

When you're about to be wheeled into surgery to have a device wired to your heart, a commercial using Europe's "The Final Countdown" is not the most comforting thing to hear.

*The number one symptom of heart disease is sudden death.
– Todd Snider, "Greencastle Blues"*

The important part is that I'm still alive to tell this story.

In the summer of 2014 I picked up a cough. Within a week it became bronchitis, which sent me to the emergency room, unable to breathe or to stop coughing. With antibiotics and a few other treatments, the cough was pretty much gone by winter.

Well, what doesn't kill you makes you stronger. But it also tries harder next time.

Current mood: pretty dang tired

April 2015 was an exhausting work month. Nearly 21 straight days on the road at multiple customer sites, and a long week of demos at an annual trade show, culminating in the loss of my voice. I came home with barely enough voice to perform at the Norman Music Festival. It would be my last show for months. By the end of April, the cough was back.

Through May, the cough worsened – a wet, throaty cough, where nothing ever comes up, it just sounds like it needs to. In June I started regular tests with my doctor, pretty sure it was a lung/pulmonary issue, with most signs pointing to asthma. Brief times off the road in the summer were filled with an assortment of tests and exams. Meanwhile, the cough kept getting worse.



Current mood: a little concerned

Soon everything was exhausting. One cough was more like 3 minutes of hacking. I wasn't hungry. I was living on DayQuil and cough drops. One morning in July, on a customer site, the coughing turned into several minutes of dry heaving. The cough got more relentless. I couldn't step into summer air without triggering the cough. I couldn't sleep lying down, feeling like I couldn't breathe (and continuing to cough). Extensive, increasingly desperate web searches of my symptoms continued to point toward asthma.

By mid-July I was a mess. The only position I could sleep in was sitting straight up in an office chair, leaning my head forward on a stack of pillows – and even then, only for an hour or two. The coughing worsened, until eventually I was averaging 5-6 minutes per coughing fit, 5-6 times an hour, 24 hours a day, dry heaves regularly part of it. I started cutting from my diet anything that even marginally seemed to make me cough. I quit beer in early July, coffee a week later, and soda soon after. I had no energy, couldn't think clearly, exhausted but unable to sleep, unable to stop coughing, unable to walk 50 feet without needing to rest.

Current mood: running on empty

Gloria & I canceled our anniversary vacation to stay home and try to rest up, during which I had a breathing test done at the hospital, with results to follow a week later. I spent the week on the couch, barely moving but still coughing my head off.

The next week I was back to work, with a trip to a customer site in Greenville, NC. During a layover en route to North Carolina, I had a severe coughing attack, one of the worst. During the flight, my legs and ankles swelled up. I'd lost a little weight by this point, although my gut was puffed out more than when I was heavier, and I generally looked and felt terrible. That night I noticed my whole neck appearing to visibly pulsate along with my heartbeat.

The next morning – ankles still swollen, cough in full force – I got an email from my doctor, telling me the breathing test results were back: I didn't have asthma or the other obvious pulmonary illness, COPD.

*Current mood: THEN WHAT THE HELL **DO** I HAVE!?!?*

Later that day, I hit an urgent care center in Greenville. I'd had an inhaler that had been helping a bit, leftover from the bronchitis treatment, but it was almost empty. The PA who saw me listened to the whole tale, and when I mentioned the swollen extremities it was like a bell went off. She said that a heart condition could explain the swelling (edema), which was fluid retention, and that the coughing could also be caused by the same fluid retention. She prescribed a diuretic and an inhaler refill. The diuretic reduced the fluids in my legs, and I finished the week and made it home to Tulsa.

The next week, everything changed. On Monday, August 10, I saw my doctor, caught him up on things from the previous week, particularly the suggestion my symptoms could be heart-related. He put in a referral to a breathing specialist, who set me an appointment a few weeks later. And he scheduled an echocardiogram ("echo") for that Thursday to rule out a heart condition. Thursday morning I got the echo (an ultrasound of the chest), came home and napped for an hour, and woke up to a message from my doctor about the results.

Severe Dilated Cardiomyopathy. (That's bad.) Recommendation: see cardiologist, *immediately*.

The next morning I was in front of a cardiologist. She explained how the heart is supposed to pump 55-70% of your blood with every beat. This measurement is called the Ejection Fraction. An EF of 40-55% is considered low and may indicate damage to the heart. Below 40% most likely indicates heart failure, and below 35% is considered high risk for cardiac arrest and sudden death.

My ejection fraction was 20%.

I had heart failure. The left ventricle was failing, and in straining to work hard enough to keep up, it stretched out and thickened, but was still losing ground. The heart's inability to push enough blood around was causing fluid to collect in my extremities and lungs, causing the cough. This condition had had me, for some time now, at high risk of cardiac arrest. Basically, at any time for months now and in any place, I could easily have just dropped dead.

So that's reassuring.

One thing heart specialists can't do is pin down heart failure onto a specific cause. It can be congenital or hereditary, other times it's caused by a virus, other times it's caused by a physical trauma of some kind. There's little history of heart trouble in my family, save one grandfather (RMG1), so mine most likely came from a virus. The one that made me so sick *last* year.

Remember what I said about what doesn't kill you?

A low EF is not necessarily a death sentence. It's treatable with medicine, diet and exercise, and can actually be brought back up to normal levels over time. I was given a picture of the first 3 months of treatment. I would immediately start taking 3 medications, steadily increasing dosages and eventually adding up to 3 more. The medication would treat the fluid retention and lower my blood pressure to lessen the strain on my heart. I'd get blood tests often, and adopt a very-low-sodium diet, which would also reduce the heart's workload. I would also begin wearing a device called a LifeVest – an external defibrillator, capable of restarting my heart if it happens to quit.

After a month I would begin Cardiac Rehab – a heart-monitored, supervised physical therapy session 3 times a week – to condition my heart and body to start moving and exercising again after months of increasing inactivity. Finally, after three months of treatment, diet, medication, exercise and LifeVest, I would have another echo, to see if it had all made any improvement.

Within 24 hours of the echocardiogram, I had started 3 prescriptions and was wearing the LifeVest.

All summer, as I got worse and worse, I started paying more and more attention to TV commercials for prescription drugs. *I have that symptom, is that disease what I have?* Now I could finally start ignoring those.

Current mood: cautiously optimistic

Ah, the LifeVest. It's a wearable defibrillator, not unlike a bra or a highway safety vest. Worn 24/7 except for bathing – it can only save your life if you're wearing it – it has 4 thick electrodes and three iPhone-sized pads built in, all connected to a 4-pound controller worn on a strap or beltclip. The controller monitors the heart and watches for irregular conditions, and the whole unit is capable of delivering a defibrillating shock to jumpstart the heart if it flakes out or stops. The belt-pack is pretty large, and apparently looks like a walkie-talkie – or a pricing gun, judging by the number of times I was in stores and people assumed I worked there.



Humor aside, I now had a device designed to restart my heart if it stopped beating. Which, come to think of it, is a little unsettling. Unsettling, but also reassuring.

Humor no longer aside, holy cow, it DOES feel good to take off a bra at the end of the day.

During the 3-month treatment period, I did everything I was supposed to do, eating the proper diet, dosages eventually increasing (and a fourth prescription added), Cardiac Rehab starting after the first month, LifeVest in place 24/7. Within 1 week I could sleep on my back. Within 2 weeks I wasn't coughing anymore. Within 1 month, I was down nearly 50 pounds from my original pre-cough weight. Within 2 months, I was ready to perform a little again, doing a handful of shows with the Crispy Family Carnival in October, but without my trademark medley – just too demanding physically to risk yet.

The day before Thanksgiving brought echo #2. This would tell what, if any, improvement had been made since I was first diagnosed three months earlier. How would this go? Would there be signs of progress? Would I be on the path to a full recovery?

The results from echo #2 that afternoon: ejection fraction 20-25%. Basically no change.

Current mood: now what?

Medication, diet, and exercise would continue, but no more LifeVest. Instead, I would get a pocketwatch-sized device called an Internal Cardiac Defibrillator (ICD) surgically implanted in my chest. Like the LifeVest, the ICD monitors heart rate and function. It's able to automatically deliver a shock to reset the heart when heart rate drops below or above the normal range. Unlike the LifeVest, there is nothing worn on the outside, and there's no cancel button.



On December 7, 1941, my father, then 8 years old, had his first surgery.

On December 7, 2015, at the age of 45, I had mine.

Current mood: going under

It's not open-heart surgery, in fact, it's not even that invasive. They make an incision below the collarbone, and feed two electrical leads all the way to the heart where they are connected to the tissue. They make a little pocket under the chest muscle wall for the ICD to fit inside, and connect the leads. You're sedated but awake for most of it, albeit with your face covered with an oxygen mask and a cloth so you can't see anything.

Before sewing everything up, they put you fully under, and induce a cardiac arrest to make sure the defibrillator kicks in properly. I didn't really know about that part until just before the surgery, so we didn't have a lot of time to freak out about it in advance. But apparently that part went fine and that's all I care to know about it. When it's all done, you recover overnight in the hospital, and you're back home the next day, armed with antibiotics and painkillers.

Current mood: recovering

My surgery was three weeks ago. I feel OK. I have a nifty new scar on my chest, and last week I had a check-up at the surgeon's office to make sure the device is working. It is, and it has 10.5 years' worth of battery charge right now. The LifeVest is on its way back to the company it came from.

I couldn't lift anything with my left arm for 4 weeks, to avoid pulling the leads out and having to get them reattached – which does not sound fun. I had to stop Cardiac Rehab for a couple weeks, but I'm back now and into my last round of sessions. I'm often the youngest patient there by about 15-20 years or so, but I seem to be one of few who haven't had at least one heart attack. Unless you count the medically-induced one I mentioned a few paragraphs back.

Current mood: thinking long-term

Like I said, a low EF is not necessarily a death sentence. One person I met at Cardiac Rehab has had an EF of 20% for over four years, and a family friend had a low EF steadily improve back to normal levels over the course of several years. And a low EF doesn't necessarily mean quality of life is rotten, either. Mine isn't. I feel good. I'm sleeping well. I'm eating well. I'm exercising. I'm 45 pounds lighter. I have an internal backup generator for my core power unit, and I'm doing the best I can.

I'm thankful for a lot of things. I'm thankful to be in the hands of a great cardiologist, surgeon, and Cardiac Rehab team. I'm thankful for great coworkers, and I have to single out Caleb Graves, who was just supposed to shadow me to train this summer, and instead had to master a lot of things way faster than normal as I was grinding to a halt. I'm thankful for my wonderful family, and that I was well enough to travel to Ohio to see them at Mom's 80th birthday less than 3 months after my diagnosis, and I'm thankful for my wonderful family-in-law here in Oklahoma too. And I'm thankful for my awesome wife Gloria, who has been at my side every step of the way, helping in every way imaginable, during what otherwise *still* would have been her busiest semester of school. I didn't get here alone.

My beard is longer these days. It has a lot more gray in it, and there's a bit more 'weary' in my singing voice. I think I've earned both. There's probably a concept album in here somewhere.

I have more stories to tell.

And, most importantly, I'm still alive to tell them.

But I will never hear "The Final Countdown" quite the same way again.

- RmG³, 1/4/2016