LIVING WITH ATRIAL FIBRILLATION
CONTENTS

05  Foreword
06  What is atrial fibrillation?
09  Who gets atrial fibrillation?
10  What causes atrial fibrillation?
12  How do you know if you have atrial fibrillation?
14  Are there different types of atrial fibrillation?
16  Atrial fibrillation and stroke
18  Ray’s story
20  What are the symptoms of a stroke?
24  Lindy’s story
27  What helps to lower stroke risk?
31  Maintaining a healthy lifestyle
33  Where to find more information
35  References

The information contained in this booklet is not designed to 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.
DID YOU KNOW?

In Australia there is little awareness of atrial fibrillation. In a recent survey, people were asked to list what medical conditions they thought were associated with the heart and cardiovascular system.

They responded: 1

- 54% Heart attack/heart disease/condition
- 32% Stroke
- 25% High blood pressure
- 20% Blocked arteries
- 2% Atrial fibrillation

Atrial fibrillation is a condition that doesn’t really have a high profile, yet it impacts over 400,000 Australians. It’s a condition affecting the heart, making it beat faster and out of rhythm. Having atrial fibrillation also means some patients have a higher risk of stroke.

Patients who have atrial fibrillation have said that there was a need for a simple, easy-to-read booklet on the condition. They asked for information explaining what atrial fibrillation is, how it can impact their lives, what treatment options are available and how to live well with the condition. Patients also wanted a handy booklet they could give to their families and carers so they could also learn about atrial fibrillation and its impact.

That’s why this booklet was produced in conjunction with the National Stroke Foundation, which also recognises how important it is to provide factual, evidence-based information to patients so they are well informed about their medical condition.

Two patient stories have been included to illustrate the real impact atrial fibrillation has had on the lives of other Australians, and these stories bring the condition to life. There is also a handy guide in the back of this booklet listing organisations that can provide more in-depth information.

We hope that patients and their families find this booklet to be an easily-accessible reference on atrial fibrillation.
Atrial fibrillation (AF) is a heart condition in which your heart beats fast and out of rhythm. AF affects approximately 400,000 Australians. The risk of developing the condition increases with age; approximately 10% of people over 75 years of age have AF. If left untreated or poorly managed, AF may lead to serious health complications including heart failure and stroke. AF costs the Australian economy over $1.25 billion per year, through:

- Medical costs
- Costs of long-term care for those with a stroke-related disability
- Lost productive output

If you have AF, your heart beats with an irregular rhythm. The upper chambers of the heart (called the atria) beat rapidly and out of rhythm with the lower chambers of the heart (called the ventricles). As a result of this rapid and irregular heartbeat (called fibrillation) your heart does not pump blood as efficiently as it should.

The heart consists of four chambers which pump blood around the body, enabling the delivery of oxygen and nutrients. In a healthy heart, all four chambers beat in a synchronised rhythm. Normally the heart beats around 60 to 100 times per minute.
There is no typical AF patient. AF occurs in both men and women of all races and can occur at any age, though it is more common in those over 75 years of age. While AF can run in the family, most people diagnosed have no family history of the disease. Some illnesses and diseases can make a person more susceptible to AF, but it can also occur without warning.
WHAT CAUSES ATRIAL FIBRILLATION?

The exact cause is not known, but the risk of developing AF increases with age, and it is associated with some of the following conditions (this is not an exhaustive list):

- High blood pressure
- Coronary heart disease
- Mitral valve disease (caused by rheumatic heart disease, valve problems at birth, or infection)
- 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

In addition, alcohol and drug abuse or misuse may predispose you to AF.

While the risk of AF can increase with the conditions mentioned, you don’t have to have one of these conditions to develop AF.\(^2\)

When I was told I had AF, “I felt concerned and puzzled. The only person I’d ever heard of suffering from AF was elderly”. AF patient quote\(^6\)
How Do You Know If You Have Atrial Fibrillation?

If you have AF, you may experience a ‘pounding’ or ‘fluttering’ heartbeat known as heart palpitations. Some people with AF also experience symptoms such as dizziness, tiredness, shortness of breath or chest pain, or may feel faint or light headed. Some people may not notice any symptoms at all.

If AF is suspected, your doctor will check your pulse and recommend some tests to confirm the diagnosis and to look for any underlying causes (e.g. problems with the heart valves) which may include:

- An electrocardiogram (ECG) recording of your heart may be made by your GP or cardiologist, or you may have to wear a monitor for 24 hours or more. The monitor will continuously record your heart activity. Heart monitors are painless and allow your doctor to record your heart rhythm for up to several days while you carry out your normal daily activities.

- An echocardiogram (an ultrasound of the heart) will help your doctor assess the structure and overall function of your heart.

- You may have some blood tests to rule out any reversible causes of AF e.g. a thyroid function check.
ARE THERE DIFFERENT TYPES OF ATRIAL FIBRILLATION?

Put simply – yes! Early on in the disease AF can be paroxysmal, which means it can come and go without warning, and you may go for long periods of time between episodes.

When AF first occurs, early episodes may be brief and cause very mild symptoms and it is not uncommon at this stage for some people not to know they have it. However, stroke risk is the same whether AF is persistent or paroxysmal.

There are different categories of AF and these describe the progression of the disease from occasional episodes through to the complete absence of a normal heart rhythm. These categories are:

- **PAROXYSMAL AF**: AF may be intermittent – the irregular heart rhythm can come and go without warning and you may go for long periods of time between episodes. Episodes stop without treatment, usually within 48 hours and, because they are often brief with only mild symptoms, paroxysmal AF can often go undetected in many people.

- **PERSISTENT AF**: AF episodes lasting longer than seven days or requiring treatment in order to cease.

- **LONGSTANDING PERSISTENT AF**: Continuous AF of more than one year duration.

- **PERMANENT AF**: When the presence of the arrhythmia is accepted by the patient and doctor and no further attempts are made to return the heart to normal rhythm.
The fast, irregular rhythm that occurs with atrial fibrillation prevents the heart muscles from contracting properly. This means the heart cannot pump blood as effectively as it should. Since blood is not properly pumped away from the heart, it may collect or 'pool' in the heart chambers, leading to the formation of a clot. The clot can break off from the heart wall and travel to the blood vessels of the brain, where it may lodge and block blood flow to that region of the brain, causing a stroke.

People with AF are five times more likely to have a stroke compared to those who do not have AF. Clots may also lodge in arteries supplying blood to your arms or legs, or one of your vital organs, such as the bowel or kidney.

Some people with AF are at relatively low risk of stroke (e.g. 1% or even less each year). However, some people with AF are at very high risk of stroke – as high as 20% each year.

Doctors have tools to work out an individual’s risk, and thereby decide the best treatment option.

When I was told I had AF, “I felt anxious, frightened and unsure of what to expect. Scared at having to take medication and overwhelmed at the prospect of having a stroke”.

AF patient quote

HOW AF CAN LEAD TO A STROKE

- Clot forms in the heart
- Clot leaves the heart
- Clot travels to the brain
- Clot blocks blood vessels in the brain
When I got out of my car I felt like I was walking slightly imbalanced but apart from that everything was fine. I was 49 at the time, not even 50 yet. I didn’t even know what a TIA was.”

When Ray experienced a TIA, he usually attributed his symptoms to the flu or stomach infection.

“A year earlier I was really sick at work, my eyesight went dark and I began vomiting. I thought I’d eaten something bad and one of the guys gave me a ride home. I went straight to bed and woke up feeling fine. Doctors have said to me this was probably a TIA.”

Another TIA episode resulted in Ray losing sight in his right eye. He had phoned his doctor to book an appointment regarding an unrelated minor shoulder injury, but upon mentioning his eyesight loss, he was told a house call was necessary.

“Ten minutes later I was in an ambulance heading off to hospital.”

Ray spent eight days in hospital. He felt “embarrassed” to be in the stroke unit with patients who had suffered major strokes, as he felt as though nothing was wrong.

“The specialist said he wanted to keep me in. I’m glad I did stay, looking back. I could see pictures of my brain and they showed me where I had issues. If I had had a bit of knowledge about TIA and stroke I would have known what to do.”

Ray was informed that the TIAs he had experienced were the result of AF. He was prescribed medication to reduce his risk of blood clots and stroke, and medication to manage his blood pressure.

Ray now ensures he has regular check-ups and, fortunately, has not had any major health issues since.

“Around twenty years later Ray began experiencing transient ischaemic attacks (TIAs) – sometimes also referred to as ‘mini-strokes’. “My first TIA happened a couple of years ago. I was driving to work and a song came on the radio. I was singing along and all the words were coming out in the wrong order. It was really weird. It didn’t last very long, only half an hour.

“The specialist told me to keep an eye on it because it may happen again and I could be in danger of a stroke. Being so fit, I believed I was unsinkable and his words fell on deaf ears.”

Ray was an ex-long distance runner in his early 30s when he developed AF. A specialist prescribed medication to help manage the AF, but informed Ray that he could still experience AF episodes in the future.

“A house call doctor arrived and said they were ringing an ambulance for me. I thought it was over the top. I said I didn’t need an ambulance. Ten minutes later I was in an ambulance heading off to hospital.”

“Ray’s Story

Ray was an ex-long distance runner in his early 30s when he developed AF. A specialist prescribed medication to help manage the AF, but informed Ray that he could still experience AF episodes in the future.

“He made the mistake of thinking I was unsinkable. I’m sure it’s a view of many people who have never had any illness before. I got off lightly. I know it won’t be the end and more TIAs are expected, but I believe I’m extremely lucky. My biggest issue is that I never went to the doctor regularly, only for sports injuries. When you get a little bit older you need to go and get some help.”
WHAT ARE THE SYMPTOMS OF A STROKE?

It is important to be aware of stroke symptoms, particularly if you have AF. There are some simple things you can look out for that can help you recognise a stroke – facial weakness, arm weakness and difficulty with speech are the most common signs. Strokes can happen suddenly and have immediate and lasting effects.

The National Stroke Foundation recommends using the FAST test when you suspect someone is having a stroke.

The main thing to remember is to act FAST. It’s also a good idea to let your family and friends know what to look out for as well.

FAST will help you and your family recognise the symptoms of a stroke quickly so you can get medical assistance as soon as possible. The faster you seek medical assistance, the better your prospects of recovering from the effects of a stroke.
Other signs of stroke may include one, or a combination, of:

- 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 an unexplained fall
- Loss of vision, sudden blurring or decreased vision in one or both eyes
- Headache, usually severe and abrupt in onset
- Difficulty swallowing

The signs of stroke may occur alone or in combination and can last from a few seconds up to 24 hours and then disappear, or they may persist indefinitely.

The most important thing to do if you experience any of these symptoms is to ring 000 immediately and ask for an ambulance.
LINDY’S STORY

Lindy Cooke, 53, was a ‘blue’ baby at birth, meaning she was born with a hole in her heart.

Doctors recognised she had a ventricular septal defect (VSD) and she underwent surgery to repair her heart at age 9. At 13, she developed an atrial flutter and an irregular heartbeat after exercise and needed to be cardioverted back into normal rhythm.

At 26, Lindy had a permanent pacemaker inserted and an ablation (a procedure to try to destroy the heart cells responsible for triggering her irregular heartbeat).

“I was permanently reliant on the pacemaker. It would speed up with movement so I could exercise. But I had no idea my heart was still in atrial flutter. Even though I wasn’t fainting, it was still out of rhythm.”

In 2008, Lindy suffered a major stroke when three blood clots left her heart and travelled to her brain. After returning home from the hospital, Lindy required a 24-hour carer as she was in a wheelchair and needed someone to help her onto a commode and in and out of a car.

“I had no movement in my left hand, arm, or leg. Luckily I have improved enough to walk again, with the assistance of an ankle-foot orthotic (AFO) brace, and I now live independently and cook for myself. I can also help my daughters with their children.”

Lindy says exercising at her local gym and gardening are big on her list, as well as meeting with other stroke survivors regularly. Lindy became a member of the Stroke Association of Victoria and now runs a stroke support group for survivors and carers.

“A lot of people do have AF but they don’t always know they do. About 20% of my stroke group have it. I warn everyone with AF about stroke, but people need to stay optimistic. Having AF just means life is different and it’s not the end. The risk of stroke can be avoided.”
WHAT HELPS TO LOWER THE RISK OF STROKE ASSOCIATED WITH ATRIAL FIBRILLATION?

There are a number of treatment options available for people with AF. You should talk to your doctor about which treatment option is best for you. Many factors can influence which treatment will best suit you, but the good news is that there are more effective treatments available now than ever before.
BLOOD THINNERS
Patients with AF are commonly prescribed blood thinners to reduce the likelihood of stroke by preventing the formation of clots. There are two different types of blood thinners, which act in different ways.

ANTICOAGULANTS
These help to block specific chemical reactions in your body that are responsible for blood clotting. Blocking these reactions means a blood clot takes longer to form and this helps to prevent a stroke. Heparin and warfarin are types of anticoagulants. Apixaban, dabigatran and rivaroxaban are new anticoagulants, known as novel oral anticoagulants (NOACs), for stroke prevention in non-valvular AF.

ANTI-PLATELET THERAPY
Platelets (very small blood cells) clump together during blood clotting. Anti-platelet medicines help to prevent this clumping, thus preventing blood clot formation and helping to prevent a stroke. Aspirin, clopidogrel, ticagrelor and prasugrel are all examples of anti-platelet medicines.10

In general, anticoagulants are recommended over anti-platelets to prevent AF-related stroke.7,11 For the majority of AF patients the benefit of taking an anticoagulant therapy outweighs the risk of a bleed. You should talk to your doctor about which treatment option is best for you.

RATE/RHYTHM CONTROL IN ATRIAL FIBRILLATION

MEDICINES FOR RATE AND RHYTHM CONTROL
Often the symptoms of AF can be reduced by using medications to slow the heart down (rate control). Sometimes medications may be given to try and convert the abnormal rhythm associated with AF to normal sinus rhythm, or to improve the chances of electrical conversion (see adjacent column), or to prevent episodes of AF if episodes are intermittent (rhythm control). Often patients taking these medications still need to take blood thinners, and this should always be clarified with your prescribing doctors.

Some people experience severe and frequent episodes of AF which affect their quality of life and do not resolve with medication. Others may suffer unpleasant side effects from their AF medications. In some of these situations non-drug treatments may be an option. These treatments include:

CARDIOVERSION FOR PATIENTS WITH PERSISTENT AF
In this procedure an electric current is delivered through special gel pads positioned on the chest, which may 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
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 or arm. Radio waves emitted from the tip of the catheter destroy (or ablate) small areas of the heart tissue that may be triggering the abnormal heartbeats in AF.7

These interventions are not 100% successful. It is essential that you speak to your doctor to determine which treatment is best for you and the risks and benefits associated with treatment.
Having AF does not mean you have to stop enjoying all the things you love to do. 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. Remember to discuss these lifestyle changes with your doctor to ensure they are suitable for you.

**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, another health condition that may contribute to AF.

**EXERCISE**
Regular physical activity not only helps with weight control, but also helps to improve your mood and maintain a positive outlook. Make sure you speak with your doctor before you start any new forms of exercise to ensure that it is safe for you to do so.

**STRESS**
Stress is an important risk factor in AF. Manage stress through deep breathing, healthy eating and daily exercise – even a brisk walk around the park once a day can work wonders.12
WHERE TO FIND MORE INFORMATION

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

- Arrhythmia Alliance Australia
  www.aa-international.org/au
  Email: info@aa-australia.org

- Atrial Fibrillation Association
  www.atrialfibrillation-au.org
  Email: info@aa-australia.org

- National Heart Foundation of Australia
  www.heartfoundation.org.au
  Health Information Service: 1300 36 27 87

- National Stroke Foundation
  www.strokefoundation.org.au
  Stroke Line: 1800 STROKE (787 653)

- More Than Medication – provides information on general health, lifestyle and wellbeing
  www.morethanmedication.com.au
REFERENCES


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