

# New, personalized online community helps patients live with dangerous heart rhythm

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Many people experience a slight quivering or racing heart at some point and usually give it little notice. But for those diagnosed with atrial fibrillation (AFib), that irregular heartbeat can be a serious condition that can increase the risk of stroke and needs medical attention.

[My AFib Experience](#) is an innovative and unique online community that can help people understand the condition, learn how to better manage it and connect with others who also experience it. A collaboration of the American Heart Association/American Stroke Association and StopAfib.org, with support from Janssen Pharmaceuticals, Inc., My AFib Experience is designed to help people through all stages of the condition, from newly diagnosed through various treatments and risk-reducing options with medications or procedures. Most importantly, it raises awareness about the seriousness of this condition.

"AFib is associated with an increased risk of heart-related death and a five times greater risk of stroke, but many people don't fully recognize how serious and debilitating this condition can be," said Patrick Ellinor, M.D., Ph.D., a member of the My AFib Experience advisory committee and a cardiologist at Massachusetts General Hospital and Harvard Medical School in Boston. "Many people live with AFib and don't feel the symptoms, but the risks are still present and it's important to know how to manage those."

More than 2.7 million people are living with AFib. Although the [irregular heartbeat](#) can feel debilitating and frightening, an "attack of

AFib" usually doesn't have harmful consequences by itself. But knowing the risks and how to lower them can help people with the condition live long, healthy lives.

My AFib Experience is laid out in a way to help people manage the condition as they navigate through all phases of their daily life. There are special sections with information on:

- Healthy eating and dining out
- Taking part in regular exercise
- Tips for traveling
- Explanations about blood work and other medical tests
- Questions to ask the doctor

The experience is tailored to the individual need. Users develop profiles based on their age, physical activity level and specific health conditions that help personalize the information they receive during their online visits.

Resources and information included in the latest treatment guidelines can help patients be more engaged with their provider in making treatment decisions.

"My AFib Experience bridges the information gap for patients with atrial fibrillation and their healthcare providers with clear, understandable and useable information," said Debbe McCall, who was diagnosed with AFib five years ago and is a member of the My AFib Experience patient advisory committee from Murrieta, California. "It provides patient, caregiver and family support through member forums and downloadable guides and trackers. For healthcare professionals, there are the current AFib [treatment guidelines](#), updated clinical research links and patient information."

McCall knows the importance of having correct information and strong support. After decades of being the family caregiver and working in healthcare, the tables were turned on her in March 2009 when she had her first episode of atrial fibrillation. It was more than a year before she was correctly diagnosed, but now after finding the right treatment for her, she's AFib free and helps in offering support for others dealing with the condition.

"Early in the diagnosis process, I joined multiple online support groups looking for information and help and they became an online 'home'," McCall said. "I know the importance of having something like that and My AFib Experience is a terrific new resource that gives all of us in the world of [atrial fibrillation](#) a place to learn, to share and to be supported."

Along with extensive and personalized information on AFib, users can connect with others going through similar journeys through the online forum. They can share stories, [experiences](#) and tips, as well as offer emotional support.

Provided by American Heart Association

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