# **Patient Perspectives**

# A Matter of Trust: How to Build Adherence with Afib Patients

# Patient Perspectives from the Sixth Annual Western AF Symposium

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trial fibrillation can be a scary ailment. Out of nowhere, the heart can race, causing fatigue, dizziness, and a profound sense of loss of control. Afib patients don't feel in

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charge of their own bodies. Then, doctors give them instructions with little or no explanation, making their scary condition even worse. Unfortunately, there is a lot of conflicting information out there about afib.

As healthcare providers, non-adherence can be frustrating. You're trying to set your patients on a path to

success with their condition, yet they don't listen. As doctors who have one-on-one contact with patients, you have probably noticed how adherence initiatives focus on the symptoms, not the root cause. This means that too much time and effort is wasted on tools and techniques to help patients be adherent when it would, in so many cases, be better to focus on the root causes of non-adherence. That's what we'll explore here.

Fortunately, you can get your afib patients to listen and follow your recommendations by first understanding why they don't. There are some simple strategies that can promote better adherence, and the payoff may mean helping patients live afib free. As the founder of StopAfib.org, I've tapped into the website's extensive network of afib patients to share some ideas about engaging afib patients so they'll follow your recommendations to manage afib.



Figure 2: As an afib survivor, one of the reasons Mellanie True Hills founded StopAfib.org was to help healthcare providers and patients work together to find the best treatment options for each individual situation.

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Figure 1: As one of the primary destinations for afib patients, StopAfib.org is the No. 1 arrhythmia site and among the top five heart disease sites in the world. StopAfib.org is a trusted site for atrial fibrillation news, information, and research, holding the Health on the Net Foundation (HON code) seal, which is that red, white, and blue icon at the lower right side of the page.

## WHY PATIENTS DON'T FOLLOW RECOMMENDATIONS

First, let's look at some of the reasons why afib patients don't do what doctors want. Through forums and talking with thousands of afib patients, here is what afib patients indicated as seven main reasons they may be non-adherent with medications or treatments:

- 1. May not have accurately heard what you told them.
- 2. Didn't comprehend medical jargon.
- 3. Didn't understand the rationale behind the advice.
- 4. Their opinions or questions were dismissed, leading them to distrust any decisions.
- 5. Recommendations didn't consider lifestyle or other needs.
- 6. Preferred to be given other treatment options, such as trying a medical procedure instead of ongoing medication.
- 7. May have heard horror stories from other afib patients.

Some of these reasons for not listening to doctors may seem familiar to you. Perhaps others you may not have heard, but that doesn't mean your nonadherent patients aren't thinking these very thoughts. They are.

# FIVE WAYS TO CREATE TRUST AND IMPROVE ADHERENCE

Doctors are frustrated with afib patients, and afib patients are frustrated with doctors, but we can bridge this gap. Here are five ways to get afib patients to follow your recommendations:

#### #1: Respect Them.

This was the No. 1 thing patients said impacts their adherence. When afib patients feel like their condition is being addressed seriously and their concerns are taken to heart, healthcare providers go a long way to building mutual respect

and trust — as well as getting your recommendations followed. Here are some tips, based on actual patient experiences, for showing that you respect your afib patients:

- Look and listen. When you walk into the room, shake the patient's hand, look the patient in the eyes, and say hello. Don't barge in without introducing yourself. If you walk in looking at your notes, you're conveying that those pieces of paper are your priority, not the patient. Look at patients, not your computer or EHR, when you ask them questions.
- Don't be dismissive. Afib patients aren't stupid. Instead, think of afib patients as smart people who don't speak your language. Avoid treating afib as something patients can just ignore, and don't tell them to just get on with their lives because they can't afib has hijacked these patients' lives. Don't underestimate how much the condition has impacted their everyday lives. One afib patient summed it up nicely by saying, "When you dismiss my questions or concerns, I won't trust or listen to you, either."
- Respond promptly to inquiries. Try to have a policy of responding the same day, or at least the next day, to afib patient questions. Some afib patients have reported having to wait days, even weeks, for answers to questions and even prescription refills.

#### #2: Communicate Clearly.

Because afib is a condition that can be vague, overt, and scary, and because it is inherently different for everyone, clear communication specifically for each patient is essential. Here are some ways to achieve this:

- Speak with clear and simple language.
   Slow down, especially if you have an accent or if a patient is on beta blockers and may have brain fog. Avoid jargon, and even if a patient doesn't ask for a term to be explained, offer up your own definitions and clarifications.
- Answer questions effectively. Imagine this: One cardiologist yanked the list of questions from an afib patient's hand, went down the list of questions, saying "yes, no, yes, no" without explanations. If your answer is too brief, it's useless.
- Spend time. Two or three minutes can't help allay an afib patient's concerns and fears or explain the condition or treatment options. It's also not enough time to build the respect you need for patients to understand how

- and why to adhere to your recommended treatment.
- Don't say "afib won't kill you." I admit, this one particularly annoys me. But once patients hear the word "kill," they'll zone out and miss whatever else you say. Even if you mention the stroke risk related to afib, they may not hear you. What's more, overall it's simply not true.

#### #3: Educate and Provide Support.

Research, information, and treatments related to afib are continually evolving. Embrace your afib patients as partners in their care by encouraging them to find out more about the condition. Also, by providing a place for these patients to find others, they can find support that is critical for battling afib. Here are a few things you can do to educate and support your afib patients:

- Don't dissuade individual research. Some doctors actually tell afib patients to "stay off the Internet and only listen to me." Engaging patients in seeking out information about the condition and treatments encourages them to manage their condition and creates an atmosphere of trust. Thus, your recommendations will carry more weight, despite the Internet. Encourage patients to look for the HON code seal (from the Health on the Net Foundation) on websites as a sign of a trustworthy and credible website. Also, be open to what they find on such quality sites.
- Recognize the emotional needs. Patients
  find comfort and support from conferring with patients who have the
  same condition. When patients don't
  feel alone and have support even from
  places such as online forums, they're
  more apt to not be as anxious and to
  more effectively collaborate with you.
  - Suggest StopAfib.org. As the No. 1 arrhythmia site in the world and among the top five heart disease sites (along with the American Heart Association, British Heart Foundation, National Heart Foundation of Australia, and CardioSource), StopAfib.org is a HON code certified site that serves as a gathering place and support center for those who have afib. Last year, we had 700,000 visits and more than 1.7 million page views. These patients are out there and want to connect to and support each other.

#### #4: Personalize Care.

There is a very good reason to personalize care for afib patients: The condition can be different for every patient.



**Figure 3:** Through the StopAfib.org patient discussion forums, those suffering from afib can provide support and encouragement along with sharing information. Many of the suggestions for improving adherence in this article came from ideas expressed in StopAfib.org patient forums.



**Figure 4:** By handing out StopAfib.org patient cards, healthcare providers can connect patients to a wealth of information and sources of support. Contact us at http://www.stopafib.org/contact.cfm to receive some patient cards.

Symptoms may be different and, more importantly, successful treatment may also vary from patient to patient. In addition to being direct and honest, personalize care with these ideas:

Ask about experience with afib, lifestyle, and concerns. Lifestyle issues have a direct impact on treatment results. For example, a vegetarian afib patient was placed on warfarin, and with a diet high in vitamin K, her International Normalized Ratio was hard to manage, which put her at risk for stroke. If her doctor had asked, perhaps instead of warfarin, she could have received a new novel anticoagulant that is effective regardless of diet. In addition, if patients don't understand why they should be on anticoagulants, they may not take

them, and may not tell you.

- Recognize that women communicate differently from men. "Just the facts" may work well with male patients and some female patients, but some women communicate more with emotion. Healthcare providers may have to listen more closely to distill symptoms and side effects.
- Constantly seek patient input. The mantra of the ePatient movement is "Nothing about me without me." Don't make treatment decisions for patients; make them with patient input and involvement.

#### #5: Coordinate Care.

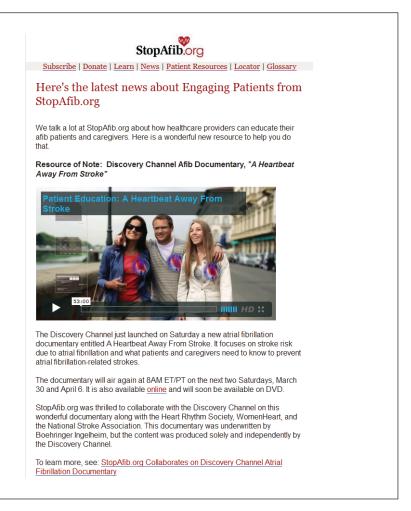
Teamwork pays off when you're trying

continued on page 52

### **Afib Patients**

Continued from page 51

to get an afib patient to be adherent with a care plan. Don't put the patient in the middle between other doctors and you.



**Figure 5:** Healthcare providers can subscribe to the StopAfib.org Engaging Patients ezine. The electronic newsletter is an invaluable resource to help you engage and improve communication with afib patients.

If possible, cooperate with other doctors to develop the best treatment for your afib patients. Here's how, based on patient experiences:

- Don't put patients in the middle. If there
  is a problem between you and another doctor, don't take it out on the patient. Take the initiative and open a
  line of communication with the other healthcare provider.
- Don't force patients to choose between you and other doctors. The team approach will likely make a patient feel more comfortable. Also, if you force it, you may end up on the wrong side of the choice and lose the patient.
- When in doubt, refer. If treating afib isn't a regular part of your practice, or if a patient is asking about treatment options you may be unfamiliar with, provide a referral. Please don't leave the patient trapped in afib. Also, don't make their decision for them by choosing not to provide a referral.

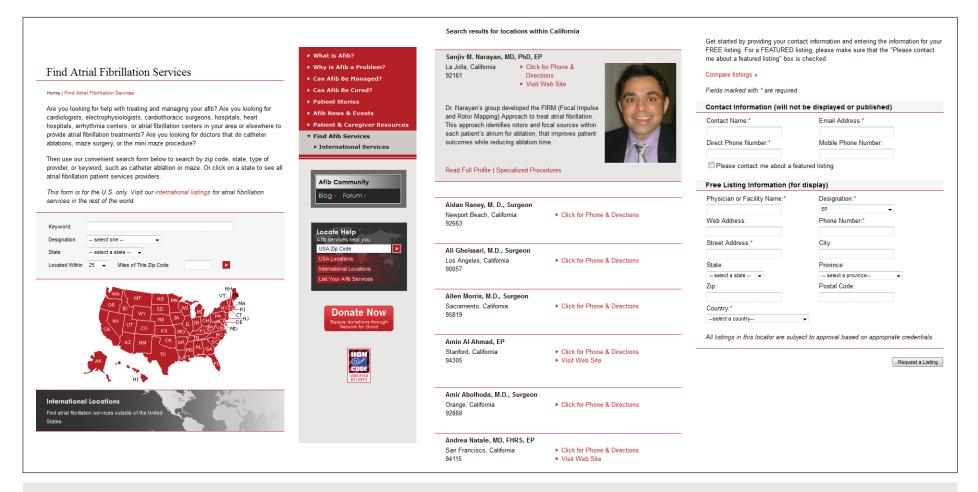
## HEALTHCARE PROVIDERS' AFIB RESOURCES

Would you like some ideas for engaging your patients? My mission is three-fold: To help you and your afib patients work together to find treatment solutions and avoid strokes, to help healthcare providers actually enjoy connecting with your afib patients, and to make your jobs less time consuming so you

can even have more time for your family.

To accomplish those goals, healthcare providers can have a wealth of free resources from StopAfib.org. Here are a few that benefit you and your patients:

- Patient cards Provide your patients with information about the condition and where to find support by providing them with the patient cards in Figure 4. Use this link to request patient cards, telling us how many and where to send them: http://www.stopafib.org/contact.cfm
- Engaging Patients newsletter This free emailed newsletter (Figure 5) provides tips for healthcare providers for connecting with your afib patients. Sign up here: http://bit.ly/ engagepatients
- Listing on the Afib Services Locator Patients can easily find you with this afib services locator (Figure 6) that helps patients find electrophysiologists, cardiologists, surgeons, and hospitals or afib centers that treat afib. Learn about the service and enter your free listing at http://www.stopafib.org/sponsor.cfm. It only takes a minute or two.
- Free Breakthrough Strategy Session for doctors To schedule a call where I can personally help you uncover your pain points in dealing with afib patients and suggest some ideas for dealing with them, follow this link: http://bit.ly/BSSApp



**Figure 6:** Through the Afib Services Locator, patients can search through more than 450 afib specialists worldwide. Patients can search by name, location, specialty, or other keywords, such as type of procedure. The graphic interface also allows searches by clicking on states or countries for extensive listings.