Parents share story of daughter’s heart battle in BBC Lifeline appeal

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The parents of a baby girl born with a serious heart defect are speaking about their experiences on national television to raise awareness for charity The Sick Children’s Trust.

Zara Ward, 21, and partner Nathan Fox, 25, from Middlesbrough feature in the BBC’s Lifeline appeal, airing on Sunday 21 January at 15.15 and presented by renowned actor and president of The Sick Children’s Trust Michael Crawford CBE. The Lifeline appeal will help raise awareness and vital funds for the charity’s ‘Home from Home’ accommodation, supporting families with seriously ill children in hospital across the UK.

At 20 weeks pregnant, Zara and Nathan were told that their baby had a heart defect called hypoplastic left heart syndrome in which the heart doesn’t develop properly. When their baby, Darcie-May, was born she was transferred the Royal Victoria Infirmary to Freeman Hospital in Newcastle upon Tyne for specialist treatment. For seven months, Darcie-May underwent lifesaving treatment and during this time Zara and Nathan were never more than a few minutes from their daughter’s side as they were supported with free ‘Home from Home’ accommodation run by The Sick Children’s Trust. **Zara says:**

“When we found out that Darcie had a heart condition it completely shook our world. I felt so sick with guilt and worry that she may not survive.

“It was unbelievably stressful knowing that our baby was going to be born with a life-threatening illness and from day one she would have to fight for her life. And that we would be so far away from home in Newcastle, leaving all of our family and support back home in Middlesbrough. When we were told that The Sick Children’s Trust would support us in free ‘Home from Home’ accommodation, it lifted a weight off our shoulders.”

At two days old, Darcie-May had her first major open heart surgery called the Norwood. And despite initially recovering well and being allowed home, she was soon readmitted back to Freeman Hospital. **Zara continues:**

“I was terrified. Darcie was so tiny, and I didn’t know how her body would cope undergoing such an extensive procedure. But we were there to hold her little hand and give her lots of kisses and cuddles because of Scott House.”

The couple were supported at The Sick Children’s Trust’s Scott House, which is just a few minutes’ walk from the hospital’s children’s heart unit. During their time there, they met Michael Crawford CBE who was presenting this month’s BBC Lifeline and told him what a difference Scott House had made to their experience. **Dad Nathan says:**

“I wouldn't wish this experience on anyone – having a seriously ill child in hospital. Every minute of every day, all you can think about is your child and what they are having to go through in order to survive. By the time Darcie was seven months old, all she had spent at home was five days. For seven months we were in Freeman Hospital anxiously waiting for good news. Fortunately, for all that time we had a 'Home from Home' at Scott House which is run by The Sick Children’s Trust.

“Being in Scott House meant we were never too far away from our daughter. We were literally on the doorstep of the hospital and could be at her side as much as possible. When we were in Scott House making food or doing the laundry, we were comforted to know that if we were needed urgently, the ward could call us directly and we could be there straight away – rather than making a long, stressful trip from our home in Middlesbrough.

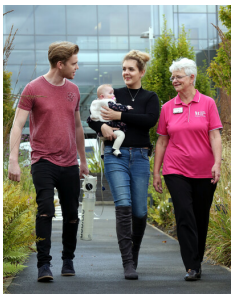
“As a parent all you want to do is be there to support your child. Scott House and The Sick Children's Trust makes that possible.”

Darcie-May was discharged in November but is currently back undergoing further treatment at Freeman Hospital. And Zara and Nathan are once again being supported at Scott House **Zara adds:**

“Darcie-May is doing really well, and we’re hoping to be out of hospital for a longer period of time and just attend clinic every fortnight.

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“Next on the list for Darcie is to fit a peg feed into her stomach and remove her naso-gastric tube and then we will wait to hear when she needs to go in for her next open heart surgery. Because of her condition.

“We’re not too daunted about it at the moment because the doctors have reassured us that this won’t happen until she’s at least ten kilos or her heart starts to struggle. But we know when that day comes, Scott House will be there for us again. Keeping us by our daughter’s side.”

Zara and Nathan, along with other families The Sick Children’s Trust has supported, feature in this Sunday’s BBC Lifeline appeal to raise money to fund the charity’s ten ‘Homes from Home’. **Michael Crawford CBE, who receives regular updates on how Darcie-May is doing, says:**

“The Sick Children’s Trust is a remarkable charity in both the simplicity of its mission and the huge impact its work has on families and children.

“I still remember to this day being left alone on a hospital ward as a child after I underwent surgery to remove my tonsils. I was terrified as I waited for my mother to collect me, a wait that felt like an eternity. The relief when she walked through the doors and gave me a kiss and a hug was overwhelming. That worry is a feeling I do not want any child to ever have to endure.

“That’s why I support The Sick Children’s Trust and remain so committed to this cause. As a charity, we are working towards a future where every child will be able to have their family by their side as they undergo treatment in hospital.

“Thank you to everyone who watches the BBC Lifeline appeal and helps us provide such vital comfort to so many children across the UK.”

Watch The Sick Children’s Trust BBC Lifeline appeal on Sunday 21 January at 15:15 and visit the BBC website to find out more about the charity and the families it supports.

For further information visit http://www.bbc.co.uk/programmes/b09pw6gpb

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