

The Patient Story

I was born ten days late at Ashington Hospital on the 14th February 1976 weighing 7lb 7oz, which is also my Dad's birthday after a normal pregnancy. In those days there were no antenatal scans! I had the umbilical cord around my neck and was grey in colour. I was taken to the special care unit as I wouldn't feed and as a precaution.

When the Doctor listened to my heart they knew there was something wrong but not sure what. I continued to be monitored as an outpatient at Ashington Hospital for about six months, in which there was no technology. I was referred to Newcastle General Hospital as Cardiology at The Freeman Hospital wasn't open! I was seen by Dr Hunter (who became my consultant) and Dr Goodwin who as my parents say; nearly hit the roof when they listened to my heart! I had a few Catheterisations and various Echo's at the General Hospital. My diagnosis: Aortic Stenosis and Co-arcuation of the Aorta.



In January 1978 I had my first open heart surgery at The Freeman Hospital. I was one of the first kids to have surgery there. I was on adult ITU and then transferred to an adult ward. The other patients enjoyed seeing me recover and toddling around. They would buy me sweets from the volunteer who brought the newspaper bag around the ward. They waited until after my brother was born, he was healthy to plan my second open heart surgery. I had this in September 1978 and was a patient on Ward 23. My parents say the staff were fantastic. They not only looked after me but also my Mam who stayed throughout.



In January 1989 I had an Aortic Balloon Dilatation and stayed overnight on Ward 23 myself, I was now a teenager. My parents said the lovely staff always helped me to be ready each morning and doing my hair.

Over the years I had yearly check-ups in outpatients which were all absolutely fine. The staff were always kind, caring and supportive to me and my family. I lived a "normal" life; being in the Girl Guides, ski-ing with the school, socialising with friends, learning to drive, going to college studying Nursery Nursing, having a part time job in a coffee shop. I was never allowed to do cross country at school but I was pleased with that! It looked awful! At the age of 18 I was transferred over to Adult Congenital Heart care in which Dr O'Sullivan eventually became my consultant. In my early twenty's I had some plastic surgery at the RVI on my sternum scar in which it made a good improvement.



In May 2006 I had my third open heart surgery. I was a bit poorly afterwards and had to stay in hospital for about five weeks. The staff were amazing; flexible with Ivan my partner and family visiting me, caring, helping me to get ready and very kind. Amanda who at the time was my liaison nurse was always there to listen, support and give the best advice. In January 2008 I had my fourth & final open heart surgery. I had lots of complications afterwards & was very poorly. I was in hospital for about ten weeks this time. Again the critical care, ward staff and Amanda (liaison nurse) were fantastic AGAIN.

Myself, Ivan or family could not have got through it without their support & care. Dr Crossland then became my consultant. Both myself and Ivan have the greatest respect & trust for him.

I did absolutely fantastic for the next ten years. Every time I have an outpatient appointment I would take the lovely staff some cakes I had baked for them. The Liaison Nurses are always at the end of the phone remembering who you are; questions are always answered efficiently and are always positive & caring. Debs and Lorna are now the two Liaison Nurses who I have contact with. When my Dad was sixty he had a party but instead of presents he asked for donations for the ACHD fund raising about £1000. When I was forty I had a weekend away with my Mam and friends (there were 47 of us) we raised about £250

In August 2018 I returned from Zante feeling unwell; Ivan and my Mam took me to Cramlington Hospital. Two weeks later I woke up in Critical Care at The Freeman Hospital, I had Bacterial Meningitis, Sepsis and temporary renal failure. I recovered amazingly and was back to work within three months as a Teaching Assistant for children with Autism. There was some damage done to my heart as a result of this. Dr Crossland, Debs and Lorna have fully supported me throughout this, they are always at the end of the phone or an email, at my appointments and as an inpatient. I had a Body Shop Party in the November and raised £225 for the Critical Unit to say thank you.

I was invited to the CHD network launch event in January at The Freeman Hospital. It was very informative and meeting professionals from different aspects of CHD. During a patient group at the event there were lots of different ideas discussed about ACHD. I spoke about how as an adult it is very boring in hospital, no free TV, restricted visiting etc and how this can have a big impact on recovery. I suggested that an activities co-ordinator would be a way forward. This person could provide activities on the ward, give information before coming into hospital, be involved in the transition from paediatric to adult services and support in outpatients. After being in contact with Kaye Walsh, Lead Nurse CHD Network for North east & Cumbria she has spoken to the clown doctors who are funded by the CHUF and are looking at funding an activities co-ordinator for ACHD.

I am going to be, as a patient advocate involved in the progression of this programme. By being part of this network I can speak on behalf of myself and other patients to move forward.

Everything the Freeman Hospital has done for me, Ivan and my family it is a way of saying a HUGE THANK YOU ♥

