



## Faces of CHD | Lisa's Story



Meet Lisa D of Whitby, ON

Age 48

CHD Diagnosis: Pulmonary Valve Stenosis

When I was born, and it was discovered that I had CHD, open heart surgery was in its early stages. Surgery to repair the heart was quite experimental and offered in only larger hospitals. Due to my infancy, it also meant that I would need to get a lot stronger before they would contemplate performing the experimental surgery on me. Fast forward to age 4 (almost 5)...in July 1975 I was admitted to the Montreal Children's Hospital where Dr. Anthony Dobell (a pioneer in both adult and pediatric cardiovascular thoracic surgery and was one of the first physicians in Canada to perform open heart surgery!) performed an open pulmonary valvotomy on me. It was a success and a few months later I had recovered enough to be able to start kindergarten.

From there I never looked back, I enjoyed school and continued my educational pursuits, went on to college, then university and more recently completed a post-graduate certificate in Human Resources Management.

It wasn't until we moved to Ottawa from Montreal in my twenties and I started to see a new physician that I was told I should be seeing a cardiologist on a regular basis for my CHD. I never knew that it was a lifelong condition that had to be continuously monitored. And thank goodness I was because at 27 I found out I was pregnant with my daughter. I was terrified! I never thought I would be able to have children due to my heart condition. I had never really even discussed it with my doctor and all of a sudden, here I was expecting my first child! I was excited but anxious beyond belief because I feared that given my heart defect that my baby might also be born with one. But she was born beautiful and healthy. A few years later I delivered my son, Isaac, and again, I was blessed with a healthy baby with no serious medical

concerns. For the next several years I was focused on raising my family and didn't think much about my own health.

That all changed at my annual visit to the cardiologist when I was told that I would likely need surgery to replace my valve. At the same time we moved from Ottawa to Whitby where the incredible team at Toronto General commenced monitoring my condition. After a thorough review with the medical team, it was decided that I should undergo heart valve replacement. I opted for the porcine valve as I did not want to have a mechanical valve due to the blood tests and medication that it would require.

I would say the preparation for this surgery was my biggest challenge so far along my CHD journey. As a child I don't really remember that much about the surgery or the recovery, but at 40 I was fully aware of what was about to transpire – at least technically. Emotionally and physically I had no idea what the journey of recovery was going to be like, I just knew that there was no way I was going to die on that table. I had far too much to live for and so much more to do! Thankfully I survived, enrolled into rehab as soon as I had clearance and there I met an eclectic bunch of cardiac patients.

It was through them that I learned about CCHA and was able to connect with groups of other people living with CHD and expand my support network, and I am so grateful for this.

My advice for those in the early stages of their own CHD journey is to remember that the journey is lifelong and never ends, because of that make sure you are familiar with and know the possible conditions that can arise throughout your life because of your CHD. Learn where the major CHD clinics are wherever you are living. Be selective about the sources you go to for medical information - there is a wealth of information out there but they are not all accurate or credible. And most important of all - Be an active participant in your care - both physical and mental. Know yourself and be self-aware of how you are feeling.

As I look ahead I guess my next surgery (valve replacements only last about 10 years) is what concerns me most - getting through it. I keep thinking, "there's got to be only so many times they can restart a person's heart." But I am sure I won't be ready to go then either, I don't want to miss out on the life I will still have to live.

I really have been blessed through this journey; the physicians and surgeons I've had, my two healthy babies; the fact that I live in Canada with a flawed but wonderful healthcare system that has allowed me to live a pretty healthy life despite my heart condition. Somedays I feel like I am living on an extended warranty and what a blessing that is.