Welcome

Anna (above) is 7 years old and has been coming to The Donna Louise for 3 years after having a kidney transplant at Birmingham Children’s Hospital. Her family were introduced to The Donna Louise when Anna started Peritoneal Dialysis at home and the care team supported them by spending time with Anna days after her transplant.

Her family had reservations about coming to The Donna Louise, Anna’s Mum, Lisa, explains “Anna’s grandma said that she did not want her to go to The Donna Louise after her transplant, she said that she could go to stay at her house, which of course she couldn’t, but we didn’t know what the hospice was, and what sort of a place it was. Once Anna came here we realised that it is not what you would expect at all. It’s just like a house, a normal place surrounded by other houses, shops and a playground; it’s really tranquil and it gives us somewhere calm as life is such a whirlwind.”

Anna’s life is full of doctors’ appointments and medicine, coming to the hospice gives her a chance to get some peace and quiet. The whole family come to The Donna Louise as often as they can and Lisa says, “It’s a calming and relaxing place, it gives us a normal life back away from doctors and medicine. It allows us to be parents, and not just carers.”

You can read more about how you help Anna’s brother and sister too later in this report.

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

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

This report demonstrates the impact you, our supporters, made to families throughout Staffordshire and Cheshire in 2016/2017 and:

• What we do
• Why we do it
• How we do it
“Just being able to have a good sleep, being able to switch off and relax, the difference it makes is huge. I stay in the family accommodation when Cameron is at the hospice; everybody is respectful of your space. I am able to relax knowing that Cameron is being cared for, it’s a home-from-home and I feel so comfortable being here. I don’t get the chance to relax in this way at home as Cameron’s needs always come first.”
This impact report is all about the difference you, our supporters, have made to the lives of more than two hundred families across Staffordshire and Cheshire.

Throughout the last year we’ve spent time talking to our young people and their families, to understand how we can meet their needs as young adults. Through these conversations, it became clear that they need a place to go where they continue to feel supported, by people they know and trust. They need to have space to socialise with other young adults, in an environment in which they feel comfortable, and they need to have facilities which will help them to develop skills to become more independent.

With all this in mind, at the end of 2016 we announced exciting plans to construct a purpose-built facility for our young adults on our existing site in Trentham. The new building will offer facilities for day care and overnight respite, along with a wide range of dedicated specialist services. The new building will be funded by The Denise Coates Foundation.

Without your continued support we wouldn’t have been able to even consider extending our service to young adults, let alone plan to build a purpose-built facility for them. And that is in addition to continuing to deliver and develop our existing service.

And that doesn’t mean that we don’t still need your support, because it will be you, our loyal supporters, who will be making the service itself happen.

You’ll be enabling teenagers like Charlotte and Chloe to come here for art therapy and respite stays together, and you’ll be giving Kav the chance to carry on playing Xbox with his friends. So it’s your support that will continue to make a real difference to their lives.

Although a lot of time has been focused on developing exciting plans for the future, at the same time we’ve continued to extend the care given to more than two hundred families who come to The Donna Louise for a wide range of care. We’ve been able to do this thanks to your continued support. So on behalf of all the families thank you for making all this possible.
“We’d also like to recognise and thank the entire team at The Donna Louise. Their hard work and commitment over the last year has enabled us to progress our ambitious plans, at the same time as continuing to provide a vital service to our families. So thank you everyone.”

Sue Read, Chair & Mike McDonald, Chief Executive
The Donna Louise is such a valuable service, and it makes such a positive difference to the lives of kids, parents and siblings. If you don’t have a child with a life-limiting illness you may think it’s a sad place but it isn’t, it’s wonderful.

Oscar has been coming to The Donna Louise for 3 years. He has CHARGE syndrome, a rare genetic disorder which affects his heart, ears, growth and eyes. He has had heart surgery, breathes through a tracheostomy, uses a walking frame and is unable to eat orally. Oscar is also on a ventilator during the night. Despite all these challenges he is a happy, smiley 4 year-old who lights up the room, and loves to play with his brother and sister, Oliver and Lily.

Oscar comes for respite stays, 3 or 4 times per year. The first time he came, he had just come out of hospital and the whole family stayed, now he comes and stays here alone, which gives his mum and dad some much-needed time with his siblings.

Oscar’s Dad, Mark, explains how important it is to have this time with their other children. “It’s important for siblings to feel recognised and know that they are special, it’s what they need. We try to be equal with all three children but it’s hard as Oscar needs so much care and attention. When he’s staying at the hospice it gives us time to focus on the others and Oscar just loves coming here; it makes a real difference to him.”

The family lives 16 miles away from The Donna Louise which makes it difficult for them to come to the hospice, so it’s really helpful that the care team are able to go to their house to help. The most important thing for the family is that they play with Oscar and look after him, meaning that the rest of the family can go out and spend time together. During Oscar’s hospital stays, care staff from The Donna Louise have sat with him, allowing Amber and Mark to get something to eat or go home for a shower.

Mark added:

“The Donna Louise is such a valuable service, and it makes such a positive difference to the lives of kids, parents and siblings. If you don’t have a child with a life-limiting illness you may think it’s a sad place but it isn’t, it’s wonderful.”
Until the day they lost their 3-year old son, Tommy, the Smith family from Tamworth hadn’t heard of The Donna Louise. That day changed their lives forever and now The Donna Louise will always have a very special place in their hearts.

His parents explained, “We never visited The Donna Louise with Tommy for respite, we didn’t need to - Tommy wasn’t ill. He had Asthma and the slightest cold would set that off which meant that he was quite regularly at the hospital. But we mainly controlled it at home and he was a normal healthy-ish three year old.”

Then Tommy contracted Meningitis. His condition deteriorated rapidly and he died within a few hours of being admitted to hospital. After his death, a nurse explained to his parents that The Donna Louise was near to the hospital and was a place for the family to spend more time with Tommy and say their goodbyes.

In the days after his death, Tommy’s whole family was able to spend time with him, in the privacy of the Garden Rooms. Our Care Team helped the family with his funeral arrangements and accompanied his parents when they had to register his death.

This time is so precious to his parents.

Since Tommy’s death we’ve been back to The Donna Louise on numerous occasions, each time has been emotional and it may sound strange but it brings us closer to our little man. We will never be able to pay The Donna Louise back for what they’ve done for us but we will continue, while we have breath in our bodies, to keep fundraising for this great cause, helping them to help others and all in the memory of our little Tommy.
It makes a massive difference, we can spend time with Ella and Scott and do normal things with them; and it is less about Anna, as her condition is very time-consuming and means that we can’t always give Ella and Scott attention.

Ella and Scott, Anna’s sister and brother are able to access the sibling service. Ella loves to use the playground and she says that “It’s a special place.” Scott plays on the X-Box in the teenage lounge, he has also been on a sibling trip to Alton Towers. A few months before Scott started high school, the family found out that Anna was in Renal failure and she began dialysis just as he started high school. Scott explains that it was a really difficult time but that he benefited from the sibling activities. “The sibling group is a chance to have a day for me, and to forget about Anna’s condition. We don’t talk about our poorly siblings when we are out, we just enjoy the time away and that we can do normal things.”

Dad, Nathan, explains that whilst Anna is enjoying respite at the hospice, it allows them to spend time with their other 2 children.
The life expectancy of children with life limiting conditions is increasing; yet appropriate care provision that fulfils the specific needs of these young adults is currently non-existent in our area.

The news of our new development came a year after our announcement that we would no longer discharge young adults in our care when they reach 19. The new building will be located on the same site as our existing hospice in Trentham and its construction will be funded by The Denise Coates Foundation.

Speaking when plans for the new facility were announced, Denise Coates CBE explained;

“Since its inception in 2012 The Denise Coates Foundation has developed a strong relationship with The Donna Louise providing significant funding to support its day-to-day activities. I am delighted that we are developing that relationship further with the Foundation’s commitment to support the construction project to deliver the new facility specifically for young adults.

"From the moment we started to discuss the project it became very clear to me that it is incredibly important that The Donna Louise is able to continue to support those in its care beyond the age of 19. The state-of-the-art facility should enable The Donna Louise to deliver a high quality service in surroundings appropriate for young adults whilst at the same time providing the assurance of a familiar environment.”

MEETING THE NEEDS OF OUR YOUNG PEOPLE

Our new building will provide facilities for day care and overnight respite, and will encourage independent living as much as possible for our young adults. There will also be the space to offer physiotherapy, art therapy, counselling and spiritual therapy.

On the ground floor there’ll be a large, open plan communal area, entertainment area, group and physiotherapy rooms, WC and changing facilities and a large communal garden. There will also be a large kitchen where our young adults will be able to practise their cooking skills.

The five bedrooms will be located on the first floor – this is something that our service-users felt very strongly about, as they wanted to feel like they were “going up” to bed. It also means that our young adults won’t be disturbed by those coming in for day care services. There will be four standard bedrooms and a larger "sleepover" room and each bedroom will have access to an ensuite bathroom.

On the top floor, set in the roof space, there will be two large meeting rooms and one small meeting room, as well as a small kitchen / tea room. This design will give lots of extra storage space within the roof voids and there will also be a lift which will allow wheelchair access to all floors. It will also enable us to develop existing space within our current building to develop our services.

Throughout 2016 we conducted numerous focus groups with our young people and their families to understand their needs as young adults and that we currently meet. It became clear that there is a real need for our young people to have somewhere to go where they can be supported by people they know and trust, have the space to socialise with other young adults and have facilities that will help them develop the skills they need for more independent living.

Plans for the new building have now been submitted, following detailed consultations with the young people who will be using the building, and key members of our care team.

The next step is to refine the specification for the design and fit out of the interior so that we can put a detailed specification out to tender. There will be further consultations with our service users and key care staff to achieve this.

We hope that the building will open its doors by Spring 2019. It’s a really exciting time for the future of The Donna Louise and we look forward to sharing more information with you as the project progresses.
Meet Kav

16 year old Smiley Kavanagh (Kav) has faced serious health problems all his life, but still makes it his mission to make other people happy. Kavanagh was diagnosed with heart problems when his mum Sharon had her 20-week scan. As well as three heart conditions, Kavanagh also has Evans Syndrome, which affects his platelets, Kabuki Syndrome, which causes developmental problems and learning difficulties, and three years ago, was also diagnosed with epilepsy.

Mum, Sharon, said: “Life is hard for Kavanagh when he can’t go out like others his age. He misses out on a great deal of things, but he has always got a smile on his face. Kavanagh is just so happy and special. No matter how bad his day is, he will always try to cheer other people up.”

Kav has been coming to The Donna Louise for 12 years, he was 4 years old when he first came and it has been his home-from-home ever since. Sharon says, “The Donna Louise is a big security blanket, no matter what problems you have, what help and support you need, it’s here.”

Sharon is delighted that Kav will be able to continue to come to his second home, “Thank God it’s still going to be here, and everything will be altogether. Kav absolutely loves coming here, he can’t wait to come. Kav is football-mad, he is a huge Stoke fan and has a season ticket; when he comes to the hospice he likes to play FIFA on the X-box, and football outside. On one stay, there were 4 lads, they played on the X-Box and went to Subway for tea, and he loved it!”

“Life is hard for Kavanagh when he can’t go out like others his age. He misses out on a great deal of things, but he has always got a smile on his face. Kavanagh is just so happy and special. No matter how bad his day is, he will always try to cheer other people up.”

The New Young Adult’s Unit

IMPACT REPORT 2016/2017
MEET JACK

17 year old Jack, from Tamworth, comes to The Donna Louise twice a year for respite stays, giving his family the chance to have a break and a well-deserved holiday themselves.

Despite his serious medical conditions, Jack has the mental age of a three month old and is wheelchair bound; he loves his visits to the Donna Louise.

His Mum, Julie, explains, “Whenever Jack is going to The Donna Louise I tell him that he’s going on his holidays because that’s how I feel. The Donna Louise is such a lovely place and the Care Team do so many activities with the children, so I know he’s really well looked after and always entertained while he’s there.

“Jack is such a placid person and loves having people around him, so he really enjoys his stays. It’s great for him to just have a change of environment and see some new faces.”

The family relocated to Tamworth from Leeds around three years ago. Jack had used a hospice in York before the move so Julie was keen to find an alternative within the local area. She added, “We’ve been coming to The Donna Louise for a couple of years and it’s such a lifeline for us. Unfortunately it’s a bit too far away for us to just pop in, but knowing that we can book Jack in for stays while we have a holiday and a chance to recharge our batteries, is such a relief.”

As Jack is about to reach his 17th Birthday, the family has already begun the transition from child to adult services. Julie explained, “It’s a frightening time as I’m not fully aware of what’s available for young adults. We’ve already started the transition for Jack’s medical needs and it’s already really daunting because he’ll be moving from all his care being based at Birmingham Children’s Hospital to being spread over four separate hospitals.”

Despite the many changes which the family faces in the next few years, Julie is relieved that the care Jack receives from The Donna Louise will remain the same, thanks to the decision to continue to care for young adults.
“Knowing that we can continue to rely on The Donna Louise for as long as we need to gives us huge peace of mind. The Donna Louise is our lifeline and at a time when everything else about Jack’s care is so uncertain, it makes a hell of a difference to know that he’ll still be able to come here.”

Julie, Jack’s Mum.
“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. My children call The Donna Louise the ‘fun house’ and the care staff ‘angels’.”

“Our family live 16 miles away from The Donna Louise, and it can be difficult to come in to the hospice so it is really valuable that the care team come to their house to help.”
HOW WE PAY FOR IT

INCOME

- FUNDRAISING INCOME: £2,579,438
- INVESTMENT INCOME: £20,095
- CHARITABLE ACTIVITIES: £170,527
- STATUTORY INCOME: £434,404
- ACTIVITIES FOR GENERATING FUNDS: £63,976
- TOTAL INCOME: £3,268,440

EXPENDITURE

- FUNDRAISING COSTS: £758,746
- GOVERNANCE: £25,443
- CARE SERVICE: £2,282,646
- OTHER: £105,310
- TOTAL EXPENDITURE: £3,172,145

FUNDRAISING INCOME

- INDIVIDUAL & COMMUNITY: £1,096,992
- GRANT MAKING TRUSTS: £164,551
- COMPANIES: £836,558
- LEGACIES: £481,337
- TOTAL FUNDRAISING INCOME: £2,579,438
“Staying at Donna Louise is a great experience. The staff are very caring of individual needs and make you feel at home. You also meet new families who are going through the same thing as you and you know you are not alone, there’s always someone to talk to and counselling if required. All children enjoy spending time there with all the friendly staff doing different activities or playing outside on the playground. You find time to relax and spend time with your other children knowing that your poorly child is safe and having fun.”

Family Feedback
Without our army of dedicated, enthusiastic and skilled volunteers, we simply wouldn’t be able to function. We have a team of more than 200 hundred volunteers who volunteered over 24,500 hours and they play a huge role within the hospice, at our events and in our shops.

In January we were delighted to achieve the Investing in Volunteers Award following a year long project that examined every aspect of our volunteering programme.

The process is about improving the effectiveness of how we work with our volunteers and enhancing their overall experience. This is part of a long term strategy to ensure we have excellent volunteer management in all areas of the charity.

“From the moment I set foot inside the building I was enveloped in the warmth of this amazing environment. Everything about The Donna Louise just oozes positivity. The staff are so committed, passionate, enthusiastic, energised and full of empathy; and the environment is warm, friendly and full of smiles. I feel I am a worthy member of this very special team as a volunteer, and, in some small way, make a difference.”

Margaret, volunteer
**OUR PATRONS**

“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 strength 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**

Bill Alderton
Christopher Barry
Dr Gordon Carpenter
John Tyler
David Milburn
Anthony Swift
David Carr OBE (from September 2016)

**OUR CHAIR**

Professor Sue Read

**OUR CHIEF EXECUTIVE**

Mike McDonald

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

**OUR TRUSTEES**

Julie Arkle
Dr David Brookfield
David Carr (retired September 2016)
Nick Evans
David Gladman
Karen Gladman
Amanda Harrison
Lynne Ingram
Jonathan May
James Rushton
Valerie Wood

**OUR EXECUTIVE TEAM**

Director of Operations – Andrew Colclough
Director of Care Services – Dot Gillespie
Director of Income Generation – Liz Gratton
HERE ARE SOME OF THE WAYS OUR WONDERFUL SUPPORTERS HAVE BEEN FUNDRAISING FOR OUR CHILDREN AND YOUNG ADULTS...

HELPING HANDS - Our business supporters gave 1126 hours in 2016/2017.

Our 12th ANNUAL GOLF DAY in September saw 30 teams tee off at Trentham Golf Club and raised almost £14,000 which funded 13 respite stays.

Our FAMILY FUN RUN saw 1200 runners complete the 5K & 10K courses around Trentham Gardens which raised more than £41,000 funding a social worker and associated costs such as translators and transport.

Our CHRISTMAS FAYRE at the bet365 stadium raised more £7,000 - that’s enough to pay for the care of a nurse for two months.

Our FIFTH ANNUAL BALL raised almost £14,000 which funded 13 respite stays.

HELPING HANDS - Our business supporters gave 1126 hours in 2016/2017.

A red, white and blue ball organised by THE ECCLESHALL FRIENDS Group to celebrate the Queen’s 90th Birthday raised an amazing £20,000 and has given 27 families the security blanket of knowing there’s always someone to talk to through counselling sessions.

Ready for the SCRAPHEAP CHALLENGE was our most successful third party event ever, raising a massive £150,000 which funded the work of 4 nurses.

The now annual WESTON CHRISTMAS LIGHT DISPLAY raised an astounding £22,680 – which means we were able to deliver sibling support groups and youth club sessions for 12 months.

Our 8th ANNUAL BALL raised a record-breaking £51,000 which funded the care and support for 4 families for 12 months.
CONTACT US

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

Fundraising enquiries and support:
01782 654444

Like us, follow us and visit us for our latest news and events:

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@DONNALOUSEUK

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