

Living With CHD: The Patient's Perspective

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Gratitude and resilience - cheesy but true

It is so easy to go down the “why me/woe is me” route when you’re living with any chronic condition. I learned my biggest life lesson through my maternal grandmother: “everything happens for a reason”. The challenges I’ve faced through my CHD journey have prepared me to handle the other challenges life throws

at me. I can approach barriers at work, or challenges in relationships with optimism, armed with the knowledge that “if I could get through that (i.e. surgery or whatever), then I can get through this”. That doesn’t mean I don’t get anxious or overwhelmed, but ultimately, I know it’s all going to work out, even if I don’t understand why it’s happening.

My other recent life lessons are to live in the moment and be grateful for each day. I know it sounds cheesy, but not knowing what the future holds for me, health wise, motivated me to knock a lot of my “bucket list” items off the list in my early 20’s. Now I’m in my early 40’s and my list keeps growing the longer I live. I am grateful to have had the experiences I have had and grateful to my body for its resilience and endurance.

“Missing out” has translated into getting involved



When I was a child, my parents were cautioned about my participation in physical activity. This meant that I couldn’t participate in PE or run around like other kids did. Instead of “missing out” on these activities, I was always reading a book, watching film and TV, drawing or watching people interact with each other. This translated to me seeking out education in English and Psychology and having a Major in Film Studies. Throughout my life I’ve become an avid reader, an academic, a “Jill of all trades” and extremely flexible and adaptable. In my career, I anticipate the actions and reactions of my colleagues and can easily learn new skills or contribute to any level of an organization. I’ve run my own business and am a confident public speaker. I organized an event celebrating International Dance Day which had an attendance of over 5,000 community members (I also emceed the event).



UBIVIVO: Reena Jannomahmed, 13, is proving teens with congenital heart to enjoy healthy lives: Prior to undergoing open heart surgery more than a year ago, she was unable to walk without losing breath – and running on her treadmill was out of the question. (photo by Mark Patrick)



Reena Clarkson, continued

We need a “harmonized” approach to healthcare - beyond just our hearts

For me, the extreme focus on ACHD or only looking at a patient through that singular lens has been particularly frustrating. I am a multi-faceted individual who has physical and mental health concerns beyond my ACHD. While ACHD is very important and requires life-long care and learning, I would like ACHD providers to consider a more holistic approach to patient care. We have some health care needs that need to be prioritized and, for lack of a better word “harmonized” along with the ACHD. For me, this has come up numerous times in my adult life and I have become an advocate for a holistic approach to patient care as a result.

Peer-to-peer connection and support is the key to a healthy outlook

No one truly understands the journey of an ACHD patient the way other patients do. Connecting with individuals with similar experiences or those who have stories to share and learn from, has been extremely helpful in so many ways. First, the peer-to-peer connection and support is key to having a healthy outlook towards our health, which at times can be daunting if you feel “alone”. Secondly, sharing knowledge or products or just empowering each other about what questions to ask, where to keep advocating and where we might find resources has been so valuable. I continue to be an active member of several peer-to-peer social media groups and continue to advocate for this type of connection through my work with the Canadian Fontan Connection (canadianfontan.com/registry).

