

LAF is Not a Death Sentence

By Don P.

I wanted to share my journey with, what was described at the time as, lone atrial fibrillation. It may help others, it may not.

It seemed like I always had episodes of PACs and 'skipped beats' from my early teens. Most of them evolved around stressful situations and caffeine. As I entered college, I had access to better medical care and underwent several Holter monitor tests, EKGs, etc. The EKGs of course showed normal cardiac rhythm but I knew there were times when something wasn't right. Holter monitor showed a few episodes of PACs. They continued to come on a regular basis...they always came when I was tired, drinking caffeine or stressed out. And they continued to be a source of worry for me.

One night, my heart went into hyper mode...it was the most terrifying event of my life at the time. Typical atrial fibrillation episode but I had no idea what it was. Eventually made it to the ER and was told I had a pulse of 180+. I was rushed into the ER to see a cardiologist and several doctors were surrounding me as they started a blood thinner drip and a beta blocker drip.

I was convinced I was dying because they hadn't made the atrial fibrillation diagnosis and the doctors seemed very concerned. I was admitted and was told that if I didn't convert to sinus rhythm within 24 hours, they would have to electrically convert me and they told me a little about the process. At about the 22 hour mark, I spontaneously converted to sinus rhythm. One of the nurses came running into my room...I couldn't even feel it at that point. I don't know if my body got used to it or if the drugs somehow dulled the activity enough to make it seem less pronounced. I was assigned the worst cardiologist in the world. He told me it was paroxysmal atrial fibrillation and that I'd have to be on a course of drugs for the rest of my life – a beta-blocker, a blood thinner and the dreaded digoxin.

I got out of bed to be released and found I had zero energy. I could barely walk from the car to my house after being driven there. Twelve hours later, my heartbeat was at 40 bpm thanks to Betapace (a very high dose from what I understand). I called the doctor and he told me to take half instead of the full dose. That did very little in giving me back any kind of energy. So I decided to quit taking it altogether. I was still taking digoxin and the blood thinner...I was horribly depressed, nervous, stressed, basically spending each day waiting for the next episode and the accompanying rushed trip to the ER. I was afraid to drive, I was afraid to go to work. I was afraid to eat much food. I was afraid of EVERYTHING. It was like living in full terror....I spent as much time in bed as possible.

I had just got an internet connection and found *The AFIB Report* by Hans Larsen. I spent literally days and nights reading others' stories, research, triggers, etc. I became obsessed with it. And I was obsessed with dying as well. I participated in a study of afib by Mr. Larsen and was absorbing constant information about the situation. I printed out a lot of info and went to my general physician for an update. He knew a cardiologist whose mother has Afib and he referred me to her. That was the best break ever. My new

cardiologist tapered me from digoxin and discontinued it completely. She also started me on atenolol at the lowest dose to be taken as needed.

I didn't have any dental fillings at the time so I was sure mercury wasn't an issue. So I was basically off of all heart meds for the first time in 4 months.

I did try to live a healthier lifestyle... I discontinued caffeine completely and quit smoking and drinking alcohol. I started drinking a lot of water, exercising lightly daily and ate smaller meals (though I was never overweight). I also went to a hypnotist for some relaxation advice and education.

Literally 10 years later, after spending a year in sheer terror afraid of the next attack, I've had one episode that led me back to the hospital that was the direct result of no sleep and extreme fatigue and heat.

I still get PACs from time to time (generally after a large meal or when I'm tired or stressed) but I know now that I have to take care of my body and mind and that will take care of my heart. There are times when I have to do spontaneous meditation during stressful events but I cannot believe how blessed I have been in the past 10 years since my first real episode of LAF. I would have dreams and nightmares about ablation procedures, I struck up friendships with people who had undergone the MAZE procedure, I was constantly checking my pulse and afraid to drive long distances and fly.

These days, I have travelled the world without much thought of AF. I did decide that mine was vagal in nature without doubt...I had read a story where a man claimed to have cured himself of atrial fibrillation by taking a dose of an antacid every day. His theory was that gas and pressure pressed against the vagus nerve and would trigger his episodes. I noticed that there was a direct connection to feeling full and having indigestion during a lot of pre-afib activity in my chest.

Regardless, I really did have to wait to tell this story until the 10 years was up. My hope is that I can keep people who have a single episode from freaking out the way I did. I was convinced that it was all downhill from there – I'd have constant problems, a huge array of medications I'd have to take, etc. I was 30 years of age when it first started and I'm 40 now. Having said that, I know there is no way of knowing what tomorrow brings. I do know that as we get older, it tends to appear more frequently. And I'm ready for whatever may come, I hope. But my message is this: LAF isn't the death sentence I was convinced it was a decade ago. If you have an episode and you're young and otherwise healthy, realize that you may not have another one for 10 years even if you take ZERO medication for it. It's hard to find a cardiologist who is sympathetic and understanding of atrial fibrillation but try to find one who will keep you off the heavy beta blockers and digitalis (if my experience is worth anything....though I am not a doctor and do NOT suggest taking your med regime into your own hands.)

My sincere thanks to Hans Larsen (who answered a few emails back when this all started and included me in a survey) and to all the members in the forum. I met a lot of nice, supportive people there. Each of us have our own unique journey with atrial fibrillation...10 years later, I cannot say I don't think about it altogether; I can only say that I look back at the constant fear I lived in and am grateful that I had only one further episode that I am aware of (and I felt my Afib BIG TIME). Fear causes adrenaline, adrenaline, in turn, causes an increase in heart rate, etc. Do not fall for the fake fear. Get as healthy as you can without overdoing it, eat smaller meals, light exercise, drink plenty of water to stay hydrated, consider transcendental meditation or some other kind of meditation, manage your stress and see if you find any improvement. I was never a heavy drinker of alcohol but cutting out that and caffeine I believe played a big part in the 'success' I had.

If the ugly beast ever rears its head again, I will be back to *The AFIB Report...*you can bet on that. In the meantime, I say a little prayer every night that I remain in sinus rhythm and do the best to not over indulge in anything or drive myself too hard mentally or physically.

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