Harry takes on fundraising challenge as brother Max waits for life-saving donor heart

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The older brother of a little boy who is currently waiting for a life-saving donor heart is raising money for The Sick Children's Trust, a charity that is keeping the siblings together.

12 year old Harry Johnson, from Winsford, will be taking on a sponsored 5km run to raise money for The Sick Children's Trust which has been supporting his family in free 'Home from Home' accommodation while his brother, Max, waits for a heart 180 miles away from home.

Last year, Max (now nine) became seriously unwell with suspected asthma. After numerous visits to the GP and an X-Ray, Max was rushed in an ambulance from his house to Leighton Hospital, in Crewe. It was discovered that he had a very enlarged heart, a strong murmur and his resting heart rate was extremely high at 145 beats per minute. The following day, he collapsed and was taken to The Royal Manchester Children's Hospital where he was diagnosed with a serious heart condition called dilated cardiomyopathy. Max spent a month in the Manchester hospital on a heart drug, but when his condition deteriorated even more, he was transferred over 180 miles away to Freeman Hospital in Newcastle where he had open heart surgery to fit a mechanical heart pump and was put on the urgent heart transplant list.

Max has now been in hospital for over six months and for five of those he has been waiting for a life-saving donor heart. During this time, his parents Emma, 47, and Paul, 44, alongside Harry have been supported at Scott House - free 'Home from Home' accommodation run by The Sick Children's Trust. **Mum Emma says:**

"Max has been waiting for a heart for a long time – a heart which just hasn't come yet. We know that when it does, it'll happen suddenly. But we can't spend every day in hope, thinking it could come today, tomorrow or next week. It's too painful and we'd be setting ourselves up for disappointment – which is not what we want to do.

"As we wait for our son's life-saving heart, one of us remains by his side nearly every hour of every day – he is rarely alone. This is because we're being supported by a charity called The Sick Children's Trust which runs free 'Home from Home' accommodation across the country, supporting families like ours and keeping us near to Max, while he is in hospital in Newcastle.

"Home is far away. It's over 180 miles and can take nearly four hours to drive from Cheshire to Newcastle. There is no way we could do that journey every day and because of The Sick Children's Trust we don't have to. We're currently staying at the charity's Scott House, a few minutes' walk from Max's bedside which is very reassuring. We have a room with three beds which is a huge help as it means our oldest son, Harry, can stay with us – which makes all the difference to Max."

Harry, along with neighbour Neil Chapman, will be lacing up his trainers for a 5km run on Saturday 1 July in a bid to raise £2,000 for The Sick Children's Trust. **Harry, who attends The Grange School, Hartford, says:**

"If we couldn't stay at Scott House, I wouldn't get to go visit Max as much as I do. I sometimes go at weekends and during the school holidays and love surprising my little brother when he's not expecting me! I know the hospital are doing all they can to help Max before he gets a new heart and while we wait at least I can be close to him because of The Sick Children's Trust. So I wanted to thank them for giving us a home by raising money."

Neil, who is a very close friend of the family, is also doing a 3.8km open swim in Derwent Water on Sunday 9 July where Harry will be encouraging people to donate. **Neil says:**

"Emma and Paul have spoken so much about Scott House and how it's helping them. I spend a lot of time with Harry and he is such a great boy. Harry said he wanted to do something to help, and I told him I would support him in whatever way possible."

Alongside Harry and Neil's fundraising, Max's Headteacher at St Oswald's Worleston Primary School, Mr Goodwin, is also doing a 10km run and half marathon to raise money for The Sick Children's Trust. **Emma adds:**

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“Everyone’s support and backing makes a huge difference to our experience and gives us something positive to look forward to and focus on. Alongside The Sick Children’s Trust, Paul and I would also like to say a big thank you to all the amazing staff at The Freeman Hospital, The Royal Manchester Children’s Hospital and Leighton Hospital in Crewe for all they have done and our doing for our son.

“Max is hoping his new heart will come soon, as are we. But until that day comes we will carry on waiting and remain positive, ensuring that our family stays strong and that we take each day as it comes.”

The Sick Children’s Trust runs ten ‘Homes from Home’ across the country, supporting families with seriously ill children in hospital. Although accommodation is provided to families free of charge, it costs the charity £30 to support a family for one night. **Scott House Manager, Andrew Leadbitter, says:**

“Max’s family are going through an unimaginable time. We hope that by being able to support them with accommodation at Scott House, which is just a few minutes’ walk from Max’s bedside helps ease some of the worries and stresses they are experiencing.

“Max and Harry are very close, and when Harry comes to visit Max’s face just lights up. We’re wishing Harry, Neil and Mr Goodwin all the best with their challenges and would like to thank them very much for raising money for The Sick Children’s Trust, so that we can continue to support families with seriously ill children in hospital.”

To help Harry reach his fundraising target of £2,000 – please visit:
https://www.justgiving.com/fundraising/maxjohnson030108

For further information about The Sick Children’s Trust, please visit http://www.sickchildrenstrust.org/

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