



## CHD and Me

### Talking With Adults With CHD

A concern that “heart parents” often have is how our children will do in the future. Will they be able to lead productive adult lives? Will their heart defects prevent them from doing activities or jobs that they want to do? In this edition, we feature the story of Anne-Marie Koeslag.

**B**onjour! My name is Anne-Marie and I was born in 1979 in Ottawa. I was born with Tricuspid Atresia. I spent a lot of time in the hospital and had a couple of surgeries within my first days and a few more in the following years. Throughout my childhood, I was seen at the Children’s Hospital of Eastern Ontario (CHEO). My major surgeries, however, were done at Sick Kids in Toronto (where I first learned to speak English, as I am French-Canadian). When I turned 4, the doctors explained to my parents that I could have a Fontan procedure and there was a small chance that it would be successful (since they hadn’t performed this surgery on anyone else this young at that time). My mom knew I was stubborn and wanted to live longer so she went with her instinct and said yes to the surgery. The cardiologists said the surgery would give me a longer life but I would not live past 11 years old. Before heading to the operation room, the doctor asked me if there was anything I wanted after my surgery. I told him that I desperately wanted a bag of chips and a puppy! He was about to give me an answer when he noticed my mom’s face (she was absolutely petrified of dogs), so he turned to me and said: You can have chips when you wake up but you will have to wait until your eleventh birthday for the dog. Tricky, tricky doctor!

I soon surpassed the age of 11 and the doctors told me that I was doing so well that they would wean me off my medication and I would be allowed to integrate more sodium into my diet. All I could think was: That’s nice, but someone owes me a dog. I got my first puppy (Dési), my mother faced her fears and made a new best friend, and I got to eat chips: I was feeling great!

I had a normal, fun childhood: I spent my summers swimming with my best friends and my winters playing in the snow. The only difference is that I couldn’t participate in gym class (which was horrible because I had to go to typing instead) and I was on a very strict low-sodium diet. Although I’m a sucker for salt, I still stay away from it to this day.

My teenage years were just like everyone else. I was reckless at times and I wasn’t always smart about my choices, but I survived it all and I had good friends looking after me. When I was 16, I was on my first travelling experience alone. I went to the south of Spain for the summer to take Spanish classes. It was an amazing experience, but I had a mini-stroke while I was there and it was scary. When I returned, an MRI confirmed that I had had a huge blood clot on the right side of my brain. I felt so lucky that none of the symptoms were permanent. From that day forward, I have been taking anticoagulants.

It is also in my adolescence that the doctors told us I couldn’t be pregnant: it could kill me and the baby. It was strongly suggested that I have a tubal ligation. I had the surgery when I turned 18. At that age, I graduated from CHEO and moved on to adult care: the Ottawa Heart Institute. The wonderful people there have been taking care of me ever since.

In my 20s, I started to develop pretty bad arrhythmias and my heart symptoms started to affect me emotionally. Before then, I had never felt different than anyone else (or at least I didn’t take the time to think of it much). By the time I was 25 years old however, I was realizing that I had limitations and side effects to this heart malformation. It’s as if I

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woke up one morning as an adult and realized that my health wasn't perfect and that I would have obstacles throughout my life because of it. They tried different drugs to manage my symptoms, but they were always there.

Before turning 30 years old, I married my amazing husband Matt. Our wedding was awesome, barefoot on the beach down South, with 60 close friends and family. We are so happy together but I do realize that seeing all my friends and siblings have children is a bit difficult. We have tried surrogacy and now we are on a waiting list for adoption. My husband and I are lucky to be Godparents to 5 amazing kids!

Due to my symptoms and some complications that were arising, the cardiologists decided it was a good idea for me to undergo a revision to my original Fontan surgery. So, at the age of 33, I had an extra-cardiac Fontan to try to fix some of the problems. This was done at the Peter Munk Cardiac Centre, by a group of amazing doctors. During this surgery, they also did a maze procedure, they removed an aneurysm in my heart and they placed a pacemaker in my chest (the pacemaker was a surprise when I woke up!). The recovery was very slow and wavering, but I am feeling much better now. I have days where I'm ready to do anything and other days where all I can really do is watch some Netflix and rest on the couch. Since this surgery, I have been taking more medication (antiarrhythmic meds, anticoagulants and Lasix). I'm hoping this recent surgery gives my heart a strong boost to keep on keeping on (because I plan to live past 100).

When I think of quality of life as an adult CHD survivor, I realize I have some obstacles. Yes, I have regular medical visits and tests, surgeries, various daily pills, a pacemaker, limitations when it comes to family planning, my diet and exercise, BUT I feel so happy and blessed for everything I DO have. I don't feel that my heart defect stops me from living a happy, healthy life. I go to the gym - mind you, I'd rather not ;), I snowboard, I love trying any new activities and I travel A LOT. My travels have led me to: work at Disney Land Paris for a few months,

swim with sharks, hike down inside a volcano, sleep in airports, and trek through so many different cities and National parks. My heart defect and health problems have not affected my career either. I completed an undergrad in psychology, a Master's in counselling and a degree in teaching. Presently, I am a teacher and I teach French and social Studies at the intermediate level in a high school by my house.

I know what keeps me happy and healthy is a positive attitude and the amazing people that surround me and constantly support me.

You will be going through this with your child their whole life and one day they will realize just how much worry and attention you placed on them while they were out having fun, without a care in the world. As I was growing up, my mom was my protector, my medical advisor, my advocate, my nurse. Still to this day, if I don't feel well, I call her. Looking back, I realize that she wasn't an expert in any of this; it was also new to her. She just always made sure I felt safe, hopeful and confident that everything would be ok. She also made sure that I didn't miss out on great experiences because of my heart defect.

I try to remember:

**YOU  
ONLY  
LIVE  
ONCE**

so live it up as much as you can!

**YOU ONLY HAVE  
ONE HEART**

so nurture it and appreciate it as much as you can.

## SHARE YOUR STORY

We invite you to share with us your experience with congenital heart disease. We would like to hear from parents, as well as children, teens and adults who themselves have a CHD. Your story may provide the encouragement and support someone else needs. For assistance in preparing your story, or to submit your story, contact the Newsletter Coordinator at [jenb@heartbeats.ca](mailto:jenb@heartbeats.ca)

