

FAMILIES FIRST

AUTUMN/WINTER 2022



Inside:
Helping families
living with
childhood
cancer

**A snapshot
into the life
of a Family
Support
Worker**

**Your
support
really
matters**

**RAINBOW
TRUST**

**SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD**

Dear Supporter

As I write this, we have just heard the very sad news that Her Majesty Queen Elizabeth II has died. We send our sincere condolences to His Majesty King Charles III and all members of the Royal Family on the sad news of her death. Her life was dedicated to serving others and our heartfelt thoughts and love are with all who mourn.

Thank you for continuing to support families with a life-threatening child. It is only thanks to you that we can be there for families living with a terminal illness.

I am pleased to share that our new care team in Reading is open and Liverpool will follow shortly. This gives us capacity to offer face-to-face support to around 200 additional families each year and ensure that they receive the practical and emotional support that they need.

We hope shortly to bring you news about the Kentown Children's Palliative Care Programme which is a collaborative programme between Rainbow Trust, Together for Short Lives and The Kentown Wizard Foundation to join up support for families with a seriously ill child.

We were pleased to see the introduction of the 'Neonatal Care (Leave and Pay) Bill' in Parliament, which charities and families have been calling on for many years.



Cover photo: Family Support Worker William says he has the best job in the world. He walked alpacas in the Lake District with Kenzie, who has spent the majority of the last two years in hospital.



This Bill provides for paid leave from work for parents with children receiving neonatal care whilst their ill baby remains in hospital.

We know only too well that parents can be pushed into desperate situations when they cannot afford to take unpaid leave at such a traumatic time and have to balance work alongside constant visits to hospitals, as well as managing other caring responsibilities. This adds immensely to the stress already experienced by parents coping with the challenges of having a premature and seriously ill baby.

We are very grateful to CarFest for choosing us as one of their benefitting charities again and thank all the amazing fundraisers who have taken up challenges raising phenomenal amounts of money. Thank you for all you do to help families with a seriously ill child.

Best wishes

Zillah Bingley, Chief Executive

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Rainbow Trust Family Support Workers help families practically and emotionally as they navigate the challenges of living with childhood illness. To many of us, family means everything so when serious illness affects a child, and family life is turned upside down, this tailored and expert support enables families to make the most of their time together.

STAY IN TOUCH

Call us: 01372 363438

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supportercare@rainbowtrust.org.uk

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CELEBRATING VERY SPECIAL WORK ANNIVERSARIES

This edition we wanted to highlight and thank the entire team of Family Support Workers, especially those who have been supporting families with a life-threatened child for over a decade.



Family Support Worker Marlene

“ My daughter was diagnosed with liver cancer at the age of 12. Marlene became part of my family and even supported me and my younger daughter after the death of Laura. I will always be grateful for her support. ”



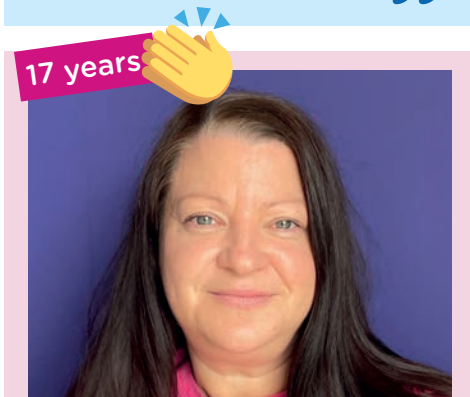
Family Support Worker Mandy

“ The families I work with are dealing with trauma and stress, facing the unthinkable. Some can't see a way out. I help the whole family in any way I can to adapt to and cope with their new reality. I am there for them. ”



Family Support Worker Nicki

“ When I meet parents for the first time, they are usually at their lowest. I know they are in crisis. We have the knowledge, the experience and the empathy to make a positive impact. One dad even said that he wished every family could have a 'Nicki'. ”



Family Support Worker Monica

“ Thank you, Monica. I'm so glad the children have someone like you in their life, they love you ❤️ You make me feel so comfortable being away in hospital as I know the children are in some lovely hands. ”



Family Support Worker Zak

“ The families we support need so much help: from practical solutions, like driving to hospital, to helping parents and siblings cope with anxiety and fear. I am happy I can help them at a time they may be unable to cope. ”



Family Support Worker Janet

“ Janet is always there when I need her, or when I need to talk to someone. She's not just a Family Support Worker. Janet was like a member of the family and a very good friend of mine. We all love you and are so thankful to have you in our lives. ”



Family Support Worker Jayne

Please read from Family Support Worker Jayne, who has been supporting families with seriously ill children for 15 years on page eight, where she talks about her work with families with a seriously ill child.

Thank you to our Family Support Worker team for your dedication and work for families with a seriously ill child.

A BRAIN TUMOUR TOTALLY CHANGED ZACK AND OUR LIVES

Family Support Worker Kate supports Zack and his family after he was diagnosed with a brain tumour.

“ I am Zoe, mum to four boys: Kyle, 28, Declan, 15, Zack, 13, and Riley, 10.

At the end of August 2021, just before starting year eight at school, Zack had what I thought was a sickness bug but he also told me he had a really bad headache. I was very concerned so I took him to A&E and, whilst we were there, he had a seizure. He was taken for a scan which showed that he had a brain tumour. He was immediately transferred to James Cook Hospital in Middlesbrough for emergency brain surgery to relieve the pressure of fluid on his brain. I was terrified. I was so worried and anxious about all of what was happening.

After that we were admitted and spent the next three months at the Royal Victoria Infirmary in Newcastle for treatment. He is now back home but I take him to the hospital every week to have chemotherapy.

Unfortunately, the tumour also left Zack with a brain injury and he is now registered disabled. Whilst Zack's disability does not affect his ability to move, long walks are difficult. Brain injury manifests in different ways and, in Zack's case, he may become emotional and he forgets little things easily. Zack does remember his Family Support Worker, Kate, very well though.

Kate started supporting our family on the hospital ward, while Zack was going through the first stages of treatment. She now supports us mainly by taking Zack out. They spend three hours a week together which gives Zack some special time, one-to-one support, and allows me some respite, enabling me to do other things and catch up with family admin and chores.

The brain injury has completely changed Zack's personality and at times he can be totally unpredictable. At one point he told people that Kate had abducted him! Kate takes it all in her stride and is fantastic with him and with me, she is a great addition to our support network.



All aboard, Zack about to get a ride at Beamish Museum, County Durham



Zack proudly shows off his bowling score



Zack with Family Support Worker Kate enjoying a day out at Beamish Museum, County Durham

Zack's life has changed so much.

He can't attend his usual school now so we are in the process of finding him a specialist school that can meet his needs.

In the meantime, the local authority has arranged home schooling and Zack has a tutor four days a week. He loves maths so he's really pleased with this arrangement and recently asked his tutor for something harder. I am proud of him for how he is dealing with his situation and also for being such a keen student.

Being 13 years old, Zack understands what is going on and may get emotional about how his life is now. The time he spends with Kate helps him to manage and deal with what he is going through. Kate helps Zack with coping techniques and by talking about the challenges he faces everyday.

Living with teenage boys, like any parent, I am very busy and I simply try to cope with this challenging situation. I am very practical, very hands on and try to stay positive. Zack's outlook is uncertain. The MRI scans have shown that the tumour hasn't shrunk and he will definitely need more treatment after he has finished the current round of chemotherapy.



Zack at the amusements. Together with Kate they won 600 tickets

Zack tells me that he loves going out with Kate as he feels safe and he always has fun.

Without the support from Kate I feel we wouldn't get the break we both need.

I would encourage other families to ask for support from Rainbow Trust if they are facing living with the worries and stresses of childhood illness; they are a lifesaver.

Having a child with complex needs is tough on parents; Rainbow Trust Family Support Workers like Kate help the whole family, tailoring the support to each family member, in the hope that we can make life a little easier, giving them time to focus on what matters the most to them.

rainbowtrust.org.uk/donate-magazine

HELPING FAMILIES LIVING WITH CHILDHOOD CANCER

Family Support Worker Wendy supports Krystal and her son Kahmari as they deal with his leukaemia diagnosis

One morning in February 2021 five-year-old Kahmari woke up unable to move his arms. He was in a lot of pain so his mum, Krystal, took him to the doctor, who prescribed painkillers. The next day Kahmari was worse. Krystal was very worried so took him back to the GP who referred him to the local children's hospital.

This appointment was not until the following week and by the weekend Kahmari was feeling so unwell that Krystal decided to take him to A&E. The doctors checked him for broken bones and infection and, after several tests, on 14 February 2021, they gave Krystal the devastating news that Kahmari had Acute Lymphoblastic Leukaemia. Krystal said: *"I could really not comprehend what was happening. I couldn't believe what I was hearing. I felt really upset, I was angry, I was so very sad"*.

Kahmari was in hospital for two weeks. His first course of chemotherapy treatment and steroids was for six weeks; this treatment made him feel very ill and he was very upset.

Krystal is a single parent and she doesn't have a wide network of support. This scary situation was making her feel isolated and very tired and stressed, coping alone with the pressure and worry of Kahmari's diagnosis.



Kahmari having fun in the park

Kahmari was referred to Rainbow Trust by a social worker. The initial assessment with Family Support Worker Wendy was completed over the phone due to the ongoing restrictions of the pandemic at the time.

In March 2021 Wendy started to support them and both Krystal and Kahmari were very shy and quiet the first time they met Wendy. Krystal also thought it would take a while for Kahmari to open up and connect with Wendy so, hoping to

build a relationship with Kahmari until he was happy to spend time alone with her, Wendy offered to support them whilst they were at the hospital for treatment.

Wendy worked on building their bond to eventually allow some much-needed respite for Krystal. Kahmari found it hard to pronounce Wendy's name so she took the new name of 'Wenshy'.



Family Support Worker Wendy



Kahmari enjoying an art and craft session with Family Support Worker Wendy



Wendy organised tickets for Kahmari and Krystal to have a special day out at Cotswolds Wildlife Park

Krystal said: “Kahmari would ask everyone at the hospital if Wenshy was there, he would call out Wendy’s name to any lady with brown hair and I had to count down the days until he next saw her”.

In April Wendy started supporting the family at home too.

When Wendy visits, she takes Kahmari to the park to ride his bike and play football, or they do arts and crafts. But what Kahmari likes most is when Wendy helps him reach the next level on his Nintendo game. This fun time with Wendy provides respite to Kahmari’s mum and also an outlet and emotional support for him, as he navigates and understands what it means to go through treatment and live with cancer.

On top of the challenge of dealing with her son’s serious condition, and to make things worse, Krystal lost her job due to being in hospital all the time with Kahmari. Like many people in this situation Krystal is anxious about money. Wendy provides emotional support to Krystal and also helps by signposting her to information and financial benefits to which she might be entitled.

Kahmari is now at school and having his treatment at home. He has had the occasional hospital admission where Wendy has supported the family but most of the support now is at home.

Although Kahmari’s treatment will not finish for another two years, Krystal is feeling much more positive and has started an Occupational Therapy course at university.

Wendy will continue to support the family until they feel able to cope on their own.

Krystal said:

“ I just want to say thank you to Wendy for putting in the extra effort during this difficult time in our lives. Just having Wendy around playing with Kahmari and keeping him entertained whilst I have a break has really helped. I couldn’t imagine life without her. Her positive attitude has helped us to continue to feel motivated. ”

Acute Lymphoblastic Leukaemia (ALL) is a rare, acute blood cancer which affects the lymphocytes (white blood cells) in the bone marrow. Chemotherapy and steroids are the main treatment for ALL. Every year some 800 children and adults are diagnosed with ALL in the UK.



Help families and sponsor a Family Support Worker like Wendy today.

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



Scan to donate

Some names have been changed.

A SNAPSHOT IN THE LIFE OF A FAMILY SUPPORT WORKER

Family Support Worker Jayne gives us an insight into some of the families she supports in London and the South East

By Jayne Dickens

I started working for Rainbow Trust in September 2007 so I am celebrating my 15th anniversary this year. The families I have supported and currently support are all very different: they have different needs, the children's conditions are varied, the families' situations are diverse and living with childhood illness and the trauma and stress this may cause manifests in many contrasting ways.

Sometimes, there are also cultural, religious and language differences that we have to manage because we want to support every family that needs us in the way that works for them. We listen and help practically without judging. We are there when families who are going through immense pressures and difficulties need us the most.

I like to look after and comfort people and that is what makes caring for and supporting seriously ill children and their families so rewarding to me.

“ You listen, you just care. ”

Mum supported by Family Support Worker Jayne

NOAH is four years old with a heart condition and complex needs. Noah was born with his organs back to front and has just had major surgery which will hopefully see him into adulthood.

Noah's mum, Clara, has some support from family and I mainly provide face to face emotional support, two hours every week. It is very stressful and isolating to have a child with such complex needs. Emotional support is mainly about listening rather than giving my opinions. I am a sounding board and can suggest techniques to cope with difficult situations, manage negative emotions and I can offer potential solutions that may help in some instances. Sometimes a cup of coffee or getting out of the house with somebody like me could be just what is needed to help keep everything together.

We also talk on the phone twice a week, usually for about half an hour, to discuss anything that may be worrying her, and I go to some hospital appointments with them too.



DANIEL very sadly died from cancer in 2018. He was 12 years old and I had been supporting the family since 2016, following his diagnosis. They needed practical and emotional support as, at the time, Daniel's mum, Sandra, was pregnant with her third child.

Both Sandra and her husband Ryan gave up work when Daniel was diagnosed. Ryan did most of the driving to and from their home in Brighton and the Royal Marsden Hospital in London. Because Sandra doesn't drive, I took Daniel when Ryan was not able to.

I used to go to the house and spend time with Sandra giving her emotional support and helping with household chores whilst Daniel went to London for treatment.

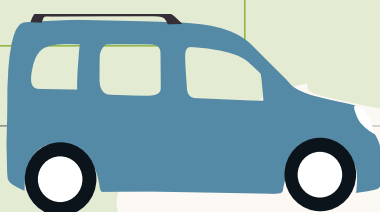
Six months after the funeral Sandra told me that she would like to have a stone and plaque for Daniel's grave. Ryan found this very difficult to cope with so I went with Sandra to the stonemasons to organise the delivery and unveiling.

I now pick Sandra up from home every month and take her to the cemetery to tend his grave. We used to do this every week but this is less frequent now that she is better able to cope. Sandra has no gardening tools so, when we go, I take mine. While we tend the grave we talk about her feelings, her grief and about when Daniel was alive. I know she gets a lot of comfort from these visits.

For some of the families that we support they feel that medical professionals become almost like a second family to them. And yet, after the death of their child this medical provision stops immediately because it is no longer needed. This can be very difficult for families, who suddenly feel they have nobody to go to who knew their child and their situation.

“ You're the only professional that is still with us and that means the world to me. ”

Sandra, mum to Daniel



I have been supporting **CAITLIN'S** family since March. Caitlin is 10 years old and is being treated for a severe heart condition at the Evelina London Children's Hospital.

Caitlin and her mum, Andrea, had a whole day of appointments at Great Osmond Street Hospital (GOSH), involving lots of tests, meetings and check-ups to see if she is eligible for a heart transplant.

I drove them to this appointment, leaving home at 5am to pick them up at 6am. Whilst I drove, I listened to Andrea, who was very concerned about what was going to happen at the appointment. We arrived 20 minutes early which allowed me to show her around and try to make her feel more at ease.

Caitlin is scared about what's going to happen, she knows her heart is not working well. Andrea is very upset because Caitlin may not be able to have a transplant. They both need support to be able to cope with this very traumatic situation.

“I'm scared Jayne, I'm scared.”

Andrea, mum to Caitlin

BEN, six years old, had a brain tumour and his mum, Corina, needed support. She was heavily pregnant and Ben was having treatment in Southampton Hospital. I used to take Ben there for treatment accompanied by his dad. Whilst Ben was having treatment, Corina gave birth to baby Ava in the same hospital. Sadly, Ben's treatment was unsuccessful and when Ava was only weeks old he died.

Some weeks after the funeral Corina was really struggling so she now has professional bereavement counselling from the hospice where Ben died. I look after Ava and her three-year-old sister, Lily, whilst Corina goes to these appointments. I try to arrive at their house at least half an hour early so if Corina needs to she can talk to me before she goes so that she can better organise her thoughts and priorities for her counselling session.

POPPY is two years old and had cancer. It damaged one of her kidneys which had to be removed and Poppy needs dialysis at hospital four times a week.

All of the London and South East Care team is involved in transport support for Poppy once a week to help Poppy's mum. She is a single parent who doesn't drive and also has two sons to look after, one six and the other nine years old.

Two people need to be in the car at any one time: one to drive and one to sit with Poppy. She is being treated at GOSH which is a three hour round trip and starts with Poppy being picked up at 6am.

I cover a large geographic area which includes East and West Sussex so I have to plan every week carefully to make the most of my time supporting families. This means in a week I could be in Hastings, Bexhill on Sea, Worthing, Hove, Ewell, our Leatherhead office for our team meeting and the Royal Marsden or GOSH in London.

Some days are very rewarding: a family may have positive news, or I can see that my help is really making a difference. It may even be that a family doesn't need me anymore, which is always lovely because it means that they are doing well and able to cope. But some days can be very challenging. You can't close the door and forget about what families are facing whilst living with their child's illness. I am a keen gardener and my garden is my sanctuary; gardening is my coping mechanism.

As Family Support Workers we are provided with specialist supervision from a professional external counsellor once a month. Of course, I can access this support more often if needed. Seeing the counsellor is really good. They ask about my caseload, anything I would like to talk about in particular, how I am in general, and offer advice if I need it.

I also have monthly supervision with my manager and, once a week, we have a team meeting, where we share and support other team members. Being a Rainbow Trust Family Support Worker is a wonderful and very rewarding job.



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 Jayne today. rainbowtrust.org.uk/sponsor-us



YOUR SUPPORT REALLY MATTERS

Your support helps change lives

Some of the children and families you have helped us support during the past months.



↑ Pola was born with a hole in her heart and Down's syndrome. Family Support Worker Brodie helps with transport to the hospital and emotional support for her mum.



↑ Fun at Stewarts Park with sibling Owen, after Family Support Worker Shelly dropped her mum and brother Erhun off at the hospital. Erhun, two, has a serious condition and complex needs.



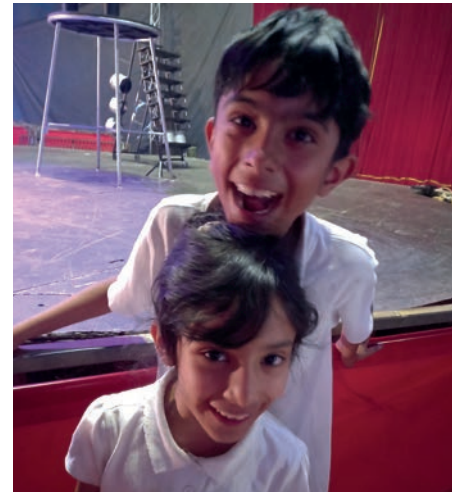
↑ Family Support Worker Sammii hard at work supervising sibling Jayden on the slide! Having lots of fun at a toddler group and giving his mum a well deserved rest after a night shift.



↑ Isabel, three, has a narrowing of the airway and chronic lung disease. Together with brothers Max and Jack she had fun colouring in animal canvases and covering Family Support Worker Ema with stickers during a play session to give her mum some respite.



↑ Charlie, four, was born with a heart murmur and is receiving ongoing cardiac treatment. Family Support Worker Jaimie took Charlie and his sister Lily, 10, to the park to enjoy the sunshine.



↑ Family Support Worker Monica took siblings Eisa and Nooriya to the circus (with tickets kindly donated by Planet Circus). Their five-year-old-brother Musa has a brain tumour.



↑ Ezekiel is nearly three years old and has complex diagnoses. Family Support Worker Mandy helps the family with emotional support and does sensory play with Ezekiel to help stimulate his senses.



↑ Scarlett was born prematurely with holes in her heart and spent her first six months in hospital. Family Support Worker Georgia took Emily, Scarlett's sister, to the park after school whilst waiting for Scarlett to come home from hospital.

It is only thanks to your generosity and support that we can help families with a seriously ill child

The families we support face difficult and challenging circumstances whilst they care for their life-threatened child.

Family Support Workers tailor the support they provide to each family, giving the ill child and brothers and sisters a break with outdoor activities and fun, playing, doing arts and crafts, reading and providing a safe space to talk. These sessions give the parents some respite and help the children to have some normality, at the same time as they improve their wellbeing and increase their self-esteem.

Thank you for all your support.

A CELEBRATION OF DAVINA HODSON'S LIFE AND LEGACY

Davina made her first Will when she was 21 years old.

Davina Hodson, a long-standing supporter of Rainbow Trust, was kind, considerate, fun to be around and a very practical lady. Davina had the foresight to pledge a gift to Rainbow Trust in her Will and her generosity will help change the lives of many families living with serious childhood illness.

A woman of independent means, Davina considered herself very lucky with what she had in life and wanted to share this. She was active in the community and her church. Despite being a self-proclaimed “not very good cook”, Davina was head of the catering committee of her church in New Malden, helping to organise Sunday roasts after the service and welcoming members of the community.

A music fan and keen golfer, Davina was twice Ladies Captain of Malden Golf Club, Chair and President of the charity Counsel and Care, and a Patron of English National Opera. What drove and motivated her involvement with these and many other organisations was the people in them and the challenges they often faced.

Davina was very charitable and preferred to give money to causes she was interested in rather than spending money on herself. She was also always there for her friends, showing kindness and generosity to them. Davina grew very fond of Rainbow Trust's work as well as building a great friendship with our former CEO, Heather Wood.

Davina wanted families with a life-threatening child to benefit from the support that we provide, where the pressure on parents and siblings of a seriously ill child is immense and dealing with everyday life can be totally overwhelming. Davina was very aware that **to some of the families we support the help of a Family Support Worker is a lifeline.**

Her friend Martin Green said:

“ We will mourn her loss, but we will have so many memories of happy times and the friendship of this amazing woman. Davina will continue to live in our hearts and our memories. ”

Thanks to her very generous legacy gift Davina will continue transforming the lives of many more families with a seriously ill child.

Davina pledged a gift to Rainbow Trust in her Will not only because she believed wholeheartedly in our work but also because she wanted to lead by example and encourage others to do the same. She would have completely approved of publishing her support in this way.

Leaving a gift in your Will is a very personal decision but is also one that can change the lives of many families living with a seriously ill child in the future.



Davina enjoying her favourite sport

A gift in your Will is a wonderful act of kindness

that will enable families to have the support they desperately need.

No matter how big or small, a gift in your Will can make a difference to families living with serious childhood illness.

For more information on how to leave a gift in your Will and our free Will writing service option please call us or visit rainbowtrust.org.uk/legacy



FUNDRAISING HEROES

We are grateful and delighted that supporters continue to fundraise in different ways to help families with a seriously ill child. Thank you.



A sea of rainbow was spotted at the Great Manchester Run as Greenhalgh's Craft Bakery team of 63 took to the streets to raise over £15,000. We are hugely grateful for your support.



Jill Therkelsen from Bishops Waltham held an exhibition in May of her impressive collection of over 1,000 bookmarks raising over £500.



Chris Girardi-Moore marked his 40th birthday by cycling from Land's End to John O'Groats in ten days with his best friend Richard Patterson raising over £6,000.



K2 Corporate Mobility reached the incredible fundraising milestone of £100,000. We are very grateful for K2's ongoing dedication and commitment.



Teddy, diagnosed with cancer, is supported by Family Support Worker Georgia. *Teddys' Tribe Family Fun Day* raised a whopping £4,000 for us and Abby's Heroes.



The wonderful Friends of Harold Wood got together for a Jubilee tea. They have supported Rainbow Trust for nearly 30 years.



Captains Kevin and Jane from Three Rivers Golf Club in Purleigh, Essex, raised an amazing £5,100, from their Captain's Day.



Helmet Head undertook *The Great Charity Motorcycle Challenge* dressed as Batman and, together with a group of bikers, rode 2,200 miles around the country raising over £3,000.

To all our amazing supporters and fundraisers
thank you!



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