

# 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.



Mellanie True Hills

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 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.

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## 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!

**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?**

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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 incidents happened after getting off planes) to all my speeches and meetings. We planned our route to be near hospitals, and I knew every hospital along the way.

You can't imagine, unless you've lived through it, the toll that atrial fibrillation takes. It takes a huge physical toll and a huge

emotional toll, not just on you, but on your whole family, too. Worst of all is the financial toll — huge medical bills, inability to get insurance once you have atrial fibrillation, lost time from work and lost income, and for some people, lost jobs and careers and even lost houses and life savings.

Of course, then there was also the impact of the Coumadin, along with:

- Weekly blood draws, at home or on the road, to check my International Normalized Ratio (INR). You haven't lived until you've tried to find a place on the road every week to get a blood draw, and to get a motorhome there to do so! My husband is a saint.
- Adjusting dosages weekly as I ping-ponged between blood that was too thick and blood that was too thin, worrying about blood clots or bleeding to death.
- Avoiding yard work, kitchen knives, and even shaving my legs to keep from getting cut.
- Blood that was too thin leaking from my blood vessels and turning me black, blue, and purple all over — on my arms, legs, torso, even face. My family was embarrassed to take me anywhere as I looked battered.
- Being told that if I just ate right, I'd be under control. I ate right, but it didn't help.

When research came out saying that many Coumadin patients have trouble being stable for genetic reasons, I knew that I couldn't continue this nightmare for the rest of my life.

Catheter ablation was one option for my paroxysmal atrial fibrillation, and surgery was another. The decision is not clear-cut for most atrial fibrillation patients, but due to having had blood clots on my very first episode, and living in fear of blood clots and a stroke because I wasn't stable on Coumadin, the idea that surgery could eliminate the source of most afib-related clots — the left atrial appendage — made my decision easy. I needed to get on with my life.

On September 13, 2005, I had minimally-invasive (mini-maze) surgery. Though it was surgery, with risks and anesthesia, and was in an area that is very delicate for women, I have no regrets. I had been grounded from flying for two years, and was now able to fly again and travel by myself. You can't put a price on getting back your life and your freedom.

I have now been afib-free for three years, and am thankful every day to have my life back. But like most patients who have had a procedure to cure atrial fibrillation, I keep looking over my shoulder in hopes of forever keeping that afib beast at bay.

## StopAfib.org and the Atrial Fibrillation Blog

Once I was afib-free, I couldn't just stand on the sidelines and watch others suffer with this terrifying and debilitating condition. I set out to create <http://StopAfib.org>, a non-profit Web site for patients by patients, to improve their quality of life, support the doctor-patient relationship by helping them better partner with their healthcare providers, and decrease afib-related strokes. Our goal is to be among the most trusted of communities for atrial fibrillation patients.

Between <http://StopAfib.org> and our new Atrial Fibrillation Blog (<http://AtrialFibrillationBlog.com>), we offer information and resources about atrial fibrillation, newsletters, the latest atrial fibrillation news, audios, and videos, and opinions and tools to stimulate discussions. We also offer an Afib Services Locator to help afib patients find help.

StopAfib.org is now the #1 Arrhythmia site on the Internet and in the Top 20 Heart Disease sites and has received HON (Health on the Net Foundation) Certification as a trustworthy health Web site.

We welcome you to join us in this mission to support atrial fibrillation patients by:

1. Linking from your Web site to StopAfib.org to provide your patients with credible atrial fibrillation news, information, and resources.
2. Adding your *free listing* (for hospitals, arrhythmia and atrial fibrillation centers, EPs, cardiologists, and surgeons) to our Afib Services Locator — just click on "List your Afib services" on the U.S. map on our home page — or request a featured listing to help patients learn about you and your services and to help us provide more resources and tools for patients.

We're here to help you and your patients work together to save their lives!

The screenshot shows the StopAfib.org website interface. At the top, there are navigation links: "About Us | Sponsor Us | Contact Us". Below this is a banner with the text: "Never miss a heart beat. Restore your life and freedom. Stop Afib." accompanied by a photo of a smiling couple. To the right of the banner is a red sidebar with a list of links: "What is Afib?", "Why is Afib a Problem?", "Can Afib Be Managed?", "Can Afib Be Cured?", "Patient Stories", "Afib News & Events", "Patient & Caregiver Resources", and "Find Afib Services". Below the banner is a section titled "Atrial Fibrillation: Patient to Patient" with a sub-header "Patient Stories" and a photo of a woman. To the right of this section is a "Sign up for our Newsletter" form with fields for "Name" and "Email". Below the form is a "Locate Help" map of the United States. At the bottom, there is a "News from StopAfib.org" section with several news items, including "September is Atrial Fibrillation Month Focusing on Life-Threatening Irregular Heartbeat — 8/18/2008" and "MSNBC.com Story Shares our Stressful Disaster — 8/14/2008".

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

For more information, please visit:

<http://mellaniehill.com/heart.htm>

<http://StopAfib.org>

<http://AtrialFibrillationBlog.com>

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>.