In truth, it’s hard to put into words the profound and lasting impact your support is making on the lives of local children, young people and families. For most of us it’s hard to imagine the challenges they face.

But, thanks to your continued generosity, we’ve been able to support more than 260 children and young people, their brothers and sisters, and their families across Staffordshire and Cheshire. In 2017 / 2018 you enabled us to provide more overnight respite stays, art therapy sessions, counselling sessions and end of life support. We simply wouldn’t be able to do this without your commitment to supporting families in your local community, so thank you.

Throughout the last year we continued to develop our plans for a young adults’ service and in December we “broke ground” on the new, purpose-built facility for young adults. The building will offer facilities for end of life care, day care and overnight respite, along with a wide range of dedicated specialist services.

Construction of the new building, next to the existing hospice in Trentham, is now well underway and phased opening will start in early 2019. However, we will need your ongoing support to develop the young adult service and maintain the existing children’s service.

We’ve also continued to develop a range of care and support services for younger children. The amazing care team provide stimulating activities and experiences, from summer garden parties to messy play sessions, art therapy and days out. Your support makes this happen and means every moment truly counts.

Each year the amount of money required increases as we strive to meet the growing needs of existing and new families. In February we launched the “One in a Million” fundraising appeal to help us raise an additional £1 million each year. We now need your help to raise at least £4.5 million each year to be able to offer the services children, young people and families need.

They rely almost entirely on you and the local community to raise this huge amount of money. We are continually overwhelmed by the lengths you will go to support them. Whether it’s jumping from an aeroplane, climbing a mountain, organising a bake sale, filling a home collection box, or encouraging others to support The Donna Louise Hospice, every penny you raise and donate has a lasting impact on people’s lives.

So, on behalf of all the families who benefit from your support, thank you.

Sue Read, Chair

Simon Fuller, Chief Executive
This report demonstrates the impact you, our supporters, made to families throughout Staffordshire and Cheshire in 2017 / 2018 and:

• What we do
• Why we do it
• How we do it

The hospice in Trentham is the main focus of our service, however we provide care and support for children, young adults and their families:

• Where they need it most
• When they need it most

MEET WILLIAM

“When William comes to The Donna Louise, he's a boy and not a diagnosis. He's a child who can play, run, smile and do all the things he wants to do”, explains his Mum, Tracey.

William is 11 years old and has a complex cardiac condition which was diagnosed when he was just a few months old. He had his first heart operation at 7 months, and an artificial heart valve fitted at 10 months. During the operation, one of his arteries was damaged, making it impossible to ever change the valve as it deteriorates, which it will, and he was placed on the heart transplant list.

Since that time, William, and his family, have faced years of health concerns and uncertainties. They know that one day his heart will fail and, such is the pressure on his lungs, that he now needs a heart and lung transplant. He will only go on to the transplant list when he goes into heart failure.

William is surprisingly mature for his years. Tracey explains, “Children with complicated health conditions can lose their childhood. William has spent so much time around adults, doctors and consultants, and he has heard so many things about his health, his body and his prognosis, that he’s had to grow up very quickly.”

And that’s why the family value their visits to The Donna Louise so much. Tracey says, “William is more easily tired than his peers and he can be held back from doing all the things that his friends do. But at The Donna Louise all the children are restricted in some way. They can play together, regardless of their condition, and William can really just have fun.”

Tracey also appreciates spending time with other families who are caring for a child with complex needs. She says, “Our family and friends at home are obviously going through things with us, but they don’t understand everything. The other families we meet here may have a child with a different condition, their journey may be different to ours, and they may be at a different stage of that journey, but they know...they really know what it’s like.”

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OUR STRATEGIC GOALS

TO BE FIT FOR THE FUTURE
By focussing on a range of deliverables, including innovative and standard practices, we will continue to ensure that children, young people, and their families continue to receive the most efficient and effective palliative care and respite service. This includes ways to secure on-going, planned, and sustainable income, and developing the organisation’s infrastructure to meet and support demands and on-going regulatory compliance.

AIMING FOR EXCELLENCE
We want to be the best we can be, offering a ‘centre of excellence’ for children and young people’s palliative care. We have developed a programme of continuous improvements to ensure the organisation maintains excellent service delivery and outcomes as well as fostering innovation and creativity.

MAKING CONNECTIONS
We recognise and value the role of children, young people, and their families in the delivery of services, as well as that of professionals, staff and volunteers who work with us to provide an excellent palliative care service at the hospice and at home. Locally we are part of the Stoke and Staffordshire Children’s Palliative Care Network as well as Staffordshire Children and Family Bereavement Alliance. Regionally we are part of the West Midlands Paediatric Palliative Care Network.

We have strong relationships with many corporate partners and could not continue without the generous donations from them and members of the public.

We work closely with other children’s hospices across the UK to share expertise and knowledge. Representatives across the Charity are involved in a number of committees, forums, and steering groups for Together for Short Lives (formerly ACT and Children’s Hospices UK), helping to contribute to the hospice movement in the UK. We want to continue to build and strengthen our partnerships with all our key stakeholders, involving and enabling them to influence and contribute to our service planning and delivery.

OUR VALUES

OPENNESS
We encourage an open and transparent culture which fosters trust, collaboration, continual learning and community spirit.

FAIRNESS
We endeavour to provide a balanced approach at all times which is equitable and non-discriminatory.

ENABLEMENT
We support and empower our children, young people families, staff and volunteers to have a say in the way our services are delivered and to influence the future direction of the organisation.

RESPECT
We foster a culture of respect and maintain the environment of team work, growth and diversity.

EXCELLENCE
We strive to be efficient, effective and innovative, giving our best with passion and consistency and continually searching for ways to do things better.

INTEGRITY
We are ethical, professional, honest and accountable in our approach to everything we do.
When little Tommy went into heart failure at 3 months old his mum, Kirsty, felt like her worst fears were coming true. She’d had a feeling that there was something not quite right with his health for some time but had struggled to get anybody to listen to her concerns. Kirsty had woken in the night to find her baby boy silently choking on vomit. This happened a lot. He was putting on weight but only as a result of Kirsty constantly working to get fluids inside him – everything was incredibly difficult.

A paediatric appointment and scan revealed that Tommy had an enlarged heart, lungs and kidney. In 5 minutes he went from having a routine scan to being admitted to the High Dependency Unit. In that 5 minutes Kirsty went from being told that she had a normal baby to being told that her baby was very likely to die.

Tommy was diagnosed with Critical Aortic Stenosis, a narrowing of the aortic valve. He was rushed to Birmingham Children’s Hospital for an operation and spent 4 months there as he struggled with his feeding. Tommy will need more surgery, but the doctors want to wait until he’s bigger. He’s 3 years old now and has severe developmental delays, his speech and communication are that of a 15-month-old. He has hypermobility too.

Kirsty explains how it felt when the family first came to The Donna Louise, when Tommy was 1 year old, “I was so tired from caring for Tommy.

To keep his weight up I was literally feeding him 24 hours a day, and he was sick constantly. It was an ongoing battle to keep him nourished. I was exhausted! He came to the hospice at first just for day care. It was so hard to leave him though, I felt very nervous as he goes down-bank so quickly.”

But with 2 other children to care for, Kirsty and Tommy’s dad, Dan, rely on the hospice to give them a much-needed break and the chance to spend time with his brothers, Josh and Oscar. Kirsty says, “The other kids miss out on quality time with me and Dan because we are so busy caring for Tommy. When he’s at The Donna Louise, not only is he having a fun time, but we get to spend some precious time with the boys. It gives everybody the time they need for them, and for us as a family.”

Kirsty explains what the support of The Donna Louise has meant to them all:

“When Tommy became ill we began to grieve. We grieved for the baby we felt we had lost. We had to accept that we’d gone from having a healthy baby to a baby with very complex needs. The Donna Louise pulled us back together again. We don’t know how we’d have coped without their support.”
“On the 19th December 2015 our eldest daughter Jocelyn was diagnosed with ALL Leukaemia (blood cancer), 2 weeks before her 9th birthday. Our lives were totally turned upside down. She has amazed us by her strength, bravery and courage dealing with needles, tablets, surgery, sickness, being in hospital and losing her hair.

“Over the last few years we have had many low points but also shared some lovely memories. Joss has been able to go to The Donna Louise whenever she has been unable to go to school for various reasons. During her 2 years of treatment Joss’s confidence has been knocked and so many times she just said to us, “WHY ME?” – A question we often still ask ourselves.

“Spending time at The Donna Louise has enabled her to really develop her singing and she’s even written two very meaningful songs regarding her thoughts and feelings during her treatment. Without the support of The Donna Louise, her feelings and thoughts may have gone unnoticed. Her confidence and achievements have shone through all the horrible times she’s had to endure. Joss now has guitar lessons and will soon be attending singing lessons which has all been inspired by The Donna Louise. We are so proud of our amazing little family!”

Written by Jocelyn’s Mum, Nicola.

“Her sister Laila (age 7 at the time), and her brother Jack (age 1 at the time of Joss being diagnosed), have made us so proud and given us strength when we needed to carry on and fight. The support from the Donna Louise, other charities, family, friends and new acquaintances has been truly amazing and there’s no way we could repay such love!”
to entertain the boys and just having another pair of hands is unbelievably helpful.”

Meghan and her husband are able to participate in individual and family therapies through the Hospice. “The pamper days that mums and carers are invited to are the only time every year that I have my nails, make-up and hair done. If I’m really lucky I can squeeze in a massage too.”

The groups have also helped to put Meghan and Kip in touch with other families at the Hospice. “We asked if other families wanted to talk and share their experiences as this journey we’re on can be lonely and frightening and it’s a very uncertain future for us all. Being able to speak to someone honestly about what’s going on and how I feel about it is a huge relief.”

Meanwhile Jamie and Connor love the art therapy sessions which help them to talk about their feelings and they also attend the siblings group which they absolutely love as it’s something just for them.

The family came to The Donna Louise when Lyla was nine months old. Meghan says, “I was exhausted with worry from trying to be strong all of the time for everyone else. I was broken, Lyla was very ill. The Donna Louise came in to our lives, just at the right time.”

Your support provides respite stays for Lyla and sometimes for the whole family as well. Meghan says, “We’re not able to leave Lyla with anyone else because of her high level of needs. For us to leave Lyla with them is a massive relief that I find it difficult to explain, even to be able to just have a night’s sleep is magic. I cannot begin to explain the value of Lyla being in a safe environment with trained people who know her well. Since Lyla has begun her respite stays at The Donna Louise, I can breathe again.”

When the family come to the Hospice the two older boys enjoy making the most of the facilities available. Meghan said, “Sometimes I have to talk to the nursing team about something medical or serious, but there’s always someone to entertain the boys and just having another pair of hands is unbelievably helpful.”

“ They saved us, they literally picked up the pieces of our broken family and now we have a strong support system and a very strong family unit, thanks to all the work the Hospice does. ”
We’ve made a promise to be there for our young adults, no matter where or when, for as long as they need us – and we will.

In December 2016 we announced exciting plans to build a new multi-million pound young adult facility. Without this service, the future for more than 40 young people currently in our care looked bleak, with no appropriate care services available to them.

Just one year later, in December 2017 we broke ground on the new building. The construction of the unit, located alongside the existing hospice in Trentham, will be funded by The Denise Coates Foundation.

The new building will provide facilities for day care and overnight respite, and will encourage independent living as much as possible for the young adults. There will also be the space to offer a wide range of physical and emotional therapies.

Professor Sue Read, Chair of The Donna Louise Board of Trustees, said, “This is by far the biggest single change to the charity since it opened. As a charity, we rely almost entirely on donations and fundraising to run our services. We cannot thank The Denise Coates Foundation enough for this very generous support, which means that we can forge ahead with our plans to deliver a meaningful service to our young adults as soon as possible.”

Building work is well underway and we hope that the new service will be completed by early 2019.

While funding for the new building has been generously provided by The Denise Coates Foundation, we now need your support to raise more money each year to develop the support we offer to our young adults, grow the services we offer to existing families, and reach new families across the region who need our help.
As the needs and demands of the young adults who rely on The Donna Louise increase, we're constantly looking at ways to support them.

Last year we recruited an adult social worker / transition co-ordinator, Linda, who works with all our young people to ensure they are able to access the services and support they need, and are entitled to.

Linda worked closely with one young adult in particular, Chloe, and has made an enormous impact on her life.

Chloe was a perfectly happy and healthy baby until she reached 2 and a half when she contracted an unknown virus. She was quickly diagnosed with Transverse Myelitis, an extremely rare and devastating condition which affects the spinal cord, and given just two weeks to live.

Seventeen years later, Chloe is now 19 and has defied doctors’ expectations throughout her life. She’s paralysed from the neck downwards and is just one of seven people in this country to live with the condition.

Yet, with the support of her family, friends and The Donna Louise, she’s grown into a thriving and independent young lady. And, just like many other 19 year olds, Chloe dreamt about being able to live on her own, but never thought it would be possible.

Chloe explained,

"I'd always talked about moving out of home and The Donna Louise gave me the confidence to do it. Linda helped me sort everything out; she did lots of research helping me with the applications for the flat and a car. I don't think I would have been able to do it without the help and support from The Donna Louise. It’s amazing and has made my confidence much better and helped me to be myself. I don't know what I would do if The Donna Louise wasn’t there any more – there’s always someone there to talk to and they’ve helped my family a lot."

In August, with the help of Linda, she made the brave and exciting decision to move out of her family home to begin a new and independent life in her own flat.

Linda explained more about her role at The Donna Louise,

"My main focus is to co-ordinate the transition period for young people from the age of 16, ensuring the right people are involved, at the right time. I work with multiple agencies to ensure that young adults and their families are supported with anything they need, from accessing the benefits they’re eligible to, to preparing for hospital stays when they can no longer access children’s wards."

Linda has worked particularly closely with Chloe, helping her to be come as independent as possible, she added, "I met Chloe during my first month at The Donna Louise, she was very clear then about her desire to become as independent as she was able. Over a period of about 18 months I’ve liaised with the Department of Work and Pensions to ensure Chloe is in receipt of all eligible benefits, helped her to understand and manage her own finances and assisted her in applying for her own wheelchair accessible vehicle through the Motability Scheme.

“I've also supported Chloe to register with various housing providers and ultimately move in to her own apartment, as well as arrange and chair many multi-disciplinary team planning meetings to support Chloe in her journey towards independence.”

Thanks to your support, Chloe will be able to continue coming to The Donna Louise for as long as she needs to and Linda will continue to support her, and other young adults like her. She will also be one of the first young adults to benefit from our new young adults' facility, where she will continue to learn independent living skills, alongside her friends.
If The Donna Louise wasn’t there anymore I don’t know what we’d do. We’ve made friends for life. We don’t really know what Sam’s future will hold, although it is unlikely that he’ll have as long a life as someone without his issues. It’s one of the brutal realities that we have to face. But, we also know that when the time comes when we lose him, we won’t lose The Donna Louise. We’ll never leave the place – we’ve both said we’ll volunteer after Sam has gone.
“Super Sam (as we call him) is a happy little chap. He has a gentle soul, he’s very caring and is so, so funny and he does like to be the centre of attention. We knew this when he decided to arrive 2 weeks early with a frantic delivery.” Carolyn, Sam’s mum, explains how her gorgeous little boy came into the world and how he’s kept his mum, and dad Jonathon, on their toes ever since.

At birth Sam was breathing fine but Carolyn found that feeding him was difficult. The doctors and nursing staff said this was perfectly normal as he’d stopped growing at 35 weeks. But Carolyn just had a feeling that something wasn’t quite right. And at 14 weeks Sam had his first seizure.

The ambulance came, and Sam was blue-lighted to hospital. That ride is etched in Carolyn’s memory, “He had another seizure in the ambulance and they just kept coming, they couldn’t get the seizures under control and they had to give my baby really strong medication to sedate him. It was the only way he got some relief. Over the next 5 days his little body was a pin cushion as they tried to find out what was causing the seizures. Eventually the diagnosis came – epilepsy.”

Sam was sent home and only 4 days later he was back in hospital after 6 massive seizures came one after the other. An ECG revealed catastrophic brain activity with aggressive brain waves. Sam had “Infantile Spasm”. He was immediately put on to a high dose steroid therapy. And so began 8 months in and out of hospital. They never got the seizures under control. At 12 months Sam had a massive seizure and stopped breathing. Carolyn had to give him CPR and resuscitate him. That time he came home from the hospital with oxygen.

Now, at 7 years old, Sam has been diagnosed with severe brain malformation. The left-hand side of his brain is much smaller than the right as a result of his brain not developing properly in the first few weeks of pregnancy. But a Vagus Nerve Stimulator has reduced the number of seizures by 70% and calmed the activity and Carolyn and Jonathon have built a wonderful life for their son, full of fun and laughter.

Sam has profound and multiple learning difficulties, is profoundly visually impaired and is on the autistic spectrum. He can’t walk or sit up, he can’t swallow safely and has been PEG fed since the age of 4. Yet he lives a happy and full life. He enjoys going to school, loves building LEGO with his dad and swimming is his absolute favourite! Carolyn explains, “It’s not an unhappy life, people assume that it must be with a disabled child, but it really isn’t.”

And for the 3 of them coming to The Donna Louise is like visiting their second family. Carolyn explains how the hospice supports them, “The first thing that happens is that somebody gets you a cup of tea! Sam can play with his mates and I get a hot drink and a bit of peace and quiet. A child like Sam can’t entertain himself and so needs constant attention. He’s on the go from Sam until midnight most days and there is no break in that time. He can’t move himself and so gets easily bored. It’s really exhausting. So, for him, The Donna Louise is great because he gets to do lots of fun activities and play with friends. And for us, Sam’s respite breaks mean we get a chance to relax and have some time to ourselves.”

The family have been grateful for the support of the hospice during emergencies too. Two years ago, Carolyn had emergency surgery for a very serious case of appendicitis. It was all very sudden and very frightening. They made a call and within 30 minutes Sam was booked in for a stay. It meant that Carolyn and Jonathan could focus on getting her better, knowing that Sam was safe, being cared for properly and having a fabulous time.
267 families with 436 brothers and sisters cared for in 2017/2018

1637 nights of respite stays provided and
1338 hours supporting families in their home and in hospital
HOW WE PAY FOR IT

INCOME

- FUNDRAISING INCOME: £3,051,735
- INVESTMENT INCOME: £19,912
- CHARITABLE ACTIVITIES: £12,693
- STATUTORY INCOME: £434,404
- ACTIVITIES FOR GENERATING FUNDS: £84,048

TOTAL INCOME: £3,602,792

EXPENDITURE

- FUNDRAISING COSTS: £978,742
- GOVERNANCE: £131,663
- CARE SERVICE: £2,546,280
- OTHER: £101,924

TOTAL EXPENDITURE: £3,758,609

FUNDRAISING INCOME

- INDIVIDUAL & COMMUNITY: £1,070,147
- GRANT MAKING TRUSTS: £1,027,734
- COMPANIES: £639,281
- LEGACIES: £314,573

TOTAL FUNDRAISING INCOME: £3,051,735

IMPACT REPORT 2017/2018
The annual Weston Christmas Light display raised an incredible £25,870. This means we’re able to fund a new play leader for a year and provide 8 specialist sensory play activities for the children.

Our second Christmas Jumper Day raised £25,000. £22,000 will pay for 18 overnight rest days for families.

8 dedicated supporters took on the London Marathon and raised more than £31,000 between them. £31,000 will contribute to the salary of a social worker.

The Donna Louise simply wouldn’t exist without you, our brilliant supporters. You continue to amaze us every day by raising money to support the children and young adults, and their families.

1167 runners took part in our Family Fun Run and together they raised a fantastic £40,000. That’s enough to pay for a nurse to care for children and young people when they come to The Donna Louise, or in their own home, for a whole year.

From climbing mountains to soaring down zipwires, cycling across countries to jumping from planes, and from organising bake sales to holding golf days, your dedication never ceases to amaze us...
26 Business Volunteer groups came to the hospice, giving up their time to paint, clean, weed and tidy. That means the hospice is always neat and tidy, without costing us a penny.

Employees from TIP Trailers took on a 320km bike ride from the foothills of the Alps to Venice, over 2 days, and raised £27,250. That’s given 37 families the security blanket of knowing there’s someone to talk to through counselling sessions.

64 supporters trekked to the top of Mount Snowdon in the middle of the night, pushing on through wet and windy conditions to raise £15,000. £15,000 will pay for a care supporter for 10 months.

Training Bytesize and Dorfold Hall held a fun-filled Superhero family picnic, complete with costumes, games, giggles and more and raised £10,000. £10,000 will give 7 families an overnight respite stay at the hospice, or in the family home.
VOLUNTEERS

The Donna Louise simply would not function without our small army of amazing volunteers.

We have a team of more than two hundred volunteers and they play a huge role within the hospice, at our events, in our shops and in the local community.

Our volunteers gave more than 18,200 hours of their time at the hospice alone, helping with everything from pamper sessions to housekeeping, gardening to manning our reception. On top of that we have volunteers who help in our shops and help to run our events – last year these volunteers gave more than 6,500 hours of their time!

One of our longest serving volunteers Cedric, has given up his time to support the children and young adults here for more than 14 years and plays a vital role in the day to day running of the hospice by completing important health and safety checks each week.

Cedric said, “I’ve had a great deal of satisfaction in volunteering at The Donna Louise and I’d always said I’d like to put “a little back into the community” if I was able to do so and The Donna Louise has been ideal for me to do that.”

We know that it’s not always easy to find the time, but just a few hours each week can really help. We’re always looking for new people to join our team, so whether you can spare a few hours each week, or just the odd day here and there, you can make a huge difference.

I get great joy from seeing the lovely smiles on the faces of the children while they are enjoying the many activities they are able to join in with, and the friendliness and helpfulness of the staff is second to none.

OUR VALUES

- Openness
- Fairness
- Enablement
- Respect
- Excellence
- Integrity
“I’m proud to be a patron of a charity which is making such a huge difference to the lives of so many families. The children and young adults who rely on The Donna Louise are a real inspiration and I’m honoured to be able to support them.”

Robbie Williams

“Any parent knows how difficult it is when your child is unwell. To be the parent of a child or young adult with very complex medical conditions requires an inner strengthen which is hard to imagine. To be able to lend my support to these families as Patron of The Donna Louise is a privilege.”

The Lord Stafford DL

**OUR VICE PATRONS**
- William Alderton
- Julie Arkle DL
- Christopher Barry
- David Brookfield
- Dr Gordon Carpenter
- David Carr OBE
- David Milburn
- John Tyler
- Anthony Swift

**OUR CHAIR**
Professor Sue Read

**OUR CHIEF EXECUTIVE**
Simon Fuller

Secretary – Sindy Jones
Treasurer – Valerie Wood
Bankers – Barclays Bank PLC
Auditors – DJH Accountants Ltd
Legal Advisors – Knights Professional Services Ltd

**OUR TRUSTEES**
- David Gladman BA (Hons)
- Karen Gladman MCSP., SRP.
- Amanda Harrison
- Lynne Ingram LLB (Hons), PG Dip Law
- Helen Inwood
- Jonathon May
- Prof. Sue Read Phd, MA, RNMH, Cert Ed, Cert Bereavement (Chair)
- James Rushton BSc. (Hons), FCA., CISA.
- Valerie Wood

**OUR EXECUTIVE TEAM**
Director of Care Services – Dot Gillespie
Director of Income Generation – Liz Gratton
CONTACT US

General enquiries about the Hospice and the care we provide:
01782 654440

Fundraising enquiries and support:
01782 654444

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