The Inside Scoop

Four WomenHeart Champions provide the practical wisdom they wish they had in their journeys with atrial fibrillation (Afib).

Many women with Afib say they can feel their heart racing. Some notice a wave of fatigue and shortness of breath – having to stop to catch their breath mid-way up one flight of stairs. Still others don’t feel much, but know in their hearts that something is wrong.

Living with Afib can be scary. But with the right information, treatment and support, you can live a full and active life.

**Trusting your intuition**

Kathy, 60, of Kansas City remembers having a nagging feeling her heart was out of sync. Born with a congenital heart condition, she developed Afib in 1999.

“I knew something was wrong, but I didn’t know what it was,” she said. “I felt so very tired and I could feel my heart flip-flopping in my chest.”

For Shannon, 41, of Poulsbo, WA, the story was quite different. She was busy making sandwiches for her two little girls in 2006 when she suddenly suffered a “mini” stroke. Her doctors said it was likely brought on by Afib.

“They did an EKG and it showed my heart was way out of whack,” she said.

**Adjusting your expectations**

Low energy levels are fairly common among women with Afib. The key, according to those who have it, is to slow down.

“My friends like to think of me as the Energizer Bunny, but when I’m in Afib I can’t go at that pace,” Kathy explains. “There is so much to do in life, but with Afib you have to learn that you don’t need to get everything done all of the time.”

Part of pacing yourself is listening to your body and knowing when to make changes.

“My Afib is almost non-existent some days, unless I get really stressed or I’m really tired,” said Pamela, 42 of Atlanta, GA, who works 60+ hours a week. “If I feel it coming on, I’ve learned to pull myself back.” (continued on page 3)
Dear Reader,

WomenHeart: The National Coalition for Women with Heart Disease is pleased to present this issue of Her Heart Matters: What Women Need to Know About Afib and Stroke – our magazine devoted to the topic of women, atrial fibrillation and stroke risk. Inside this issue you will find important information and tips to live well with this condition and help prevent complications. You’ll also hear from other women who have what is often called Afib for short.

The good news is there are many treatments for Afib. Treatment options are focused on helping to reset your heart’s rhythm and reduce the risk of stroke. It’s important to partner with your health care team so that treatment decisions align with your preferences and values – to be successful, your treatment plan must fit your life.

Learning about Afib will also help you feel more in control and better equipped to cope. Many of the women I see are understandably anxious about this condition. They tell me that they worry about passing out or knowing when they should go to the emergency room. As a clinician, my job is to help these women learn how to deal with episodes of Afib so they don't get overly anxious, which makes it worse. It's important for women to trust in their health care provider and openly share any concerns and fears.

We hope that you find this issue interesting, informative, and above all, that it empowers you to take charge of your heart health!

Annabelle Volgman MD
Medical Director, Rush Heart Center for Women
Professor of Medicine, Rush University
WomenHeart Scientific Advisory Committee

This magazine is not intended to be medical advice or in any way take the place of information provided by a woman’s health care provider. Women are encouraged to talk to their health care provider about atrial fibrillation if they suspect they are at risk or have this condition.

The content of this magazine has been reviewed and approved by a member of the WomenHeart Scientific Advisory Committee.
It’s not a one-time episode
Afi b is often an ongoing condition that needs to be managed. These women say having regular appointments with their cardiologists and taking medicines to steady their hearts is their new reality. It also gives them comfort.

“It’s really important to keep up with your medication and any other recommendations your doctor makes,” said Pamela. “I’m no longer afraid of how Afi b makes me feel because my heart has gotten so much stronger.”

She, like many others with the Afi b, has a history of heart problems. It’s also important to tell all of your providers about this health condition.

You may be in and out of the hospital
Kathy has had many treatments for her aﬁ b since 1999, but remains a full-time executive, wife, mother, and very active volunteer with WomenHeart.

Use it as a wake-up call to commit to a healthier life
Make time for you – even if it’s against your nature.

“You need to eat properly, exercise, pay attention to your body and take care of yourself first,” says Shirley. “Women are the primary caretakers, and we often don’t take care of ourselves as well we should.”

Taking steps to keep your heart healthy can give you more control over your health.

Stay positive
Shannon says coping with Afi b was hard in the beginning. While it is part of your life, she says it shouldn’t take over your life.

“I can stay upbeat and positive, which I think is important,” she said.

Seek support
These women also say their work as WomenHeart Champions has made all the difference.

“We all have different hearts, but we can help one another get through and keep a positive attitude,” said Shirley.

For more information and support, visit www.womenheart.org

“Afi b explained

“My doctor told me to think of having your car in neutral, but your foot down on the gas pedal. So your engine is working really hard, but your car isn’t going anywhere. That’s what happens with Afi b. Your heart is beating, but it’s beating very erratically, so it’s not efficient at all. That’s why when you go up a flight of stairs, you feel like you just ran a marathon because your heart is already beating harder than it needs to just to get upstairs, and then you’ve got the added exertion on top of that.”

Kathy, 60
Afib & Women: Research Highlights

Afib appears to cause more severe health problems in women than in men, and scientists are working hard to find out why. Several studies from the past year offer intriguing glimpses into the burden of Afib on women and what may contribute to it. This and other emerging research may help inform new approaches to prevent and treat Afib in women.

Women with Afib have higher risk of dying and suffering with cardiac events

Women with Afib are slightly more likely to die prematurely than those without the condition, according to a study of more than 34,000 middle-aged women. While this isn’t necessarily new news, these women also have a higher rate of nonfatal cardiac events, such as stroke, heart attack and congestive heart failure (a chronic condition in which the heart can no longer pump enough blood to the body). Experts say this could partly explain the higher death rate in this group.

“We know Afib increases mortality, but this study shows women also face a higher risk of living with a stroke or congestive heart failure,” said Annabelle S. Volgman, MD, FACC, professor of medicine and medical director of the Heart Center for Women at Rush University Medical Center in Chicago, who was not involved with the study. “It’s a huge burden for these women, and certainly reinforces the need for prevention efforts to help women avoid developing Afib and the increased risks associated with it.”

Women who developed Afib were also found to have more risk factors for heart and vascular disease including hypertension, diabetes and smoking. The research was published in the *Journal of the American Medical Association (JAMA)*.

Women with Afib more prone to stroke, even when taking blood thinning medication

A study of more than 80,000 hospital patients in Canada showed women with Afib have a higher risk of stroke than men with the condition. This remained the case whether or not they were taking warfarin, a blood thinning medication used to break up or prevent blood clots.

Although the women in the study were on average older than the men, the higher risk of stroke held true even after accounting for these age differences. Dr. Volgman said, “In both men and women, the older they are, the higher the risk of stroke. It’s just part of aging. But above and beyond being older, women with Afib are at higher risk for stroke—and that’s what we don’t understand.” (Continued on next page)
Researchers are unsure about what is contributing to the gender differences. They suggest future studies look into the roles of hormones, genetics, valvular heart disease that affects one of the heart's valves and other factors.

“There is an urgent need to better understand what’s going on in women’s bodies that puts them at higher risk of stroke,” added Dr. Volgman. “Every woman with Afib should know her risk of stroke.”

Other experts agree. In fact, a recent consensus report from the Afib Optimal Treatment Task Force of the Alliance for Aging Research calls on health care providers to routinely use scoring tools to assess patients’ individual risk of stroke.

Tracking the benefits of exercise
Physical activity is known to reduce the risk of heart disease. A study published in the journal Circulation found those who exercised more were less likely to develop Afib. However, it is unclear whether this risk reduction is due to higher physical activity, or to lower body mass index (a measure of body fat).

Depression not likely a trigger for Afib
A woman’s risk of getting Afib is not affected by depression, according to research published in the Journal of the American Heart Association.

“It’s not surprising that depression was not found to be associated with Afib,” commented Dr. Volgman. She explained anxiety, high stress and hyperarousal (a state associated with the “fight or flight” reaction) are more likely to trigger episodes of Afib in women who have it.

Future directions
Recent studies represent important steps forward in our understanding of how Afib affects women. But they also open new questions about how to best prevent and treat the condition. Researchers hope future studies will help illuminate the role of hormones and genetics in the development of Afib, or lead to new strategies for reducing stroke risk in women with the condition.

In addition, efforts to examine how medical care might contribute to outcomes are needed – for example, how doctors recognize and manage atrial fibrillation and related problems in men versus women.

Dr. Volgman noted, “In addition to improved stroke prevention and medications, we want to figure out the role of catheter ablation because women are often referred [for that treatment] much later and less often than men. We don’t want to put women at a disadvantage, or deprive women of valuable treatment.”

Because no two women are exactly the same, no two cases of Afib are either. In fact, even in the same person, Afib can feel very different from one episode to the next.

In general, symptoms of Afib include:
• Very rapid or irregular heartbeats – some women say they feel their heart flip-flopping in their chests, skipping a beat or fluttering
• Unexplained shortness of breath
• Chest pain
• Weakness or difficulty exercising
• Dizziness or feeling faint
• Fatigue

While many women have one or more of these symptoms, some don’t notice any. Others say they had a nagging feeling that something wasn’t quite right with their body. Tell your health care provider about all of your symptoms. Don’t wait to see if they go away on their own or try to diagnose yourself.

Afib can occur:
• Every once and a while (called paroxysmal Afib) for a few seconds or days, and tends to go away on its own
• On an ongoing basis (persistent), but medications or electrical shock (cardioversion) can help the heart return to its normal rhythm
• All the time (persistent), which often requires certain medical procedures
Managing Your Heart’s Beat — 
Things You Can Do to Stay in Tune with Your Heart

There are a number of things you can do to live well with Afib and help prevent problems. Here are some tips to get started.

1. **Pay attention to modifiable risk factors for Afib, heart disease and stroke.** Make sure your blood pressure and cholesterol levels are where they should be. If you smoke, talk with your health care provider about how to quit.

2. **Eat a healthy diet.** Fill your plate with fresh fruits and vegetables, lean meats and fish. Try to limit or avoid alcohol. Studies have shown that drinking more than two alcoholic beverages a day can increase the risk of Afib.

3. **Exercise and keep your weight down.** While extreme sports are certainly out, moderate exercise can be very good for you. Experts recommend exercising 30 to 60 minutes 5 or 6 times each week.

   If you find you are too busy to work out or even take a walk, invest in a pedometer or find an app on your smartphone to convert it into one. It can help you track how many steps you take each day. If you make it to 10,000, you’re probably getting enough physical activity. If not, it’s time to make a date with yourself to exercise, recharge and take care of your heart!

4. **Know what triggers an episode.** Doing so will help you prevent or better anticipate Afib. Some common triggers include alcohol, caffeine, extreme physical exertion, upper respiratory infections and stress.

5. **Learn how to pace yourself.** Most women living with Afib will tell you it is a livable condition — once it’s being treated. But you need to listen to your body and know when to pull back.

6. **Have a plan to stay calm.** When you start to feel symptoms of Afib coming on, you will worry, maybe even panic. But anxiety can make these episodes much worse. Work with your health care team and talk with other women with Afib to get advice and tools to help stay calm. Deep breathing exercises and meditation can also help.

7. **Stick with your treatment plan and take your medications as prescribed.** Tell your doctor about all of the medications and supplements you take in addition to your medications for Afib. Some medications can interact with other medications, foods and/or alcohol and may not work the way they should or cause severe reactions.

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**Women, Afib and Stroke**

If you have afib, one of the biggest dangers is stroke. In fact, people with Afib are five times more likely to have a stroke.

That’s because when the heart doesn’t beat in a normal rhythm, blood can pool in crevices in the heart. As it collects, this blood can clump together to form a clot. If the clot breaks away and travels to the brain, it causes a stroke.

“If these clots break away, 95 percent will go straight to the brain,” explained Dr. Volgman. “That’s why with atrial fibrillation, the stroke is devastating. It’s not just a small stroke; it’s often a debilitating one.”

Studies have shown that up to 20 percent of strokes — 1 in 5 — can be blamed on Afib. It’s also why leading medical societies and experts have made stroke prevention a key part of treating Afib.

Know your risk of stroke

The CHADS2 Score* is a simple tool to help women (and their health care providers) figure out their personal risk for stroke. If you answer ‘yes’ to any of the following conditions, write the number 1 in the column to the right (for stroke or transient ischemic attack, add 2). Add these numbers together (for maximum score of 6) to calculate your risk of stroke.

<table>
<thead>
<tr>
<th>CHADS2</th>
<th>Score</th>
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<tbody>
<tr>
<td>Congestive heart failure</td>
<td></td>
</tr>
<tr>
<td>Hypertension (high blood pressure)</td>
<td></td>
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<tr>
<td>Age ≥75</td>
<td></td>
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<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Stroke/mini stroke or transient ischemic attack/thromboembolism</td>
<td></td>
</tr>
</tbody>
</table>

0 points = low risk  
1 point = intermediate risk  
2 or more points = high risk

If you are at an intermediate or high risk of stroke, talk with your doctor. Since women have a higher risk of stroke, they may need blood thinners other than aspirin if they are in the intermediate risk category. Your doctor should determine your risk of stroke and bleeding and decide your best treatment. He/she may also use the CHADS-VASC or HASBLED scores.

*Note: this assessment tool is not applicable for people with valvular disease who have increased risk of strokes.
Getting the most from your health care visits

As women, we tend to put everyone else’s needs before our own. In fact, you’re probably so busy tending to other people and things that you barely have time to make an appointment with your doctor, let alone prepare for it. But as with anything in life, you will get out of it what you put in. So make time for your heart health. The more active you are in your health care, the better you will feel.

Preparing for medical visits – whether it’s with your cardiologist or general practitioner – can also help your health care provider better evaluate and manage your condition.

For example, you may want to:

- Identify and write down your top concerns, questions and symptoms before each appointment
- Keep track of when Afi b-related symptoms occur and what seems to make them better or worse
- Think about asking someone to accompany you to give you additional support, take notes or ask questions

Be prepared to talk about:

- Your symptoms – what they are and have they gotten better, stayed the same, gotten worse or changed in some way
- How Afi b is affecting your emotional wellbeing -- remember, life stressors and anxiety can make Afi b worse
- What you can or can’t do because of Afi b or other related problems
- Your medications – report any side effects or other concerns
- What risk factors you can better control through a healthy lifestyle

Is it a Stroke?
Know when to dial 9-1-1

Be prepared. Know the signs of stroke. It can save your life (or someone else’s) and help prevent permanent brain damage.

Call 9-1-1 right away if you have any sudden:

- Numbness or weakness in your face, arms or leg, especially on one side of the body
- Trouble walking or loss of balance or coordination
- Trouble seeing in one or both eyes
- Confusion, trouble speaking or understanding
- Severe headache

For more information about stroke, visit the National Stroke Association at www.stroke.org.

Must-Ask Questions for Your Health Care Provider

- How can I prevent episodes of atrial fibrillation?
- How serious is my Afi b?
- What are the main goals of my treatment?
- How long will I need treatment and how will we know it is working?
- What are my options to prevent stroke?
- At what point is surgery considered?
- I’ve heard I should stay active, but I’m scared to push myself too hard. What exercise program would you recommend?
- Are there other lifestyle changes that I should make?
Resetting your heart’s rhythm

There are a number of treatments for Afib. The exact course of treatment depends on a number of factors, including:

• How often you have symptoms and how bad they are;
• Whether you already have heart disease; and
• Your risk for stroke.

In addition to lifestyle changes, treatments may include one or a combination of the following:

• Blood-thinning medications to prevent clots
• Heart rate control medications that bring the heart rate to a normal level
• Heart rhythm control medications that restore or maintain normal heart rhythm
• Electrical cardioversion – this is usually done in the hospital where paddles are applied to the chest to shock the heart back into a normal rhythm
• Catheter ablation – wires are inserted into veins in the leg or arm and threaded to the heart to alter abnormal areas that may be causing the abnormal heart rhythm
• Surgical maze – small cuts are made in the heart, creating a “maze” that prevents the abnormal beats from controlling the heart. This is a very effective treatment but because this requires open heart surgery, it is often used when other options have failed or if patients request it.

Additional Resources

For more information about Afib and to find support, visit:

WomenHeart: The National Coalition for Women with Heart Disease
www.womenheart.org
WomenHeartTV on YouTube
Facebook
Phone: 202.728.7199

National Heart Blood and Lung Institute
www.nhlbi.nih.gov

StopAfib
www.StopAfib.org

TeamAfib
www.TeamAfib.com

National Stroke Association
www.stroke.org

WomenHeart: The National Coalition for Women with Heart Disease

WomenHeart: The National Coalition for Women with Heart Disease is the nation’s only patient-centered organization serving the 42 million American women living with or at risk for heart disease – the leading cause of death in women. WomenHeart is solely devoted to advancing women’s heart health through advocacy, community education, and the nation’s only patient support network for women living with heart disease. WomenHeart is both a coalition and a community of thousands of members nationwide, including women heart patients and their families, physicians, and health advocates, all committed to helping women live longer, healthier lives. To receive a free online heart health action kit or to donate, visit www.womenheart.org/kit.

To learn more about WomenHeart’s free support services for women living with heart disease, how to become a WomenHeart Champion patient advocate, or to donate, visit www.womenheart.org.

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