



Faces of CHD | Shelley's Story



Meet Shelley of Sarnia, ON

Age 51

CHD Diagnosis: Dextrocardia, atrial and visceral situs inversus, cc-TGA, AV and VA discordance, pulmonary atresia, VSD (repaired), heart block

I had minimal limitations from my CHD and it was largely ignored by my family, other than the day I was dropped off at the hospital for surgery. We never talked about it. As I got older I started to worry about what I would have to face and deal with because of my CHD. I didn't begin to have any problems until my early 40s when I started to take meds. This was a huge adjustment for me and it forced me to admit that I had a heart condition and that I needed to deal with it, come to terms with it. I had been in denial for many years.

If I could go back to my child self, I would tell myself to TALK ABOUT IT! Talk about my CHD, don't ignore it. It is so much healthier to talk about it, understand and be involved in my health care decisions and to develop healthy coping skills and emotions to deal with it all. It would have allowed me to be better equipped for the changes that were going to happen as I got older.

The best advice I ever received was from my cardiologist when I was considering pursuing a career as a registered massage therapist. I really wanted to become an RMT, but wasn't sure I would physically be able to perform, as the job is physically demanding. The intern had told me no, it was not something I could do. My cardiologist explained to both the intern and myself that there are 'textbook cases' vs real life. As I was doing better than textbook cases with my conditions, then I should pursue my goals, enjoy life. If RMT was something I wanted and felt I could do it, then go for it! Just make sure I planned for the future as one day I might not be able to continue with that career. I was a RMT with my own business for 15 years before choosing to become a stay at home mom.

In the future I am most worried about the possibility of decline in abilities, slowing down, not being able to do things and the psychological issues that come with that. I hope that the progress that I have made in coping with my CHD so far, will help me better prepare for the changes that are to come in the future.

My best advice for those transitioning into adult CHD care is to stay in CHD care. It's so important to keep your scheduled follow up appointments, that way your healthcare team can catch any changes in your health early on and be proactive, sometimes even before you realize that your health has changed. Also, there is a lot of information on the web, but not all of it can be trusted and your own cardiologists understands your unique defects and condition. They are the most knowledgeable and best able to provide specialized and individualized advice.

I am very grateful that I was born at a time when there were options and surgeries available to treat my CHD. I am also grateful for the adversity I have faced, the things I have had to overcome in coming to terms with my CHD. It has put me on a path of learning and has expanded my personal, spiritual, physical and emotional experience and growth.

I hope that CHD and CCHA become more nationally recognized and awareness increases to the levels of other diseases. A lot of people don't learn or educate themselves about CHD until they are in crisis, they don't make it a priority when they are healthy and feeling good, but that's not healthy for anyone living with a chronic condition.