

# FAMILIES FIRST

AUTUMN/WINTER 2019

IT'S  
ABOUT  
TIME

Our new campaign to support every family that needs our help

**Giving families time to be a family**

"When I first found out, I didn't know what to do or how I could cope"

**A week in the life of a Family Support Worker**

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

# Dear Supporter,

A very warm welcome to our Autumn/Winter edition of *Families First*.

We have the very exciting news that we are preparing to launch our **It's About Time** campaign. We think *It's About Time* that every family coping with a seriously or terminally ill child has the support they need to face the challenges ahead. We hope that you will get behind this campaign to raise at least £25m in the next five years. If you do we will be able to help more children and families in desperate need of practical and emotional support.

As many of you know, our service is regulated by the Care Quality Commission and three of our teams have recently been inspected. I am delighted to share with you that two achieved a rating of Good and one the top rating of Outstanding. These ratings demonstrate the passion and hard work of everyone at Rainbow Trust, dedicated to ensuring that every family we support receives the best service possible. What a great achievement. Well done!

It is utterly devastating for parents to hear that their child has a life-threatening illness. The whole family is affected as they deal with fear, grief, panic, pain and frustration. In these situations, everyday activities can seem impossible and even supporting each other can be overwhelming. Time becomes more precious than ever.



Our Family Support Workers across the country work tirelessly and over the past year supported over 2,500 families with children who have a life-threatening or terminal condition. But there are many more families who need our services and in many regions we simply don't have the resources to take on every family that turns to us for support. Without our help many of these children and families will struggle to cope.

We can only respond to the increasing demand from families thanks to generous gifts from supporters such as you and the help of our volunteers. We are very grateful for your invaluable support. Thank you.

Zillah Bingley, CEO

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When serious illness affects a child, family life is turned upside down and **time** becomes more precious than ever. Rainbow Trust pairs each family with a dedicated expert Family Support Worker to help them face and make the most of each new day.

## 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/cookieandprivacypolicy](http://rainbowtrust.org.uk/cookieandprivacypolicy)

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**Head Office address:** Cassini Court, Randalls Way, Leatherhead, Surrey KT22 7TW

Registered Charity No. 1070532.

# YOUR SUPPORT REALLY MATTERS

A snapshot of the children and families you have been helping us to support



Family Support Worker, Eleanor, sharing a giggle with Fraser, whose younger brother has complex health needs.



Eight 11-15 year old sick children and siblings had a great day out with their Family Support Workers in Hampshire. A lot of fun was had on the climbing wall.



Coby, Asher and Kingston enjoy a day out in Middlesbrough. Asher has leukaemia and his brother Coby and friend Kingston also receive our support.



After 21 years helping over 500 families as a Rainbow Trust Family Support Worker, Shirley Walker retires. We wish her all the best in a well-deserved retirement.



Family Support volunteer Annabel baking cakes at Siblings Day to celebrate the Great Rainbow Bake fundraising campaign.



Family Support Worker, Sarah, has fun with Emily and Penny, sisters of children who have cancer, at Colchester Zoo.



Southampton Family Support Worker, Liz, plays dress up with George whose older brother is ill.

**When a child becomes ill routines change, families face a traumatic experience, and the ill child and their brothers and sisters need support.**

Playing, fun days out and arts and crafts not only give the children a break but also are some of the ways we support the children to look after their mental health and wellbeing. These activities help to increase confidence, self-esteem and independence at a time when the children need it most and help to give them tools to cope with life in future.



# GIVING FABIAN'S FAMILY TIME TO MANAGE CANCER TOGETHER

**When doctors found a tumour in her son's liver, Marte found it difficult to cope. This is her story.**

When Fabian, my son, was two and a half, he was seriously unwell but specialists and doctors told me he was completely fine. I knew he wasn't.

When he stopped eating and was in pain I took him to our local hospital, where they couldn't identify what was wrong with him and we were referred to Brighton Hospital. Within half an hour of being there we were told he had a big tumour on his liver. I didn't know what to do or how I would cope.

He started his chemotherapy at The Royal Marsden Hospital soon after. As the tumour was very big, doctors wanted to shrink it as much as they could before operating. When they did operate they had to remove part of his liver and chemotherapy continued for two months to try and ensure all of the tumour had gone. Unfortunately, Fabian's hearing was damaged by the treatment and as a result, he now has hearing aids in both ears.



*"When you have lots of problems having an expert, dedicated person like Jayne helping is invaluable"*

My husband had to take days off work to come to hospital but he couldn't do this every time. A friend referred me to Rainbow Trust and our Family Support Worker, Jayne, started working with us shortly thereafter.

Jayne helps and supports us in many different ways. We couldn't travel by train due to the risk of infection for Fabian so she helps by driving us to and from hospital. This is of huge help because it means one less thing to worry and stress about. There are always problems parking at the hospital so having Jayne there means I am not late or stressed when we arrive for treatment or to see consultants. The time in the car is good for me too: while Jayne drives we chat about my worries and concerns, about how this is affecting me - she gives me emotional support which I really need.

***"When I first found out, I didn't know what to do or how I would cope."***

By the time Fabian had finished his chemotherapy, I had given birth to my daughter, Hania, so going to hospital with Fabian became even more stressful. Jayne would help by looking after Hania while Fabian had scans and X-rays. Doctors tell me there and then what is going on so I have to concentrate and listen carefully. Knowing that Hania is safe with Jayne means I don't have to worry about her and I can have all my attention and focus on what the doctors are saying.

All of our extended family is in Poland, so we don't have much support around us. Jayne has been amazing, a constant presence with practical solutions and really helpful. She would always think about how she could help us and would offer advice if we need it. I was really lucky to find Rainbow Trust as I didn't think there would be anyone to help families such as mine. We were on the edge. Everything was too much to cope with.

It's always so good to open the door to Jayne and her smiley face. She is literally the right person, in the right place, at the right time - she has helped us so much.

Jayne is doing a very difficult job, helping parents and ill children; she is amazing and I am really grateful for all the incredible support she has given me over the past three years.



*"Jayne is a trusted and needed presence in our lives"*



Your donations enable families who have a child with a life-threatening illness to make the most of time together, helping us provide expert, practical and emotional support, where they need it, for as long as it is needed.



## Our new campaign to support every family that needs our help

**If there's one thing we all wish we had more of in family life, it's TIME.**

When a child suffers from a serious illness, time becomes more precious than any of us can imagine. We think **It's About Time** that every family with a seriously ill child has the support they need to help them face the challenges that lie ahead, in their own way, in their own time.

In the past ten years the number of families referred to Rainbow Trust has doubled. There are many families we are unable to help at the moment and we can't meet the increasing demand for our support.

We want to be there for every one of them.

This is why, for the next phase of Rainbow Trust's growth, we will be launching our **It's About Time** campaign. We would be delighted if all our friends and supporters would be part of our future by getting behind the campaign by donating to our appeals, sponsoring Family Support Workers, sharing our news, helping us raise awareness, attending our events or creating your own local supporter group and fundraising event.

On average, it costs just £1,780 to support a family for an entire year. By getting behind **It's About**

**Time** you will ensure a parent who is trying to come to terms with their child's devastating diagnosis, brothers and sisters of a terminally ill child or parents going through traumatic bereavement have the time and support of an expert Family Support Worker. We can't wait for you to join this special group of friends and supporters and, like us, know that **It's About Time**.

Sign up for more news straight to your inbox here  
<http://bit.ly/register-enews>

# Family Support Worker Mandy gives Claire and Ali **TIME** to focus on each of their children

## Helping and supporting Claire and Ali so they can make the most of **TIME** with their family

Ali's 12-week pregnancy scan revealed that one of their twins, Marlowe, was at high risk of having Down's syndrome and that she had a hole in her heart.

This heart condition made it difficult for Marlowe to feed and breathe at the same time, so she had planned heart surgery at seven months old. A month after the surgery, Marlowe caught flu which damaged her lungs and all of her organs started to shut down.

The family was told that Marlowe wasn't going to survive. She was on a ventilator to help her breathe. Doctors advised that they should plan to withdraw life support. However, Marlowe started making progress, totally unexpectedly. It took six months to wake her up and a further six months for her to start crawling.



Family time: (left to right) Ali, Faith, Claire, Henley and Marlowe

Marlowe was in hospital for 22 months.

Just before she was discharged home, nurses mentioned Rainbow Trust to Claire and Ali. Sibling support was highlighted for Henley, Marlowe's twin brother, and Faith, Claire's 13-year-old daughter, who was struggling with revision for her school exams at the time.

The family was introduced to Rainbow Trust and Family Support Worker, Mandy, started supporting them. "When Mandy takes Henley or Faith out they can chat about their worries and problems and forget a little about their concerns when they play. Henley and Faith adore Mandy" says Claire. Faith felt pushed out for a long time while Claire and Ali were looking after

Marlowe so Mandy spending one-on-one time with her has made a huge difference to her confidence and self-esteem.

Marlowe has between five and 10 appointments a month so Mandy looks after Henley while Marlowe attends hospital appointments; that way he doesn't have to sit through hours of consultations. The situation has made a huge impact on him so Mandy's dedicated and expert time with him helps Henley to cope better and means a constant friendly presence.

"We drifted apart from friends. None of our friends or family knew how to cope with Marlowe's condition and our situation.



"Mandy gives us that time to breathe and to focus on each of our children and that is so important to us"



**"We don't have many people like Mandy in our life. When your life is like this, it's very reassuring to know that there's somebody on your side regardless of your situation."**

"Being a parent of a child with special needs and with all these complications can be very isolating. Isolation takes hold and suddenly you don't have anyone to rely on or if something goes wrong. Having somebody like Mandy is very special. It's great to have her help and support; she understands what's going on and gives us practical, hands-on help" says Claire.

"We don't have many people like Mandy in our life. When your life is like this, it's very reassuring to know that there's somebody on your side regardless of your situation.

"Mandy gives us that time to breathe and to focus on each of our children and that is so important to us" adds Claire.

Each year Rainbow Trust Family Support Workers support over 2,500 families with children who have a life-threatening or terminal condition, regardless of diagnosis, and even when there is no diagnosis. This work is only possible thanks to friends and supporters like you.

Sponsor a Family Support Worker like Mandy today. You can help make every precious moment count for families with a seriously or terminally ill child.

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

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



## MAKE A LASTING DIFFERENCE – CHANGE THE FUTURE TODAY

### Why leaving a legacy gift to Rainbow Trust is a wonderful thing

The challenge of living with the reality that your child is seriously ill, and may die before you, is one that is faced by every family Rainbow Trust supports. Many families are coping with disruption, chaos, worries and frustration that may shatter their lives. We want to continue providing the children and their families much needed practical and emotional support, whether it's helping with hospital appointments or visiting the family at home or in a hospice today and in the future.

After remembering your loved ones, a gift in your Will to Rainbow Trust will provide help to families of children that have a life-threatening or terminal illness in the future.

To request more information or to pledge a gift in your Will please call 01372 220033, email [hanne.widmer@rainbowtrust.org.uk](mailto:hanne.widmer@rainbowtrust.org.uk) or visit [rainbowtrust.org.uk/legacy](http://rainbowtrust.org.uk/legacy)

We couldn't give our expert and dedicated family support to so many families of seriously ill children without such important and meaningful gifts.

Legacy gifts are crucial to Rainbow Trust and have an incredible impact on the support we are able to offer children with life threatening illnesses and their families, for as long as they need us. A gift in your Will, however large or small, would help us to continue to provide the support that families so desperately need for years to come.

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

“ I am leaving a gift to Rainbow Trust in my Will. I want to continue helping terminally ill children and their families after I am gone.

I hope you will join other supporters and consider making this very special decision today. ”

Margaret



## A WEEK IN THE LIFE OF A FAMILY SUPPORT WORKER

Angie has been at Rainbow Trust for three years and shares one of her working weeks with us



### By Angie Pinnock

#### MONDAY:

I visited a mum whose seven-month-old baby had died. She is struggling most days as her husband works; she's alone at home and cries because she misses her baby so much. We talked about the day Mia died and her funeral.

Mum asked me to call the Department of Work and Pensions about a payment she's received. They confirmed that the carers allowance continues for eight weeks after a child has died. Mum was so grateful as they've been struggling financially after her self-employed husband wasn't paid for the days he took off following their baby's death.

#### TUESDAY:

I took David, 12, and his mum to Great Ormond Street Hospital. David has a brain tumour. He has suffered brain damage due to radiotherapy he's had over the last six years and Mum finds it too difficult to take him alone on the train. David had an MRI scan which showed that his tumour is currently stable. It was a long day and both Mum and David slept while I drove them home.

#### WEDNESDAY:

In the morning I had counselling. All Family Support Workers have monthly sessions to ensure our

wellbeing in such a stressful job. We talked about baby Mia's funeral.

Afterwards I visited one-year-old Ash and his mum. Ash suffered severe complications at birth and his respiratory system is irreversibly damaged - he's being supported by the palliative care team. His life expectancy is thought to be about 18 months old. As this gets closer, Mum is getting very anxious and I am supporting her by listening and helping her to think about what she'd like to happen when she has to say goodbye to Ash.

#### THURSDAY:

This morning I took Amelia and Anthony, Emily's siblings, to school. Emily is two and has a heart condition. She is often in hospital and Mum spends most of her time caring for Emily and worries that her other children feel left out. Sometimes I look after Emily so that Mum can spend time with them.

After I dropped them at school, I drove to Dami's home. Dami is four and has Stage 4 Neuroblastoma. Dami has four brothers and sisters including a new baby. Dad is working whilst Mum is at home caring for Dami, her youngest daughter and the new baby - she's very tired. When I arrived, I washed up, did some dusting and prepared some vegetables for dinner. I made Mum some tea and looked after the children so she could have a shower.

In the afternoon I picked Amelia and Anthony up from school and we went to the park for an hour.

#### FRIDAY:

Our whole team meets to discuss our week including our successes and things we've found difficult.

After the meeting, I put my week's notes onto our database, texted all my families to see how they were and to arrange my appointments for next week.

“ *Being a Family Support Worker is an amazing job. It's a highly skilled role and experience with children and families, dealing with illness and uncertainty are the most important qualifications. The hardest part is when we are unable to help a family because we are already at full capacity. We need so many more Family Support Workers to fulfil the needs of all the families out there who are having the life changing experience of a seriously or critically ill child.* ”

You can make every precious moment count for families with a seriously or terminally ill child by sponsoring a Family Support Worker like Angie today.

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

# DIARY OF EVENTS

## The Big Hour

27 October 2019

When the clocks go back this winter give your extra hour to Rainbow Trust. Take that time to hold your own fundraiser or you can gift an hour of your salary. Check our handy calculator to donate online and find out more [rainbowtrust.org.uk/big-hour](http://rainbowtrust.org.uk/big-hour)

## Grate48

07 November 2019

The Leadenhall Building (Cheesegrater), London

Your chance to climb one of the UK's tallest buildings, with 48 floors and over 1,200 steps, with incredible views across London. You will have the opportunity to climb different distances and enjoy a glass of fizz on completion. [rainbowtrust.org.uk/events/grate48](http://rainbowtrust.org.uk/events/grate48)

## Bookham Carol Concert

03 December 2019

St Nicolas Church, Bookham

Join Downsend School, Epsom Primary School and All Aloud Community Choirs for a mixture of hymns and carols to start the festive season.

## London Carol Concert

05 December 2019

St Pauls Church, Knightsbridge

During this magical evening you will enjoy carols from the Elstree School Choir and other musical guests plus special readers including current Waterstones Children's Laureate, Cressida Cowell. A wonderful opportunity to ease yourself into the Christmas spirit.

[rainbowtrust.or.uk/carolconcert](http://rainbowtrust.or.uk/carolconcert)



## Trust in Fashion

24 April 2020

Grosvenor House Hotel, London

Our special annual fashion show with lunch; guests will enjoy a champagne reception whilst shopping in an exclusive boutique, followed by lunch and a catwalk show featuring leading fashion designers and fine jewellery from Boodles.

## Corks & Couture

24 April 2020

Grosvenor House Hotel, London

This unique evening starts with the chance to taste a selection of exceptional wines, followed by a three-course dinner with wine, a catwalk show featuring leading fashion designers, and the opportunity to bid on 'money can't buy' items in our auction.

## One Step at a Time

Any time, any location

Join our virtual run! Whether you run, walk or complete it in your wheelchair, take part at your own pace and in your own time. You can do a little every day or conquer 5K in one go. All you need to do is log your progress using a fitness tracker or by sending us a post-5K selfie, and we'll send you your medal. [rainbowtrust.org.uk/virtual-run](http://rainbowtrust.org.uk/virtual-run)



Henry (bottom row, right) is waiting for a kidney transplant and he and his family have been supported by Family Support Worker Rachel. His dad, Godfrey, rode the Prudential RideLondon 100 miles to raise funds for Rainbow Trust.



Marian, mum of Family Support Worker Rachel, abseiled down the Northampton Lift Tower in rainbow leggings raising over £700.



Families and volunteers across the country joined the Great Rainbow Bake. Pictured: a local fundraising event.

## Bring Back the Colour

Any time, any location

Attention schools and companies! Hold a rainbow day and Bring Back the Colour at work, school or wherever you are! Departments, teams, groups or classes choose a different colour to wear for the day and each person donates £2. [rainbowtrust.org.uk/rainbowday](http://rainbowtrust.org.uk/rainbowday)

## Skydive

Any time, nationwide

With free fall at 125mph from 10,000 feet above the ground - skydiving is a truly once in a lifetime experience! [rainbowtrust.org.uk/skydive](http://rainbowtrust.org.uk/skydive)

# FUNDRAISING HEROES

## IT'S ABOUT TIME

Join friends, supporters and volunteers today to help give precious **time** to terminally ill children and their families by supporting Rainbow Trust. Get family, friends and colleagues together for a fundraising event and do something amazing. For tips and ideas visit: [rainbowtrust.org.uk/get-involved](http://rainbowtrust.org.uk/get-involved)

Follow us on social media and sign up to our e-news on <http://bit.ly/register-enevs>

Facebook: /RainbowTrust  
Twitter: /rainbowtrustcc  
Instagram: /rainbowtrustcc

## THANK YOU!



Our superhero fundraisers at One Great Day, West One Shopping Centre in London.



Betsi and Seren painted pebbles in rainbow colours and sold them to neighbours raising £56.10. Thank you, girls!



Helen and Louise cycled 400 miles in four days with their Cycle for James event, raising £7,000 for us and CLIC Sargent.

## Is it TIME you did something amazing? Sign up online!

Inspired? From London Marathon to Three Peaks Challenge, from bungee jumping to mountain climbing, to view even more events please visit [rainbowtrust.org.uk/events](http://rainbowtrust.org.uk/events)



To celebrate their partnership with Rainbow Trust, the Lynch Haulage rainbow lorry made an appearance at CarFest North and South this summer.



48 climbers, brought together through the Slimming World community and Instagram, conquered Mount Snowdon, raising a phenomenal £15,000.



Intrepid skydiver, Danny Casely, from Decanter magazine bravely took flight for Rainbow Trust and completed a skydive which raised a whopping £10,000!

Support provided by our  
Family Support Workers across the regions

There are 8,760 hours in a year. This is how much time of practical and emotional support you have helped us to provide to terminally ill children and their families.



**8,990**  
hours of home support



**5,210**  
hours of hospital support



**5,473**  
hours of parental support



**5,157**  
hours of support for siblings



**13,517**  
hours of transport



**457**  
hours of parental respite support

Some of the ways in which a  
Family Support Worker helps

- Keeping a sick child entertained with arts and crafts activities and one to one support
- Spending time with a sick child's brothers and sisters so that they don't feel forgotten
- Being there to give emotional support to parents as they go through their child's diagnosis and treatment
- Helping around the home, freeing up time and taking the pressure off parents
- Providing transport to and from hospital appointments
- Offering bereavement support; being there for families however long they need us.

**£26** is enough to provide an hour's vital support to a family with a terminally ill child, giving them quality time together

**£156** pays for a family's bespoke bereavement support from a Family Support Worker for one month helping with plans that will need to be made as well as offering emotional support at a devastating time

**£608** will pay for the car costs and travel expenses for a Family Support Worker's car to transport distraught parents and

their sick child to the hospital so that they don't have to travel on public transport for a month

**£1,780** is the average cost of support for a family with a seriously ill child for a year

**£22,250** will pay for a Family Support Worker for six months of the year. We are there for families from diagnosis, through treatment and if necessary, through bereavement.

**YES!** I want to give families with a seriously ill child precious **TIME** together

Title \_\_\_\_\_ Name \_\_\_\_\_ Surname \_\_\_\_\_  
Address \_\_\_\_\_ Postcode \_\_\_\_\_

I would like to receive emails: \_\_\_\_\_

Please call me on: \_\_\_\_\_

£15  £25 Other:

I enclose my cheque made payable to Rainbow Trust Children's Charity or

Please charge my:  Visa  MasterCard  Maestro  Amex

Name on card:

Card No:

Security Code:  Issue No:  Start Date:  /  /  Expiry Date:  /  /

Please send your donations to:  
Rainbow Trust Children's Charity, Cassini Court,  
Randalls Way, Leatherhead, Surrey KT22 7TW  
T: 01372 220083 E: supportercare@rainbowtrust.org.uk  
[rainbowtrust.org.uk/donate](http://rainbowtrust.org.uk/donate)



giftaid it

Please tick, sign and date here to boost your donation by 25p of Gift Aid for every £1 you donate, at no cost to you.

Date:

I want to Gift Aid this donation and any donations I make in the future or have made in the past four years to Rainbow Trust Children's Charity. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all of my donations in that tax year it is my responsibility to pay any difference.

You are helping us to support over 2,500 families each year and we would like to keep you informed about the difference that your support is making to those families' lives. We will stay in touch by post based on our legitimate interest to communicate with you but please tick here  if you would prefer not to receive information by post. We will keep your details safe and you can change your preferences at any time.