

All in the Timing

Debra North, MA Ed

Born a heart warrior, I was diagnosed at birth with myxomatous mitral valve prolapse, a degenerative heart valve disease. When I was 15 years old, my pediatric cardiologist broke the news. “You’ll need a valve replacement someday,” he warned, but then reassured me: “Not until you’re in your sixties.” Oh, good, I thought. Not for a *long* time.

Some 15 years later, in 2006, when I was only 30 years old, I underwent my first surgery, a valve repair. After landing in the emergency room with severe shortness of breath, I saw my cardiologist. My symptoms were swiftly accelerating—I could barely load a dishwasher without getting out of breath—and my cardiologist, unconvinced that my valve was failing 30 years ahead of schedule, tested me several times over the next few weeks. First an echocardiogram, then a heart catheterization, then a transesophageal echocardiogram, and finally a pulmonary function test. All with the same reluctant reply when I asked him if it was time for surgery. “No. I don’t want you to have surgery.” “I do,” I protested. Valve surgery had always been lurking in the shadows of my life, and I wanted to get it over with. However, my cardiologist thought the valvular regurgitation was not severe enough.

He referred me to a surgeon anyway. “The surgeon will be your second opinion,” he said. A few weeks later, I met with the surgeon, who told me bluntly: “Your valve is bad and something needs to be done about it.” Shortly thereafter I had the valve repair. Minimally invasive heart valve surgeries, often referred to as “thoracotomies” had only been possible for about a year when I had surgery, and I have a tidy little scar tucked away on my right side near my ribs.

It was about 4 years after that first surgery when my cardiologist broke the news, much as my pediatric cardiologist had years before. I would need another valve surgery—a replacement—someday, but likely not until I was in my 50s. I relaxed a bit, but at the same time I was on guard.

But then, in late 2014, I noticed the symptoms creeping up. The vague shortness of breath, slowly escalating. The subtle changes in my exercise tolerance. Running 3 miles, then 2, then 1, before wearing out. Going to bed at 7 PM most nights, exhausted. Though at this point I knew that I would require another valve surgery, I was not exactly sure at first that the symptoms were because of my valve. My cardiologist had been monitoring me regularly. A heart catheterization after a questionable stress echo in early 2015 had resulted in good news. My cardiologist was thrilled to see that I should only had a mild leak and slightly elevated pulmonary artery

pressure. I, however, was disappointed. I wanted to have the surgery. I wanted my life back. Symptoms were interrupting my life, and they were increasing in increments. I even took the initiative to see a pulmonary hypertension specialist on my own who assured me that my symptoms were not related to pulmonary artery hypertension. After a failed ablation, my electrophysiologist concluded that my symptoms were because of a failing valve.

February 2016

On this chilly southern California morning, I am nervously waiting for my cardiologist. Normally, seeing him does not provoke any uneasiness, but today is different. Today can determine the trajectory of my treatment. It is time to discuss my latest test results.

Soon he comes into the examination room. We discuss surgery, much like we have throughout the past 18 months. He says no to surgery; I say yes. The risks, he has always reasoned, are wide and various. Though heart surgery today is much less risky than, say, 50 years ago, the danger is still significant. Replacing the native valve with an artificial one can cause the heart muscle to expand and weaken, he says, trading one problem for another. He thinks that it is better to wait until surgery is critical rather than have me be exposed to the risks when I am still relatively healthy.

A stress echocardiogram a week earlier had been the tipping point in pointing to another valve surgery. “Your exercise tolerance dropped about 20 percent,” he says, examining my report on the computer monitor. This was strange but not surprising. I had walked 8 miles with the American Heart Association float in the Rose Parade a few weeks earlier, but I could barely walk 7 minutes before my doctor stopped the test. Sometimes when valves begin to fail, they fail fast. Mine had been headed that way for some time. My B-type natriuretic peptide, a hormone that is secreted in response to negative cardiac changes, which should be <100, is now 250. If I am not exactly in heart failure right now, I am definitely headed that way. This concerns my doctor.

“I don’t want you to have surgery,” he says.

“Doc,” I begin, “you and I both know it’s time.”

“I don’t know, Debra.” He sighs. “Are you ready to do this?”

I tell him that I do not want to wait. I had always hoped that my next surgery would be a planned surgery. “I don’t want to get to the point where I was ten years ago when I

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was so short of breath I could barely walk two feet.” His eyes soften. He knows exactly what I had gone through then.

He resigns himself to perform a 3-dimensional transesophageal echocardiogram on me a week later. Though sedated, I am amazed to see the particulars of my (failing) valve on the monitor. After the test, my cardiologist says hesitantly, “I want you to see the surgeon.” Again, a second opinion.

Three weeks after that transesophageal echocardiogram, I meet my surgeon. It is not an emergency yet, he says, but it is time to consider a valve replacement. My valve will not support another repair. Though I am now 40 years old, he wants to give me a tissue valve. He shows me research to support the fact that tissue valves have as much longevity as mechanical valves do. He tells me that this new valve will likely last me a good ≥ 20 years. And by then, he assures me, when I am in my 60s having surgery #3, it will be a transcatheter mitral valve replacement—even more minimally invasive. I am relieved.

November 2016

Five months post-op, I am sitting in my surgeon’s waiting room, wearing a red blouse and jeans, poised with questions on a clipboard on my lap. I notice a woman, probably ≈ 15 years older than me, looking at me. Her skin is pale, and her bloodshot eyes seem nervous behind her tortoise-shell rimmed glasses. I say hi; she says hello. Then she asks me: “Did you already have your surgery?”

I nod.

She says, “You look great. Red is your color. A fighter’s color.” I smile at that and thank her. “How long ago?” she asks.

I tell her about mine. Almost 5 months ago, in the hospital for 3 days, feeling stronger every day. Just got back into running. I tell her that my cardiologist and I had argued for some time over surgery timing.

She tells me her story in return. Born with a heart defect called bicuspid aortic valve. Quick development of symptoms. Worse every day. Her cardiologist also reluctant to send her to a surgeon. She is here for a consultation.

She says, “I’m here even though my cardiologist says it isn’t time yet.”

“They don’t understand,” she continues. “Here I am, I can barely walk up the steps to my house without getting short of breath, and my cardiologist says he wants to wait until things get worse. And all I can think about is how much better I’ll feel after I get through the surgery. I don’t want to have surgery, really, but I was born with a heart defect so you can’t avoid that.” I have argued the same with my own cardiologist.

“Why don’t cardiologists see it that way?” she asks almost rhetorically. Because they want to avoid putting us through surgery as long as possible, I think. Because they think the risks outweigh the benefits, but we patients think the benefits often outweigh the risks. It is not as if we ignore the risks—we just want to get to the other side of surgery. We want our lives back.

As a patient, I realize there is no golden moment in pursuing surgery. My surgeon understands this, too. He wants to fix valves early enough before the problem escalates and further affects cardiac function—before congestive heart failure sets in—especially as a patient begins developing symptoms. It is important for providers to recognize this, partner with, and listen to their patients once symptoms, such as shortness of breath and fatigue, grow from mere annoyances to severe impediments in daily living. My cardiologist, though often conservative in his assessments, acknowledges this fact. However, patients have a responsibility, too. We must be proactive in our own care. We must communicate our symptoms to our doctors and work with them to find the best plan in treating our heart valve disease. The longer surgery is delayed, the greater the risk to the heart. Patients must partner with their cardiologists in taking symptoms into account when considering surgery even if the progression of valve disease seems relatively mild.

I am called into the examination room. I excuse myself, and we wish each other the best. I turn to her and say, “I’m glad you’re taking the initiative.” She looks reassured as if in the undercurrent of my voice I am telling her she is doing the right thing.

I ask my surgeon what I had wanted to know for months. “How much longer would you have given my valve before surgery became an emergency?”

“Not much longer,” he says. “It was time.”

Disclosures

In February 2016 and March 2017, D. North attended the Orange County (OC), CA, office of the American Heart Association (AHA)’s Go Red for Women Luncheon as a survivor guest. In July 2016, she was the passion speaker for the OC AHA’s Go Red for Women Circle of Red fundraising event. In October 2016, she was the featured guest speaker at Edwards Lifescience’s Champions for Life employee recognition dinner/ceremony and was the passion speaker at the AHA Western States Affiliates New Employee Conference in Los Angeles. In February 2017, she attended Edwards Lifesciences’ Patient Day. She became part of the volunteer Patient and Family Advisory Council for Long Beach Memorial Hospital in Long Beach, CA, in April 2017. In May 2017, she spoke at Edwards Lifesciences’ Global HR Conference as a featured patient speaker. She is a prospective AHA Heart Valve Ambassador for 2018.

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