

# FAMILIES FIRST

SPRING/SUMMER 2020

IT'S  
ABOUT  
TIME

**New report:** "Parents Matter:  
The impact on parents'  
mental health when a child  
has a life-threatening illness"

**Find out about**  
A week in the life of a  
Family Support Worker

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

# Dear Supporter

It's been an exciting few months since your last issue of *Families First*.

Thanks to the wonderful gifts of friends and supporters like you we continue to plan to recruit new Family Support Workers in the future. We are very grateful to everyone who has contributed to this great achievement.

Over the last two years 20% more families have turned to us for support and, in some places, we just don't have the capacity to help every family. New Family Support Workers will enable us to support more life-threatened children and their families who desperately need us. This will only be possible thanks to generous donations and our ambition is to do more.

We still have a big challenge ahead as more life-threatened children and their families in desperate need of practical and emotional support turn to us.

On average it costs just £1,780 to support one family for an entire year. By getting behind our *It's About Time* campaign you will ensure that a parent 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 all have the **time** and support of a dedicated expert Family Support Worker.

I am also delighted to say that we have now published a new and important report, *Parents Matter: The impact on parents' mental health when a child has a life-threatening illness*. You can read more about it on page three.



We are strongly encouraging commissioners and health professionals to make sure that the particular needs of parents with seriously ill children are recognised in local mental health services, and that, if parents need it, access to psychological support or counselling is available promptly.

We can only help give precious **time** to life-threatened children and their families and respond to the increasing demand thanks to generous gifts from organisations and people like you. We are very grateful for your wonderful support. Thank you.

Zillah Bingley, CEO

# Contents

From the CEO	2
Parents Matter: The impact on parents' mental health when a child has a life-threatening illness	3
Specialist sibling support for Freddie	4
The emotional rollercoaster of a neonatal ward	6
Your support really matters	8
A week in the life of a Family Support Worker	9
Holding space, opening our hearts and stopping judgement	10
Fundraising heroes	11
Diary of events	12

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.

Pledge your support to fight for families and join the *It's About Time* movement here [mailchi.mp/rainbowtrust/its-about-time](https://mailchi.mp/rainbowtrust/its-about-time)

## STAY IN TOUCH

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# PARENTS MATTER:

## The impact on parents' mental health when a child has a life-threatening illness

**Our new report shows how practical and emotional support from a Rainbow Trust Family Support Worker can be a protective factor for parents' mental health.**

Hearing that your child has a life-threatening or terminal illness is one of the most stressful and traumatic experiences that a parent can have. Parents can be under severe strain for many months or years and many will experience feelings of anxiety, distress, depression or trauma.

Timely counselling or psychological therapy by professional practitioners is fundamental for parents with mental health problems when their child is seriously ill. Alongside this, the involvement of a Rainbow Trust Family Support Worker can help parents' mental health in a number of ways.

Our Family Support Workers provide both practical and emotional support, such as listening to parents as they share their emotions, keeping a seriously ill child entertained and offering one-to-one support, spending time with healthy brothers and sisters so they do not feel forgotten and giving bereavement support if needed.

The training and experience of our Family Support Workers equips them to spot potential mental health issues and to respond at an early stage. Regular support from them can reduce parents' need for additional professional help by sharing coping strategies and offering emotional support. And when a parent has significant issues, their Family Support Worker can help refer them to mental health or counselling services.

With the right support at the right time, parents can develop ways of managing their mental health during an incredibly difficult period.

We are calling for the particular needs of parents with seriously ill children to be recognised in local mental health services, and that, if required, there is prompt referral and access to psychological support or counselling.

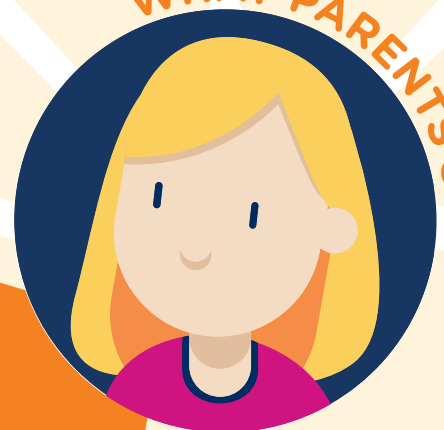
*Look after yourself.  
Make the time to get  
out of the hospital.*

*Talk! Find someone  
you click with, another  
parent, a friend, a nurse,  
Family Support Worker  
and tell them how you  
feel! Use professionals,  
as they may be able to  
help you even more.  
This is how we found  
Rainbow Trust.*

*It's OK to feel how  
you feel. It's OK to  
be authentic with  
how you feel.*

*I'd say ask for help,  
you're not alone.  
Just ask.*

WHAT PARENTS SAY



For parents' tips to manage mental health go to [rainbowtrust.org.uk/tipsforparents](https://rainbowtrust.org.uk/tipsforparents)

To find out how to help parents check [rainbowtrust.org.uk/helpparents](https://rainbowtrust.org.uk/helpparents)

Find out more and download the full report at [rainbowtrust.org.uk/parentsmatter](https://rainbowtrust.org.uk/parentsmatter)

# SPECIALIST SIBLING SUPPORT FOR FREDDIE

Family Support Worker Charlotte gives Freddie time and space to understand his own feelings and emotions



Freddie and Freya with Family Support Worker Charlotte

After a normal pregnancy, when Freya was born, Kelly knew immediately there was something wrong. But it took almost six months of insistence, perseverance and determination before doctors acted on Kelly's requests. Kelly says *"It was awful. I remember sitting in the doctor's surgery chair saying, 'I'm not leaving until I see a doctor'. They eventually conceded - if they hadn't, Freya would not be here right now"*.

Just before her first birthday, Freya was diagnosed with a very rare inherited metabolic condition, Pyruvate Dehydrogenase Deficiency (PDH), characterised by a build-up of lactic acid in the body and a range of neurological problems. Neither Kelly nor David are carriers - it is a random mutation.

They were devastated when they first had the diagnosis. Leaving the children's hospital they were distraught, their whole world had been blown apart. Freya's parents were told she wouldn't even be able to hold her head up, yet she is now walking.

At seven years old she is a medical marvel and is doing brilliantly. Although PDH affects every part of Freya's life - she can't dress herself, her speech,

vision and mobility are affected and she needs a specialist diet because her eating and drinking is compromised - Freya is a determined, sociable little girl. Freya is non-verbal but she lives life to the full and wants to be treated as any other child would.

One of Freya's nurses recommended Rainbow Trust to Kelly and David as they also have a four-year-old son, Freddie.

Kelly explained to Family Support Worker Charlotte, from Rainbow Trust, that their life unintentionally revolves so much around Freya that Freddie wasn't getting enough attention. Both their extended families live a long distance away and they have no support from friends or family at all so they asked for specialist sibling support for him.

***"I can't put into words the difference that Charlotte's presence, expertise and specialist support has made to Freddie."***

Before Rainbow Trust, when Freya was unwell, it was very upsetting and distressing for Freddie to see his big sister seriously ill. He didn't understand.

Freddie talks to Char-Char (his nickname for Charlotte), he opens up and tells her how he's feeling. She listens to him and she's trained to deal with anything he brings up. With Charlotte, he can get out any frustrations he is having - that time is just about him, not Freya's feeding time, medicine time or therapy time, it is just about him.

Freddie loves Char-Char. She is there just for him. She takes him to the park or plays in the garden with him. Whatever Freddie wants to do, they do. Kelly says: *"I can't put into words the difference that Charlotte's presence, expertise and specialist support has made to Freddie"*.

Charlotte's support also takes the pressure off Kelly from feeling quite torn: *"I'm the mum of a child with severe needs and that time is very precious - I'm grateful for any time spent with Freya. But I feel guilty as Freddie is so different and both children's needs are at opposite ends of the spectrum. So, the time that Freddie gets with Charlotte is all about him, nobody else. He sometimes says,*



With Family Support Worker, Charlotte, Freddie can express any frustrations he is having

*'Mummy, can you go out, so I can have Char-Char to myself', so I leave the house and when I get back, I know he has had the time he needs".*

Specialist support is very important for siblings of seriously ill children: it helps them understand that their sibling may die soon; they also get the tools to cope with that reality and to deal with the issues they face living with a seriously ill brother or sister. Freddie has seen Freya at her worst in a hospital bed and needed to understand and manage his feelings. He is a child living in an adult world so it is invaluable for him to have the time and space to let off steam and explore his emotions with Charlotte.

Rainbow Trust's support gives Freddie a safe outlet and, if he raises anything that he is worried about with Charlotte, his parents are informed so they can talk about it. *"I think it is important that every sibling affected is able to share their feelings and worries. I think for Freddie, in the long run, it will make a big difference"* says Kelly.

This vital support now, when it is seriously needed, will mean that further down the line Freddie will understand what is going on. *"The earlier the intervention, the better. I wouldn't want Freddie to have been without Char-Char and Rainbow Trust. I know he is getting the best possible care and support he needs. Every sibling of a seriously ill child should have it".*

84% of families had felt isolated since their child's diagnosis with a life limiting condition\*.

Your donations and support enable families with a life-threatening or seriously ill child 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. Thank you.

\* Source: Together for Short Lives

**We receive no central government funding and rely entirely on donations to fund our work.**

We support over **2,500** life-threatening or seriously ill children and their families every year.

So far this year **426** new families are receiving our support.

Thanks to the wonderful gifts of friends and supporters like you we continue to plan to recruit new Family Support Workers in the future. But we need to do more. There are more families who need our services and, in some areas, we simply don't have the resources to take on every family that turns to us for support. We can't do this alone.

It is only thanks to your donations that we can give seriously ill or life-threatening children and their families expert, practical and emotional support for as long as they need it.

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



# THE EMOTIONAL ROLLERCOASTER OF A NEONATAL WARD

**Ella-Mae was supported by Rainbow Trust when her twins were born at 26 weeks. Here she describes what life was like and how their Neonatal Support Worker helped her and her partner to cope**

My partner, Giovanni, and I had been told early on that the chances of our twins surviving were slim. I had problems with my cervix throughout my pregnancy and was placed on immediate bedrest under doctors' orders from 20 weeks. Despite having numerous appointments and scans, and receiving the best medical care, our hope began to dwindle, and fear set in that our girls might not make it. We knew that even if the twins survived, their health might suffer in the long term, and we had no idea how to handle this. Our future felt uncomfortably uncertain.

I managed to carry both girls to 26 weeks and 4 days. Although their birth was straightforward, we knew their fight was far from over. Like many mothers who find themselves in the neonatal ward, my experience was a far cry from any expectation of how I'd imagined parenthood would be. The dreams of holding my babies close in my arms were replaced by tubes, wires and scary medical terms we had never heard before. I found myself in an environment laced with fear and worry, a place where no parent wants to be.

The realisation that there was no certainty that my fragile twins would survive was almost too much to bear. At birth, both our daughters, Bella and Ruby, weighed under 2lb and could fit in the palm of my hand. Their skin was translucent, and they were placed into an incubator immediately after birth to give them the best chance of survival. In the days that followed, I did my best to remain strong.

The days on the neonatal ward felt like they never ended. Each day grew longer and more uncertain as Bella and Ruby's health improved and deteriorated interchangeably, at what felt like unstoppable speed. Giovanni and I found ourselves stuck on an emotional

rollercoaster which we simply couldn't get off.

Between them, the girls had over 10 blood transfusions and other procedures in the days that followed. Neither of us had any knowledge of this new and scary world we found ourselves in, and we needed support.

*“ When I thought the girls may not make it, I felt my world had crashed down around me. I was certainly hopeless. ”*



**“ We will never forget the kindness and support shown to us by Rainbow Trust during the hardest days of our lives. ”**

I reached out for help from Rainbow Trust when I saw a leaflet in the hospital parents' room offering help to parents of seriously ill children. After a brief phone call, a date was made for a home visit. I wasn't sure what to expect and was incredibly anxious about talking to anyone about how I was feeling. I needn't have worried, as a kind Rainbow Trust Care Team Manager came and sat with me to listen to my situation and ask where I felt the best support would be. We all agreed some practical help would be the best place to start, and within a few days we met Fiona, who became our dedicated Family Support Worker. Fiona supported us immensely in the challenges that lay ahead.

*“The realisation that there was no certainty that my fragile twins would survive was almost too much to bear”*



We anticipated that once the girls were home from hospital our problems would disappear. Much to our despair, the girls required round-the-clock care, as we were told they had chronic lung disease and required 24-hour oxygen support. During the next eight months Fiona provided a cushion to the heavy blow for our whole family. She gave us much-needed respite and support and attended hospital appointments with us.

Due to their prematurity, the girls' lungs hadn't developed at the same rate as other babies. The oxygen support worked to help their tiny bodies receive the oxygen they needed while not putting too much pressure on their already weak bodies. The hospital gave no indication of how long

both twins might need this care. However, eight months later, we celebrated having two babies free from oxygen support.

Both girls are now happy and healthy, and the twins' early difficult days in this world are a distant memory for us. We will never forget the kindness and support shown to us by Rainbow Trust during the hardest days of our lives.

Rainbow Trust is dedicated to supporting families like mine and have Neonatal and Family Support Workers like Fiona across the country, providing tailored care to suit families' needs. Last year alone, they provided over 5,000 hours of hospital support to families, allowing parents to take a much-needed break from spending endless hours in hospital.

Rainbow Trust Family Support Workers help the whole family, as everyone is affected when a child, let alone two, are seriously ill. Many parents feel that they can't or shouldn't ask for help but the truth is that at a time when their world feels as if it is falling apart, help is vital.



Sponsor a Family Support Worker like Fiona 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.

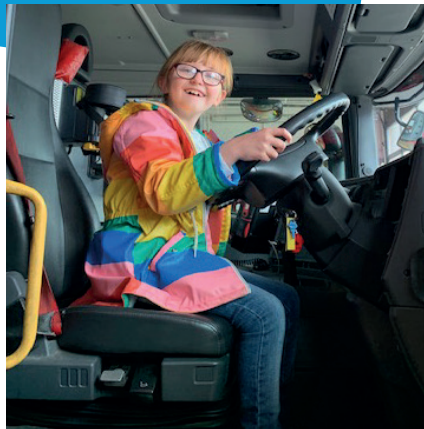
**[rainbowtrust.org.uk/sponsor-us](https://rainbowtrust.org.uk/sponsor-us)**

# YOUR SUPPORT REALLY MATTERS

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



Keely enjoys a fun Lego afternoon. Keely's brothers have Duchene Muscular Dystrophy, a disease that causes muscle weakness and wasting



Sophie had a shunt fitted to relieve pressure caused by the build up of fluid on her brain. She really enjoyed a morning at the Isle of Wight Fire Station



Phoebe and Family Support Worker Ema decorated wood houses. Phoebe's sister has a rare neurological disorder, Rett Syndrome



Wivine modelling one of the beautiful wigs donated by The Magic Yarn Project, helping her get through chemotherapy



Siblings of seriously ill children having a fun time bowling at a youth group night where they meet with other children in similar circumstances



Esmae visited hospital and conquered her anxiety about her two-year-old sister's dialysis with Family Support Worker Liz



Twins Lucas, who has a rare disorder, Lymphoblastic Lymphoma, and Emily enjoying a nice breather spending some time in nature



George, whose brother Tommy has Neurofibromatosis, loving some time out at the Winchester Science Museum

**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, arts and crafts, time in nature and chats give the children a break and are also mechanisms we use to help look after their mental health and well-being. These activities help to increase their confidence, self-esteem and independence at a time when they need it most. They also help to give the children tools to cope with life in future.



# A WEEK IN THE LIFE OF A FAMILY SUPPORT WORKER

Sophie is a Rainbow Trust Family Support Worker in the North West and shares a typical week with us.



By Sophie Harris

## MONDAY:

I visited Lucy (aged seven) and Ben (aged six), Jamie's siblings, in school. Jamie, who is nine, suffers from Nonketotic Hyperglycemia, a rare disorder that causes serious neurological problems. I am supporting Lucy and Ben due to Jamie's diagnosis, preparing them for bereavement and to feel able to talk about their worries and fears.

Next I visited Tom (aged 15) after school for support in coming to terms with his sister, Annie (aged 12), not being able to have any more treatment. Tom is struggling with the fact that Annie will die and seeing her deteriorating so we talk about this, what is changing and ways he can deal with it. Tom tries to protect his parents by not telling them how he feels.

## TUESDAY:

Every other Tuesday we have a team meeting to discuss our caseloads, new families, share information and complete some admin work.

After the meeting I visited Molly's sister, Katie (aged eight). Molly (aged three) is in hospital far away and Katie doesn't often see her due to the distance. Today we went bowling and had tea out. This is Katie's special time giving her one-to-one support. Katie often talks about worries she has; I listen and offer some reassurance to her. Our time is a change away from home or extended family who help to look after her.

## WEDNESDAY:

I visited Lewis (aged three), who has been in hospital for several months. Today I supported Lewis' mum emotionally whilst playing with him. Mum was very upset. We spoke about this and I helped her focus on the positives. Lewis' development has become delayed due to the long stay in hospital so it is good for his development to play and engage in activity with me; it is also something different for him to do, with someone other than his mum.

Next, I went to see a newly referred family. I will provide sibling, sick child and emotional support. Their ill child had a high-risk cancer and the whole family is struggling. I will visit the children in school for one-to-ones and at home for the whole family. The visits will help build a positive relationship for the children and parents to be able to face their worries and settle into their new 'normal'.

## THURSDAY:

Today I visited Sienna (aged six) and Millie (aged four), Blake's sisters. Blake (aged three) has Vacterl association, a disorder that affects many body systems. This is some special time for them to relax and have fun. Mum worries that the girls sometimes miss out on being able to do fun things especially when Blake is very unwell. We went out to soft play and for a burger and the girls had a great time.

## FRIDAY:

I visited Zach (aged seven), who has Treacher Collins Syndrome and cannot communicate clearly verbally. Mum understands him, but I find it difficult. I encourage Zach to use his talker to communicate with me so we can have conversations with full understanding. Today Zach and I were playing with his Lego and, without being asked, for the first time, he chose to use his talker to tell me exactly what he wanted to say. My visits allow Mum to do some jobs that she is unable to do when she is with Zach alone.

I went on to collect Mila from school. Mila is a twin sister to Lexi (aged eight). When I started working with the family Lexi had a tracheostomy and their parents were worried about Mila missing out. Later, Lexi had her tracheostomy removed. Today was my last visit because they are doing so well. We spoke about why they no longer need our support. Mila said she really enjoyed Rainbow Trust being involved because she got to do fun things. Mum thanked me a lot for the support we gave before I said goodbye.

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

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

# HOLDING SPACE

## Opening our hearts and stopping judgement

By Fiona Rankine

When there is so much to say and no space in the day to say it, having someone who will create room for you to just be yourself can be the thing that keeps you from being overwhelmed and less able to cope.

There can be few things that are more upsetting than managing the feelings generated from having a seriously ill child, yet parents will rarely prioritise their own well-being, and this can lead to both emotional and physical health issues.

It is a normal reaction when we see a friend or colleague suffering to want to make it better, to say something helpful or to make them feel that we understand by sharing our own experiences and, of course, there is nothing wrong with this. Rainbow Trust Family Support Workers do things a bit differently. We fully understand that each parent's experience is unique; we can't change what is happening, but we can consciously create **time** for parents to feel that they can be heard, without fear of judgement, by someone who will not be shocked by what they say.

Family Support Workers endeavour to validate the feelings that parents express by truly understanding their



**When we hold space for others we open our hearts, accept their experience and emotions as they are and offer unconditional support**

point of view and through being present in their pain and loss.

Holding space for another person can be incredibly profound. In a fast-paced, problem-solving world, where we fear the impact we can have on others, taking risks in offering to truly hear someone talk about their situation can be a unique experience and one which is both empowering and transformative. One parent told me *"I hate that look I get when I talk about my child's treatment, the fear and upset makes me want to make it better for them! I just end up saying everything is OK, but it's not"*.

We recognise that parents need to be encouraged to take **time** to talk: it is hard for them to set aside their caring role for just a while. Commonly parents under extreme stress feel that they cannot afford to think about or express how they are feeling for fear of buckling under the

strain of their situation. They convey concern that they will be judged unfairly and, worse, that they will be viewed as not coping. Rainbow Trust Family Support Workers give permission to parents to voice their doubts and heartache knowing that rather than draining them, the conversations they have with us empower them to carry on doing their very best for their child. Their well-being is a key component to managing the day-to-day pressure of having a seriously ill child.

A mum told us that spending **time** with their Family Support Worker was *"like releasing the cork from the bottle. The intense pressure is gone, and I can see that I'm doing OK - considering. It is so comforting to have someone believe in me"*.

**Fiona is an Advanced Practitioner Family Support Worker with Rainbow Trust.**

## Pledge your special day and make it inspirational

Share your big day and change lives

If you have a special birthday, your wedding, a baby shower, a naming ceremony or if you are celebrating your engagement or a milestone anniversary, why not ask for donations for Rainbow Trust instead of presents and help us support life-threatened children and their families?

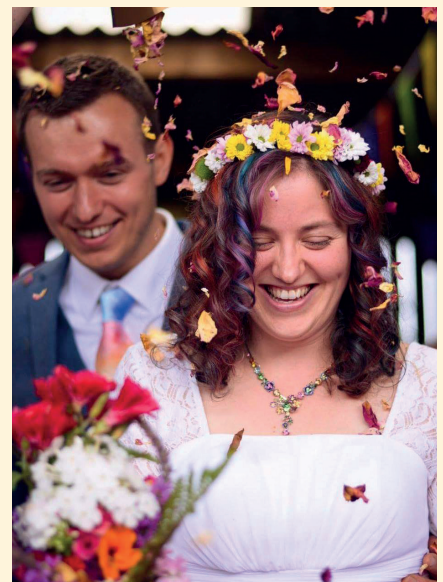
Composers Joe and Anna (pictured)

chose Rainbow Trust to benefit from donations in lieu of presents for their wedding after Anna had a tough time when she was expecting their twins, Ben and Nathan. She and Joe were given very worrying news during the pregnancy, but, happily, the twins were born safely and with no complications.

We have decorations, place cards, balloons and personalised donation envelopes to help you organise your special day.

To find out more and ask for your lovely **Big Day Pack** call Karen on 01372 220083 or visit

[rainbowtrust.org.uk/weddings-and-anniversaries](http://rainbowtrust.org.uk/weddings-and-anniversaries)





Thank you to ILC for their tenth year of support. Their latest Networking Lunch celebrated ILC reaching a whopping £842,000



Kurt Geiger supports us through volunteering, sales of their rainbow Kensington Crystal bags and by running up 48 flights of stairs - eight times! Go Team KG



Nell McAndrew climbed the 'Cheesegrater' in London at our Grate48 event that raised £37,213

# FUNDRAISING HEROES

*Thank you!*



Bella cut short her hair to raise money for Rainbow Trust. She has raised an amazing £856. Thank you!



Diana has already smashed her 2020 Virgin Money London Marathon target raising £3,244 to date



The Lunch Box Leatherhead, a local sandwich shop, raised a fantastic £2,688 from having our collection tins on the counter



Writer, presenter and former MP, Gyles Brandreth, recorded the voiceover for our Christmas animation



We were very happy to meet the Mayor of Bath, who showed his support at our Bath Christmas market stall



Families joined us at Chessington Garden Centre to help raise funds during Halloween

