

Lucy's Story

My name is Lucy White, and I was born with hypoplastic right heart syndrome which is a type of congenital single ventricle heart condition. This means that I have half a working heart. I have had 3 open heart surgeries, the BT Shunt, Glenn, and the Fontan operation. In the future I will need a heart transplant. I take many different medications daily to help my body function and to give me the best quality of life before we have to take the next steps.



**PATIENT AND FAMILY
ENGAGEMENT GROUP**



My heart condition was detected on my mother's 20-week ultrasound scan during pregnancy, where she was told I would die at birth and if I did survive, I would be oxygen dependent. She was then advised on termination. She then spoke to a cardiac doctor who said I am compatible with life; however, I would need three palliative surgeries and transplant when necessary. After speaking to many other families who had children with single ventricle heart defects and to the charity little hearts matter, it was decided that she was going to have me and that we were going to go on the congenital heart disease journey together.

My childhood has consisted of uncertainty, countless hospital admissions, medications, and instability. However, on the bad days we look forward to the good and on the good days we make the most of it. My health issues throughout my childhood impacted me emotionally as I didn't have the normal experiences children are meant to have and my health restricted me from doing many things. My heart condition on a day-to-day basis makes me very fatigued and breathless. I am more susceptible to infection due to my condition as well. My health issues also impacted me socially within my childhood, this is because I had to miss a lot of school, my skills to socialise with individuals deteriorated and I struggled to keep the friendships that I had made previously before falling ill with different illnesses. Even the common cold affects me more than it would a "heart healthy" child.

Throughout my life my parents were always open to me about my health and what it meant for me as an individual and the impacts that it will have on my life however, when reaching early teens, I found out the details such as life expectancy, what my future may hold, what it was like as a baby and how I have defeated the odds.

I know that my future is uncertain, and no one knows what will happen however, currently I am living life to the full. I am getting good grades within college and have been accepted into my dream university to start in September. I have recently turned 18 when no one thought that day would come. I am making the most of my life with my friends and family by my side. Congenital heart disease cannot be cured, and I would love to spread awareness but also give hope to other families who are also affected by CHD.



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