

IMPACT REPORT 2021

A LIFE CHANGING
DIFFERENCE



Julia's
House 

A LIFELINE OF CARE

Providing care across Dorset and Wiltshire, Julia's House supports the most seriously ill children and their families in the local community. Children and young people with life-threatening and life-limiting conditions who require round the clock care that often leaves families isolated, lonely, anxious and exhausted. Julia's House nurses and carers provide vital respite to these families, helping to prevent them from reaching breaking point.

The critical role played by children's hospices, such as Julia's House, in supporting the NHS throughout COVID, has been recognised by the Government with one-off emergency funding to ensure services could be maintained as the crisis continued.

The quality of the clinical care and emotional support Julia's House provides in the community and at their hospices, was recognised with the award of an 'outstanding' rating by the Care Quality Commission (CQC), following an inspection in December 2021.



"No matter how strong you are, it's not until you're put in a position like ours that you realise how fundamental children's hospices like Julia's House are for your wellbeing."

Parent, Julia's House

The CQC noted that the families Julia's House supports **"felt listened to, cared for and respected."** One family told the inspectors their child was **"always happy and excited when the care team arrived."** The care team were described as being **"thoughtful, practical, thorough"** and that they **"always thought ahead and planned activities to get the most out of the time they spent with children to make it as good an experience as possible."**



**hours of expert care provided;
an increase of 29% over the
first year of the pandemic**



The need for Julia's House is growing...

Children with life-limiting conditions are living longer due to medical and scientific advances, so Julia's House will be caring for more children and for longer. A recent study conducted by the University of York, revealed that the number of children in England with life-limiting or life-threatening conditions increased from 32,975 in 2001/2 to over 86,625 in 2017/18.*

... but the funding isn't

Economic research conducted by Scope and the Disabled Children's Partnership exposed the continuing funding gap for disabled children's health and social care. This gap has now increased to £2.1 billion – an increase of over £500 million since the last calculation in 2016/17. ** Additionally, according to the Disabled Children's Partnership, in 2019 only four in ten families with seriously ill children received support from their local authority and only once they had reached crisis point.

This means the most seriously ill and disabled children and young people are not getting the support they need; while exhausted and isolated parents and families are not getting respite care. So, in this medical and economic context, the support that Julia's House provides free to families couldn't be more vital. The ongoing pandemic put this critical need into further relief, as we worked hard to ensure we were there for families with continuity of care, when other services were often cancelled.

Even as social restrictions lifted for many of us, the families we support were often still shielding, so the resilience of our service and its ability to adapt to the individual needs of each family has never been more paramount. For many, the presence of our nurses and carers over the last two years has been a lifeline.

* Make Every Child Count study, conducted by the University of York, <https://www.togetherforshortlives.org.uk/new-research-reveals-a-significant-rise-in-the-number-of-children-with-life-limiting-conditions/>

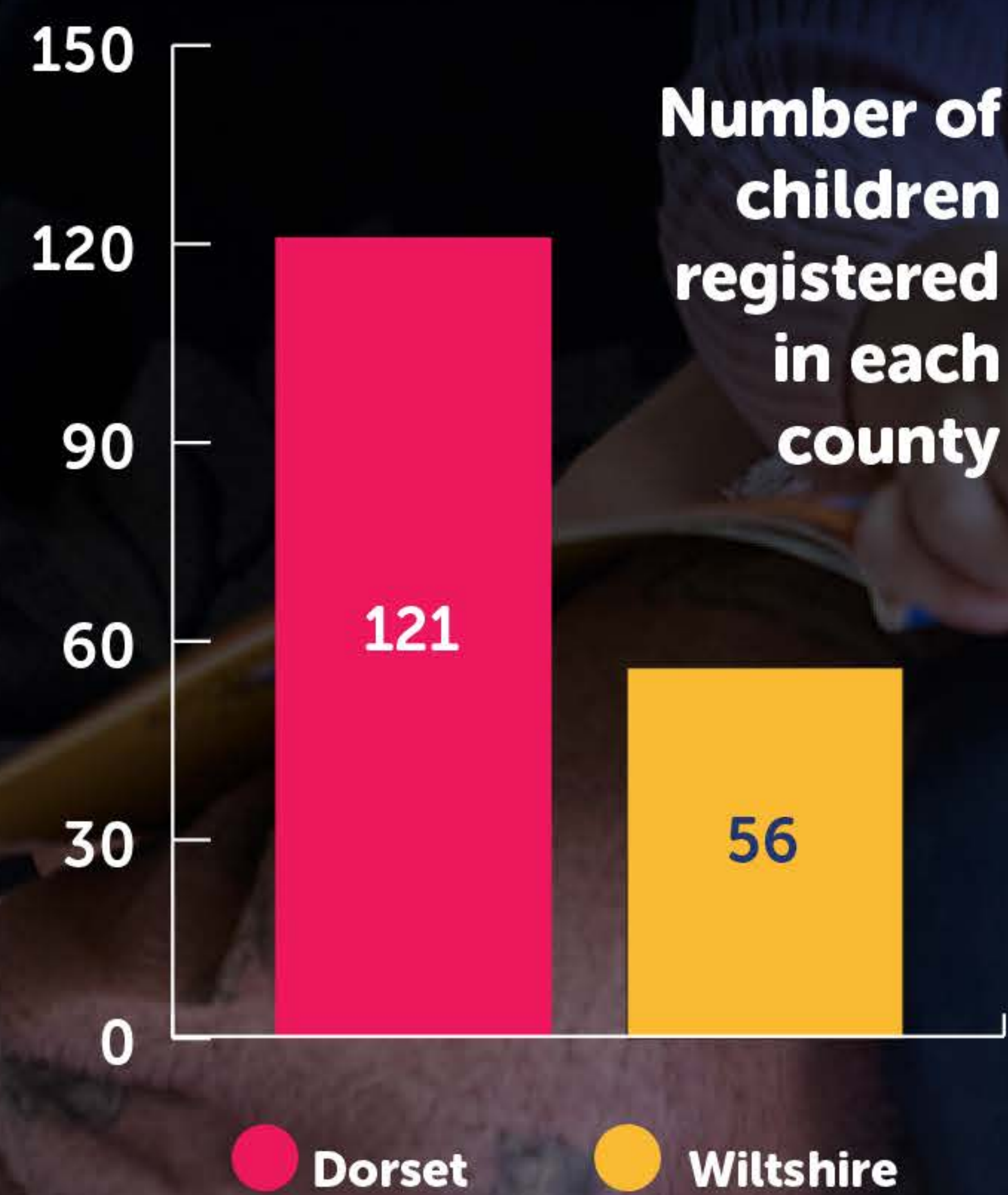
** <https://disabledchildrenspartnership.org.uk/the-gap-widens/>

MAKING A DIFFERENCE

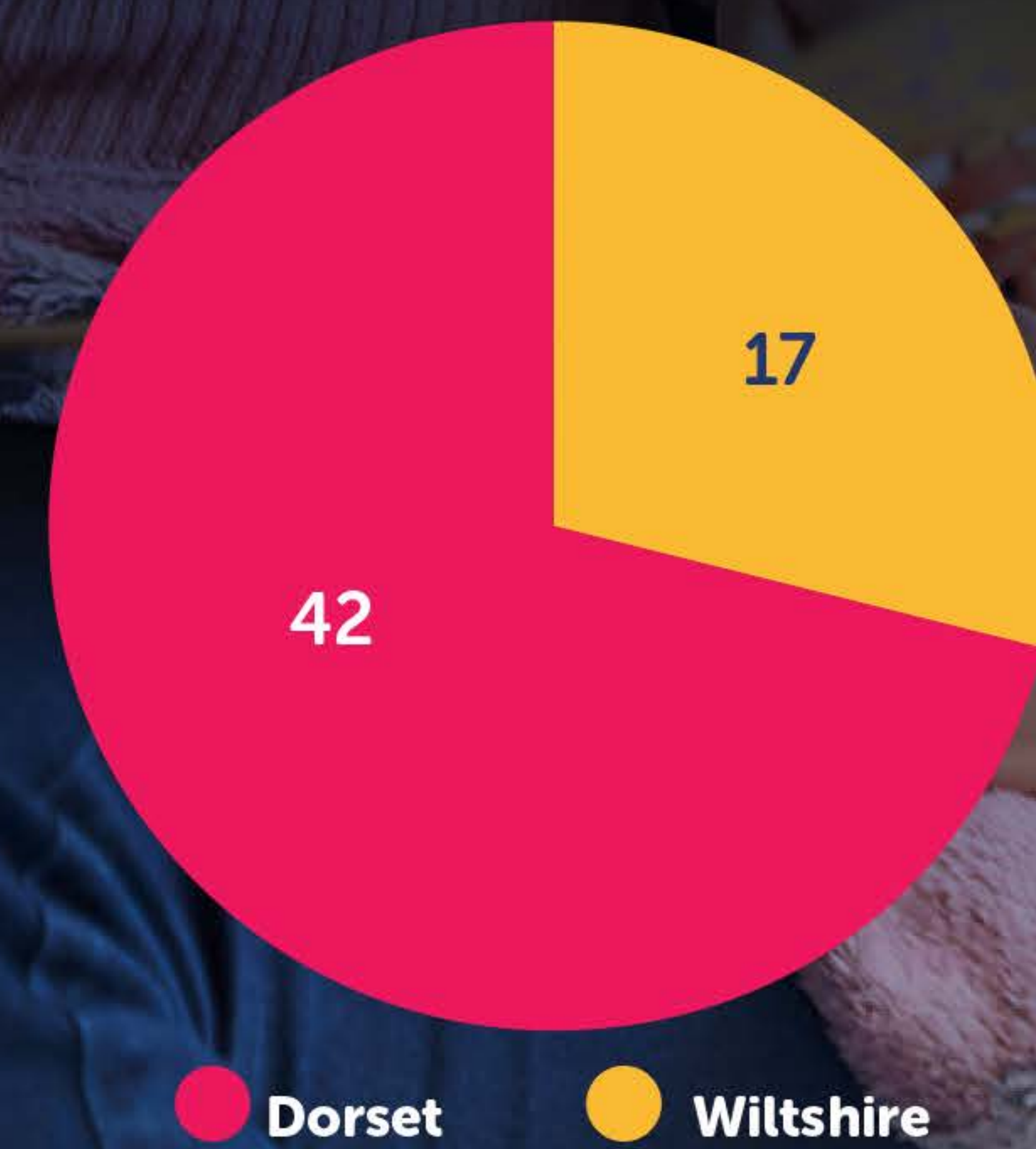
In another year of restrictions, our nurses and carers focused on caring for children at home and provided nearly 3,000 community respite sessions - the most ever. That's almost 60 sessions of specialist, individually tailored care every week.

We found new and innovative ways to care, including one-to-one support for siblings and virtual sessions for children and families. In total, we provided 20,500 hours of expert care, an increase of 29 per cent over the first year of the pandemic.

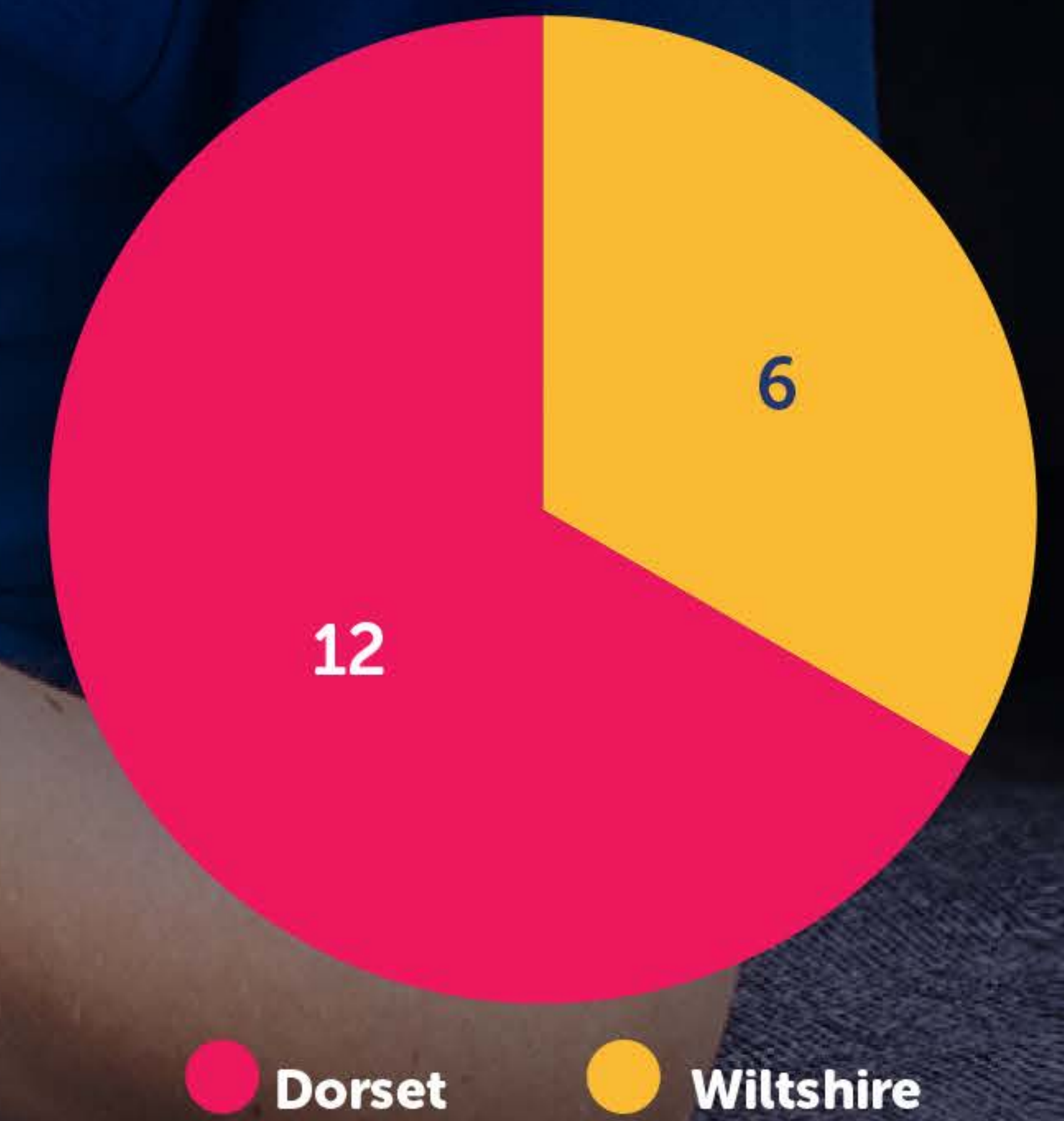
Due to the complex conditions of the children we support, more than one nurse or carer attends 90 per cent of the respite sessions we provide in family homes.



We bought smiles to 59 siblings



We supported 18 bereaved families





Ruby, sister to Elisa

TIME TO TALK

Ruby (16) has been supported by Julia's House for seven years, after we started caring for her younger sister, Elisa, who has cerebral palsy. Ruby meets regularly with sibling worker, Maria, who has been able to give her some special time just for her, helping Ruby cope with the anxiety and worry of having a sister who is seriously ill.

"Julia's House has made me feel less alone. You can feel that no-one else can relate to you but that isn't the case."

"Having Julia's House there has made me feel less alone. You can feel that no-one else can relate to you but they helped me understand that isn't the case. Things that aren't normal for others just became normal for me – I never minded if plans were cancelled if Elisa had to go into hospital, that was just my life."

Sibling worker, Maria, meets Ruby regularly: "It's been really nice now I'm more grown up. Maria and I have had time to get to know each other, going for walks or chatting over coffee – I've found a great café with amazing brownies! It just feels natural now when she messages to arrange to meet. I always worry about Elisa, it's constantly in the back of my mind but knowing I can talk with Maria really helps."

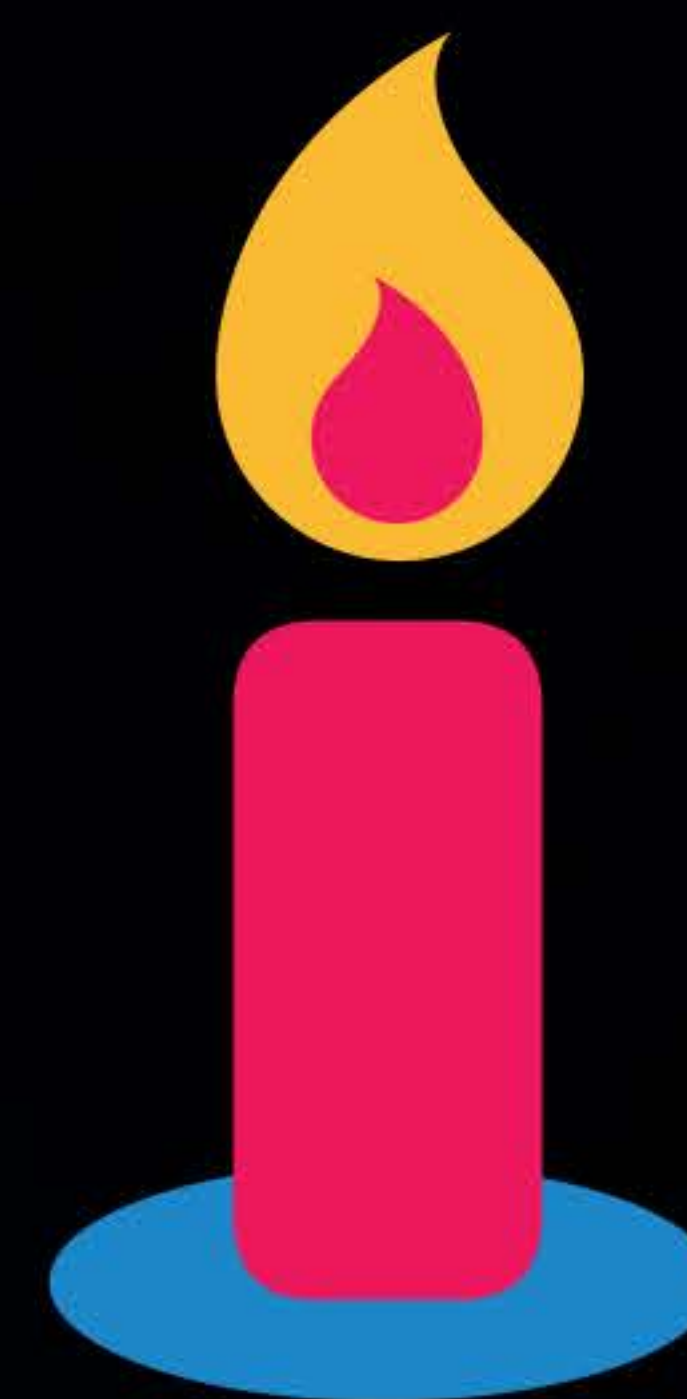
Ruby has been inspired by Elisa's care and plans to go into nursing – she's studying health and social care at college after doing well in her GCSEs during the pandemic. "I didn't always find it easy to talk to people, but I love it now and have a great time at college. Julia's House has given me the confidence to make these decisions. They have changed my life."



highest ever number of community respite sessions to care for children at home



new children joined the Julia's House family



Sadly, 10 children we cared for died last year

EVIDENCE IS BUILDING

There is an increasing pool of research on the positive effect of respite care in reducing the emotional and physical impact on families who are caring for a child with a life-limited condition. Additionally, some of the latest studies point to a reduction in the wider economic impact of supporting these families if respite care is in place:

Worse health outcomes

Research published in March 2021 by Prof. Lorna Fraser et al (York University)* followed the health of 35,600 mothers over ten years. The study showed that mothers caring for a child with a life-limiting condition had substantially worse health outcomes than those of healthy children, including being twice as likely to suffer serious mental illness.

Respite has positive relationship impact

A national study conducted by Julia's House with Bournemouth University in 2017** showed that 74 per cent of parents who responded rated respite breaks as having a positive impact on their relationship with their spouse or partner. The remaining 26 per cent all used the breaks to spend time with their other children. Seventy-five per cent of separated parents questioned were not receiving short breaks when their relationship broke down.

Reduced burden on health services

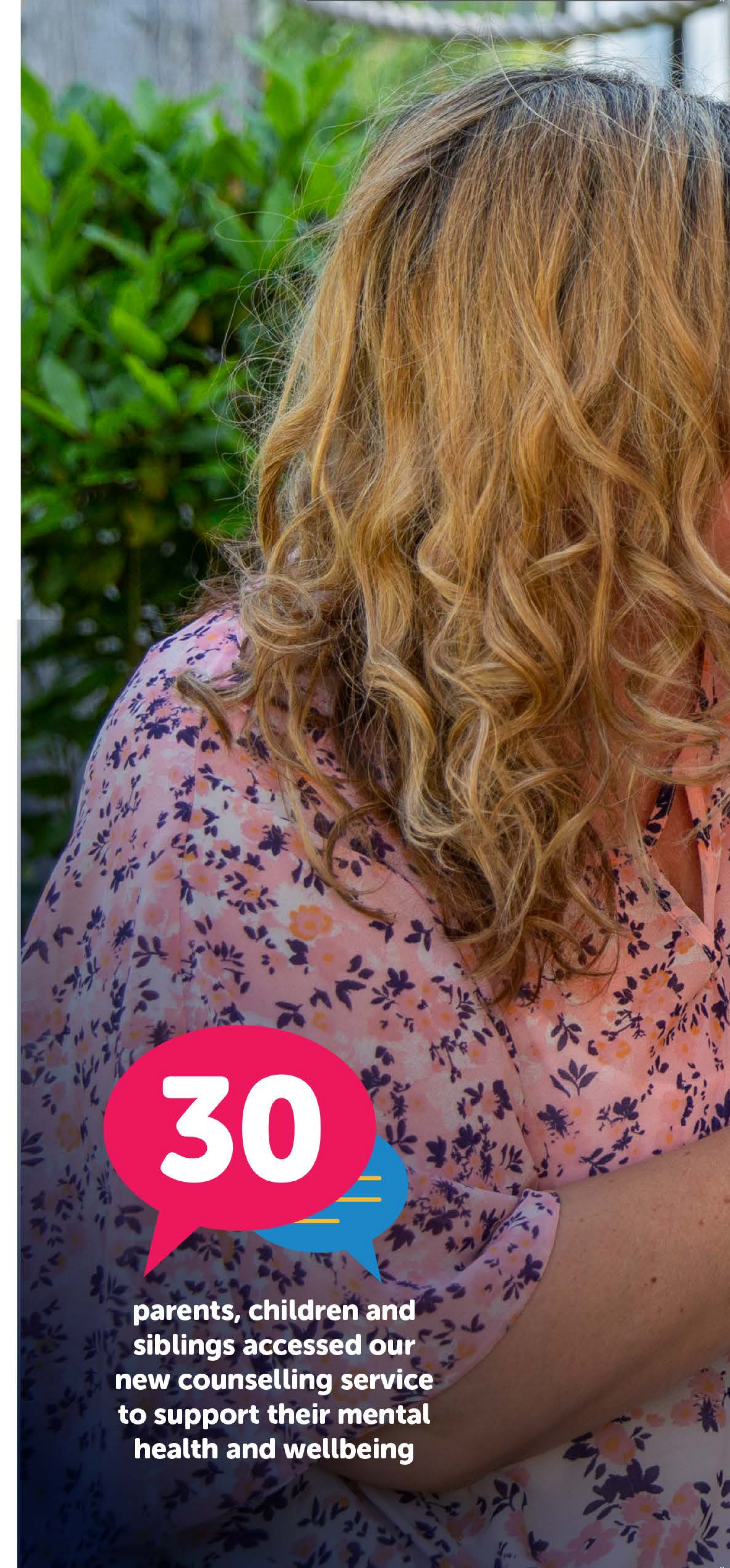
Recent research we conducted in partnership with Together for Short Lives*** found that respite care reduces stress and leads to fewer visits to the family doctor for parents of terminally ill children.

- An estimated 11 per cent of parents of children who need respite delivered by children's palliative care providers would experience significantly less stress as a result of receiving breaks – moving them out of the 'most stressed' category of society. This would reduce their demand for NHS services and the number of days they need to take off work.
- Reduced stress leads to improved mental health among carer parents, which in turn reduces the use of mental health services and the associated costs. Demand for mental health services falls by 49 per cent as an individual moves out of the 'most stressed' category.

* <https://adc.bmj.com/content/early/2021/03/01/archdischild-2020-320655>

** 'Can we fix it?' report by Julia's House with Bournemouth University, 2017

*** Research conducted by Pro Bono Economics, in association with volunteers from Compass Lexecon and published by Julia's House and Together for Short Lives in "Give Me a Break" report, October 2020]



parents, children and siblings accessed our new counselling service to support their mental health and wellbeing



PRESSURE ON MENTAL HEALTH

Zoe, is mum of Ted (12), Emilia (6) and Miles (16). Ted has an incredibly rare and terminal condition called Aromatic Amino Acid Decarboxylase Deficiency (AADCd), which is like a childhood Parkinson's disease. He's one of only five children in the UK to have it and there's only around 150 children with the condition worldwide. Zoe and Ted's dad, Sven, care 24/7 for Ted and receive respite care from Julia's House.

"Over the last 12 months, I think everyone's mental health has been hit hard during COVID-19, but pressures build up over years when you have a disabled child. Sven and I both work as well as caring for Ted and our two other children, and we can be incredibly exhausted from week to week. I don't know how we would have survived lockdown without Julia's House coming in really. And it made such a difference for Ted's mental health to have that social interaction from the carers. When the pandemic hit, most of our other care seemed to stop overnight, but Julia's House has been there with us throughout all three lockdowns."

"Over the last 12 months, I think everyone's mental health has been hit hard during COVID-19, but pressures build up over years when you have a disabled child."

2021: OUR ACHIEVEMENTS

We are continually adapting our care model to meet the evolving priorities and needs of the children and families. Our care is truly bespoke, delivering a lifeline of support wherever and whenever a family needs us.

Care in Changing Times

Increased flexibility of our care service

- Increased the number of sibling one-to-one visits and provided additional and emergency support to parents by accompanying them on visits or stays in hospital with their child.
- Expanded our Family Support Services to incorporate new social care-based skills and experience in providing personal and practical care and assistance, so we could help families to access the extra support they may need, from driving lessons to at home medical equipment.
- Provided more community hours of care per month than ever before, in a safe way, during the pandemic and beyond.

Enabled more families to access the service on a daily basis

- Created a library of online activities from music sessions to story time that families could access 24/7, at a time that worked for them.
- Augmented our virtual support programme, with play workers on line to guide a session and carers sat with the children bringing the play activity to life.

Extended our Family Support Services team

- Thirty parents, children and siblings accessed our new counselling service in 2021, to support their mental health and wellbeing.

Expanded choices for families at End of Life and increased referrals

- Appointed a second Hospice Doctor.
- Entered a Memorandum of Understanding with children's hospice, Naomi House, to enable us to provide increased access to Specialist Paediatric Palliative Medicine Consultants and offer families more choice at the end of their child's life, in line with NICE guidelines.



sessions of
specialist, individually
tailored care every week



Improved our care service for young people

- Offered new whole family sessions at the hospice, so every member of the family could benefit from respite care at the same time and in the same place. Different members of the care team worked collectively to offer a range of care and support to meet the individual needs of each family member, from 121 time with our sibling workers to a massage for parents with one of our complementary therapists.
- Created social 'bubbles' for small groups of young people, so they could enjoy evening gaming and pizza sessions at the hospice with their friends from other families or make new friends, while still staying safe.

People, Culture and Standards

Maintained our Care Quality Commission 'Outstanding' rating

- Retained our 'Outstanding' rating, following a CQC inspection of our care service in Wiltshire in December 2021 - a rarely awarded rating and testament to the dedication and commitment of our nurses and carers.

Optimised staff retention and recruitment

- Ranked 12 in the Top 30 Charities nationally in the 2021 Best Companies survey – the highest ranked hospice or palliative care charity in the UK – and retained our two star ranking, officially described as 'Outstanding'.

Finance, Fundraising and Communications

Increased the extent and level of donor support in Wiltshire

- Launched the Together We Care appeal in Wiltshire in September 2021, which generated over 300 media articles and an uplift in giving across all areas of income.
- Wiltshire-based subscribers to our monthly email newsletter rose by almost one third.

Improved diversity of staff and board

- Continually challenged our own thinking in how we recruit, address barriers to inclusion and are sensitive to differences between people at work as well as how we care for our families.
- When asked in an anonymous survey 95.5 per cent of those families that responded said that Julia's House meets its needs in terms of their race, culture or ethnicity (4.5 per cent answered Don't Know with no-one answering in the negative).
- We estimate that eight per cent of the children we care for are from ethnic minority backgrounds.
- Seventeen per cent of the charity's senior leadership team are from an ethnic minority background.
- All Board members and staff with management responsibilities received diversity training and future topics for Equality, Diversity and Inclusion working groups were identified.

Innovated in fundraising

- Launched our first ever virtual challenge – Seven Wonders of the World – which involved seven challenges, across seven countries.
- Moved more of our supporter communications online, giving existing supporters more informative updates and acquiring more new supporters for the charity.
- Expanded our digital marketing programme with monthly supporter emails and Facebook advertising to improve awareness, engagement and acquisition among new and existing supporters.
- Ran our first ever Christmas tree collection service with 647 trees collected by staff and volunteers across both Dorset and Wiltshire with donations totalling over £9,000.

Increased retail presence

- Opened the doors to a new Julia's House shop in Chippenham, Wiltshire.
- Relocated our Poole shop to a location with increased footfall.

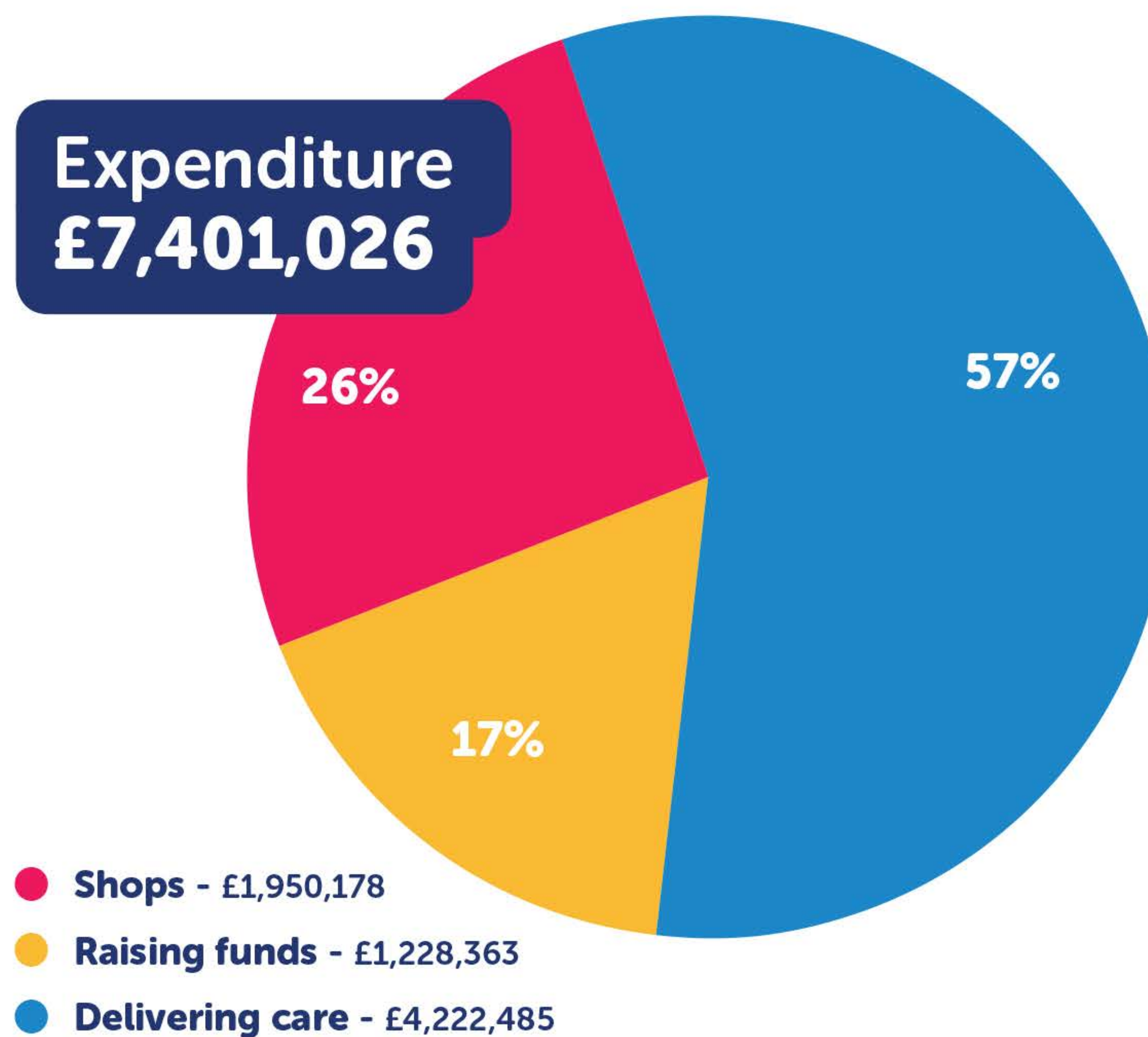
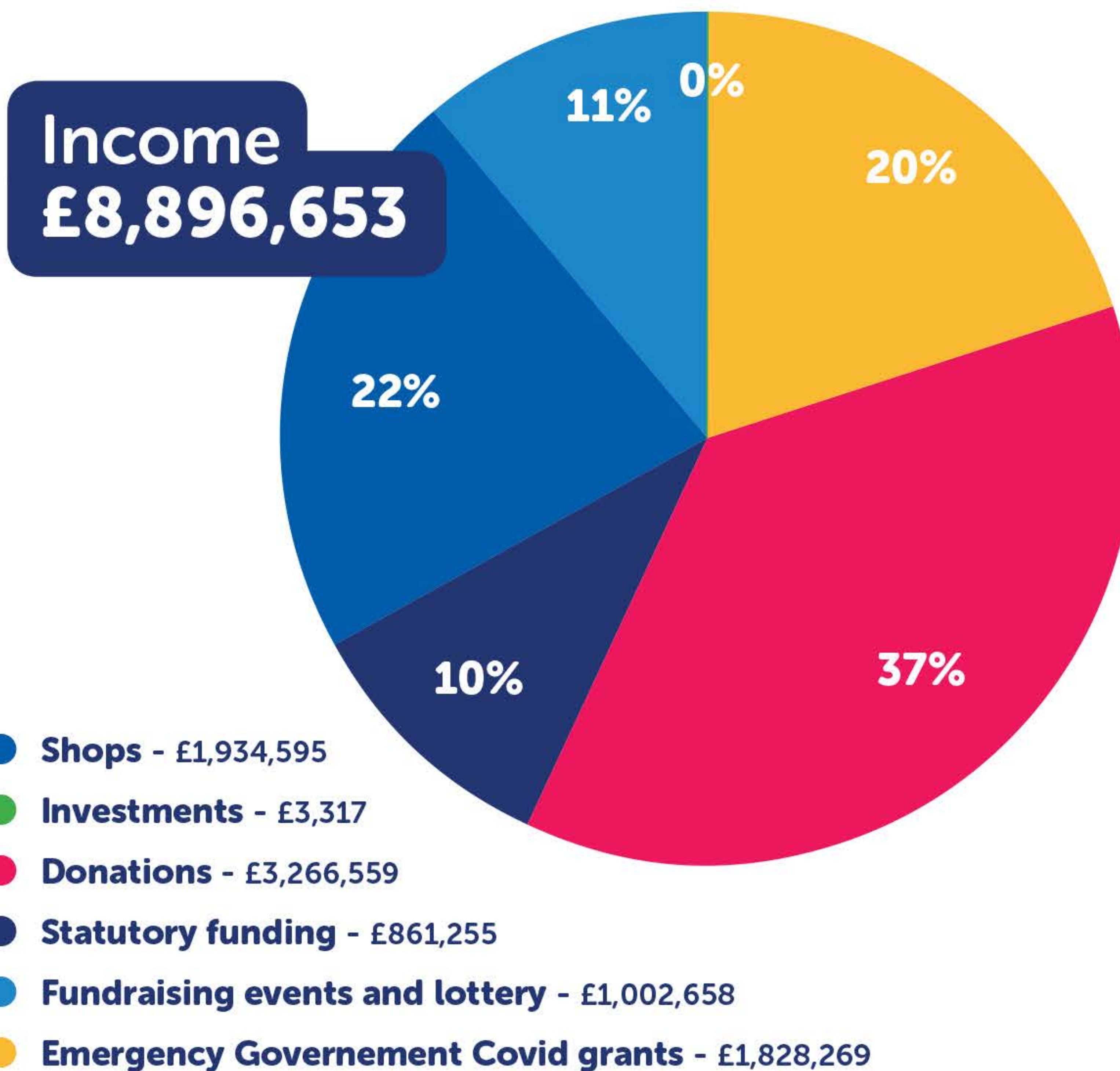


FINANCIALS

The pandemic has brought about closer collaboration between statutory and voluntary services in healthcare, and greater appreciation of the role of hospices.

At Julia's House we continued to make our hospices available to relieve pressure on local hospitals, and completed a daily 'capacity tracker' of the emergency standby assistance we could offer. The charity received emergency funding from Government for this extra capacity.

As a result of this and other government COVID relief support schemes, in 2021 Julia's House received 30 per cent of its total income from Government sources. This included a lump sum negotiated from NHS England to compensate for historic underfunding of Julia's House relative to other services.

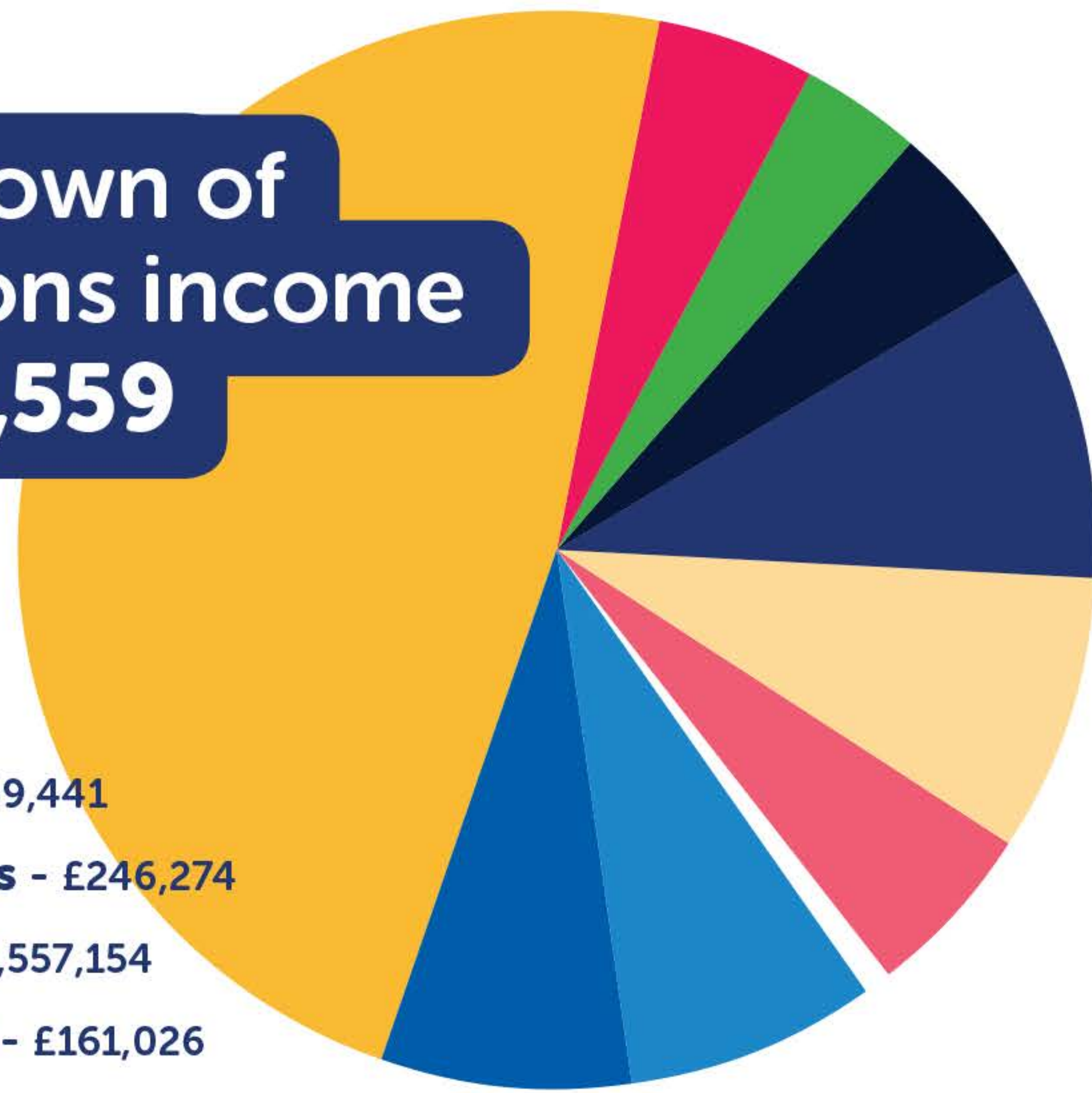


Julia's House receives only eight per cent on going statutory Government funding. This has increased slightly due to a negotiated funding agreement with NHS England.

While our current reserves are stable at 13 months of operating costs, trustees are comfortable with this higher level as we are forecasting a reduction in 2022 and 2023 as economic uncertainty continues, the cost of living is rising and COVID is still affecting our communities and putting huge pressure on our healthcare services. We can also not rely on legacy income as this can vary from year to year. Additionally, we are anticipating the need to increase expenditure on our care services to meet growing demand and the evolving and highly complex needs of the children and families we support.

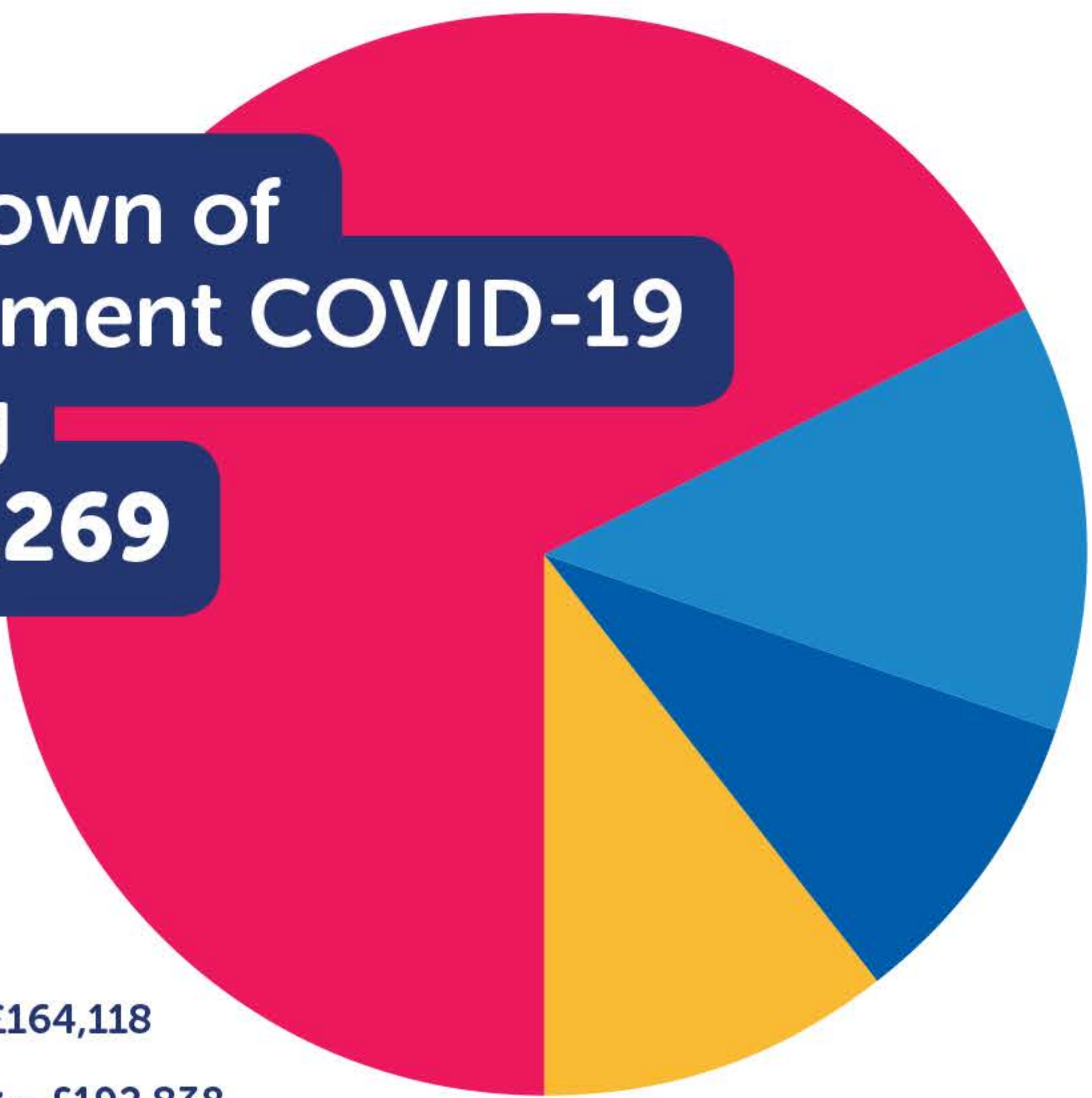
Seventy-eight per cent of expenditure (excluding retail) was spent on delivering our care

Breakdown of donations income £3,266,559



- Gift Aid - £249,441
- Major donors - £246,274
- Legacies - £1,557,154
- Gifts in kind - £161,026
- In memorium - £111,683
- Corporate support - £163,737
- Individual donations - £309,837
- Community fundraising - £273,133
- Trust & foundation grants - £174,441
- Miscellaneous income - £19,833

Breakdown of Government COVID-19 funding £1,828,269



- Kick Start - £164,118
- Retail grants - £192,838
- Job retention scheme - £235,612
- Hospice UK extra capacity grant - £1,235,701



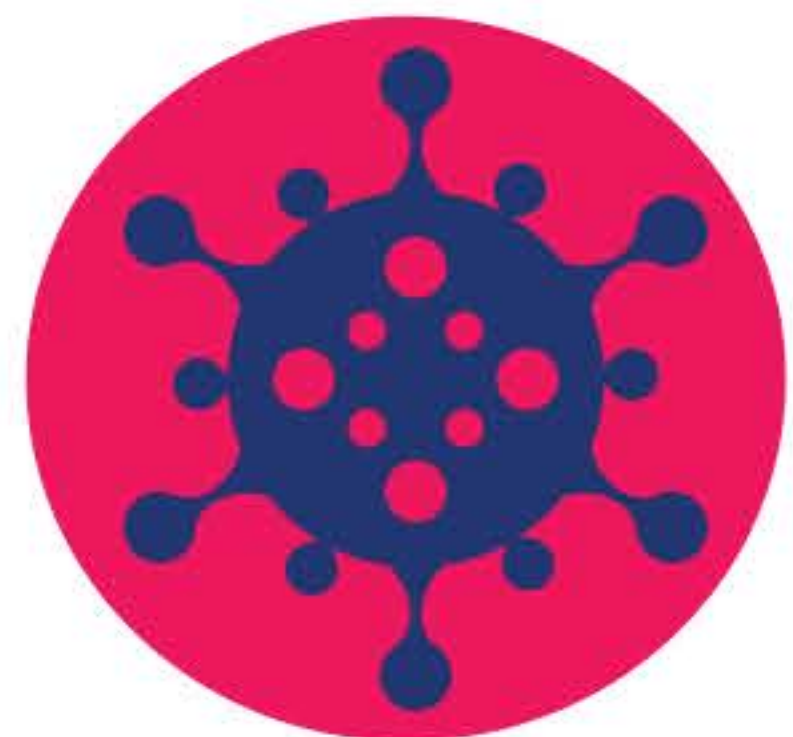
Julia's House has more than 500 registered volunteers – that's three volunteers for every member of staff. Our volunteers make a substantial contribution to the charity's services, fundraising and cost-effectiveness, as well as raising awareness of Julia's House in their communities.

In 2021 they gave 41,587 hours of support: a cost saving to the charity of £370,545 (based on National Minimum Wage) in addition to the substantial income that all those in fundraising and retail roles helped to generate.

KEY GOALS FOR 2023

Our 2022-2025 strategic plan focuses on four key areas:

Support growing numbers of children | Enhance end of life services | Broaden family support | Be the best run charity with the best people



Maintain continuity of care in the community and in consideration of potential fluctuations in cases of COVID-19, remaining alert and agile in our services to respond in case of any resurgence. Keep both Julia's House hospices on emergency standby to assist the NHS if a new wave causes local hospitals to become overwhelmed.



Focus on nurse and carer recruitment, and staff retention, given national shortage of clinical staff, and explore new and innovative approaches to recruitment.



Continue to support and enhance the mental health and wellbeing of children and families as well as our staff.



Maintain CQC Outstanding rating and vigilance in all areas of quality assurance, risk management, incident learning, safeguarding and staff training.



Double our Family Support Services team to increase support for siblings, complementary therapy and social activities for children and families.



Move towards balanced income and expenditure by 2024, adapting fundraising methods and generating widespread PR.



Further develop the specialist medical cover in place to provide more choice of care location for families whose child is approaching end of life, and generate increased referrals for end of life care.



Promote widely the need for legacy giving, so that one in four children in our care continue to be funded through legacies.



Complete the Together We Care Appeal in Wiltshire and launch The Big Dog Art Trail in Swindon (a free community sculpture trail culminating in a fundraising auction), building our fundraising base to provide consistent annual income in Wiltshire of >£2m by 2024.



Hold between 6-12 months' worth of operating costs in Reserves to ensure service continuity in the event of a serious shortfall in the charity's income, and given the reliance on public support for 92 per cent of funding.

Find out more about the children and families we support
Visit juliashouse.org/ourcare




In the heart of your community

 Registered with
FUNDRAISING
REGULATOR
Registered Charity No. 1067125