Heart Surgery in February, 2003

The Condition

The Cause

Valve and Dilation

Mental State

The Surgery

The Recovery

The X-Ray

<u>Acknowledgments</u>

On February 21, 2003 7:45 AM PT, my heart surgery was complete. My aortic valve was replaced in what is called a Bental Procedure. I came home from the hospital February 25, 2003 approximately 5:00 PM PT.

Short version: I had a congenital heart defect. It had been watched for about 15 years. In 2003, I met the surgical criteria and surgery was scheduled. HOOORAAAY! I lived.

I've recovered nicely. I live a normal healthy life. The reason I keep this web site in this state is because it might help someone else who is about to have surgery. I found it very heartwarming and helpful to read similar stories before my surgery. I was scared and found comfort in the thoughts of other people who shared.

The Condition

Heart Home

Bicuspid Aortic Valve (BAV) and Dilated Aortic Root (DAR)

Hey, gimme a break with the medical jargon. Maybe it is a bit too much so quickly but I find that it is generally useful to set the ground rules right away. My condition can be described that simply: BAV with DAR or DAA (dilated ascending aorta).

Brief History and Prognosis

I have a bicuspid (two-flapped) aortic valve. Normally, this valve is tricuspid. This is a congenital defect meaning that I was born with it, though it isn't hereditary. The BAV was diagnosed when I was 26 years old. I am now and have always been completely asymptomatic.

I have seen a cardiologist every year since 1987. During that time, they have used echocardiography (ultra-sound) to view my heart and aorta. This test tells the doctor if my heart and valve are working properly; it also tells them if my aortic dilation is within certain limits. My current cardiologist, Dr. Fendley Stewart, is a very good doctor who takes his time with me, explaining every aspect of the tests.

Apparently 1-2% of the U.S. population (2.7 million people) has this same BAV condition. <u>Arnold Schwarzenegger</u> has this condition. He has had similar surgery twice (no DAR), the first time in 1997.

I suspected that this day was inevitable from the first time I met with a cardiologist. I didn't expect it to come before I was 50, but then again, I am young and healthy and a good candidate for surgery. I already had my moment of facing my mortality when I was 26. My physician told me that I had a heart murmur and that he was going to send me to a cardiologist but in the meantime, not to do anything strenuous. WHAT!!!! I was working out a lot then (running, triathlons, etc.) and to discover that I would have to change my lifestyle to possibly avoid dying was a bigger blow than the recent news that I needed surgery. Now, the goal is to collect the facts and make good decisions.

I have no other risk factors so everything else is good: my cholesterol is low, my valve function in the rest of my heart is strong, there is no calcification of my aortic valve despite it being malformed, my heart size is good, and I am not obese. This is all good. I am now, after a little panic attack, focusing on the positive steps that I can take to be well-informed and healthy for any potential surgery. I can and still do exercise to maintain good heart function. I can live life normally with no restrictions.

You can find a good discussion of my condition here: http://www.medhelp.org/perl6/cardio/archive/11982.html

The Cause

Heart Home

The cause of this heart condition is unknown. Congenital abnormalities happen in a fetus 1 out of 28 times according to some doctors, resulting in many benign things including unbalanced ears, one leg slightly longer than the other, or <u>BAV</u>. It could be as simple as a solar flare happening at just the wrong time. See the flapping of a butterfly wing story in a book on <u>chaos theory</u>.

The underlying mechanics of my problem are either a DNA mutation or some kind of perturbation when I was an embryo. When the cells that form the upper chambers of the heart came together, they didn't

quite have the right instructions. They formed the aorta but not quite correctly. One cell went left when it should have gone right and ska-bam! I have a weird valve. Instead of opening like a three-petal tulip, it opens more like a fish mouth. You can imagine that the flow of blood might tend to squirt out differently through the valve as it opens, which in turn might compromises the wall of the hose (the aorta), weakening it and causing a blister.

The other possibility is that my connective tissue got the wrong recipe and isn't as strong or resilient as it might be. That could be a genetic mutation. Thus my tissue will be sent to a geneticist who will look at it in the course of his research. This is where it might be like <u>Marfan's syndrome</u> but not exactly the same. It could be that people like me have something similar to Marfans, but seemingly not as severe or pervasive. The UW has one of the leading Marfan clinics in the world according to the doctor. That's comforting because if there is a genetic and possibly hereditary component, it's nice to think I am helping to advance the research, because my own offspring might someday benefit.

The Marfan's connection is tenuous, but the indirect result is good. Marfan's patients need to have their aortas patched frequently. Some have grafts (I think that's the term) from their heart to their groins. As a consequence, the UW surgeons do a lot of this type of surgery, relatively speaking. That's good for me. You want a surgeon who has done this type of thing before.

Valve and Dilation

Heart Home

The Valve

When they replace the valve, there are two types to choose from: mechanical or animal tissue (pig or cow). My cardiologist, Stewart, strongly suggested that I not really even consider leaving my existing valve. He said it simply: it is defective and there is no good reason to take any chances.

Mechanical

Pro: They last forever in most people.

Con: You have to take blood thinners every day for the rest of your life. Due to the blood thinner, you have to refrain from some activities that could lead to serious injuries, e.g. bungee jumping, boxing, tackle football.

Tissue

Pro: No blood thinner needed, thus no limitations on activities.

Con: Will likely need to be replaced in 15-20 years.

My inclination and the majority of advice (thanks to brother Mike's friend, Nadine, and <u>John Whiteman</u>) points toward the tissue rather than the mechanical valve. Given my age and the age of my children, I would like to allow myself to maximize my life choices for the next 15 to 20 years. Should I want to bungee jump or ice climb, then I'd like to be able to do those activities. If I can get 20 good years of living out of a tissue valve, then perhaps new technologies will be available, or I'll be around sixty then and perhaps more amenable to a more leisurely approach to life with a mechanical valve.

The Dilation

Essentially, my aorta has a blister in it, like a garden hose might. The diameter of my aortic root had measured at about 51mm since 1987 or so. That put me in the upper percentiles in terms of root size, but not at a point where any action was required. My two most recent "studies" showed a dilation of 53 mm, and last week it was up to 55 mm. That is the upper limit before they recommend surgery.

The major goal of my surgery involves re-secting the aorta. The doctor will remove the blister and replace it with a section of Dacron.

My Mental State

Heart Home

This whole thing has been a bit sobering but the surgeon, Verrier, said something very comforting at the end. He simply extended his hand and said somewhat dismissively, "You'll do fine," like I was about to take my SATs or something. That was a nice touch.

I am increasingly confident about the surgery. I am in the hands of excellent professionals who do this job nearly everyday. They are well-trained and experienced. Heart surgery is done thousands of times every year; I find that reassuring.

I also appreciate the way people have extended themselves to me - particularly people who have had significant surgery themselves. Each of them has told me that I have the right attitude. Most of the post-surgical people have said that the fear of surgery is out-weighed by the benefits the surgery provided in hindsight, adding that they wished they had done it sooner.

People at work have been very understanding and reassuring.

As for sending me prayers, don't bother, I'm an atheist. This is news to some of you and I'll avoid getting on a soap box here about religion. On the other hand, I'm emboldened by my predicament so I don't care if this offends you. If you care about me, cut out the middle man; talk to me or email me directly. I'm happy to be in your thoughts, but that doesn't provide me any support unless you tell me about it. I am happy to receive it.

I hope my lack of belief isn't embarrassing to my dad. Sorry, Dad. It's not your fault or Mom's. That's the only thing I feel slightly bad about. For that reason, I'll post my diatribes on religion and other heady matters someplace else.

The Surgery

Heart Home

Letter from my surgeon

The upshot is that surgery is inevitable. I more or less knew this but now it is definite. The surgery will take place on February 21, 2003. It will start at 7:45 AM and last about 5 hours.

Amy and I met with the chief of cardio-thoracic surgery at the University of Washington Medical Center. His name his Dr. Ed Verrier. He was incredibly nice to us, though for the first 30 minutes of an hour-long meeting he looked only at Amy. Maybe he glanced at me two or three times. Now I know what it is like for a woman when a couple has to deal with a car salesman. Of course, Amy is better looking but it's my heart.

Verrier emphasized that, as a surgeon, he is generally inclined to make the repairs when you meet the criteria. I meet the criterion, so he said, let's do it. He suggested that I not wait a year but a couple of months would be fine. Verrier also made the point that a person, once he knows that he is going to have surgery, generally does not want to wait too long because every little thing will worry him. I know what he means. I've lost sleep over this and don't relish the idea of perceiving every little physical oddity as indicative of an emergency.

The surgery will repair my aorta and, most likely, replace my valve as well. The surgeon won't know if replacement is required until he can look at it. My own valve might be okay but that is unusual. It is a judgment call. Imagine they sew me up then find out in two or three years that my valve is faulty. Now you have another surgery; two surgeries in less then the 15 years. If you simply replace the valve with a tissue valve, then 90% of patients get to 15 years before another surgery.

Here is a link to the program on the web where my surgeon delivers a talk about my exact condition, Aortic Valve Disease. Here, you will see almost the same speech that he gave to Amy and me. It was rather reassuring to see that he told us the same thing that he tells other doctors. The bonus was that we got an excellent presentation about the valve options. It was on UWTV on a program called Grand Rounds. For you medically oriented folks, you know what grand rounds are. For the rest of you, watch Scrubs.

http://www.uwtv.org/programs/displayevent.asp?rid=1288

My doctor starts speaking about 1/5 of the way into the webcast.

The Recovery

Heart Home

Recovery from the surgery is 6 to 8 weeks, though the surgeon emphasized that in young men there is some, what he called, "sadness" that can linger.

You cannot do any kind of lifting, golf, or other strenuous activity for at least 6 weeks until the bone heals. Then, gradually, you can return to normal activities. This part is no different from any by-pass-type heart surgery.

I spoke on the phone with a gentleman, John Whiteman, who had received his second valve eight weeks prior to our conversation, approximately in late October 2002. He had his first replacement at 47 and it lasted for 13 years. After his recent surgery, he was back to work as an orthodontist after 4 weeks. He confided that this might have been a week or two early. His stay in the hospital was less than a week, actually less time than his original surgery in 1989. I enjoyed talking with John whose upbeat attitude bolstered mine and whose information was very helpful to Amy and me.

For a real life blow-by-blow description, see this <u>woman's description</u>. It is a Word document but you can view it by choosing "Open."

After the surgery, I plan to take cardiac rehabilitation. I am anxious to get back to my workouts, though I plan to be prudent. Cardiac rehab is not required. According to my cardiologist, I am young and already in reasonably good shape. It is designed to help non-exercisers develop some good habits. But for me, it will be a controlled environment where I can get my confidence back. In the cardiac rehab, you work out on machines (treadmills, stationary bikes, etc.) while being monitored to see that your heart is responding as expected to the stress of exercise.

X-Rays of yours truly

Heart Home

Part of the heart surgery I had, or any "open heart" surgery, includes the closing of breast bone. It is held in place with wires. They hold the breastbone together while the bone heals but they stay in permanently. Some people call it a zipper.

This x-ray was taken by my chiropractor before he started adjusting me. This is what my breastbone looks like. I hadn't seen anything like this before the surgery and was amused by how much it looks like stuff you can buy at Home Depot.

Negative image

Positive image (color inverted)

Acknowledgements

Heart Home

I am naturally prone to writing stuff down. This works for me. You don't have to read it.

- Thanks to Michelle Fredette, who edited this text for me.
- Trivia My surgeon's name is Dr. Ed Verrier. "Verrier" is the French word for glassmaker.
- Book recommendation: State of the Heart, The Practical Guide to your Heart and Heart Surgery Stephenson and Rodengen.

The following site contains a nice testimonial about an experience at the same hospital and with the same surgeon I will use. Also, this site is a rich collection of people with many heart conditions and stories about their treatment: http://www.valvereplacement.com/stories/johnny_stephens.htm

Why did I make a web site about this?

I don't mind talking to people about my heart condition and surgery, but it is hard not to include everybody I care about. I can't call each person and tell them all this information. I'd rather present what I know here and talk about what makes them uncomfortable or curious.