



Faces of CHD | Sylvia's Story



Meet Sylvia G of Toronto, ON

Age 49

CHD Diagnosis: Tetralogy of Fallot

Growing up I don't think you would say I had the most normal of childhoods, with very little adult supervision I was often left to my own devices. So I learned at a pretty early age that my heart condition was what I made of it.

For the most part I didn't let it affect me in anyway, except maybe to use it to my advantage to get out of gym class or things I didn't want to do. Overall I lived a pretty normal life.

My first surgery was at 2.5 years old and I actually have a very distinct memory of that time, of waking up in a crib with a tent over it in a dark room, and there was light filtering in from the hall and I could hear the nurses talking in the hallway. Funny how those images stick with you your whole life. I guess just like this disease does.

The biggest wake-up call I had along my CHD journey was shortly after I transitioned from Sick Kids to Toronto General for my care. I smoked at the time and Dr. Coleman said, "You know, I don't really care if you smoke or not, if you really want to kill yourself go ahead. But before you do, maybe you should take the time to consider that a whole lot of doctors and nurses took the time to help you and make sure that you would live. Maybe you should show them and their efforts some respect." It was then that I realized it was my responsibility as much as my doctors to take care of my health - and I did.

Looking back on all that I went through; the social anxiety of having scars that I wanted to hide when I went to the beach as a teenager, or the fear of surgeries and procedures - it was a lot of

emotional stress. The one thing that I would go back and tell my younger-self is that it's going to be okay, you will get through this all and come out the other side alright.

As for advice I would give to people going through their own journey with CHD - Don't think you don't have a voice - You do! Don't be afraid to ask questions, take ownership of your health, know your condition and how to manage it.

I remember when CCHA started advocating for people living with CDH, I am so happy to see it is still going! I hope you can find those people that are the forefathers living with CHD, share their stories to help give the rest of us following in their footsteps some comfort to know how they have handled surgeries, and their condition as they are aging.

As for the future, I think the not knowing is the thing that keeps me up at night. I have three kids and I want to see them grow up, I want to live to 80. But, not having a lot of people that have historically lived into adulthood with CHD, I don't know what lies ahead. It feels a bit like we're charting a new course without a map to guide us.