Patient Perspectives:
Living With Atrial Fibrillation

Mellanie True Hills

In recognition of September being Atrial Fibrillation Month, EP Lab Digest had the honor of speaking with Mellanie True Hills, who is the CEO of the American Foundation for Women’s Health and StopAfib.org. She is a speaker and author of the award-winning book, A Woman’s Guide to Saving Her Own Life. As an atrial fibrillation survivor, she created StopAfib.org and the Atrial Fibrillation Blog to provide atrial fibrillation patients with information, resources, and support to conquer their atrial fibrillation. StopAfib.org is for patients, by patients.

It was 2003 and I was a road warrior, a consultant for Cisco Systems. A typical week meant being in multiple cities, having marathon meetings and conference calls, and working almost around the clock. I didn’t realize how the stress of travel and the lack of sleep were taking their toll.

I soon became very aware. One evening, as I got off of a plane, I realized that the lack of sleep were taking their toll.

One evening, as I got off of a plane, I realized that I could barely breathe and my left shoulder ached. I had just read a few days earlier that women have different heart attack symptoms from men, and that women’s symptoms are very subtle and easily missed. I had two of those symptoms.

Was it my heart? Probably not, I thought, as it was very moldy there and I’m sensitive to molds — that probably explained the shortness of breath. As for that left shoulder pain, my new company PC was heavier than the old one, and it was hanging from my shoulder (wheeled computer bags weren’t yet common). I figured I was OK, and since it was late, I went on to the hotel and left a message for my doctor.

When she returned my call the next morning, she felt that it was probably nothing serious, but we made an appointment for me to get checked as soon as I got home.

At the appointment, we both felt that it was probably just molds affecting my breathing, but she did an EKG anyway and found it to be abnormal. She insisted that I go straight to the emergency room and get someone to drive me.

On the way to the emergency room, I was scared and my blood pressure spiked. At the ER, I was rushed back to the Trauma Center and treated for a heart attack. I remember the doctors and nurses rushing around like mice in a maze. It was frightening.

Luckily, it wasn’t a heart attack. However, a catheterization indicated that I had a 95% blockage in the left anterior descending artery and had probably been just minutes from having a heart attack.

The interventional cardiologist did an emergency balloon angioplasty and a stent. He found that the blockage was at a difficult juncture, and he could barely place the stent. I almost died of a massive heart attack.

Fortunately, I got a second chance. I knew that there was something that I was supposed to do with it, but I wasn’t sure what. At the time, most women didn’t know that heart disease was the #1 killer of women, and that stroke was our #3 killer. No one was talking about that, so I decided it might as well be me.

I got myself and my health back under control, including losing 85 pounds, and then left my road warrior job to help women avoid what I had been through and make the changes that could save their lives. To help guide women in making those changes, I wrote a book, A Woman’s Guide to Saving Her Own Life, which went on to win multiple awards.

Life with atrial fibrillation wasn’t normal. I lived in constant fear of that next episode. Would I be driving or off by myself and have a stroke and die?

What Your Patients Wish You Knew

Hospitals often ask me to speak at community atrial fibrillation symposiums and to share with doctors and staff about what atrial fibrillation patients wish their doctors knew.

My own experiences were good, but I asked other patients and received blunt, even unprintable, comments rife with frustration. I’d like to share some of their thoughts with you. Please receive them in the spirit of helping you help us.

A cardiologist once told me that atrial fibrillation was the bane of her existence. Atrial fibrillation patients feel the same, but we have to live with it every day. When any of the following thoughts start to roll off your tongue, please take a moment to think about how these comments will make that patient feel.

• Afib won’t kill you.

While we know atrial fibrillation won’t directly kill us, blood clots spawned by atrial fibrillation can, and many of us have loved ones who died from atrial fibrillation.

• Just get on with your life and stop thinking about your afib.

Atrial fibrillation and warfarin force us to give up doing things we love due to the risk. Atrial fibrillation is frightening and terrifying, and we feel anxious and alone. If you haven’t walked in our shoes, it’s hard to understand.

• Stay off the Internet and only listen to me.

We need support, information, and to learn from others who have been there. We will find answers and solutions and bring them to you. Please be open to this, not intimidated by it. You should expect me to be an informed patient, so please help me by suggesting credible and trustworthy resources, such as StopAfib.org, that bear the HON (Health on the Net Foundation) Code seal.

• I’ll choose your treatment, not you.

We have to live with it, so we would like to make those decisions together.

• You’re just a hysterical female.

This is my all-time favorite. Women are open about our feelings and what atrial fibrillation does to us. Please don’t dismiss us and our atrial fibrillation experiences. We are finally starting to learn how atrial fibrillation is different for women.

Atrial fibrillation takes a huge toll on us and our families. Please listen, understand, sympathize, and compassionately help us find solutions, sooner rather than later, and provide us support groups for emotional support.

Oh, and don’t forget to pray passionately that you never have atrial fibrillation!
I didn’t have the traditional heart attack risk factors — I was simply overweight and over-stressed. At the time, stress wasn’t even considered a risk factor, but we now know that it is. Today I tell my audiences that *Stress Hijacks Healthy Habits* — if you get your stress under control, everything else will fall into place.

So where does atrial fibrillation (afib) come in? Just seven months later, in October 2003, I had gotten off a plane and was in my home office pulling email. My heart felt like it skipped some beats and started racing and pounding. I became so dizzy and lightheaded that I had to lie down. My husband, with blood pressure cuff in hand, rushed over and recognized that my right leg was as white and cold as snow. My right eye was blurry as well.

Long story short, the emergency room cardiologist said that I had had arterial clots and a close call with stroke from atrial fibrillation. I had never heard of it. They put me on a beta blocker and Coumadin® (warfarin).

A few days later, while out for a walk, my heart felt like it skipped. I was a half mile or so from home when my exercise heart rate monitor went screaming up over 300 beats per minute. I was freaking out, thinking I was going to pass out right there. Panicky, I called my husband to come get me. The two minutes it took for him to get there felt like forever. We called the doctor and she said to take an extra beta blocker. My heart returned to normal within minutes, and afterwards I never went anywhere without my cell phone and a “pill-in-the-pocket,” even just out to the mailbox.

I never knew when an episode would strike — while washing the dog, walking, talking on a conference call, sitting in a meeting — so I was always afraid. My heart was like a flopping fish inside my chest. I would get so dizzy and lightheaded that I thought I would pass out. I was paralyzed and scared. When it was over, I was so wiped out that all I could do was crash.

Life with atrial fibrillation wasn’t normal. I lived in constant fear of that next episode. Would I be driving or off by myself and have a stroke and die? My family was scared and wouldn’t let me out of their sight. We traveled together in the motorhome (I was grounded as both of their sight). We traveled together in the motorhome (I was grounded as both of their sight). We traveled together in the motorhome (I was grounded as both of their sight). We traveled together in the motorhome (I was grounded as both of their sight).

Every day, I feel blessed to be here and, through StopAfib.org, to be able to make a difference for others.

Portions of this article have been published previously in the book *A Woman’s Guide to Saving Her Own Life* by Mellanie True Hills as well as on http://StopAfib.org.