



ONE DAY AT A TIME

OUR IMPACT 2016/17

**RAINBOW
TRUST**
CHILDREN'S CHARITY

Introduction from Mark Cunningham, Chairman and Zillah Bingley, CEO

When serious illness affects a child, family life is turned upside down and time becomes more precious than ever. The vital practical and emotional support provided by our expert Family Support Workers makes all the difference, and is provided at no cost to families.

Last year, we supported 2,379 families, and our presence in the children's palliative care sector grew stronger day by day. Our income increased by 9% and supporters raised an incredible £4.6 million. We are enormously grateful to them, as this allowed us to continue to grow and provide much needed family support.

We also said goodbye and thank you to Heather Wood who retired after 28 years with Rainbow Trust and 17 years as Chief Executive. Heather was passionate about supporting families and worked tirelessly to increase the number of families we help.

This impact report is about the difference our supporters, volunteers and staff make to thousands of families' lives. Together we enabled families to make the most of the time they have, one day at a time.

Mark Cunningham,
Chairman

Zillah Bingley,
CEO (joined Jan 2017)



*Leanne, Family Support
Worker and Grace*



MORE TIME FOR FAMILIES

This year we supported more families than ever before through our nine care teams.

Expansion of our service onto the Isle of Wight, the effective management of family case-loads and the increased number of volunteers working alongside our Family Support Workers all contributed to our being able to support more families.

Our pilot project with Jessie May Trust, to provide families with volunteers to give practical support around the house, recruited and successfully paired volunteers with 23 families.

Across the organisation, 430 volunteers donated 28,034 hours of their time and expertise to Rainbow Trust. This is an enormous contribution, without which we could not achieve as much as we have.

To raise the profile of the work we do, and to highlight how much our support impacts communities, we published 'Hidden Savings', a report which sets out how Rainbow Trust saves the health and social care system money. We shared the report with supporters, MPs and within the sector, and it has been very well received.

*Dawn, Family Support
Worker, with Charlie,
Louis and Jacob*



Central London based Family
Support Worker, Diana with
Sherray and Ezekiel



WHAT WE DO

Being told that your child is so seriously ill that they might die is something no parent ever wishes to hear. Nobody knows how they would react or how they would cope. And in this new world in which families find themselves, everyday life has to continue.

Brothers and sisters still need to go to school, shopping still needs to be done, bills still need to be paid and the home still has to be maintained.

Rainbow Trust pairs each family with a dedicated Family Support Worker who becomes a trusted and constant person to help them face, and make the most of, each new day. Having someone to turn to in the chaos of a child's life threatening or terminal illness can, and does, make a huge difference

to how a family manages. We support families in their home, in the hospital and in the community. We spend time with siblings helping them maintain some kind of normality by ensuring they can get to and from school, that homework is done and that they have the support they need. We also help with transport to hospital, ensuring appointments are met and families don't have to rely on public transport.

For children prone to infection, being on public transport may not be possible due to their already compromised immune system.

We are there for the whole family wherever and whenever they need us. So many services withdraw when a child dies but Rainbow Trust supports the whole family for as long as they need.

“ When I was at home with Miracle, Diana took Sherray to the park and Ezekiel to nursery – it made a big difference having that kind of help, without it I think my other children would have suffered more. Without her help, my children would not get that one-to-one attention. ”

Stephanie, mum to Miracle, Sherray and Ezekiel.

THIS YEAR WE PROVIDED

3,136

hours of telephone support with families



4,147

hours of meetings, parental support and respite



5,305

hours of home support



569

hours of support for extended family members



2,431

hours of transport



817

hours of bereavement support



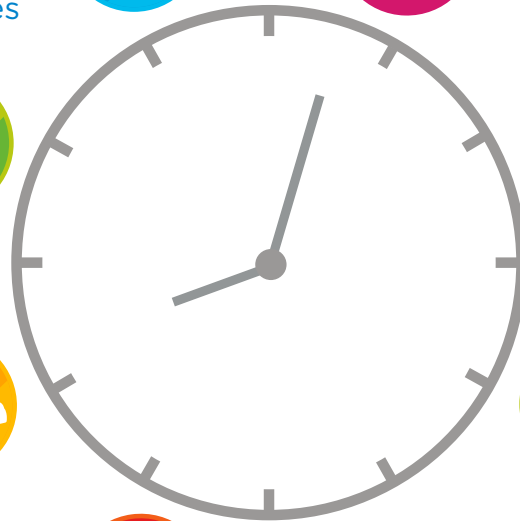
3,626

hours of support for siblings



3,484

hours of hospital support



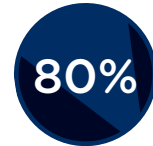
MEASURING OUR OUTCOMES

To measure the impact Family Support Workers have on families' lives, each family is asked to score themselves in outcome areas to gauge the effect of our service.

This year we measured outcomes from a number of Rainbow Trust families and asked them to review the impact of our service from referral to six months, and from families who have been supported by Rainbow Trust for more than six months.

The following pages show the difference we have made to five families this year.

The figures below show the percentage of families reporting an improvement in their ability to cope in these outcome areas.



Quality of life: being able to plan family activities at home, or to have time outside the home together



Quality time: enjoying time together as a family, and communicating well together



Stability and confidence: able to have difficult conversations with medical professionals and manage practical demands of daily chores



Managing stress: feeling emotionally stable within their situation




Economic wellbeing: the ability to pay bills and cope with the costs of travelling to appointments.

IMPROVING FAMILIES' QUALITY OF LIFE

Samuel from Essex was born with a severe heart condition and needed monitoring 24 hours a day. His heart could stop with any kind of stress. Vicky and Rick, his parents, could never leave him alone so, as well as looking after their other two children, the couple was left struggling to have any semblance of normal life.

Family Support Worker, Sarah, supports the family. From transport to hospital appointments, support in hospital during Samuel's open-heart surgery, playing with Daisy and Betsy at home or taking them out for the day and giving respite for Mum when things have just got too much, Sarah is there for them.



“ Without Sarah, I'd have no kind of break. We take life one day at a time but having her support means we can have days out or I can do chores knowing Sarah is looking after Samuel as well as I would. ”

Vicky, mum to Samuel.

*Three-year-old
Samuel and
Sarah, his Family
Support Worker*

RESTORING STABILITY AND CONFIDENCE



Ashleigh and Alisha

After Jayne's two young daughters, Alisha and Ashleigh, died of Batten's Disease in the space of two years, she and Lucy, her elder daughter, struggled to manage. The death of one child was hard enough, but going through it a second time took its toll on Jayne and she struggled with everyday life.

“ When Ashleigh passed away in May 2014, I relied on Marlene. I lost so much confidence. Marlene took me to tribute days to light a candle for Ashleigh. Just having someone there made me feel that I was not going mad. ”

Jayne, mum to Ashleigh and Alisha.



QUALITY TIME TOGETHER

Beccy and Godfrey's eldest son, Henry, was born with a condition which left him with severe kidney and bladder damage and he is fed through a tube in his stomach.

Henry will need a kidney transplant in the future. Godfrey is donating one of his kidneys and when the time comes, Godfrey will be in hospital for a while and the family won't be able to spend much time together. Nicki, a Surrey based Family Support Worker, will help Beccy juggle spending time at the hospital with Henry and Godfrey and taking care of Thomas. Nicki has been spending time with the family getting to know the boys so that when Henry has his transplant, the boys will feel comfortable with Nicki.



Nicki, Surrey based Family Support Worker, spends time with Thomas and Henry

“ This summer we went to a Rainbow Trust day out and met other families. That was fun and so good to meet families in similar situations to us. We also went to a Christmas pantomime; the boys absolutely loved it. It's so great for us to have some fun together. ”

Beccy, mum to Henry.

SUPPORTING FAMILIES TO MANAGE THEIR STRESS



Zia was born 10 weeks prematurely and weighed just 2.3lbs. Dawn, her mum, was overjoyed but felt overwhelmed with Zia's major health issues. She found it difficult to bond with Zia and didn't feel confident taking care of her as Zia was so ill.

Dawn self-referred to Rainbow Trust as she knew she needed help. Her Family Support Worker spent time with Zia in the neonatal unit and supported Dawn emotionally. Dawn was able to talk about her fears and helped her find the confidence to look after her precious baby girl.

“ I found it so hard, I wanted to put Zia into care as I didn't think I could cope. Having Marlene, our Family Support Worker, there for emotional support made all the difference. I can't put into words how much she has helped me. ”

Dawn, mum to Zia.

Big brother, Rhys, with baby Zia

IMPROVING FAMILIES' ECONOMIC WELLBEING

Kia was seven when she was diagnosed with a rare genetic disorder. Carol and Dean, her parents, struggled to manage caring for her and Brayden, her older brother.

Carol had to give up her job and eventually their home, as they could not keep up with the payments after spending more than £90 a week travelling to Newcastle for hospital visits.

Carol, their Family Support Worker, started supporting the family and took mum and Kia to the hospital, saving them train fares, which meant they could afford to keep their rented home warm in the winter. This reduced the huge financial strain on the family and they could focus on taking care of their children. Carol also spent time with the family in the home, giving mum a break and Brayden some fun.

Brayden, Kia and Carol, their Family Support Worker playing games



“ Carol signposted me to benefits that we were entitled to which helped us manage our bills. We didn't have to spend it all on travel and that meant we were under so much less financial strain. ”

Carol, mum to Kia.

OUR ACCOUNTS

How we raised our money 2016/17

TOTAL
INCOME
£4.6
million



INCOME AND EXPENDITURE

Summarised accounts

Statement of Financial Activities for the year ended 30 June 2017

Income	2016/2017	2015/2016
Donations and legacies	£3,055,171	£2,556,180
Fundraising events and commercial activities	£1,421,370	£1,544,149
Statutory income	£134,148	£121,602
Investment income	£13,202	£17,521
TOTAL INCOME	£4,623,891	£4,239,452
Expenditure	2016/2017	2015/2016
Carer and family support services	£3,094,894	£3,260,036
Fundraising costs:		
Grants and donations	£868,302	£951,694
Fundraising events	£471,351	£409,560
Commercial activities	£62,048	£466,605
Donor acquisition	£19,890	£104,471
TOTAL EXPENDITURE	£4,516,485	£5,192,366
Net expenditure	£107,406	(£952,914)

This is an overview of our income and expenditure in 2016/17. This is taken from our financial statements, which you can request by calling 01372 363438 or emailing enquiries@rainbowtrust.org.uk

OUR AMAZING SUPPORTERS



Volunteer, Martin spent time being stickered at the drop-in group he helps run at the Great North Children's Hospital, Newcastle

Corporate partner, Fidelity International, joined us for Grate 48 and stair climbed their way up 48 floors of the Leadenhall Building in London to help raise £75,000



Supporters joined our Patron, Lord Fellowes, to celebrate 30 years of Rainbow Trust

Eight-year-old Tia from Redhouse, Swindon, raised £470 when she climbed to the top of Mount Snowdon





Andre joined 46 other runners in the Virgin Money London Marathon 2017



We joined Prime Minister, Theresa May at Number 10 Downing Street to help switch on the Christmas lights



Martyn of Heald Green, Stockport ran the London Marathon to say thank you for Rainbow Trust's support to his nephew Adam and his family. Martyn described the charity as 'a real-life guardian angel'



Pam, a Family Support Worker in our Southampton team marked our 30th Anniversary by shaving her head.



Leo with Claire, his Family Support Worker and Chelsea, his older sister



**TOMORROW IS
ANOTHER DAY**

We always want to achieve more.

We believe that every family in the UK who has a child with a life threatening illness should receive the support they need. We see a strong future in partnership working with hospices and other relevant charities to support more families. Our goal is to ensure there are no gaps or duplication in the care provided to families.

Our care volunteer programmes have been a huge success. We will increase volunteering opportunities, not only to help us support more families, but also to engage volunteers to support families in their own communities. Enabling communities to support families more effectively will mean care really can begin at home.

Fundraising will remain a priority as we continue to strive to be more cost effective. Our donors remain front of mind as we

**2,379
FAMILIES
SUPPORTED**

look at improving our returns through the effective use of the resources we have. We will also continue to grow our influence on government strategy to help improve families' lives.

We remain committed to developing and engaging our staff and we will do this through an enhanced well-being, reward and benefit programme with a greater focus on learning and development to support employees' personal development.

**WE COULDN'T DO IT
WITHOUT YOU**



Thomas with Nicki, his Family Support Worker

Last year you raised an amazing

**£4.6
million**

**to fund expert Family Support
Workers who supported 2,379
families across the country.**

Thank you for every hour of support and every pound donated. Here are some of your highlights:

CORPORATES

This year we welcomed [Cambridge Online](#), [Clive Christian](#), chartered accountants [Kingston Smith](#). [Lockton](#), [My Family Care](#), [P&G](#), [Perfetti Van Melle](#), [Stephenson Harwood LLP](#), [Tek Systems](#), [Time Inc](#) and [West Cornwall Pasty](#), who all chose us as their charity partner. [I Love Claims](#) celebrated raising over **£500,000** in five years and staff from estate agents, [Cubitt & West](#) completed the Nuts Challenge assault course to raise **£11,638** as part of a long-term commitment to fund a Family Support Worker.

EVENTS

Our loyal committees, friends and ambassadors joined us at our festive Carol Concert at St Paul's Church in Knightsbridge, Trust in Fashion at the Savoy and at Sandown Racecourse for our Race Night raising over **£275,000**.

Our amazing supporters climbed, ran, jumped, cycled, walked and swam to raise an incredible **£525,000**. Our 47 strong London Marathon team raised over **£128,000** and [Hanover Dairies](#) in Tyne and Wear raised over **£16,000** with their Highland Hike.

INDIVIDUALS

This year, 5,100 donors supported our campaign and appeals, made a regular donation or signed up to Sponsor a Family Support Worker. We also launched a new lottery with a chance to win £25,000 each week.

Philip Andrews, Richard Blades, Geoffrey Davies, Sylvia Green, Diana Harris, Amy Hemmings, Doris Hind, Margaret Hood, Phyllida Stanley, Denise Wainhouse and Maggie Wakerley all showed their humanity when they kindly remembered us in their wills.

We also worked hard to make sure that all our supporters had the best possible experience of fundraising for us and that we protected their personal data and privacy.

TRUSTS AND FOUNDATIONS

We welcomed new trusts and foundations generously supporting us for the first time this year including [The Kentown Wizard Foundation](#), [The Linbury Trust](#) and [The Rank Foundation](#). [Oak Foundation](#), [Garfield Weston Foundation](#), [The Ingram Trust](#), [The 29th May 1961 Charitable Trust](#) and [The Zochonis Charitable Trust](#) also made generous donations.

[The Big Lottery Fund's](#) support for the Me Too! project ensured that more than 150 young sibling carers had someone to talk to, outings away from the pressures of home life and their brother or sister's illness, as well as support to get to school and help with homework.

VOLUNTEERS

This year our amazing volunteers donated 28,034 hours of their time so that families we support could make the most of theirs. More than 430 volunteers gave their time in our shops, offices, out in the community, at our events and alongside our Family Support workers. [Helen Huckle](#), our longest serving volunteer of 30 years, continued to support Rainbow Trust by shaving her hair and raised over £500.

Based on the living wage, 28,034 volunteer donated hours are worth **£201,844!**

WE'D LIKE TO THANK...

Chairman • Mark Cunningham • **Trustees** • Tim Bunting • Howard Dyer • Andrew Honnor • Dr Jonathan Rabbs • Mark Richardson • Fiona Smith • Michael Wainwright • Mrs Celia Woollett • **Patrons** • Sir Hugh Blackett • Sue Cook • Annabel Croft • Ashley Davies • The Hon Mrs James Dawnay • Lord and Lady Fellowes of West Stafford • Jack Gratton • Trish Halpin • Trevor Hanover • Austin Healey • Michael Howard • Josie Law • Mrs Andrew Lukas • Aled Miles • Mary Nightingale • Pauline Obee • Geraldine Peacock CBE • The Countess of Perth • Lord Redesdale • Lady Robson • Mrs Robert Ropner DL • Mrs James Russell • Mrs John Salkeld • John Scott • Alan Stevenson • Zac Toumazi • Mrs Peter Vey • Andrea White • Kevin Whitfield • Mary Wynne-Finch • **Committees and Friends** • Hampshire Friends • London Carol Concert Committee • London Friends • Race Night Committee • Trust in Fashion Committee • Upminster and Harold Wood Volunteers • **Grants and Foundations** • John Horniman's Children's Trust • The Shanly Foundation • The Sir John Fisher Foundation • The Harrop Green Charitable Trust • June Margaret Pavyer Will Trust • Hospital Saturday Fund • Gerald Palmer Eling Trust • The Hobson Charity • The Charles Skey Charitable Trust • The Taurus Foundation • **Statutory** • London Borough of Redbridge • Rochdale Borough Council • Southampton

City Council • Surrey County Council • West Sussex County Council • **Corporate** •
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Society • Fidelity International • Firefish • Hitachi Capital UK Ltd • Inconnection •
Invesco Perpetual • Knight Frank • M&G Investments • Merck Serono Ltd • Natta
Building Company Ltd • Nomura • OMERS • Paperchase Products Ltd • Procter &
Gamble (H&BC) Ltd • Project11 • Rackspace • Red Mist Leisure • Reload • St James
Group South • Smith Stone Walters • Street Runners Ltd • Super Camps • Swim
Strategy • The Berkeley Foundation • The Jockey Club • TÜV SÜD Limited • West
Cornwall Pasty • Wicked the Musical •

“ We don't know what the future holds, so I just take one day at a time. ”

Parent, supported by Rainbow Trust

**RAINBOW
TRUST**
CHILDREN'S CHARITY

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Special thanks to the children and families featured, who are, or have been, supported by Rainbow Trust.

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