

CLARA'S TRANSITION STORY

I'm Ciara and I had heart surgery when I was only four days old and I am now in my mid-20s. I feel that I have been lucky since, in that, I don't need to take any medication. I just need to visit the cardiologist once a year for some tests. I was 19 years old when I transferred to the adult clinic so I was a little older than others I know who have made the transfer. While I was a little nervous, as I had been seeing the same cardiologist for 19 years, I was ready for the transfer. It's just another part of growing up. Transition is happening at a time of your life when things are changing, it's a time to grow up anyway, so I felt that I was ready to step-up and be more independent about my condition.

As we were visiting a new hospital for the first time, we were unsure of where the clinic was and we got lost trying to find it. We ended up on the wrong side of the hospital! Once we got settled, I met with the heart nurse specialist who spent a long time with me just chatting and taking my medical history. She also told me all about the new consultant that I would be seeing so I felt prepared, more at ease when I met him. I think it would have been scarier otherwise. My parents came with me for the first visit and were able to answer the questions about my medical history that I didn't know but after that I have always seen the nurse and doctor on my own. The nurse is my liaison point for the team and I feel very comfortable asking her personal questions if I have to.

The main difference I noticed in the adult service is that the health care team speak to me and not my parents. While I was in the children's hospital, the team spoke to my parents, even though I was 19 years old. Once I transferred, the team spoke to me, they treated me like an adult and I was expected to take responsibility for my condition.

I have never allowed my condition to stop me from doing what I want to do, it has never hindered me. If I am told I can't do something that makes me want to do it!!! My advice to other young people would be for them to know about their condition/medication and their limits but not to let anything stop them from doing something they really want to! If necessary, find an alternative route to what you want to achieve.