



Shooting Star
children's hospices



Lighting the Way

Our impact in 2022/23

Registered Charity No 1042495

Why we exist

Whether lives are measured in days, weeks, months or years, we're here to make every moment count.

Shooting Star Children's Hospices cares for babies, children and young people with life-limiting conditions, and their families, across Surrey and west London.

Care at home

Our community nurses assess the nursing needs of children referred to Shooting Star Children's Hospices, providing emotional and practical support and nursing care to families in their homes during the last six months of a child's life.

Our Specialist Paediatric pAlliative CarE (SPACE) team provides expert care and advice in end-of-life care and symptom management to help improve a child's quality of life – whether the child is at home or at our hospice. They also form part of a 24/7 telephone service advising on symptom management.

Care at our hospices

Christopher's, our purpose-built children's hospice in Guildford, Surrey, still provides the same home from home environment for children receiving overnight care that it did 22 years ago when it opened. Our expert nurses and carers ensure each child's complex care needs are met and during a respite stay they will organise a range of fun, sensory and therapeutic activities while parents get a much-needed break.

At Shooting Star House in Hampton, families have the opportunity to spend precious time together making memories as a family – whether that's splashing in our heated hydrotherapy pool, getting creative in our light and airy art room or spending time in our peaceful garden. As our Outreach, Therapy and Family Support Centre, families can also access bereavement care counselling, therapies, drop-in sessions, sibling groups, family activities, interactive play sessions, and meet our Family Support Workers.



Message from our Chief Executive

Our priority is always the children and families we support, and over the year we saw many families struggling with the current financial climate. In order to support families, we adapted our services to source funding for equipment and special experiences. We also opened our facilities during the day, giving families access to our hydrotherapy pool and sensory room, and we helped facilitate access to local food banks.

Echoing the sentiment expressed by many families, a parent recently described our work as "a light when everything was in darkness, helping us focus on what we could do rather than stay frozen in fear". This serves as a fitting theme for this year's report, *Lighting the Way*. We cannot change a child's prognosis, but we will be there at every step when the unimaginable happens.

There are two simple words that we cannot say often enough – thank you. We are immensely proud to work with such an exceptional team of volunteers, staff and trustees who have continued to work diligently, embraced our ambitious new vision and who will be instrumental in steering us in this new direction over the next three years and beyond.

With your continued support, we have moved into 2023/24 with renewed energy, knowing that what we do makes a crucial difference, with the ambition to do more. Our heartfelt thanks to you all for supporting us on our journey.



Paul Farthing
Chief Executive



For every family

In March 2023, we launched *For Every Family*, which sets out our new purpose, ambition, and path to deliver outstanding care over the next three years. It embraces two important principles: providing the best care to children and families across Surrey, north-west London and south-west London, and recognising that many families aren't getting the support they need.

Based on feedback from families, partners, local authorities, staff, volunteers and trustees, our plan is to offer support to a wider range of families whose child has died, offer a choice about end-of-life care and make the best use of our resources.

There are hurdles to overcome – providing access to care, responding to individual preferences, recruiting and retaining the best people, and ensuring funding is sustainable – so we know we can't do this alone. Collaboration with local authorities, healthcare systems and hospitals is integral to delivering the best care to our families, and we rely on our incredible supporters and volunteers.

Our new purpose

We believe every life-limited or dying child and their family should have the opportunity to make every moment count and get the support they need.

Our new ambition

We will support every family with a life-limited child or whose child has died when they need us.



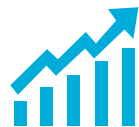
Do more:
Help more children and families



Do better:
Be seen as outstanding



Co-create:
Build partnerships that add value



Grow income:
Ensure our work is sustainable



Grow people:
Be proudly chosen by staff and volunteers

The difference we made in 2022/23



176
bereaved families used our service
(175 in 2021/22)



1,680
care nights provided
(1,505 in 2021/22)



Our bereavement suites were in use for **92** nights
(127 in 2021/22)



104
children accepted as new referrals
(84 in 2021/22)



538
children and young people with life-limiting conditions supported
(612 in 2021/22)



1,541
family members received support
(1,261 in 2021/22)



106
events were held for children and their families
(73 in 2021/22)



11,643
face-to-face and telephone contacts made by our Family Support team, community nurses and SPACE team
(9,498 in 2021/22)

Supporting children and families

Outstanding care

We are proud that Christopher's retained an 'outstanding' CQC rating in May 2022, the highest possible result. The CQC randomly picked good and outstanding rated services to test their new monitoring approach, giving hospices just 24 hours' notice. The inspection evaluated safety, efficacy, compassion, responsiveness and leadership by interviewing families, staff and volunteers, touring the hospice, seeing the care and support offered, and reviewing policies and procedures.

The inspection was a very positive experience and we welcomed the additional recommendations that CQC provided. As part of our commitment to improving care, we ran a planned mock inspection a few weeks before the CQC visit and had addressed some of the points raised during the mock inspection.



25% increase in the number of children newly referred for support

Care when it's needed most

To provide care to children and young people with the highest levels of need, we focus on providing families intervention-based care at home in times of crisis. Last year we introduced a 'silent rota', ensuring the team was ready to step in immediately if and when nursing care was needed at home. Our nurses were actively on call for a dying child 180 nights of the year.

So that families and experts have advice and support when needed, we work with The Royal Marsden to offer a telephone helpline, open 24 hours a day, seven days a week for children and families with specialist palliative care needs.



12% increase in the number of respite nights we provided

Reaching every family

As part of our strategy to support every family, including those whose baby is unlikely to survive birth or the neonatal period (under 28 days), we submitted a successful bid to NHS England (in partnership with South West London Integrated Care Board (ICB) and Surrey Heartlands ICB) to fund a Perinatal Clinical Nurse Specialist to work in neonatal intensive care units (NICU) in local hospitals. This ensures families have access to specialist care, including guidance and support in managing complex symptoms, as well as palliative care for those who need it.

'Gold standard' bereavement care

We have spent the past two years developing a 'pathway of care' for bereaved families, researching best practice and refining our offer. From preparation before a child's death to companion care, a checklist has been created to ensure the right support is in place and that nothing has been overlooked. We created a support group for parents whose child has died with sessions led by our counsellors and a Bereaved Parents' Forum to allow parents to share valuable insights.

Every six months, we audit our specialist bereavement care, which is offered for three years and three months after a child dies, to identify any improvements we can make; last year, our internal audit score increased from 83% to 91% (above 90 is excellent). We have received overwhelmingly positive feedback and consider this to be the gold standard of bereavement support, modelled on national standards of best practice and everything we know (and continue to learn) about the needs of families.





Specialist mental health support

Referrals to our Family Support Service increased by 21% in the second half of last year. We have delivered 79% more therapy and counselling sessions (both face-to-face and virtual), typically creative therapies (music therapy, art therapy and drama therapy) for children and young people, and counselling to parents and grandparents. Counselling contacts (i.e. telephone support, risk assessing and welfare checks) increased 103% with 5,560 contacts during the year.

Each week, 20 families reach out for support. We added two additional counselling rooms at Shooting Star House to meet this need and created an art therapy room at Christopher's.

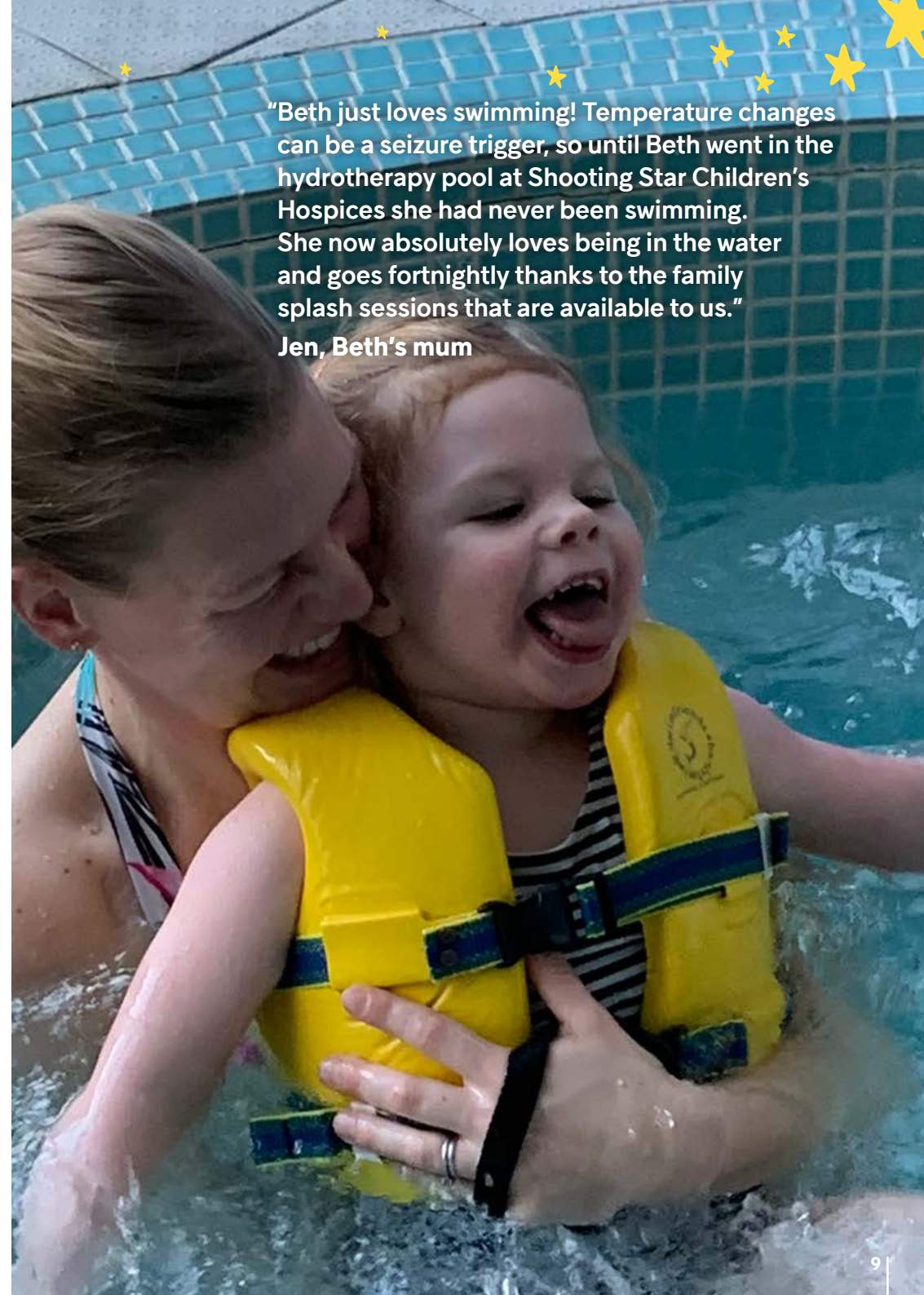
Making fun a priority

Being part of the hospice community is crucial to families, whether attending a sibling social or a grandparents' virtual cake decorating class. We asked families about the activities we offer, one parent said: "We desperately want to escape because we're exhausted, but we can't afford to go on holiday," highlighting how important activities are, especially when things are financially difficult.

In response, we hired an Events Officer and increased our annual activities programme. Attendance has increased 240%, with 879 people attending events (some people may have come to more than one event), ranging from music themed drop-ins for families and 'Just Juniors' multi-sensory days, to 'Mummy and Me' pamper days, 'Daddy and Me' Scalextric sessions, and visits to attractions such as Legoland.

Reaching adulthood

Many of the young people we support are living longer thanks to medical advances. When they turn 21, they move to being supported by adult social and healthcare, where many will be involved in planning their own care for the first time. To help young people approaching this change, we ran our first ever Transition Week. We closed the hospice to respite care for a week to give Sumi, Aiden, Sophie and Millie-May a chance to learn life skills and prepare for future challenges. Aiden and Sophie also travelled to Glasgow in the autumn of 2022 to attend the Hospice UK conference to talk about their next big journey, where they received a standing ovation.



"Beth just loves swimming! Temperature changes can be a seizure trigger, so until Beth went in the hydrotherapy pool at Shooting Star Children's Hospices she had never been swimming. She now absolutely loves being in the water and goes fortnightly thanks to the family splash sessions that are available to us."

Jen, Beth's mum

Family stories

Zoë's story

Shooting Star Children's Hospices has been part of 14-year-old Zoë's life since she was eight weeks old.

Zoë's birth was traumatic. She died for six minutes before being resuscitated and having a tracheostomy fitted to help her breathe. Zoë has a genetic bone dysplasia disorder called OS-CS. She was later diagnosed with a rare, complex neurovascular disorder, which causes chronic headaches and mini strokes.

"My GP was about to section me, but Shooting Star Children's Hospices said they could help us."

Discharged from hospital shortly before Christmas, the family weren't granted any support from their local council, leaving Britt and Adrian, Zoë's parents, to look after their baby with complex needs.

"I was slowly and surely sinking under, barely sleeping, terrified something would happen to her. I went to some very dark places," says mum, Britt.

"Shooting Star Children's Hospices' nurses came to look after Zoë for a few hours. I'd been having regular panic attacks, and I walked into the living room and just collapsed. They arranged for emergency respite at the hospice. I'm not exaggerating when I say they saved my life. My GP was about to section me, but Shooting Star Children's Hospices said they could help us. We lived at the hospice for three months, and they campaigned for a home care package. They gave me the confidence to care for Zoë and be her mum. I don't think people can ever truly understand how hard having a child with such complex conditions can be. Shooting Star Children's Hospices live it with us."



Louie's story

After a perfect pregnancy, Louie was born two months premature on 18 December 2020 and diagnosed with a tracheoesophageal fistula (TOF). In this rare condition, the upper part of the oesophagus doesn't connect with the lower part and stomach. He also had 10q26, a rare, non-life-threatening chromosome deletion.

"Louie had been home for five months and was progressing well and meeting his milestones when one day, he was sniffly and coughing. TOF children are more vulnerable, so we took him to the GP, but he worsened and we went to the hospital. He had suspected respiratory syncytial virus (RSV) and bronchiolitis, serious respiratory infections for vulnerable babies.

"Losing a child is unimaginable. Without Shooting Star Children's Hospices, it would be much harder."



"Louie deteriorated overnight. We were transferred to St George's Intensive Care Unit where he was ventilated. But they struggled to keep his oxygen levels up, so he was taken to Great Ormond Street and put on extracorporeal membrane oxygenation (ECMO). CT scans later revealed news no parent wants to hear; Louie had an ECMO-induced stroke and irreversible brain damage. After a week, Louie's machine was turned off. He died on Thursday 15 July 2021.

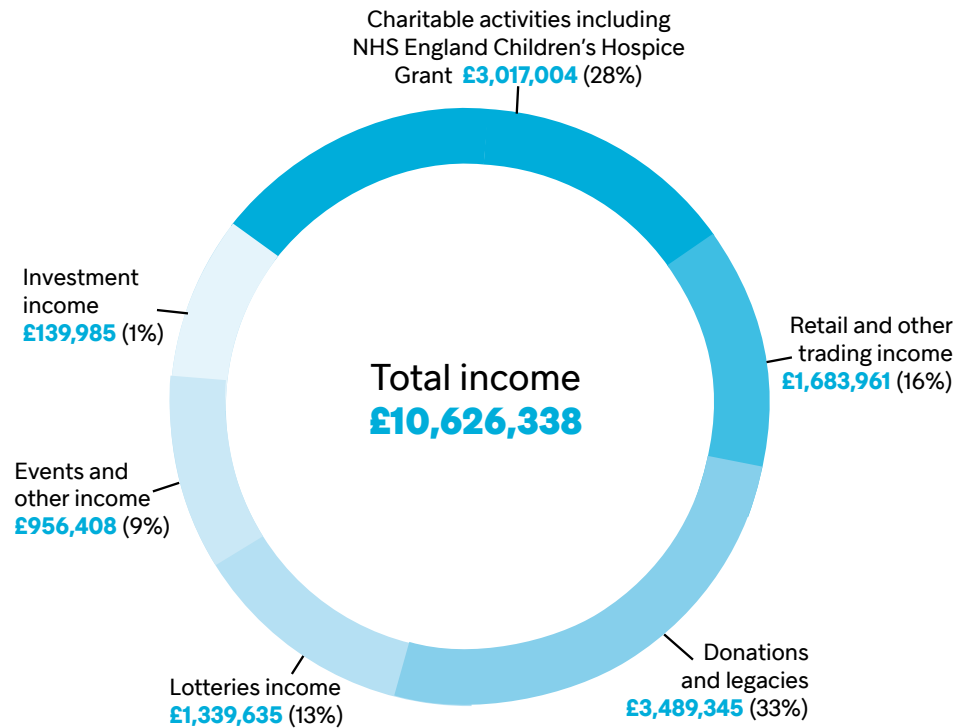
"That's when we were introduced to Vikki, a Family Support Worker from Shooting Star Children's Hospices. Vikki always checked in, leaving a message if I didn't answer.

"I fell pregnant again, and my partner James and I decided to talk about how we felt and process everything when Luca was a few months old. Vikki recommended Shooting Star House couples counselling. That talking time was crucial after our trauma. It's good to hear each other's feelings, which we don't talk about daily.

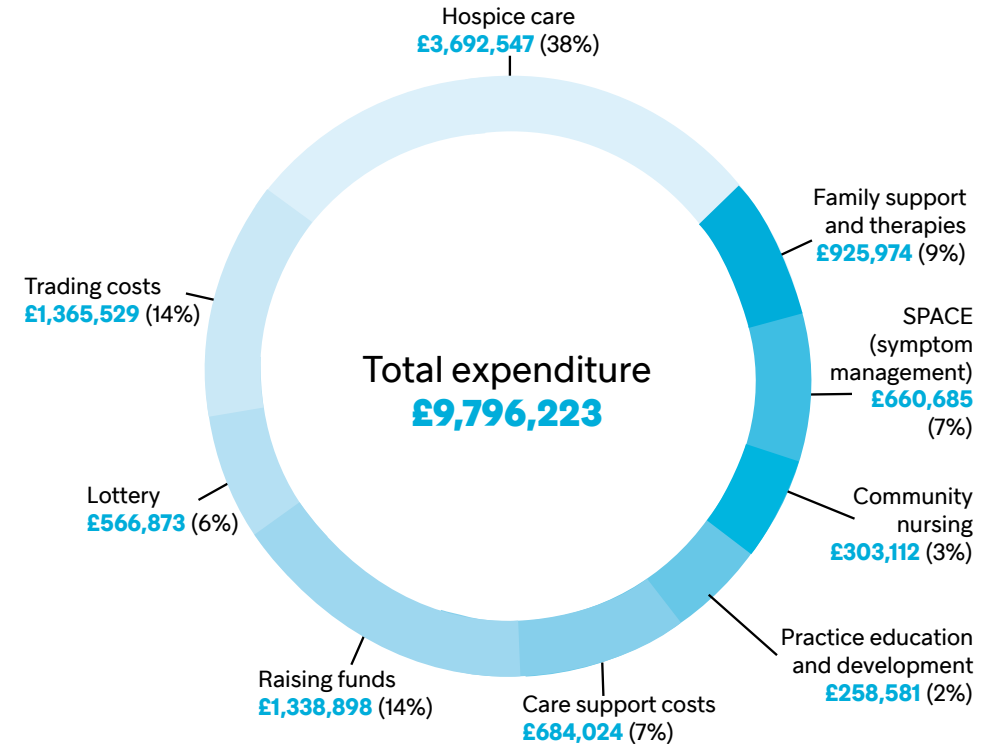
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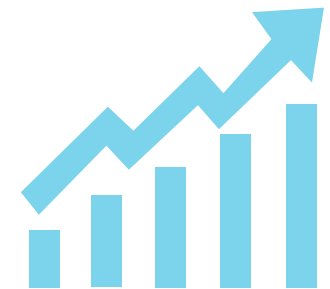
Our income



Our expenditure



In 2022/23, our income increased by 6% and our expenditure increased by 21%, reflecting planned investments to support the delivery of our new strategy. A huge thank you to our incredible supporters for helping to ensure that families facing the unimaginable got the care and support they needed last year.



Rising to the challenge



Our priorities for 2023/24

Do more

- Offer bereavement support to 40% of families whose child has died (from 74 families to 102)
- Offer palliative care to 25% of babies, children and young people who are dying (from 47 children to 57)
- Provide 90% occupancy of open bed nights (from 1,687 nights to 1,912)

Do better

- Become a 'research active' hospice
- Deliver a programme of ongoing quality improvement across the whole organisation
- Be the 'go to' expert for child death in our area – increase end-of-life referrals by 20% (from 39 referrals to 47)

Co-create

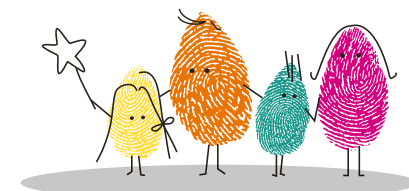
- Increase the number of life-limited children and their families who use Shooting Star Children's Hospices by 10% (from 65 children to 72)
- Build strong health, local authority and political partnerships
- Measure our reputation across all stakeholders and act on the findings

Grow income

- Increase voluntary income to £5.62m (currently £4.94m)
- Increase statutory income to £3.3m (currently £2.94m)
- Increase retail income year-on-year by 10% (from £1.01m to £1.13m)
- Increase The Care Database income year-on-year by 10% (from £0.69m gross to £0.75m gross)

Grow people

- Ensure every member of staff has the opportunity for relevant training and growth, and record and report on our progress
- Increase volunteering hours by 10%
- Survey staff and volunteers on attitudes and concerns regularly
- Decrease staff turnover by 5% (currently 26%)





To read our full annual report and accounts for 2022/23,
please visit shootingstar.org.uk/about-us or scan the QR code.



Shooting Star Children's Hospices

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