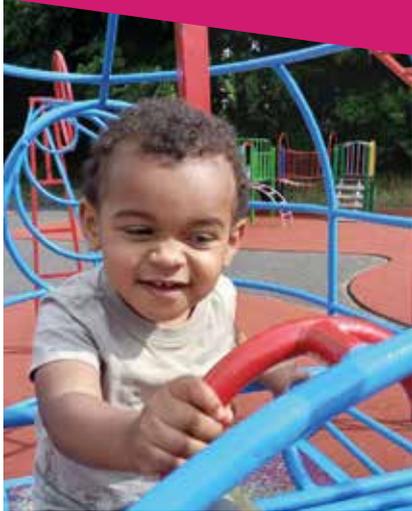
It is only thanks to your donations that we can give life-threatened children and their families this expert support for as long as they need it. Sponsor a Family Support Worker like Marlene today.

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

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# HOW YOUR SUPPORT HELPS CHANGE LIVES



↑ Family Support Worker Natalie took two-year-old Jayden to the park while mum took his brother, James, to the doctor. James has a rare skin condition and Natalie provides sibling support to help give mum a break.



↑ Amelia, six, joined the Southampton drop-in group and dressed up as superhero with Family Support Worker Laura. Amelia's brother, two-year-old Grayson, has complex conditions.



↑ Family Support Worker Cindy took three-year-old Gabi to the local park and beach, giving mum a couple of hours to do some housework and to sort everything needed to go back to hospital to be with Gabi's baby brother.



↑ Four-year-old Evie has been in hospital for four months, waiting for a heart transplant. Family Support Workers Emma and Monica visit her on the ward with lots of fun activities.



↑ Family Support Manager Natalie took 13-months-old Adriel and her sister Gabrielle, six, to the park to allow dad to get on with some work.



↑ Family Support Worker Wendy visited Bath City Farm with Ezri, six, who's sister Maya has hypoplastic left heart syndrome, and Nola, seven, whose brother Bodhi has leukaemia.



↑ Jakob is one year old and has a rare condition, had a bone marrow transplant and has been in isolation in hospital for over three months. Family Support Worker Jen visits him every week to give his mum a couple of hours to leave the hospital.

## Wonderful moments like these are only possible thanks to your generosity and support

Family Support Workers tailor the support they provide to the needs of each family. They can give the ill child and brothers and sisters some normality and parents some respite.

Days out, doing fancy dress, playing, art and crafts give the children a space to explore their own feelings and express how illness is affecting them and to improve their communication and social skills, their wellbeing and self-esteem.

*Thank you for all your support.*

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## STAY IN TOUCH

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