

A CAREGIVER'S GUIDE TO

Complicated Atrial Fibrillation



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Introduction

Atrial fibrillation (also known as AFib or AF) is a common heart condition, particularly among older people. It's estimated that AF affects 2.7 million Americans. About 11 percent of people over the age of 80 have it. Often, AF is accompanied by other conditions, such as stroke or heart failure, making the management of AF more complicated. When AF is accompanied by another condition that affects AF, it is called complicated AF. Complicated AF is very common and more difficult to treat.

Because it is so important that people with AF follow their doctor's instructions and live a healthy lifestyle, the caregiving role is very important. As caregiver to a loved one with AF, you play a critical part in your loved one's life. In this guide, you will learn about AF and its symptoms and complications, how AF is treated and managed, and how you can help your loved one stay on the road to health while living with AF.



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Guiding Your Way

Throughout this guide, use these interactive features to enhance your learning experience:



Print. Print out materials that can help you manage your loved one's condition. To use this feature, install the free Adobe Acrobat Reader (<http://get.adobe.com/reader/>).



Audio. Listen to the audio version of the information on the pages you are viewing. To use this feature, make sure you have the most recent free copy of Adobe Flash Player (<http://get.adobe.com/flashplayer/>).



Play. Play videos and animations by pressing the play button that sits on or near the images.



Highlighted Text. Click on any highlighted text (in red) and you will see a more detailed definition of that word.



Quizzes. Take the quiz at the end of each chapter to test your knowledge.

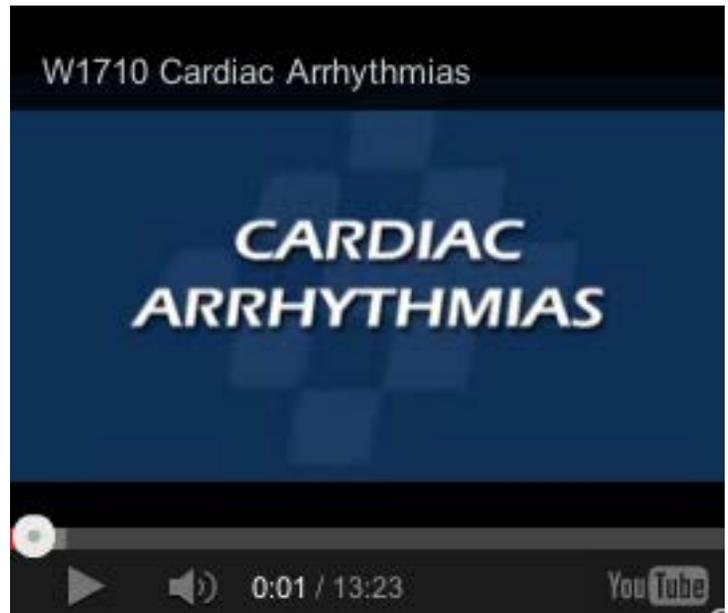


Help. Click the help button located on the Menu Bar to learn more about using this program.

What is Atrial Fibrillation?

AF is a type of cardiac **arrhythmia**, a condition in which the heart doesn't beat the way it should. In AF, the heart's upper chambers, called the **atria**, beat chaotically and out of sync with the heart's lower chambers, the **ventricles**. The result is usually a rapid heartbeat that affects how blood flows through the body.

AF is the most common type of arrhythmia in the United States, but it is not a life-threatening condition. However, AF increases the risk of **stroke** or **heart failure** in some patients. For this reason, AF should be treated. Fortunately, there are several effective treatments for AF that help reduce the risk of stroke, heart failure, and other complications.



Causes of AF

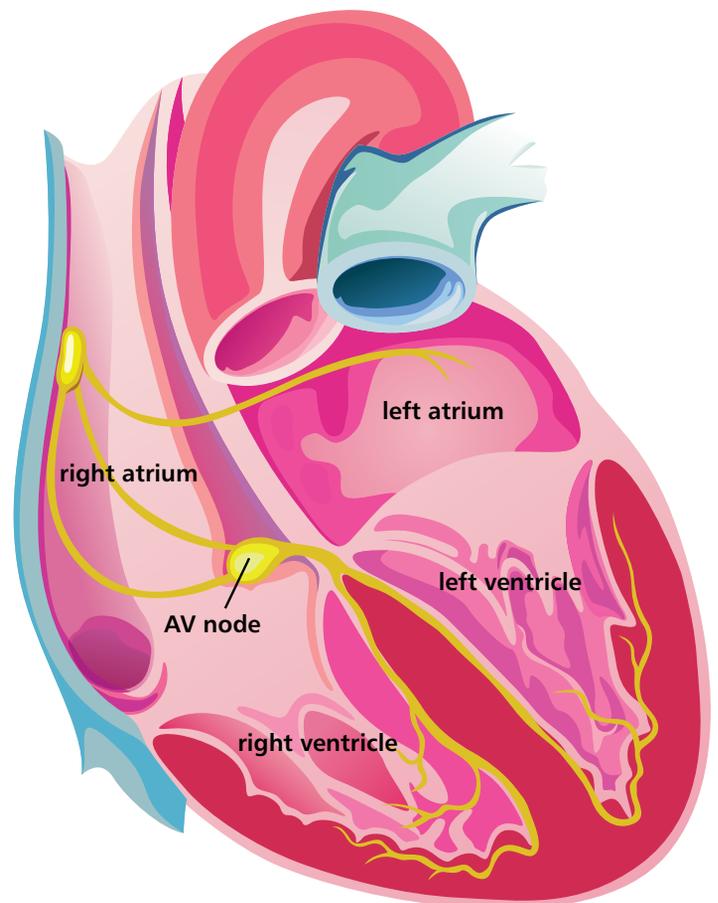
In the typical heart, there are electrical signals sent in an organized way from the atria to the ventricle by crossing a connection called the atrioventricular or **AV node**. AF is caused by tiny electrical signals in the atria beating irregularly or chaotically. The AV node gets overloaded with all these electrical signals, which cause irregular beats in the ventricles as well, but not as rapidly as in the atria. As a result, a heart with AF will typically beat anywhere from 100 to 175 beats per minute, whereas a healthy heart will beat 60 to 100 times per minute.

Many factors can cause the signals to go haywire. These range from **congenital** (i.e., at birth) heart defects to previous heart conditions, from **sleep apnea** to exposure to stimulants (whether medications, caffeine, tobacco or alcohol). They can also include:

- High blood pressure
- Valvular heart disease
- Overactive thyroid gland
- Acute or chronic lung disease
- Recent heart surgery
- Inflammation of the heart muscle (myocarditis) or the lining of the heart (pericarditis)

For some people, AF has no clear cause.

AF is considered **complicated** when a person has AF and a complicating medical factor, such as cardiovascular disease. This means that AF is itself a risk factor for a more serious condition, such as heart failure or stroke.



Symptoms

For some people, AF has no symptoms at all. Others have symptoms. As a caregiver, you should be aware of the following:

- Mild fatigue or weakness
- Difficulty breathing or shortness of breath
- Palpitations (a sense of racing or uncomfortable “flopping” of the heart)
- Lower blood pressure
- Lightheadedness
- Confusion
- Chest pain

AF comes and goes for some people, seeming to stop on its own. For others, AF is a chronic condition in which the heart rhythm is always abnormal.

Risk Factors

A number of conditions increase the risk for AF. These include:

- **Age:** The older you get, the greater your risk of getting AF. About 11 percent of people over the age of 80 have it.
- **Heart disease:** Any type of heart disease, including valve conditions and previous heart attacks or heart surgery, raises your risk for AF.
- **High blood pressure:** Uncontrolled **hypertension** (high blood pressure) increases the risk for AF, too. That’s one more reason for you and your loved one to keep your blood pressure in a healthy range.
- **Other chronic conditions:** Thyroid problems, sleep apnea and other medical problems can increase the risk for AF.
- **Alcohol:** Drinking alcohol can trigger an episode of AF in some people, and binge drinkers (i.e., five drinks in two hours for men, four in two hours for women) may be at higher risk.
- **Family history:** If the person you are caring for has a family member with AF, he or she will be at increased risk for this condition as well.



Take a short quiz on what you've learned so far.
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Preventing Blood Clots

Due to the chaotic electrical signals in the heart's upper chambers, the atria, blood does not move through as well, and stagnates in the "corners." Stagnant blood is prone to form small clots. Blood clots are dangerous because they can lead to more serious conditions, such as stroke. The blood clots escape the atria and move into the pumping chamber of the heart, where they might be pumped out into the rest of the body and become lodged in an artery of the brain, or elsewhere. Because the risk for blood clots is so high in people with AF or who are undergoing procedures to treat AF, doctors often prescribe **anticoagulant** (blood-thinning) medications.

Anticoagulants

Blood thinners work on chemical reactions in the body to slow the time it takes to form blood clots. They do not break up blood clots that are already formed, however. The best known of the anticoagulants are heparin and warfarin, both of which have long been in use. Heparin must be given intravenously and is administered in a hospital setting for several days. It requires frequent blood tests to make sure it is working properly. Before heparin therapy concludes, warfarin is usually introduced and given orally. Warfarin therapy also requires regular blood tests to see how the blood is clotting. If warfarin causes the blood to thin too much, or it is causing bleeding, your loved one's doctor may need to reverse it. Warfarin also requires a special diet. If your loved one is prescribed warfarin, it's wise to accompany him or her on all blood testing appointments.

A newer generation of medications, such as dabigatran, apixaban and rivaroxaban, also works to slow the blood's clotting action. Dabigatran, apixaban and rivaroxaban are prescribed primarily for people who have AF without heart valve disease. Unlike warfarin, dabigatran, apixaban and rivaroxaban do not require regular blood testing, and early research indicates there may be a lower risk of bleeding and stroke.

Unlike warfarin, dabigatran, apixaban and rivaroxaban cannot be reversed. But in initial studies, dabigatran, apixaban and rivaroxaban have been shown to be very effective, or more effective in preventing strokes. These drugs have also been shown to have similar or lower rates of bleeding than warfarin in real world studies. People with kidney disease or an elevated risk of internal bleeding should not take these newer medications or warfarin, however. If your loved one's doctor thinks an anticoagulant medication is right for him or her, talk with the doctor about all the available options.

Everyone taking anticoagulant medications should be mindful of the risks associated with them. Because they slow the ability for the blood to clot, they can cause severe bleeding in case of injury or during surgery or pregnancy. However, in some cases the benefits of taking anticoagulants outweigh the risks involved for many patients.

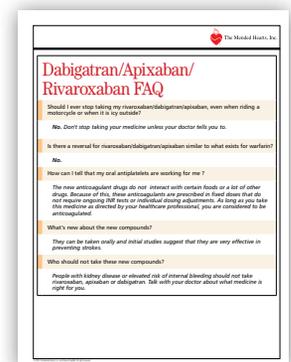
Benefits of Anticoagulants

Blood thinners are very effective drugs. They can:

- Stop clots from getting bigger
- Stop clots (or pieces of clots) from travelling to your brain
- Stop other clots from forming
- Limit your risk of complications from blood clots, such as stroke

Talk with your loved one's doctor about all the medications he or she takes, including over-the-counter (OTC) medicines, vitamins and herbal supplements, because some of these can cause interactions with anticoagulants. And be sure to tell the doctor about any side effects your loved one may have from the anticoagulants.

Keep in mind that there is a risk of bleeding with this type of medication, so if your loved one is prescribed an anticoagulant, help him or her take care to avoid injury, and go to the emergency room immediately if he or she is seriously injured. Call your loved one's doctor if you notice any bleeding or bruising. But remind your loved one not to stop taking his or her medicine unless the doctor tells him or her to, even if he or she is taking part in potentially risky behavior, such as riding a motorcycle or going out in icy conditions.



**Dabigatran/Apixaban/
Rivaroxaban FAQ**
**Click here to download
and print.**



Antiplatelet Medicines

Another type of antithrombotic therapy is **antiplatelet** medications, which include aspirin, other non-steroidal drugs (such as ibuprofen and naproxen sodium), and clopidogrel, among others. Antiplatelet medications work by preventing a type of blood cell called a platelet from sticking to each other at the site of a potential blood clot. This stops the clot from forming and helps lower the risk of heart attack or stroke, particularly in patients who have already had one or the other, and in those who have certain cardiovascular conditions.

Antiplatelets also carry the risk of excessive bleeding and have side effects, much like anticoagulants. Talk with your loved one's doctor to weigh the risks and benefits of taking an antiplatelet medication.

Diet and Exercise

It's really important that patients with AF take care of their hearts. Your loved one's doctor may prescribe a heart-healthy diet, especially one that is low in sodium intake. A typical heart-healthy diet may include:

- **Eating more fruits and vegetables:** You both should try to eat four to five servings of fruits and vegetables each day, unless you are prescribed warfarin therapy. Talk with your doctor about what your loved one can eat, if this is the case.
- **Eating more whole-grain foods:** These are rich in fiber and low in saturated fat and cholesterol. Whole-grain foods include whole-wheat bread, rye bread, brown rice and whole-grain cereal.
- **Using more olive, canola or safflower oil as your main kitchen fat:** Try to use fat sparingly in cooking, and when you do, reach for these oils.
- **Choosing chicken, fish and beans:** Skinless poultry, fish and vegetable protein are typically lower in saturated fat than beef, lamb and pork.
- **Limiting sodium:** Eat less than 1,500 mg per day.
- **Reading food labels carefully:** Keep an eye on the serving size.



Physical activity, including exercise, should be part of your loved one's routine, as well. The doctor or nurse will guide your loved one on the frequency and type of exercise he or she should be doing. In general, your loved one will want to aim for at least 30 minutes of exercise most days of the week. Exercising together can be a great way to motivate and support each other. You may want to consider joining your loved one on a walk, bike ride, or other form of physical activity.

Alcohol and Caffeine

Alcohol and caffeine can trigger AF episodes, so people with AF may need to eliminate alcohol and caffeine from their diet. Talk with your loved one's doctor about this. Also, be aware of the potential stimulant content in over-the-counter (OTC) medications and nutritional supplements, as these can also trigger AF episodes or interact with anti-arrhythmic medications.

Smoking

Smoking is terrible for your health in general. But for people with AF, it's even worse. Nicotine is a known cardiac stimulant that can make AF worse, and smoking is a known risk factor for cardiovascular disease. If you or your loved one smoke, make plans to quit now. Talk with your loved one's doctor about medications and other techniques that can help your loved one quit.



Complications: Stroke, Heart Failure and AF

Left untreated, AF increases the risk for stroke and heart failure, among other **cardiovascular** conditions. In fact, people with AF are 5 to 7 times more likely to have a stroke than are those who don't have AF.

In the heart, AF may cause some blood to pool in the atria, where it can form clots. If a blood clot leaves the heart and enters the blood stream, it can move to the brain, where it can block an artery and cause a stroke. People who have already had a stroke are at even greater risk for another one if they have AF.

The Warning Signs of Stroke

It's vitally important to be aware of stroke's warning signs if your loved one has AF. These are:

- **Sudden numbness or weakness of the face, arm or leg, especially on one side of the body**
- **Sudden confusion, or trouble speaking or understanding**
- **Sudden trouble seeing in one or both eyes**
- **Sudden trouble walking, dizziness or loss of balance or coordination**
- **Sudden, severe headaches with no known cause**



If your loved one has one or more of these warning signs, call 9-1-1 immediately so an ambulance can be sent. With stroke, time is of the essence. Take note of the time when symptoms first appeared, and tell the doctor. A clot-busting drug can be given to reduce long-term disability for the most common type of stroke, but only if it's given within three hours of the start of symptoms.

Your loved one's risk of stroke depends on several factors, including age, the presence of complications (such as high blood pressure or diabetes) and a history of heart failure or previous stroke. Keep in mind that the medications your doctor prescribes for your loved one, such as anticoagulants and antiplatelets, can greatly reduce the risk of stroke.

Another problem with untreated AF is that it can lead to heart failure, a condition in which the heart can't pump enough blood for the body's needs.

AF: Complicating Factors

In addition to the complications that AF can cause, there are conditions that can make AF more of a challenge to treat. These can include:

- **AF and uncontrolled hypertension:** Hypertension (high blood pressure) is a major risk factor for AF. If it isn't controlled, hypertension can cause changes to the heart that can trigger AF. This is why controlling hypertension (through a healthy diet, exercise, and medication if your doctor prescribes it) is so important, both to those at risk for AF and to those who already have it.
- **AF and diabetes:** Diabetes can raise the risk of getting AF by as much as 40 percent, according to one study. Although scientists aren't sure why this is, one possible reason is the inflammation related to diabetes may in turn trigger AF. Other research has demonstrated that when AF and diabetes occur together, the risk of death can increase by as much as 61 percent.
- **AF and obesity:** Over time, obesity adds to the strain placed on the heart, which can in turn lead to a weakened heart condition. One study showed a 50 percent increase in the risk of getting AF among those who are obese. Losing weight reduces the risk of getting AF and potential complications.
- **AF and stress:** Left uncontrolled, stress increases the risk of getting AF. When stress and AF occur together, the combination can make AF worse.

■ **AF and sleep apnea:** Obstructive sleep apnea is a condition in which air flow pauses or decreases while the patient breathes during sleep, because the airway has become narrowed, blocked, or floppy. At least one in 15 American adults has OSA, and people with AF are more likely to have OSA than those who don't have AF. OSA can make AF worse in patients who have both. Scientists aren't sure exactly how the two conditions affect each other, but there is strong evidence that OSA and AF are interconnected.

■ **Medication contraindications:** The medications often used to treat AF and other common chronic conditions can sometimes affect each other, both in how effective each one is and in the possible side effects each one can cause. For example, some beta blockers and calcium channel blockers used to treat AF can make heart failure worse, and several types of medicine can interfere with warfarin. Work closely with your loved one's doctor to manage your loved one's medications so that they are most effective for your loved one.

Helping a Loved One Manage AF

Managing AF effectively is a matter of leading a healthy lifestyle and following doctor's orders. You can help your loved one by encouraging him or her to eat healthy meals and exercise as often as he or she has been advised to by their doctor.

If your loved one is taking an anticoagulant medication, keep in mind that certain foods can interfere with the medication. These include spinach, lettuce, broccoli and liver, and some fruits, including cranberries, oranges and grapefruits. Talk with your loved one's doctor about how much of these foods can be safely eaten. Also, if your loved one is going to have surgery or dental work, be sure to let the relevant health care providers know that your loved one is taking anticoagulant medications.

It may help you both for you to exercise with your loved one. Don't begin exercising without speaking to your loved one's doctor first about what is appropriate exercise for your loved one. And keep an eye on possible symptoms of AF while your loved one exercises. It's sometimes easier for a caregiver to spot symptoms than it is for the patient.



Medication Adherence

It's vital that your loved one take the medications your doctor prescribes exactly as directed. Only then can you both be assured that the medications will work properly.

Using a pillbox to organize medications is one way to keep track of them. A medication log is another good way to make sure your loved one is taking medications as directed. Be sure to include any OTC medications and dietary or herbal supplements your loved one takes. Work closely with your loved one's doctor to manage your loved one's medications so that they are most effective for your loved one.

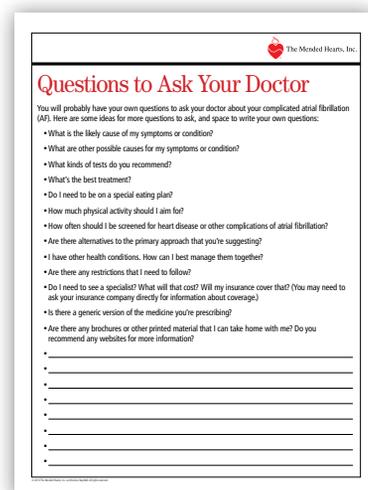
Doctor's Visits

It's a good idea to accompany your loved one on doctor's visits. This can help you both remember what the doctor says. Be sure to take notes, if that helps you remember.

Another way to help your loved one prepare is to help keep up with what is expected before any doctor's office visit. For example, some tests require dietary restrictions, such as fasting in advance of the test. You can help your loved one remember what is off-limits in terms of food or drink before the office visit.

Take a list of questions to ask the doctor along with you on every visit. It's also wise to keep a family medical history and take this along, as well. Another good document to keep up-to-date is a list of any symptoms your loved one is experiencing.

Questions to Ask Your Loved One's Doctor
 Click here to download and print questions you may have for your loved one's doctor.



Summary

Being a caregiver is one of the most important roles anyone can take on. For someone with AF, it can be a critical role in preventing stroke or heart failure. That's the main goal of treating and managing AF: to cultivate a healthy life free of serious cardiovascular events.

Being a caregiver can be a demanding job, too. That's why it's important to take care of yourself as much as you can. That means eating healthy and exercising with your loved one, of course, but it also means taking time for yourself to relax and enjoy the things that make your life good, such as hobbies and social engagements.

Here are some resources that can help you as a caregiver:

- [Caregiver.com](#)
- [National Alliance for Caregiving](#)
- [Leeza's Place](#)
- [Caregiver Action Network](#)

Glossary

Anticoagulants: Medicines that slow the formation of blood clots in the body.

Antiplatelets: Medicines that keep blood cells called platelets from sticking together.

Arrhythmia: A condition in which the heart doesn't beat the way it should.

Atria: The heart's upper chambers.

Atrial Fibrillation: A type of cardiac arrhythmia in which the heart's upper chambers beat chaotically and out of rhythm with the heart's lower chambers.

AV node: The tissue connecting the atria to the ventricles.

Atrioventricular (AV) node ablation: A procedure in which radiofrequency energy is applied to the AV node in order to destroy it. A pacemaker is implanted to take its place.

Cardiovascular: Affecting the heart and blood vessels.

Cardioversion: A procedure using medication or electrical shock to restore the heart's rate and rhythm.

Congenital: Present at birth.

Heart failure: A condition in which the heart isn't able to pump all the blood the body needs.

Hypertension: High blood pressure.

Sleep apnea: A condition in which the breathing is interrupted during sleep, often repeatedly.

Stroke: A "brain attack," which occurs when blood flow to the brain becomes blocked.

Ventricles: The heart's lower chambers.

Take a short quiz on what you've learned. [Click here to begin...](#)

Your Comments and Suggestions are Needed!

Please tell us what you think about this workbook! We need your suggestions to make sure that this has everything you need to know about complicated AF. Go to our online survey www.surveymonkey.com/s/afib_caregiver and answer just a few questions. Thank you!

