

2023 IMPACT REPORT

TOGETHER WE CARE

20
YEARS
A LIFELINE OF
CARE

MARKING A MILESTONE

2023 was a milestone year for Julia's House. It marked the 20th anniversary of the charity – two decades of providing the highest quality specialist community nursing care for the most seriously ill children across Dorset and Wiltshire.

The values that paediatric nurse, Julia Perks, dreamt Julia's House would uphold, are as true today as they were when the charity was formed in her name and memory by her friend, Mike Wise, 20 years ago. Julia wanted the charity to see that no family would be left without support at home when faced with providing round-the-clock complex care for their seriously ill child - care for the child, there for the family.

Providing responsive and flexible support ensures we are always there at the times families need us the most. Through consistent care, our dedicated nurses, carers and family support team get to know the children and families they care for and become a valued part of family lives.

Our care is centred around making the most of the short time the children and families we support often have together. We enable seriously ill children to have as much choice as possible in everything they do - we give them a chance to play, make friends, have independence and an opportunity for new experiences. And we give their parents much needed respite from 24-hour care, the freedom to rest and to experience joy with their child in a safe and supported space.

Marking our 20th anniversary was also about acknowledging the contribution of our volunteers and our supporters, as well as the contribution of our nurses and carers who have helped to make Julia's House what it is today. Without them our vital service would not be possible. Together we have been able to provide outstanding care for the last two decades.

"I still remember the first stay and play group I took Paddy along to. Walking in and seeing a room full of children just like Paddy, I felt a wave of relief that I'd found a new tribe of families I could finally relate to. The other parents I met on that very first day are still friends now, 15 years later."

Gemma, Paddy's Mum

Pictured: Paddy enjoying the hospice garden

OUR SERVICES IN 2023

- Hospice and home-based respite care to give parents a regular break
- Dedicated time and support for siblings as well as events for them to socialise with peers
- Emotional and practical support for parents, grandparents and other carers
- Additional family support and advice to navigate the cost-of-living crisis
- Complementary therapies and treatments for all the family
- One-to-one counselling for parents, children and other family members
- End of life clinical, emotional and practical care and support
- Bereavement support
- Dissemination of research around the impact of respite on family life to influence key stakeholders

Some children we care for are with us for a short time, some of them for a longer time, such as Paddy and his mum Gemma. However long or short that time, we endeavour to make it as happy, fulfilled and joyous as possible. We are there for the good days and the tough days, providing care that just isn't available for families anywhere else.



INCREASING IN NUMBER; INCREASINGLY COMPLEX

Recent NHS data shows the increasing number of children in Dorset and Wiltshire with life limiting conditions that will require support in their local community.* Support that Julia’s House provides.

For the Bath and North-East Somerset, Swindon and Wiltshire Integrated Care Board area specifically, the 2024 figures show around 1,640 children with life limiting conditions, rising to 1,788 in 2030. For the Dorset Integrated Care Board area, the anticipated growth in population figures and prevalence of life limiting conditions in children amounts to 1,219 in 2024 rising to 1,324 in 2030.

According to these figures, 2,850 seriously ill babies and children could be within the Integrated Care Board areas that Julia’s House covers now, rising to over 3,000 children potentially in need of support by 2030.

In tandem with a growing need, the complexity of conditions for seriously ill children continues to rise.

The total number of child deaths in the South-West region rose to 263 children in 2022/23 - the highest number for four years. Around 75 per cent of these children had a palliative care need. In the South-West between 2019 and 2022, three out of five children with a palliative care diagnosis who died were under one year. One out of five children with a palliative care diagnosis who died were aged 1-7 years old and one out of five were aged 10-17 years old.

*(Source: NHS hospital admission data, December 2023)



Pictured below: Finley enjoying a community respite care session with Julia’s House nurse, Jen, and carer, Sarah

Pictured right: Julia’s House carer Sarah and Finley



While sadly children are dying due to the conditions they suffer, thanks to innovations in medical science, more children are surviving and living longer. However, a higher survival rate also brings with it added complexity, as highly complicated conditions are now successfully managed through medical interventions that then have to be carefully managed and maintained by parents and care givers once a child returns home.

The weight of responsibility and risk that parents are carrying is immense for them when they take home their baby with a raft of medical equipment and instructions of what to look out for in an emergency. Mixed with the joy of going home is also the fear – will they be able to sleep? Will they remember the instructions for equipment and medicines? When should they call for help? How did that procedure work? Why is this happening?

“When you’re in hospital, your focus is completely on keeping your child alive and you battle through each day, you just can’t even imagine what the future is going to look like. But the future is really where Julia’s House comes in; the point at which you get out of hospital and return home, because you realise how much more there is to it when you’re at home.”

Gemma, mum to Finley



Pictured Addy with her family and Julia's House nurse, Sam

OUR CARE IN 2023

More children were referred to us for care than in previous years, reflecting national advances in medicine, with children surviving beyond the first few days of life and requiring our support when they are discharged from hospital. Children are also living longer with their complex conditions.

Sadly, nine children died last year. After their child has died, families will continue to be supported by us for up to five years of bereavement. This includes our annual Remembering Day, when we invite all bereaved families to gather and mark the life of each child who has passed away. Seventeen families received bereavement support in 2023.

33 

new children and their families were welcomed to Julia's House for care

181 

families were registered to Julia's House in 2023

149 

children and their families received care or bereavement support

Pictured above: Drae with Julia's House nurse, Amy, and carer, Gemma, spending some time in the sensory room at the hospice

Pictured right: Drae with mum Rachel and dad Darren

A SANCTUARY

"When I first came to Julia's House, I didn't know what to expect. The children are so poorly, but they're all so happy, this is their sanctuary. Julia's House helps with simple things, that make the world of difference. For instance, my children love biking, but I'm struggling to find the right trailer. Any trailer I look up for special needs or has disability in the descriptor automatically jumps up in price, so our Family Support Worker has offered to use her contacts and knowledge to help us research and locate the right thing."

"We've just signed up for sibling days too, so Drae's sisters can come along and join in the fun. They will be able to meet other siblings and make friends with kids experiencing similar things, not only kids with disabilities but children living in a household with a child with a disability. Having a child with a life-limiting diagnosis is hard on the entire family, so it's very reassuring to know Julia's House supports us all."

Rachel, mum to Drae



DEMAND FOR HOSPICE RESPITE CARE IS RISING

Increased demand for our hospices is a new development and reflects both investment and smarter working practices in our care team that we have employed after the pandemic.

Our services are continually flexing to meet family needs. We now provide a greater choice of sessions in the hospice and run different options throughout the day - after school as well as early evening or morning sessions, which are often suited to babies and younger children. Regular overnight sessions are offered too, including sleepovers at the hospice, which have become very popular.

Our community care is always there for children who don't feel well enough to make the journey to the hospice or where the parents would simply prefer that we visit, bringing nursing support and play to their home. Or we might need to support a child and their family in hospital.

That's what makes Julia's House so special, for every family our care is tailor-made to their individual needs.

43%

57%

Julia's House 

57 per cent of care took place in the hospices; 43 per cent in the community.

IT'S ABOUT LIFE...

"Addy was four years old when we discovered she had an ultra-rare type of Batten disease, called CLN2. It is a genetic disorder known as 'childhood dementia' and only around five children are diagnosed with it each year. When the doctors first gave us the diagnosis, it was like having the carpet ripped out from under your feet because it felt worse than the worst-case scenario. I remember my husband dissolving into tears and saying, 'We're going to have to bury our daughter'.

"Having a child with a life-limiting condition is a weird journey and one that I would say is a journey of grief. You're always trying not to let grief overtake you; you're trying to step into life and embrace every moment.

"Everyone at Julia's House is so personable and warm and kind. When people hear 'hospice' it can bring up so many connotations in your head. But Julia's House is so much more than that – really it's about life and not about death. It's about bringing life to families, who are living in a place of grief. And the hospice is such a beautiful place with the open set up and all the lights and equipment. Oh, and the massages! It's just incredible."

Hayley, mum to Addy



Pictured Addy having fun with Julia's House nurse, Sam, in the hospice garden

A HUG AROUND THE FAMILY

Our investment in our Family Support Service came to fruition in 2023, with expansion and new appointments increasing staffing capacity for the siblings programme, family support, social work and health and wellbeing. This teamwork, in tandem with clinical care colleagues, enables us to provide truly holistic support for seriously ill children and their families.

COST OF LIVING SUPPORT

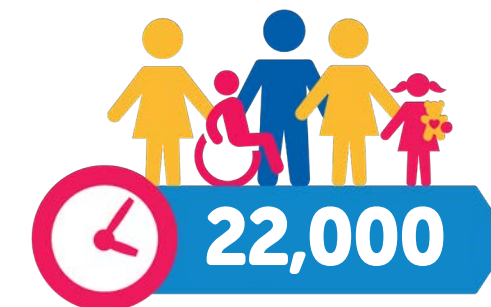
Inflation and the cost of living at home continue to disproportionately affect parents of disabled children – parents often have to give up careers to care and have to run life-saving equipment and heating 24/7 to keep their child safe and warm. Or they may require specially adapted equipment to help them such as car seats, ramps or trikes.

Our new social worker and team of Family Support Workers have been helping families navigate the practical and financial challenges of caring for a child with a life-limiting condition. They have helped families to research and apply to external sources of grants, when they just don't have the time or head space to do this for themselves – we secured over 100 grants in 2023, totalling £65,000 for families, to help pay for heating, equipment or other special assistance.

Our counselling service continues to be in high demand – 136 hours of counselling was provided to 25 family members during 2023, helping them work through the challenges and stresses they face in day-to-day life.

Our care for families included 13,000 hours of respite care in our hospices and the comfort of families' own homes, as well as 9,000 hours of support and activities for the wider family too.

Julia's House provided



hours of care to families in 2023



we secured over 100 grants in 2023, totalling £65,000 for families

We supported



siblings in 2023, up from 93 in 2022

KEY ACHIEVEMENTS IN 2023:

Maintained care staff retention, introduced innovative roles, and optimised employee accessibility.

- 10 Nurses/Team Nurse/Lead Nurse were recruited.
- We had a 14 per cent staff attrition rate.
- Offered return to nursing roles and a new advanced nursing practitioner role.
- Ranked No 1 UK ‘Charity to Work For’ in the prestigious Best Companies Awards 2023.
- Accredited as a Disability Confident Employer and implemented nationally recognised Oliver McGowan autism training.

Enhanced our Family Support Service

- Recruited a social worker to help families navigate social care needs.
- Health and wellbeing practitioner and new therapist appointed.
- 354 hours of complementary therapy to families during 2023.
- 9,000 hours of family support for parents, children and siblings including 890 hours of play sessions.
- 543 one to one sessions for siblings.
- 136 hours of specialist counselling support.

Built closer alliances with the local healthcare community and Integrated Care Boards in Dorset and Wiltshire

- Supported transition of 12 young people into adult care, working closely with local adult hospices.
- Developed the Starfish group in Dorset, a collaboration of medical and nursing expertise to enable better collaborative palliative care.
- Through enhanced collaboration with consultants, hospital staff and Integrated Care Boards, we strengthened our ability to provide excellent palliative care and respite care.



Pictured: Isla at the hospice with mum Georgia and sister Darcey

Provided more choices for families whose child is approaching end of life through greater clinical collaboration with other services.

- Provided 250 hours of end-of-life support for children and families.
- 17 families received bereavement support.
- Provided clinical care for children and their family in the hospice, in hospital and at home at end of life and post-death, collaborating externally, with community healthcare services and other hospices, and internally, with our sibling support, complementary therapy, family support and play worker teams in addition to our clinical care.

Maintained standards and vigilance in all areas of care, QA, risk, incident, safeguarding and training.

- Retained our Outstanding CQC rating following inspection in Jan 2023.
- Delivered 10,777 hours of training to care team staff.
- Tested new digital platforms to implement planned improvement in clinical benchmarking.

Utilised 20th anniversary as a platform to celebrate past and present achievements and increase support for the future.

- Anniversary sponsored walk led by Diana, a sibling from one of the first families we supported, in memory of her sister Gabby.
- Commemorative supporter newsletter raised over £13,000 in donations.
- Anniversary gala evening at Chewton Glen attended by over 100 supporters and raised almost £90,000.
- Held our first Thankathon to personally thank our long-standing supporters.

Reviewed the continuing suitability and capacity of Dorset hospice for an expanding care service.

- Board of Trustees agreed clinical case for a new hospice in Dorset to future-proof our service, but noted the move is unaffordable in the current financial climate.
- Agreed to review position annually and develop interim Dorset hospice refurbishment plan.

Promoted the need for legacy giving to maintain legacy funding for one in four of the children in our care.

- Held six face-to-face legacy events across Dorset and Wiltshire.
- Commissioned analysis to predict long-term forecasting of legacy income more accurately and collaborated with legacy consultant on strategy and messaging review.
- Commenced planning of major new legacy marketing campaign for implementation in 2024.

Undertook fundraising and marketing to generate awareness and income and move towards balanced income and expenditure by 2025/26.

- 120,000 people took part in the Swindon art trail. We raised £154,800 at the auction and 79% of people surveyed said the trail had made them more likely to support Julia’s House in the future. The trail achieved over 420 items of media coverage, including 34 TV broadcasts; equivalent advertising value of around £2.5 million.
- Christmas appeal raised £59,000 plus Christmas Tree Recycling Scheme gained 1,200 new supporters.
- Rising costs and an uncertain fundraising environment continued to contribute to an anticipated budget deficit of £1+ million in 2024.

Held 6-12 months of expenditure in Reserves by the end of 2023.

WHO LET THE DOGS OUT?

In 2023, we targeted Swindon to raise awareness in a hard-to-reach area of Wiltshire. Our pack of Swindogs and Swinpups formed a community art project that saw giant sized balloon dog sculptures pop up all across the town.

As 92 per cent of our funding comes from public donations, it is vital that we raise awareness among new supporters, especially in areas where we are currently less well known, even though we have an extensive community presence – we currently support 11 families in the Swindon area.

Brightening up Swindon’s town centre, familiar landmarks and parks with the colourful and lovable Swindog sculptures caught the attention of the public and raised huge support as well as warmth from local people.



Pictured left: Ted with the Swindogs

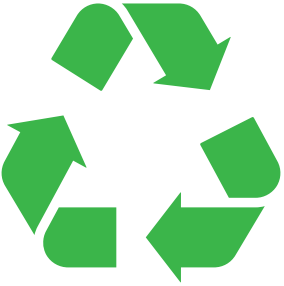
Pictured above and right: the Swindogs and Swinpups on display at Lydiard House and locations around Swindon.



PROTECTING THE PLANET

Julia’s House is committed to providing a quality service in a manner that ensures a safe and healthy workplace for our employees and minimises our potential impact on the environment.

We aim to comply with all relevant environmental legislation and strive to better our practices to minimise waste, energy and carbon footprint while achieving the charity’s service objectives.



We encourage environmental responsibility among our staff, volunteers and trustees, by promoting responsibility for the environment and communicating our aims throughout the organisation.

**17,000kg of textiles,
3,400kg shoes and handbags
and 8,000kg of bric-a-brac
sent for recycling**

COMMITMENT TO EQUITY

Everything we do in caring for the children at Julia’s House is about treating them equally, as individuals, and seeing their potential rather than their limitations: maximizing their opportunity to play, live, love and thrive within the family and the wider world. We believe in a working culture that is similarly fair to all, diverse in thought and background, and highly supportive so that people can excel.

Julia’s House advertises many vacancies nationally, highlights under-represented groups in our workforce and encourages applicants from these groups, operates ‘blind’ shortlisting good practice, and trains managers and board members in unconscious bias. The charity’s HR team and employee forum are also developing wider awareness of unseen disability among colleagues.

FINANCIALS

Throughout 2023, we maintained our engagement with the newly set up Integrated Care Boards to ensure that we are a part of and taking a lead in strategies that are developed for the regions for which we provide our respite, emergency and end of life care. Government funding accounted for eight per cent of our overall income in 2023.

With 92 per cent of our funding continuing to be found through public fundraising and most forms of public fundraising struggling in 2023 due to the rising cost of living, combined with the impact of inflation affecting our costs, 2023 was a deficit year for the charity. Julia’s House is extremely grateful for all donations and fundraising, and to everyone who works in, gives to or shops in our retail chain.

We are committed to continuity of care and support and we designate funds to sustain our nursing care and family support that our service users rely on, in the event of a serious shortfall in the charity’s income.

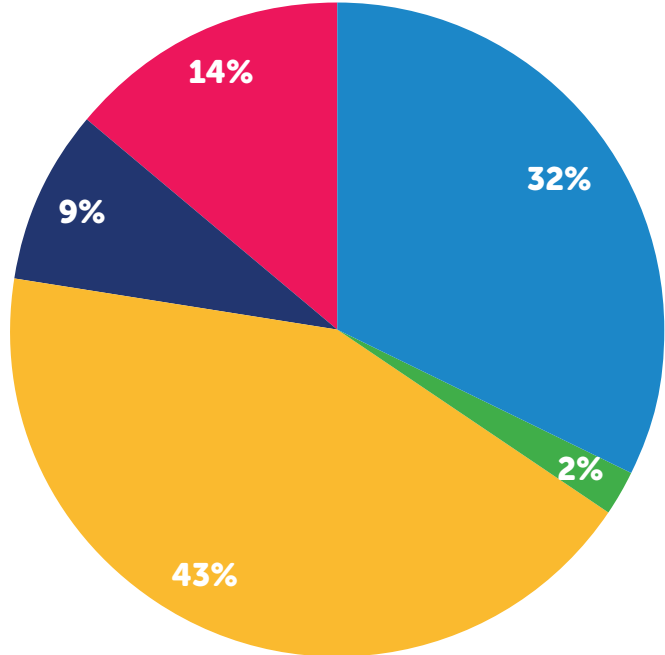
The charity’s Reserves at the end of 2023 constituted 12 months’ worth of 2024 budgeted operating expenditure. This is forecast to reduce over the next two to three years with further budgeted deficits. The Trustees therefore assess that the current level of Reserves is both prudent and necessary to maintain the charity’s care services.

LASTING LEGACY

The charity is profoundly grateful to everyone who remembers Julia’s House in their Will, with legacies accounting for 50 per cent of the charity’s voluntary income in 2023. Our retail operation continued its growth buoyed by the consumer trend towards sustainability and focus on pre-loved fashion and furnishings, achieving an increase in income to £2.9 million in 2023.

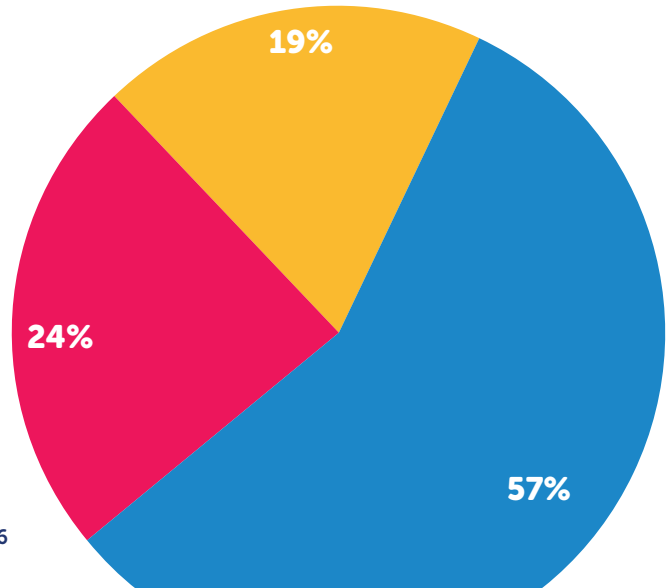
Income
£9,058,161

- Shops - £2,942,731
- Investments - £196,032
- Donations - £3,889,359
- Statutory funding - £772,371
- Fundraising events and lottery - £1,257,668



Expenditure
£10,052,417

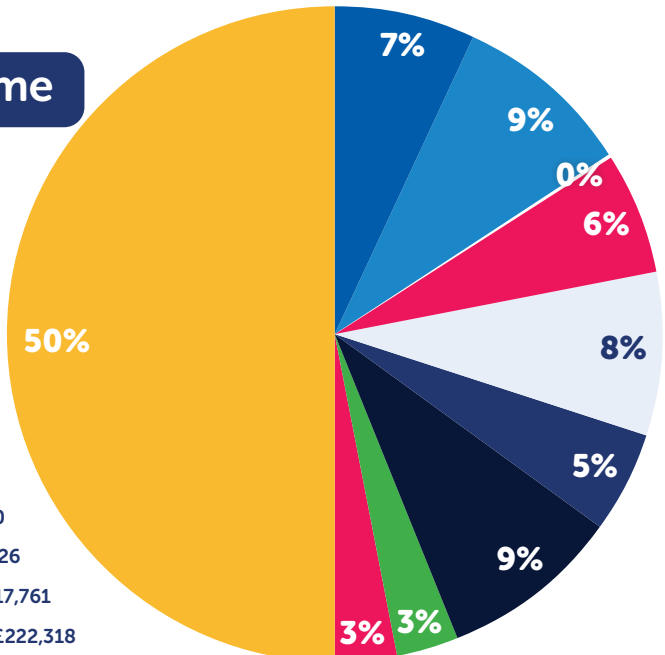
- Shops - £2,375,151
- Raising funds - £1,959,040
- Delivering care - £5,718,226



74% of expenditure (excluding retail) was spent on delivering our care

Breakdown of
donations income
£3,889,359

- Gift Aid - £360,131
- Major donors - £264,770
- Legacies - £1,945,505
- Gifts in kind - £104,897
- In memorium - £105,808
- Corporate support - £346,680
- Individual donations - £215,526
- Community fundraising - £317,761
- Trust & foundation grants - £222,318
- Miscellaneous income - £5,963



VALUING OUR VOLUNTEERS

Our volunteers make a huge contribution to the charity’s services, fundraising and cost-effectiveness, as well as raising awareness of Julia’s House in their local communities.

In 2023, volunteers gave over 73,000 hours of support, the equivalent of 40 full time staff and a cost saving to the charity of £760,000 (if based on National Minimum Wage). Additionally, many of these volunteer roles generate substantial income, in retail and fundraising. Many other volunteer roles are in care support.

We are so appreciative of their continued commitment and support and the life changing difference they enable us to make to children and families. In 2023, we showed our deep appreciation with special 20th anniversary celebrations for the volunteers and championing them in national Volunteer’s Week.

Pictured: Julia's House volunteers celebrating Volunteer's Week at a special hospice tea party



KEY GOALS FOR 2024

Our 2022-25 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

The charity aims to maintain adequate designated and general funds to ensure service continuity. In the context of current budgeted deficits and the adverse economic climate, our main goals are:



Continue to provide dynamic, responsive, innovative and essential care to every eligible child and support for their family.



Retain and recruit a highly skilled, passionate and engaged workforce.



Open more shops across both Dorset and Wiltshire.



Measure the impact of care, demonstrating the effectiveness of our holistic approach and elevating the value of comprehensive clinical and holistic support to the whole family.



Closely monitor and report on performance of income and expenditure versus budgeted levels.



Seek stronger partnerships with local Health & Social Care Integrated Care Boards to improve children's palliative care.



Continue to collaborate with our partners to provide sustainable, equitable and excellent palliative care across two counties.



Continue to invest in voluntary income generation and public awareness.



Continue to influence local and national policy makers to seek more sustainable funding for hospices.

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




In the heart of your community

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FUNDRAISING
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Registered Charity No. 1067125

