

Living With CHD: The Patient's Perspective

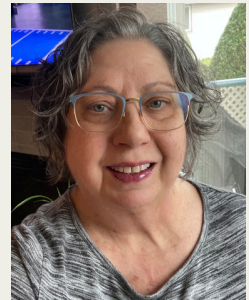
Mimi Disher, 67, Vancouver, BC
Double-outlet right ventricle, TGA, VSD



When I was referred to Dr. Perloff my life changed. The cardiac team at UCLA had all the answers to my questions. About four years later, using cutting-edge transoesophageal echo technology, my true heart anatomy was diagnosed. At 36 years old I had a modified Fontan repair, my first surgery, and went from being blue to pink! I moved to Canada in 2004, and have been seen at the Pacific Adult CHD clinic in Vancouver ever since.

Resilience and a positive outlook have shaped my life

I'm the second in a family of seven so my mom didn't have the time to coddle me. I did my best to keep up with my siblings and I've always had a positive outlook on life. From age 9 I attended a school for kids with disabilities, where I realized I could do a lot more than them. One of my best friends was born paralyzed from the waist down whereas I could easily walk on a flat surface, slowly up a hill or stairs, but I could do it! My friend was in a wheelchair most of her life.



Managing anxiety is a skill I've taught myself

It can be difficult to be a patient sometimes; I now see my cardiac team every six months. There's usually a lot of anxiety the closer I get to the appointment. Waiting is the worst part. Having a support system and someone to talk to helps calm me so I can accept that this too will be ok. During an uncomfortable procedure or long test, I have learned to meditate and redirect my thoughts, thinking that I will be doing such and such this time tomorrow. It helps me get through difficult situations.

Community and sharing: "I'm not the only one!"

Being part of an ACHD community has helped me realize that people are going through similar situations. I was just talking to a heart friend who said that she too grew up being able to swim easily swim underwater but not on top and this made me feel "I'm not the only one!" We get each other and I'm grateful!

Please listen to what we have to say

My main advice to healthcare providers is that they need to listen to us and answer our questions or address our concerns. Sometimes we have more knowledge about what might be wrong because of our unique lived experience.

