

George was born in October 1996.

I had a very healthy and normal pregnancy despite being a decrepit mother of 43.

George was born three weeks premature and quite a low birth weight but there were no obvious problems.

However, during his first few weeks , he struggled to feed and did not really put on weight. I knew there was something wrong, but never once did I suspect it was something so serious.

Within a few weeks, he was diagnosed with a heart murmur and aged just six weeks we were told that he had a condition called Tetralogy of Fallot.

Sounds posh but it isn't. Terrifyingly, it meant that there were four things wrong with his heart and he would need a number of surgeries to hopefully correct the problems.

The consultant who spend a considerable amount of time explaining to me what this meant, went to great lengths to tell me that this was not my fault.

Despite this, I carried the guilt for years that I had brought this on my child.

At ten weeks , we were told he needed urgent surgery to ensure that his blood could get more oxygen, as it was down to 57%.

I cannot describe to you how it feels to hand over your tiny baby to strangers, and watch as they wheel him into theatre, hoping that this will not be the last time you see him.

The fear becomes absolutely solid in your stomach as you wait for hours for someone to come and tell you he is out of theatre and he is in intensive care and it has gone well.

Nothing can prepare you for the gut wrenching shock of seeing your child with tubes going into and out of what initially looks like every square inch of their little body.

But , thanks to the care and skill of the staff , we were able to take George home and spend our first Christmas together with him and his older brother.

A lot of parents take photos of their child while they are in hospital.

I made the decision not take any as I did not want what could be the last image of my child, looking like that.

We then began twenty years of frequent hospital appointments and monitoring, tests and surgery.

When George was sixteen months, he had his first open heart surgery.

One of the hardest things was explaining to his six year old brother what was happening and trying not to cry when he asked 'Is George going to die?'

George was in theatre for over nine hours, and I don't think his Dad and I spoke one word to each other for the entire nine hours, we had no words, we were so very scared.

It was only the support of the consultant, liaison nurse and ward staff that got us through. I can never thank them enough for the support they gave us.

We were told he would be in intensive care for at least a week and then back on the ward for another week probably

They had seriously underestimated George. He pulled his nasal tube out within twenty four hours and he got himself kicked out of intensive care after three days as he was 'far too lively' !!

The surgeon described him as a 'very vigorous child'.

He made a rapid recovery and we were home thankfully within the week.

George couldn't walk until after this surgery, as he had no energy.

Afterwards, he was like a little dynamo and went from sitting to running almost overnight.

He spent his entire childhood running everywhere, and being into absolutely everything. He hardly slept probably because he was too scared he would miss something.!!

Like many children with serious health issues, George has always marched to the beat of his own drum and has always been a real character.

He could always charm everyone he met, including every teacher he ever had who would forgive him anything.

From the age of three, he insisted on wearing a bow tie every day!! He was the only child in infant school with a tie, let alone a bow tie. That phase lasted until he was about seven or eight.

Then he would spend entire weekends dressed as a Hobbit or Dr Who or a pirate!!

George has a really positive attitude to the horrendous scars he carries. He sees them as marks of honour for what he has been through. It helped that he had the accolade at both schools he attended of being the lad with the most scars, once making a girl faint which did his reputation no harm at all.

He also held the record for the optimum number of pencils you can get in your hair during a boring lesson. It's 33.

A few years ago, when he was sixteen, he had further open heart surgery to replace a leaking valve.

He faced this with amazing maturity, and despite being in pain and discomfort, he did everything he was asked and recovered incredibly well. I was so very proud of the way he dealt with everything.

He was thrilled to bits when the surgeon told him that his heart had stopped three times during surgery.

His only disappointment was that he wasn't going back to school after the summer holidays and he couldn't tell everyone. He reckoned that dying three times was going to beat going to Disneyland hands down.

A week after leaving hospital, he collected his exam results , doing way , way, better than we had thought he would , and two weeks after that, he enrolled on a performing musician course at college.

He plays drums and guitar and is teaching himself keyboards, so the house is never peaceful.

He decided not to go on to university to study music as he didn't think it would consistently pay the bills, so is now training to be a painter and decorator, on the basis that people will always need nice houses.

In January this year, George had more surgery to have a stent fitted. Again he dealt with it in brilliantly, although apparently , he

did ask the anesthetist when he came round, if he would be able to play the recorder again !!!

George has matured into a funny, bright, caring, talented and wonderful young man who makes me laugh all the time. And occasionally drives me round the bend, which is just as it should be.

I tell you all of this to make you understand that George, like every other child that is treated at the Glenfield, is a human being, not a case, a number or just one of the much lauded 125 surgeries that NHSE seem to find far more important than real people.

George has been attending the Glenfield since he was six weeks old,

We have had over twenty years with our son, which we would never have had, without the skill and care of the Glenfield and it's wonderful staff.

During that twenty years, we have had numerous hospital appointments every year, with various tests and scans all the time.

George has come to know the staff at Glenfield as though they were family and he trusts them completely, as do we.

They remember things that are really important to George and they have played a huge part in making him as well adjusted as he is with his condition.

He can talk to them about anything and is not embarrassed or afraid to ask them questions.

The fact that he is as confident and relaxed as he is about his condition is a direct result of that.

That continuity of care has been so important for him, both as a child, a teenager and now as a young adult.

The staff at the Glenfield have always treated George with total respect and have never talked down to him. They talked to him in a way that he would understand and always made sure that he completely understood what was going to happen and why.

He was very concerned when he knew he would be transferred to Adults, but was visibly relieved when he knew it would be exactly the same staff doing his standard tests with him.

He is now again worried.

He knows that he will need further surgeries in the future. He will need at least one valve replacement because he has a donor valve. This leaks as it is basically off the peg rather than made to measure.

He is really worried, not just about where he will have his surgery , but where his out patients care will be.

Like us , he knows that Birmingham has been named as the alternative hospital . But , like us , he knows that he may well have to go wherever there is a bed available, as there is no way NHSE can guarantee that it will be Birmingham.

The realisation that he could effectively end up anywhere in the country , is causing him, and us, a great deal of stress.

It is bad enough his being a young man and having to cope with CHD, knowing he will have to have more surgeries, it is terrible that he has to also cope with the uncertainty about where that will be.

The team at the Glenfield care for the whole family and words cannot express how grateful we are to them.

We are a very strong family but even we would have struggled without the care and support we have always been given.

Having a child with a serious heart condition is never going to be easy but having the staff at the Glenfield and the safety , continuity of care has given us, has made it so much more bearable.

They have been with our family every step of the way, guiding and supporting us through some of the most terrifying of times, times you would not wish on anyone.

I cannot imagine how horrific an experience it would have been for us as parents, and for George , as a patient, if we had not had that continuity of care throughout his childhood. It would have been so very much worse for us , if we didn't know where we would be going.

CHD children are not cases, not numbers, not surgeries. They deserve continuity of care and with staff that they know and trust.

Shirley Barnes
Parent

