

As the parent of a child who uses Glenfield Heart Unit's services I find it extremely distressing to hear a proposal for its closure.

My son, Elijah, was born in April 2016. He was born with a small ASD and a large VSD. During the first weeks of his life we were in and out of hospital due to poor weight gain and jaundice, then at 2 weeks old a cardiologist from Glenfield came to Leicester Royal Infirmary to do a scan on his heart. This is when we found out about the CHD. We had no idea what to expect and we were terrified. We have 2 other children who could not understand why they could only see us for a couple of hours in a hospital café because we could not come home. But we did have those few hours, because we were in Leicestershire and it was just about feasible. This made things that little bit easier to deal with, we had family support on hand, and that was something I desperately needed as I was already suffering very badly from post-natal depression. Elijah was prescribed some heart medicines and eventually we were allowed to take him home. We went for check-ups every few weeks at Glenfield so they could make sure it was safe to wait for him to gain weight before operating. During these check-ups all of the staff were amazing, they would explain things carefully, repeat if necessary and fuss over Elijah as though he was their own child, and it felt like he was loved which in turn made us feel safe in their hands. Every single CHD parent at Glenfield I've spoken to has said the same.

At 3 months old we were also given the diagnosis of Trisomy 21, something we hadn't expected but once again the Glenfield staff were incredibly supportive.

When Elijah was 5 months old it became clear that he couldn't wait much longer to have his surgery. His lung pressure hadn't dropped enough (something that isn't unusual in children with Down's who have a CHD) and he was at risk so the operation was set for 13th September 2016. We were allowed to walk him down to the anaesthetist, where we handed him over and walked off. It was without a doubt one of the most terrifying moments of my life. I gave my child to somebody and hoped that in 6 hours he would still be there to come back to. Although there was the inevitable feeling of nervousness over us we still felt like he was in the safest place he could be and we were not wrong. His operation went perfectly.

The aftercare was nothing short of perfect, on PICU he was fussed over and played with while nurses were administering care so that he just thought he was having fun, not that someone was actually giving him medical treatment. In the lead up to his operation I would not let Elijah out of my sight, he slept in my room near to me, I set an alarm for every hour to check he was ok, I would not go for a shower unless my husband was home to watch him. I'm aware this seems excessive but this is the reality of being a parent of a poorly child, especially a parent with PND. I am certainly not the only parent who would be feeling like that. Yet, I felt completely safe leaving him in Glenfield staffs hands, so my Mum could bring the other children to the café to see us, or pop in some dinner and give us the support I desperately needed. This would not have been possible should Elijah have had to go to Birmingham. We would have either not have seen our other children during this period, or my husband would have had to go home, leaving myself in a very vulnerable state in an unfamiliar hospital with no support. Consider how the closure will affect other new Mum's, the impact on the mental health when you are told your child is sick is already massive, let alone to then be dragged across the country with that sick child and have no support around you.

Elijah has complex needs as a result of having Down's syndrome which means we spend a lot of time in hospitals and medical settings within Leicestershire. A child who has Down's syndrome has a 50% chance of having a congenital heart defect, which means that 1 in every 2 children with trisomy 21, born in Leicestershire and surrounding areas, will need to use Glenfield's services. They will also most likely require considerable medical intervention in other areas, particularly in the early part of their lives. The continuity of care is incredibly important for a child such as Elijah, he needs the familiarity of staff he knows and trusts, otherwise he will be very uncooperative and this causes great distress and confusion for both him and us. Having all his care within one area with faces he knows makes it a lot less scary for him. This doesn't only apply to Trisomy 21 obviously, there is a wide spectrum of children who require more than just CHD care and they should not be dragged from pillar to post because of it. There are a large amount of children already under Glenfield's care who will become greatly distressed should they all of a sudden have to go somewhere unfamiliar with staff they do not know or have a rapport with.

Also, children should not have to be taken out of school for a full day to attend an appointment because they are having to travel so far to get to it, they should not be put at a disadvantage in their education because they were born with a heart problem. Children like Elijah in particular will already be at a disadvantage to their peers while learning, it is unfair to push them back any further than necessary.

A child should not be scared or put at a disadvantage because they were born with a health problem. A parent should not be put in a state of vulnerability without support because their child was born with a health problem. No one chooses to be in that situation and it should not be made any more upsetting for either party, especially when the care at Glenfield is outstanding, as the CQC put it.

Jess Whitehouse

Parent