

JUST ONE OF LIFE'S DETOURS

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Abstract

The intent of this personal essay is to increase the general public's awareness and knowledge of Aortic Stenosis. Aortic Stenosis is a common cardiac condition affecting approximately 2-5 % of people over the age of 65, and an estimated 80,000 aortic valve operations are performed each year in the United States. With the number of aging "baby boomers," Aortic Stenosis is becoming the most common valvular heart disease in the developed world. In those who have symptoms, without repair, the chance of death at five years is about 50% and at 10 years is about 90% ("Diagnosis and management of valvular aortic stenosis," Clinical Medicine Insights, 2014).

"I don't think it's wise to continue your echo stress test." These words landed like a thud and I couldn't process what the doctor was saying. "You have aortic stenosis complicated by a congenital bicuspid valve and your aortic valve opening has gone from 1.032 to .092 in two years." I stared at him, not comprehending. I could see his lips moving, but his words were garbled in my mind and not making a bit of sense.

My primary care physician (PCP) had referred me to a cardiologist last May after the annual renewal of my thyroid medication appointment. I had what I thought would be a quick, perfunctory appointment until I happened to mention my shortness of breath. That led to an EKG test. When my PCP approached me with the results, I knew by the look on her face that all was not well.

Now the cardiologist had the same concerned look. "We'll have to do some more tests." He looked so serious in his round tortoise shell glasses. We sat side-by-side on the hospital bed as if we were friends just having a casual conversation. Only he was doing all of the talking. I was too anxious and confused to even think of what to say or ask.

That little voice in the back of my head was asking, "Is that good or bad news?" But I already knew the answer just from the look on his face. My heart was thumping in my chest and I wondered if he could see it pounding through the thin fabric of my hospital gown.

Some journeys include exciting plans, making new friends and visiting strange, exotic places. This man, now my cardiologist, had thrown a detour into my life journey. This curve ball definitely wasn't expected and was the opposite of exciting.

It all began with some shortness of breath. I've always been active and even with my crossing the marker that says "senior," I have continued to walk five to seven miles a day, hike, as often as I can, and to participate in a weekly Pilate's and yoga class. So huffing and puffing was new to me. I'm known to friends and family as a minimizer, so in my imitable fashion, I chose to ignore the huffing and puffing, thinking it was my advancing age sneaking up on me. I continued on with my daily activities, choosing not to obsess about every pain or tiny symptom. I convinced myself that if I didn't think about it, the problem would go away. But now my cardiologist was telling me this was not going away and I was going to have to deal with it. With hiking, walking, Pilates and yoga classes, working full time, and adopting a 10-month old rescue lab/mix, how was I going to squeeze aortic stenosis into my lifestyle?

After getting home, I immediately turned on my computer and goggled “aortic stenosis.” I learned that there are four valves that control the flow of blood through the heart. They are tissue-paper thin membranes that constantly open and close to regulate blood flow. Aortic valve stenosis or aortic stenosis occurs when the heart's aortic valve narrows mostly due to age-related calcification but it can be caused by a birth defect, rheumatic fever or radiation therapy. This narrowing obstructs blood flow from the heart into the aorta and onward to the rest of the body. The heart needs to work harder to pump blood throughout the body, and eventually this extra work reduces the effectiveness of the heart and weakens the heart muscle.

My aortic stenosis is complicated by a defective bicuspid valve. Sometime while I was lounging in my mother's womb, as my heart, blood vessels and other parts of my body were forming something went awry. The condition is inherited and tends to run in families. I have a younger cousin with the same condition. Intrigued and concerned, I goggled on and learned that bicuspid aortic valve (BAV) is the most common congenital cardiac malformation. Whew! I thought I have something “common,” and felt a little less alone.

Knowing that others were also on this same journey, became less of a consolation to me as I continued to research and learned that severe aortic valve stenosis will require surgery in order to replace the valve. If left untreated, aortic valve stenosis leads to more serious heart problems. I freely admit, this was when I started to panic a bit. But what alarmed me the most was learning that I had a fifty-fifty chance of living beyond two years without aortic valve replacement surgery. Should I be counting the weeks? The days? I wondered.

New symptoms were waiting on my horizon. I read that aortic stenosis symptoms such as lightheadedness, feeling dizzy, fainting, or difficulty when exercising are complicated by increasing age, high blood pressure, high cholesterol, smoking, and diabetes. My age is certainly increasing, but I've never been a smoker and I didn't have high blood pressure, diabetes, or high cholesterol but I couldn't relax. While my aortic stenosis is considered moderate to severe, every day I feel myself edging closer to that two year mark. I am not just afraid. **I AM TERRIFIED!**

To complicate my journey a bit more, I am claustrophobic and unable to stay still for more than a few seconds at a time. When the cardiologist sternly emphasized, for the second time, that it was time for an MRI, my anxiety rose to a number non-existent on the charts. How could I explain that I couldn't decide which was more terrifying, being stuffed and crammed into a tiny, suffocating tube or not being able to move for 45 minutes? I wanted to cry. I took a very deep breath and as calmly as I could, explained to the cardiologist that I would have to be completely sedated for this next step.

With anesthetization, and a caring nursing staff, I survived the MRI test. My next step in this exciting journey was to meet with the cardiologist to go over my MRI results. Naturally I had already asked for a copy of my test results and goggled everything I didn't understand. “There is some good news in your MRI results, I'll start with that,” he said with a smile. You do have a borderline aneurysm but if nothing changes, when you have surgery to replace your aortic valve the surgeon won't have to replace your aorta.”

I held my breath waiting for the bad news. He continued, “The left side of your heart is slightly enlarged, but not to worry. It's a symptom of your defective bicuspid valve, which causes your heart to work harder than usual. It's not severe enough to worry about now.” Easy for him to say! He continued, “You do have some premature heart beats and some erratic heart beats but I have no idea what's causing them.” I looked at him skeptically. He's a cardiologist with many years of experience. How could he not know what was causing these irregularities of my heart? But he didn't seem worried, so I took a deep, long breath and decided I would try not to worry either.

“You are an enigma and very interesting,” were his next words. I didn’t know whether to get up and do a victory dance or to continue to sit in silence. I opted for silence, very unlike me. I wasn’t willing to go into uncharted territory, even if Kirk and Spock were brave enough to go there. “Ordinarily someone with all of your symptoms would be having surgery now, but it’s obvious you’re not ready. When your symptoms worsen or you feel faint or feel pressure on your chest, call me immediately.” Would I ever feel ready? I don’t want this surgery. I’ve read up on the surgery and even watched a video of it and it doesn’t look like it’s going to be a picnic. I will probably need 6-8 weeks of recuperation time and several weeks of cardio rehab.

Why not do the surgery now while I’m feeling good? I asked. It won’t take me as long to heal, I reasoned and droned on back and forth with the pros and cons. I felt as if I was beating a dead horse. “Another significant reason for not having the surgery now,” he said, “is that people die from this surgery.” What’s the difference if I die now or later, I responded? Since only 3% of the people having this surgery actually die, then the odds were in my favor, I reasoned, since 97% make it through successfully.

How will I know when I’m ready? “When you feel a dog sitting on your chest, you can’t walk, get dizzy, faint or are having an even more difficult time breathing. That’s the time.” Every morning as I watch the sun rise over the horizon, I wonder if this will be the day the dog is sitting on my chest stifling my breathing, that I will faint or my huffing and puffing will sound like a freight train coming over the mountain. When that day comes it will be the end of my watching and waiting. But for now, my journey isn’t over and I’m taking one day at a time. ■

Reference

Czarny, MJ; Resar, JR (2014). “Diagnosis and management of valvular aortic stenosis.” *Clinical Medicine Insights. Cardiology*. 8 (Suppl 1): 15-24. doi: 10.4137/CMC.S15716

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