

Delightful Daisy Moves Schools to Support Brother in Fight for Life

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The parents of a little girl whose baby brother is waiting for a new heart are proud as she begins a new life in Newcastle so that she can keep her brother smiling.

Miss Daisy Edwards, 5, from Burton-on-Trent, is set to start a new school this week, over 200 miles away from home, so that she can support her little brother, Thomas, in his fight against a rare heart condition.

Thomas, aged 21-months, has a complex heart condition which has meant that during his short life he has already undergone three major heart surgeries and is now waiting for a transplant. The condition – Shone's Complex – means Thomas has four problems which affect the left-side of the heart. Shone's is extremely rare and occurs in less than 1% of all congenital cardiac anomalies.

Despite successful surgeries, Thomas' condition deteriorated earlier this year. Having exhausted all other options, the family were referred to Freeman Hospital and put on the heart transplant list. **Dad Dave says:**

"From two weeks old, Thomas has been really poorly. He's had several operations for his different conditions and sometimes it's been touch and go. He had most of his treatment in Birmingham, a little closer to home, but now he's receiving specialist care over 200 miles away and we couldn't keep leaving Daisy – it was too traumatic, so we knew what we had to do."

Currently, Dave, Mum Emma and Daisy are being supported by The Sick Children's Trust's Scott House where the family receive free-of-charge 'Home from Home' accommodation so they can all be together by Thomas' side.

The family do not know when a heart will become available, but this is compounded by antibodies which Thomas carries which mean means only up to 30% of hearts will be compatible. Dave and Emma decided to move Daisy to a St Stephen's School, Newcastle, so the family could carry on 'normal family life' as much as possible in Scott House, while Thomas waits for his lifesaving transplant. **Dave continues:**

"Scott House has made it possible for us to stay together as a family and have Daisy with us. Not only is it great for us, but it makes a world of difference to Thomas. Daisy brings a huge smile to Thomas' face - he looks for her and once he sees her, he beams.

"It can be quite miserable in the hospital with him feeling unwell, but when Daisy's there it gives him a boost – to be honest sometimes we think it's a lot better than the drugs he's on. She really has a huge effect on him, and it's where she wants to be too. She wants to help her brother fight this."

The Sick Children's Trust believes keeping families together significantly improves the recovery of a sick child. The charity runs ten 'Homes from Home' across the UK that provide practical and emotional support to the families of sick children – last year, it help around 3,600 families. It costs £28 per night to provide a family with a room in one of the 'Homes from Home' so that a child can have their loved ones right by their side.

For further information on The Sick Children's Trust, please visit: www.sickchildrenstrust.org

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