Stroke FOUNDATION

Living with Atrial Fibrillation

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Introduction

This booklet is to help people with atrial fibrillation (AF) and their families understand the condition.

It explains:

- What AF is.
- How it can affect your life
- How you can live well with AF.

This 'Living with Atrial Fibrillation' booklet has also been developed to provide evidence-based information and increase awareness of AF and it's effects.

At the back of the booklet, there is a list of organisations you can contact to get help or find out more about AF.

The information in this booklet does not replace the advice of a doctor or other healthcare professional. For advice on any symptoms or conditions referred to in this booklet, please contact a healthcare professional.

For free advice call StrokeLine on 1800 787 653. Stroke is always a medical emergency, call triple zero (000) immediately if you suspect a stroke.

About AF

AF is a heart condition. When you have AF, your heart beats fast and out of rhythm.

AF affects more than 500,000 Australians.[1]

Rates of AF increase significantly with increasing age.[2]

If left untreated or poorly managed, AF can lead to serious health complications. These can include stroke and heart failure.

How AF affects your heart

Your heart has four chambers that work together to pump blood around your body, delivering oxygen and nutrients.

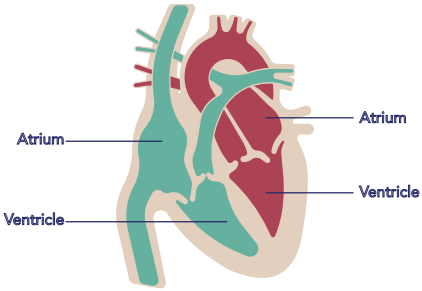
In a healthy heart, all four chambers beat in a synchronised rhythm. The upper chambers (the atria) squeeze blood into the lower chambers (the ventricles), which then pump blood to the lungs and body.

When you have AF, your heart beats with an irregular rhythm. The muscles of the atria ripple rather than pump together. In response, the ventricles beat rapidly and out of rhythm.

When you have this rapid and irregular heartbeat (called fibrillation), your heart does not pump blood as efficiently as it should.

Blood can stagnate in the atria and form a clot. The clot can break loose from your heart. It can then travel through your body and block an artery. If this blockage happens in your brain, it causes a stroke.

The structure of the heart



Who gets AF?

Anyone can get AF.

It occurs in men and women, and you can get it at any age – although it is more common as we age. The risk of developing AF doubles with each advancing decade of age and is more than 20 percent by age 80 years.[3]

AF can run in the family for some people.

Illnesses and diseases can make you more susceptible to AF, but it can also occur without warning.

Michael's Story

Michael Shaw, 65, discovered he had AF after he suffered a mild heart attack in 2014. A suite of tests revealed the condition. There was no damage to the heart muscle following the heart attack, but Michael did have to prepare for a new chapter of life: living with AF.

"I did have high blood pressure at the time of the heart attack. But I also exercised regularly and was very active, which I think was a factor in my good recovery. I was put on medication to control the AF, and that worked well for a time – I wasn't experiencing many symptoms."

Unfortunately, in 2015 Michael's AF symptoms worsened. He recalled feeling lightheaded more often, experienced

> *"It was terrifying for my wife. I had collapsed at the wheel. Christina managed to get her foot on the brake, then applied the handbrake. It was just luck we were arriving at my estate and the car was not travelling too fast. Just minutes before we were travelling on a main freeway. It could have been catastrophic."*

chest pain, palpitations and felt fatigued, especially when exercising.

In July 2015, Michael's life changed forever when he suffered a stroke while behind the wheel of his car. His wife, Christina, was sitting in the passenger seat.

Michael was rushed to hospital in Nambour, Queensland, where he received the clot-dissolving therapy, thrombolysis. Doctors were concerned the drug hadn't worked, so Michael was airlifted to Brisbane by helicopter, where it was planned he would undergo clot retrieval surgery. But upon arrival, tests revealed the thrombolysis drug had broken down Michael's blood clot during transit. It had worked.

"Higher stroke risk is a reality of living with AF – I can't stress enough the importance of being aware of this. AF can be dangerous. It's not pleasant to live with knowing it might result in stroke."

Michael's stroke impacted the left side of his body. He now has a clawed foot and limited used of his hand, which has impacted his ability to carry out daily tasks such as writing and exercising. He also experiences fatigue and finds it harder to balance.

> *"While it is challenging living with the effects of stroke, I am lucky that I got a second chance at life. I often say the planets aligned on the day I had my stroke, because I survived and I know that's not the case for many people. My hope is that people living with AF manage it correctly and take measures to reduce their stroke risk, because stroke can be prevented."*

Michael is undergoing rehabilitation. He is learning to adjust to his body. In 2016, Michael also underwent a catheter ablation, a procedure to try to destroy the heart cells responsible for his irregular heartbeat.

Causes of AF

The exact cause is not known, but the risk of developing AF increases with age.[2]

It is also more common in people with conditions such as:

- High blood pressure.
- Coronary heart disease.
- Mitral valve disease (caused by rheumatic heart disease, valve problems at birth, or infection).
- Heart surgery.
- Congenital heart disease (abnormality of the heart present since birth).
- Pneumonia.
- Lung cancer.
- pulmonary embolism (blood clot in a lung artery).
- Overactive thyroid.
- Diabetes.
- Sleep apnoea.
- Obesity.

Alcohol and drug misuse can also increase your risk of developing AF.

You can still get AF even if you don't have one of these conditions.

Signs of AF

If you have AF, you may have a 'pounding' or 'fluttering' heartbeat. This is also called having heart palpitations.

Some people with AF experience symptoms such as an irregular pulse, dizziness, tiredness, shortness of breath or chest pain, or may feel faint or lightheaded.

Some people do not notice any symptoms at all.

If your doctor suspects you may have AF, he or she will do tests to confirm this.

Your doctor will also look for underlying causes (such as problems with your heart valves).

Tests can include:[4]

- Electrocardiogram (ECG) recording of your heart – this can be a brief test, or you may need to wear a monitor for 24 hours or more to continuously record your heart activity.
- Implantable heart rhythm recorder, which can monitor your heart for AF for up to three years.
- Echocardiogram (an ultrasound of the heart) to assess the structure and overall function of your heart.
- Blood tests to look for evidence of an overactive thyroid gland.

Types of AF

Early in the disease, AF may come and go without warning, and you may go for long periods between spells.

These episodes can be brief and cause very mild symptoms. Some people don't even realise they have AF.

In later stages, AF may become persistent, and last for longer periods of time.

There are four different categories of AF.[5] These describe the progression of the disease from occasional episodes through to the complete absence of a normal heart rhythm.

Your risk of having a stroke is significantly increased, no matter which type of AF you have.*

* Except for single episodes with a clearly reversible cause.

Paroxysmal AF

Paroxysmal AF means that the irregular heart rhythm comes and goes without warning. You may go for long periods between episodes. Episodes stop without treatment, usually within 48 hours. Because of this, paroxysmal AF is often undetected.

Persistent AF

In persistent AF, episodes last longer than seven days, or need treatment in order to stop.

Longstanding persistent AF

Longstanding persistent AF is continuous AF of more than one year's duration.

Permanent AF

Permanent AF is when you and your doctor accept the presence of the arrhythmia, and make no further attempts to return the heart to normal rhythm.

AF and stroke

The main risk associated with AF is stroke.

About stroke

A stroke is when the blood supply to a part of your brain is blocked.

This can damage your brain, causing serious symptoms or even death.

Strokes happen when a blood clot travels through your body and becomes lodged in the small blood vessels in your brain.

AF and stroke risk

On average, people with AF are **five times** more likely to have a stroke compared with people who do not have AF.[6]

Most people with AF have a high risk of stroke.

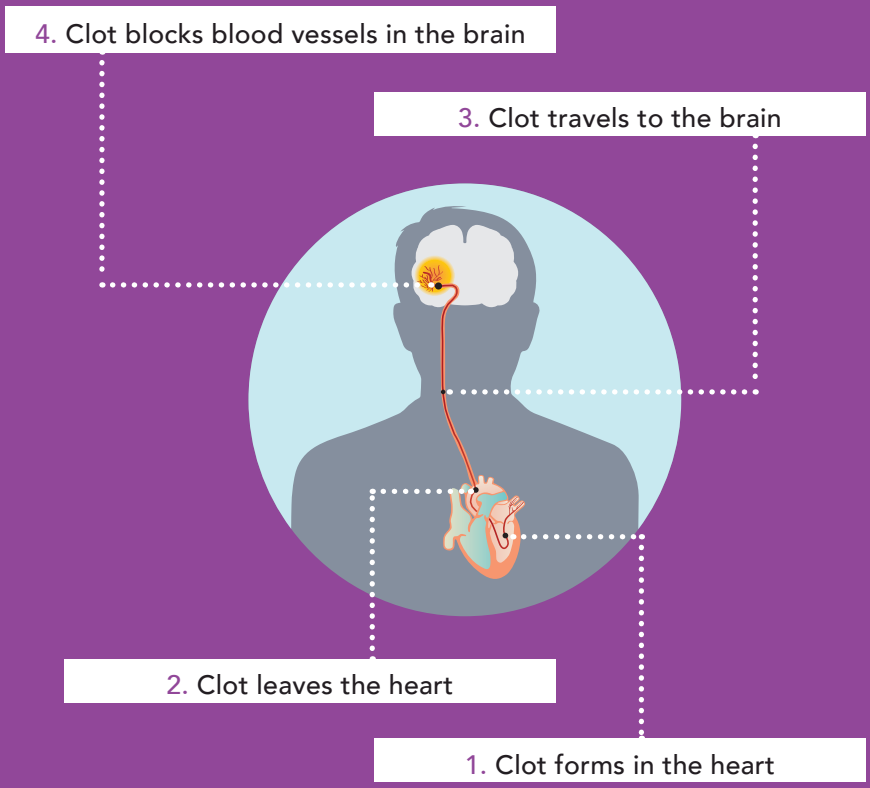
Your doctor is best placed to advise of your risk and decide on the best treatment option.

Other risks

Clots may also lodge in the arteries supplying blood to your arms or legs.

They can also affect one of your vital organs, such as the bowel or kidney.

How AF can lead to stroke



If blood is not properly pumped away from the heart, it may collect or 'pool' and a clot may develop (1). If a part of the clot breaks off, it can leave the heart (2) and travel in the blood vessels of the brain (3). Here it may block the flow of blood to part of the brain (4) and cause a stroke.

Bob's Story

Bob Carnaby, 73, was diagnosed with paroxysmal AF in 2000. His condition means he has an irregular heartbeat which comes and goes spontaneously. At the time of diagnosis, Bob recalled having AF up to 12 times a month, lasting anywhere from 30 minutes to 30 hours.

"It felt like my heart was jumping around. I was feeling a bit of lightheadedness, heavy in the chest, and my pulse was a giveaway I had AF. My cardiologist prescribed me medication which has helped reduce the frequency and duration of my irregular heartbeat."

"While the medication has helped my AF, I believe it's my lifestyle changes that have made the biggest difference to improving my overall health. I watch and limit what I put in my mouth, I've cut out alcohol and I've lost 16 kilograms of weight. Medication is necessary to control my condition, but it's my lifestyle that keeps me consistently well."

> *"Having AF, I don't treat myself in any special way, except for continuing on with my medication and lifestyle changes. I hope others keep an eye on their health too. Control what you put into your body, and exercise regularly because it makes you feel on top of the world."*

Bob said his lifestyle 19 years ago was drastically different. Then, Bob was classified as obese, described himself as a heavy drinker, had late nights and felt stressed. Since then, Bob has made some big changes, including cutting out alcohol completely, eating healthier foods and exercising regularly by walking and stationary bike riding. Bob's blood pressure is also in a normal range.

Bob's increased risk of stroke provided him with motivation to keep on top of his medication and healthier living. Bob said he would now experience AF around once a month, lasting up to a couple of hours – a major improvement from 19 years ago.

Now, Bob is proud to say he doesn't let his AF define him. He enjoys life to the fullest and is a StrokeSafe speaker for the Stroke Foundation. Bob educates others about stroke and stroke prevention. Bob has learnt to love exercising. When Bob's AF occurs, he adjusts his activity accordingly and gets on with enjoying the day.

Stroke symptoms

The Stroke Foundation recommends the F.A.S.T. test as an easy way to remember the most common signs of stroke. Using the F.A.S.T. test involves asking these simple questions:

- **Face** Check their face. Has their mouth drooped?
- **Arms** Can they lift both arms?
- **Speech** Is their speech slurred? Do they understand you?
- **Time** Is critical. If you see any of these signs call triple zero (000) straight away.

Other signs of stroke

Facial weakness, arm weakness and difficulty with speech are the most common symptoms or signs of stroke, but they are not the only signs.

The following signs of stroke may occur alone or in combination:

- Weakness, numbness or paralysis of the face, arm or leg on either or both sides of the body.
- Difficulty speaking or understanding.
- Dizziness, loss of balance or unexplained fall.
- Loss of vision, sudden blurring or decreased vision in one or both eyes.
- Headache, usually severe and abrupt in onset or unexplained change in the pattern of headaches.
- Difficulty swallowing.

Sometimes the signs disappear within a short time, such as a few minutes. When this happens, it may be a Transient Ischaemic Attack (TIA). After a TIA, your risk of stroke is higher. Stroke can lead to death or disability. A TIA is a warning that you may have a stroke and an opportunity to prevent this from happening.

If you or someone else experiences the signs of stroke, no matter how long they last, call triple zero (000) immediately.

Emergency medical treatment soon after symptoms begin improves the chance of survival and successful rehabilitation.

Lindy's Story

Lindy Cooke (pictured right), 58, was born with a hole in her heart. This marked the beginning of a number of health obstacles Lindy would experience throughout her lifetime.

Doctors diagnosed Lindy with a ventricular septal defect, and at the age of nine, Lindy underwent open heart surgery to try and repair her heart. A few years later, Lindy developed an atrial flutter and an irregular heartbeat, which was often triggered by exercise.

> *"It was very unsettling to feel like your heart was racing a million times a minute. I'd just be lying down trying to sleep, but my heart was still racing."*

Lindy was put on medication to control her irregular heartbeat, but would still go into AF. At age 12, she started receiving cardioversion, a procedure that uses electricity to convert the heart back into normal rhythm.

"Every year at high school if I'd run, my heart would go into an irregular beat, and I'd need a zap, cardioversion, to make it right again," Lindy said.

At age 26, Lindy had an ablation procedure, to try and destroy the heart cells responsible for her irregular heartbeat. She also had a permanent pacemaker inserted to prevent her heart beating too slow following the ablation procedure. Despite this, she continued to experience AF.

> *"The stroke affected the left side of my body – I couldn't move my hand, arm or leg. I needed around the clock care when I first got home. But I worked hard on my rehabilitation, and learnt to walk and live independently again."*

In 2008, Lindy suffered a major stroke after three blood clots travelled from her heart to her brain.

Lindy has undergone physiotherapy for the past 10 years to improve her movement.

"I do have a lot of positives in my life. I enjoy my volunteer position at the local health service. My two daughters have been so supportive, and I have three beautiful grandchildren who I love spending time with. It is not an easy journey, so I try to focus on the positives. Try to stay positive and don't give up."

Treatment for AF

There are a number of treatment options available for people with AF.

Talk to your doctor about the best option for you.

Blood-thinning medicine[4]

Patients with AF often take blood-thinning medicine to reduce the likelihood of stroke by preventing the formation of clots.

There are two types of blood thinners:

- antiplatelet medicine (like aspirin)
- anticoagulant medicine (like heparin and Warfarin, and also DOACs – see below).

Antiplatelet medicine does not help to prevent AF-related stroke. Most people with AF take anticoagulant medicine (unless your AF-related stroke risk is very low).

Anticoagulants block the chemical reactions in your body responsible for blood clotting. This means a blood clot takes longer to form and can help to prevent a stroke.

Apixaban, dabigatran and rivaroxaban are newer types of anticoagulants, known as non-vitamin K antagonist oral anticoagulants (DOACs).

These medicines are much less likely than Warfarin to increase the risk of brain bleeding, which is the most serious complication of blood thinning.

Cardioversion for people with persistent AF[4]

In this procedure, an electric current is delivered through special gel pads positioned on the chest. This can help the heartbeat revert to a normal regular rhythm.

Many people undergoing this procedure may also need blood thinners for a limited time before and after the procedure.

Cardiac ablation[4]

In this procedure, a catheter (a long, thin wire) is passed into the heart chambers via a large blood vessel at the top of the leg.

The tip of the catheter emits radio waves that destroy or 'ablate' small areas of the heart tissue that may be triggering abnormal heartbeats.

Left atrial appendage closure

Most clots secondary to AF form in the left atrial appendage. If your risk of bleeding from AF blood-thinning medication is very high then one option is to insert a device via a catheter into the heart to block off the source of clots. However even this procedure requires blood thinning medication at least for a short period of time, and stroke risk is probably not reduced as effectively as with anticoagulants.

Maintaining a healthy lifestyle

Having AF does not mean you have to stop enjoying the things you love. However, it is important to eat well, stay healthy and have a positive outlook on life.

Here are a few tips for living well with AF.

There is increasing evidence healthy living recommendations can reverse AF. This means being a healthy weight, exercising vigorously, eating healthily and restricting the amount of alcohol you drink.

Talk to your doctor about lifestyle changes right for you.

Sleep

Losing weight also reduces the risk of obstructive sleep apnoea which increases the likelihood of AF. Treatment of sleep apnoea may reduce AF.

Diet

Eat plenty of fresh fruit and vegetables, avoid fatty meats and minimise processed food to help control your cholesterol levels.

Lower your salt intake to help control high blood pressure, which can contribute to AF.

Exercise

Regular physical activity helps control your weight, improve your mood and maintain a positive outlook.

Talk to your doctor before you start any new form of exercise to make sure it is safe for you.

Reducing alcohol intake

Drinking alcohol increases your risk of having AF episodes. If you take blood-thinning medicine, it also increases the risk of bleeding. Men should drink no more than two standard drinks a day and women no more than one.

Alcohol guidelines have been updated by NHMRC, at https://www.nhmrc.gov.au/health-advice/alcohol

Where to find more information

The following organisations provide useful information on AF and stroke prevention, as well as ways to access support services.

Stroke Foundation

Website: www.strokefoundation.org.au

StrokeLine: 1800 STROKE (787 653)

Arrhythmia Alliance Australia

Website: https://www.heartrhythmalliance.org/aa/au

Atrial Fibrillation Association

Website: www.heartrhythmalliance.org/afa/au

The Heart Foundation

Website: www.heartfoundation.org.au

Helpline: 1300 36 27 87

Hearts4Heart

Website: www.hearts4heart.org.au

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With thanks to:

Stroke survivors Michael Shaw, Lindy Cooke and Bob Carnaby

Stroke Foundation Consumer Council

Stroke Foundation Clinical Council

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How to get more involved

- **Give time** – become a volunteer.
- **Raise funds** – donate or hold a fundraising event.
- **Speak up** – join our advocacy team.
- **Leave a lasting legacy** – include a gift in your Will.
- **Know your numbers** – check your health regularly.
- **Stay informed** – keep up-to-date and share our message.

Contact us

- **StrokeLine 1800 STROKE (1800 787 653)**
- **strokefoundation.org.au**
- **/strokefoundation**
- **@strokefdn**
- **@strokefdn**

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