

Staying well with atrial fibrillation



Welcome

If you have this booklet then, like many other people in New Zealand, heart disease has touched your life. Whether it is you or a loved one who is looking to find out more about atrial fibrillation, you are likely to have many questions. We hope the information in this booklet will give you some of the answers, but remember you can talk to your doctor or nurse about any questions or concerns you have as well.

My recovery checklist

After reading through this booklet, you should be able to check off the following statements.

- ☐ I understand the risks of atrial fibrillation, including my increased risk of stroke.
- ☐ I know how to lower my risk of stroke.
- ☐ I have checked out the Heart Foundation's website.
- ☐ I have emailed hearthelp@heartfoundation.org.nz to sign up to the Heart Foundation's Heart Help e-newsletter.
- ☐ I have a plan for my life-long heart health.

Acknowledgements

The Heart Foundation wishes to extend a huge thank you to Nikki, Ralph and Bill for generously sharing their experience of living with atrial fibrillation.

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About atrial fibrillation

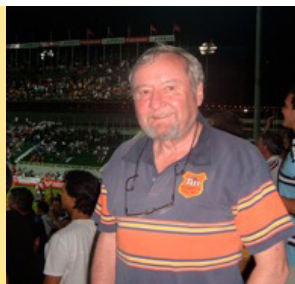
You are not alone

There are an estimated 60,000 people living with atrial fibrillation (AF) around New Zealand. AF is a common life-long condition, but your experience of having atrial fibrillation is unique to you.

It is important to remember that you are not alone. There are choices you can make today to positively manage your atrial fibrillation. Your family/whānau, friends, health professionals and the Heart Foundation are here to support you.

Bill has been living with permanent atrial fibrillation since early 2002. The diagnosis was something of a surprise to Bill as he's always been very active.

"It's a strange feeling, actually. I felt vaguely insulted by the fact my body had let me down even though I was looking after it."



Ralph hasn't let his atrial fibrillation slow him down. He has two part-time jobs, is a keen bowler and regularly rallies his MG rally car.

"My heart just seems to run rough. It doesn't speed up, it doesn't slow down, it just ticks away but it seems out of sync."

Nikki is a stay-at-home mum with two young children. Finding out that she has atrial fibrillation has been challenging for both Nikki and her family.

"We have probably lived in a bit of a daze for the last two years, but for me it's been all about protecting the children."

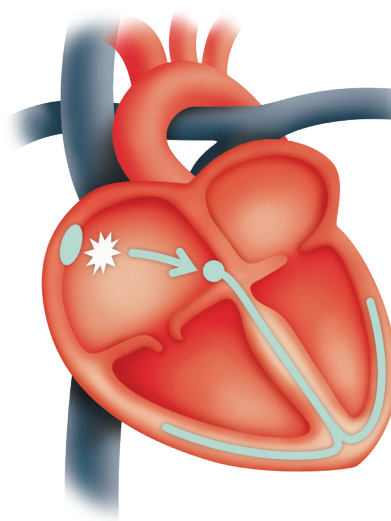


What is atrial fibrillation?

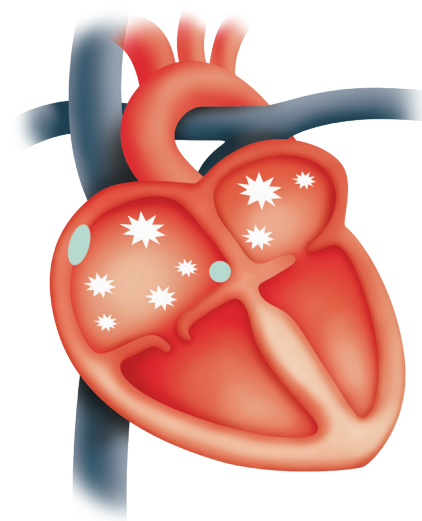
Atrial fibrillation is a common type of irregular heart rhythm (arrhythmia). This means that your heart has its own sense of timing and may beat very quickly or very slowly, rather than at a steady pace.

A heartbeat with AF

Every heartbeat starts with an electrical signal in the heart muscle. Usually these signals are timed at regular intervals to keep your heart pumping steadily. When you have atrial fibrillation, the signals start randomly. This makes the atria (the top two rooms of the heart) quiver and stops the heart from pumping blood so well.



One electrical signal starts a heartbeat



Lots of random AF signals make it hard for your heart to beat steadily

Symptoms of atrial fibrillation

Many people will have no symptoms of atrial fibrillation and only realise they have it when they visit the doctor for something else. In some cases, it is only after having a stroke that people find out they have atrial fibrillation.

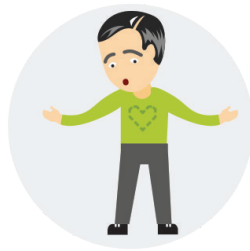
Others may have symptoms like:



feeling breathless
or having difficulty
breathing



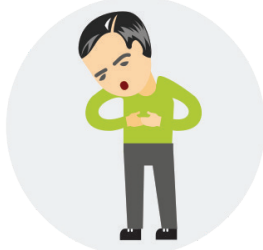
dizziness, lightheaded
or feeling faint



feeling your heart
racing (palpitations)



tiredness or weakness



chest discomfort



difficulty exercising

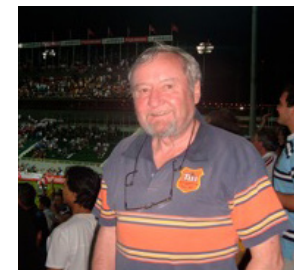
Know your AF symptoms. Some of the symptoms of atrial fibrillation can be signs of other more serious health problems. If your symptoms get worse, more frequent or last longer, talk to your doctor straight away.

Types of atrial fibrillation

Atrial fibrillation affects each person differently. You may have episodes of atrial fibrillation that last for minutes, hours or days (**paroxysmal AF**). Other people have episodes that last longer than seven days at a time and need medical treatment to bring back a normal heart rhythm (**persistent AF**). Some people have a permanently abnormal heart rhythm despite medical treatment (**permanent AF**).

Nikki's AF comes and goes (paroxysmal AF), with some episodes worse than others.

"When it's going to be a serious attack, I start to sweat, it's hard to breathe and sometimes I lose consciousness... but I know as long as I stay calm, the people around me will stay calm."



Bill has permanent atrial fibrillation.

"My heart rate doesn't even out. It's the same sort of irregular pattern all the time so I wouldn't know if it was beating properly or not."



Talk to your doctor or nurse if you have any symptoms of atrial fibrillation, or if they change or get worse.

Common causes of atrial fibrillation

The causes of atrial fibrillation are not always clear, but you are more likely to develop AF if you have one or more of the following risk factors:

- age - AF is more common as people get older, especially among those aged over 65 years old
- high blood pressure
- heart pumping problems (heart failure)
- overactive thyroid gland
- coronary artery disease (blockages in the arteries)
- heart muscle disorders (cardiomyopathies)
- heart valve disease
- lung infections such as pneumonia
- obesity
- sleep apnoea
- drinking a lot of alcohol over time or binge-drinking.

Possible triggers for AF episodes

If you have paroxysmal AF, you may find certain things trigger your episodes. Some triggers include:

- tiredness
- alcohol
- stress
- anxiety
- caffeine
- smoking and/or vaping
- illness
- medication (occasionally prescription or other medications can be a trigger - talk to your doctor if you're concerned)
- high-intensity exercise (see page 20 for how to exercise safely with AF).



For more information, visit www.heartfoundation.org.nz/af

I have atrial fibrillation, now what?

Finding out more about your heart

If you have atrial fibrillation, you are likely to need to find out more about your heart. There are several tests that can help confirm you have AF, its cause, and the best way to treat it.

Common tests



Electrocardiograph, ECG (looking at the electrical activity of your heart)



Echocardiogram (using soundwaves to look at the structure, function and size of your heart)



Holter monitor (monitoring your heart rhythm)



Event monitor (monitoring your heartbeat when you experience symptoms)



Other tests may include a blood pressure check as well as blood tests to see how well your kidneys and thyroid are working.

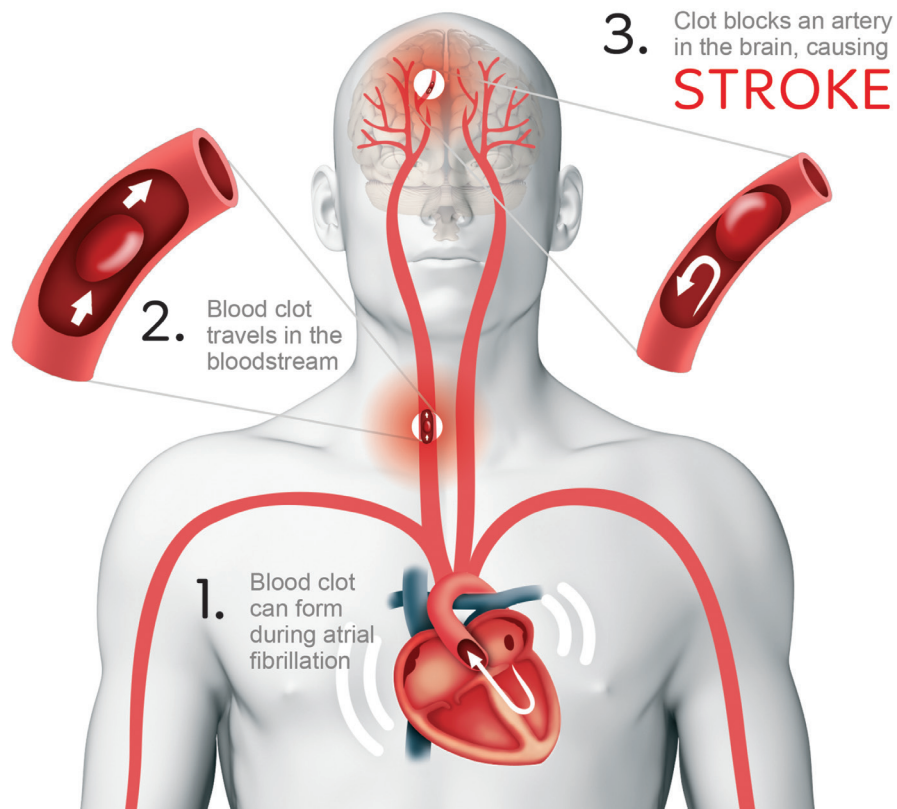
When making decisions about your heart health, it is important to talk to your doctor, nurse and other health professionals to get all the information you need. You may like to ask questions such as:

- “What do I need to know about my heart? How can I find this out?”
- “What are the risks and benefits of the tests?”
- “What other tests could I consider?”
- “What changes can I make to my lifestyle to care for my heart?”
- “What happens if I decide to do nothing?”

Atrial fibrillation and stroke

Even though atrial fibrillation itself is not generally life-threatening, it increases your risk of having a stroke. In fact, people with atrial fibrillation are five times more likely to have a stroke than people without atrial fibrillation. This is because you may develop blood clots that can travel to your brain.

When you have atrial fibrillation, not every electrical impulse in the heart starts a heartbeat. This delays blood from being pumped through the heart. Blood that is sitting in the top rooms of the heart (atria) can get stickier than normal and form a blood clot that may travel to the brain and cause a stroke.



Stroke warning signs

**AT ANY SIGN OF STROKE
CALL 111**



If you see any of these signs, call 111 immediately.
Getting help fast means a better chance of recovery.

Reproduced with permission from the Stroke Foundation of New Zealand

"I'm not afraid of my AF, what scares me is my risk of having a stroke. I've spent some time getting to know the symptoms of stroke and making sure my family and friends know what to look for too."

Nikki



For more information on stroke signs and symptoms, visit the Stroke Foundation www.stroke.org.nz

Lowering your risk of stroke

Atrial fibrillation is an important risk factor that increases your chance of having a stroke. Together with your doctor or nurse, you can estimate your personal risk of stroke. This is likely to involve answering questions about other risk factors like your age, personal and family history of heart disease or stroke, and any other medical conditions you have.

Once you know your personal risk, you can make a decision about what you would like to do to lower your chance of having a stroke. This may involve medications or other lifestyle changes like making heart healthy eating and drinking choices or moving more (see page 28 for more information).

When thinking about the choices you can make to lower your risk of stroke, it is important to take into account your personal beliefs and concerns, and those of your family. You may like to take some family/whānau along to your appointment to help you talk through your options.

Questions you may like to ask your doctor

- “What are risks and benefits of the different options?”
- “What else could I consider?”
- “What changes can I make to my lifestyle to help lower my risk of stroke?”
- “What happens if I decide to do nothing?”



For more information, visit www.heartfoundation.org.nz/af

Taking medications to lower your risk of stroke

If you have AF, you'll probably need to take medication that helps prevent clots from forming in the blood. These medications are called anticoagulants. They lower the chance of a blood clot forming in the heart and travelling to the brain to cause a stroke.

Anticoagulants lower your risk of stroke, but they do not guarantee you will not have a stroke. If you have any symptoms of stroke, call 111 immediately.

There are two general classes of anticoagulant that can be taken in tablet form: non-Vitamin K Oral Anticoagulants (NOACs) or warfarin. These medications work in different ways to prevent blood clots, but both reduce the chances of a stroke by about two-thirds.

When compared with warfarin, NOACs have two main benefits: they don't require regular blood testing and they don't interact with food. Common types of NOACs available in New Zealand include:

- dabigatran
- rivaroxaban
- apixaban.

Warfarin is useful for people who can't take NOACs. When taking warfarin, you will need to have regular blood tests to check that the dose continues to be right. You'll also need to talk to your doctor about how food affects warfarin.

The main risk of anticoagulants is that it takes longer for your blood to clot when you need it to (e.g. if you cut yourself or develop a bleeding ulcer). Patients taking NOACs may also experience stomach side effects such as indigestion (heartburn).

Managing your atrial fibrillation symptoms

Any atrial fibrillation symptoms you have can usually be controlled by:

- restoring a steady heart rhythm
- slowing your heart rate.

Your treatment options depend on the type of AF you have, how long you have had it, and any other health conditions you may have. Your doctor will talk with you about the risks and benefits of each option so that you can decide what would suit you best.

Slowing your heart rate

This is most commonly done for people with permanent AF. There are three different classes of medication used to slow your heart rate: beta blockers, calcium channel blockers and digoxin. These medications work in different ways to slow the heart rate, although the rhythm may stay irregular.

Restoring a steady heart rhythm

Sometimes your doctor may try to restore your heart rate to its normal rhythm, using a procedure called cardioversion.

Pharmacological cardioversion - uses medicines to restore the rhythm. Your healthcare professional may give you the medication in an oral form (tablet) or intravenously (through a vein).

Electrical cardioversion - a machine called a defibrillator restores the rhythm using an electrical shock. It is performed in a hospital under sedation or anaesthetic.

After your cardioversion, you may need to keep taking medications to stop your heart rhythm from going back into AF. Common anti-arrhythmics include sotalol, flecainide and amiodarone.

Managing your medications

Talk to your doctor or nurse about your medications. For you to be able to keep yourself safe when taking medication, you need to understand:

- what the medication does
- why you are on the medication
- how to take your medication safely
- how long you have to take it for
- what unwanted side effects you should look out for.

Don't stop taking your medication without talking to your doctor or nurse. Stopping some medications suddenly can make your condition worse.

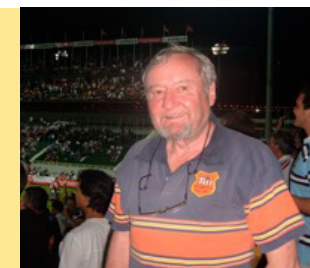


Feeling uncomfortable?

If you have questions or concerns about your medication or unwanted side effects of the medication, please talk to your doctor, nurse or pharmacist. There may be other choices of medication available so that you can be given something that suits you better.

Bill has been taking his medications regularly to help control his atrial fibrillation.

"I get out of breath sometimes, but I'm pretty fit. I play golf and chop wood for the golf club."



Catheter and surgical procedures to control heart rate

If cardioversions and medications can't control your AF symptoms, your doctor may recommend a procedure designed to interrupt the abnormal electrical circuit.

There are three different kinds of procedure designed to do this:

- AF ablation
- pacemaker and atrioventricular (AV) node ablation
- surgical maze procedure.

These procedures come with risks and benefits. Your medical team will discuss these with you, to help you decide if a procedure is suitable for you.

The graph below shows the heart in atrial fibrillation pre-procedure, and the return to sinus rhythm post-procedure.



Atrial fibrillation ablation

AF ablation (or AF catheter ablation), is a procedure that uses a catheter to destroy (ablate) the area inside the heart that is causing the abnormal rhythm.

It is usually carried out with local anaesthetic and sedation, so you'll be conscious but feel sleepy during the procedure. It takes one to two hours.

The doctor will insert a long thin tube (catheter) through your groin or wrist and guide it into your heart using an X-ray camera.

The catheter uses energy to create scar tissue in the part of your heart that triggers the irregular rhythm. This scar tissue stops the abnormal triggers occurring.



Usually you can go home on the day of the procedure, but you must have someone else to drive.

You may feel a little sore or have bruising at the point where the catheter was inserted, but that should only last a few days. You may also have some ongoing symptoms, such as palpitations, after the procedure.

It takes about eight to ten weeks to know if the ablation has been fully successful. Follow up appointments will be arranged for you to discuss this with your medical team.

They will be able to advise on:

- recovery time
- medications
- anything you should avoid
- driving
- return to work.

Atrioventricular (AV) node ablation and pacemaker

If other ablations have been unsuccessful, or if they're not suitable for you, your doctor may suggest an atrioventricular node ablation (AV node ablation) and a pacemaker.

This is usually carried out with local anaesthetic and sedation, so you'll be conscious but feel sleepy during the procedure. It takes one to two hours.

Your specialist will use a catheter to destroy (ablate) the AV node (the electrical circuit gateway between the upper and lower chambers of the heart). This stops the irregular impulses generated in the upper chambers from reaching the lower chambers and causing an irregular heart rhythm.

With this type of ablation you will need a permanent pacemaker inserted so your heart can maintain a regular rhythm. A pacemaker is a small medical device made up of a battery and an electrical circuit which is inserted under the skin, usually just below the collar bone.

Usually you will be able to return home on the day of your treatment or the following day. You may experience some discomfort for a few days at the insertion site of the catheter tube and where the pacemaker has been placed under the skin.

Your medical team will advise on:

- recovery time
- medications
- anything you should avoid
- driving
- return to work.

Surgical maze procedure

Unlike catheter ablation, a surgical maze procedure involves open heart surgery to create a pattern of scar tissue within the heart. It is done under a general anaesthetic and has a higher risk than a catheter ablation. It is usually carried out if you're already scheduled for other heart surgery, such as coronary artery bypass surgery or valve replacement.

You will be required to stay in hospital and your recovery time will depend on a number of factors.

Talk to your medical team about:

- care of your wound
- medications
- when you can go home
- anything you should avoid
- driving
- returning to normal activities and work.



Read personal stories about people who have had catheter and surgical procedures for atrial fibrillation at www.heartfoundation.org.nz/journeys

Continuing with exercise

Regular physical activity is hugely beneficial to your health, so don't let atrial fibrillation stop you from enjoying those benefits. You may be concerned that exercising and raising your heart rate might trigger or worsen your atrial fibrillation. While some people may find that exercise triggers symptoms, research suggests that people living with atrial fibrillation have fewer symptoms and feel better when they exercise regularly.

If you are just starting to exercise, or find that you get tired more easily on exertion, build up your activity gradually. Your energy levels will improve and you will gradually be able to do more exercise. Remember to listen to your body. You are the best person to recognise when you need to do more or less exercise.

There are small steps you can take to build up your confidence to exercise. You may only do five to ten minutes of walking around the house, but if you can do this without a problem, look to increase this by a minute the next day and so on. You may like to ask your doctor or nurse about a green prescription or exercise programmes that may help you.

The **talk test** may also be useful to help you find the right level of exercise for you.

- When you are at the right level of exercise, you should be able to feel your heart pumping harder but still be able to talk comfortably.
- If you are too breathless to talk, then it's time to slow down.
- If you are able to sing or whistle, then step up the pace.



Returning to work

Most people with AF can keep working. As long as you can safely manage your job with AF, work is valuable for your health and wellbeing.

Some people find it difficult to return to their existing role - particularly if their symptoms aren't well controlled. Talk to your doctor and employer if you're worried that AF will affect your job.

If you have a pacemaker for your AF, check with your doctor that it is safe to go back to work. Some work places may have machinery that interferes with your pacemaker.



Getting behind the wheel

If your atrial fibrillation is well controlled and you don't have any symptoms, you are likely to be able to continue driving without restrictions. However, if your symptoms are not well controlled you should not drive until your condition is stabilised.

It may be worth talking to your doctors and the NZ Transport Agency (NZTA) about driving when you have been diagnosed with atrial fibrillation. It also pays to check with your insurance company to ensure that you are fully covered. If you drive for a living, talk to your doctor before going back to work.

If you develop symptoms of atrial fibrillation while driving, it's advisable to pull over and, if required, seek help.



For more information, visit www.nzta.govt.nz

Living with atrial fibrillation

Adjusting to life with atrial fibrillation

Whatever your experience of atrial fibrillation, you are likely to need some time to adjust to your diagnosis as you learn about your condition and what it might mean for your future.

You may experience lots of different feelings, including anxiety, depression, uncertainty and fear. These feelings are common. One of the best ways to manage anxious, depressed feelings, and to prevent the build-up of stress, is to regain some balance in your life.

Each day, make sure you:



Keeping your relationships strong

It's likely your AF diagnosis will affect those close to you. It's normal for family/whānau and other loved ones to feel scared or anxious about your diagnosis.

Often AF has no visible signs making it hard for those around you to understand what you are going through. This can lead to frustration and resentment. That's why good communication with your family/whānau is really important.

Having open and honest conversations can lower your stress and encourage the closeness and emotional support that you need. No one, including children, should be excluded from these conversations. Children can often blame themselves when their parents become unwell, so it's important to explain what has happened and why it has happened.

Sometimes AF can run in families (familial atrial fibrillation). Have a chat to adult children and close relatives about the early symptoms you experienced and encourage them to talk with their doctor about their risk of AF.

Sex and intimacy

People with atrial fibrillation often worry that exertion, either through physical or sexual activity, might trigger or worsen their symptoms. This can lead to people losing interest or confidence in being intimate or having sex. Sexual activity is part of a loving relationship and like other forms of exercise, is good for your heart and general health and wellbeing.

Atrial fibrillation can contribute to erectile dysfunction. If you are concerned about this, or are thinking about using medication to treat this (such as viagra), talk to your doctor first to check if it is safe for you to use.

Tackling negative thoughts

It really helps to spot negative thoughts and tackle them because they are often quite wrong.

For example, many people who have atrial fibrillation are worried about going out alone. So how can you tackle this negative thought?

Start by challenging it slightly by asking yourself how far you can go without feeling worried.



Managing your atrial fibrillation

You have an important role to play in the management of your atrial fibrillation. Your experience of atrial fibrillation will be unique to you, but there are things you can do to help you take control of your condition.

Keep a diary of your atrial fibrillation symptoms, episodes and treatments

A record like this can be helpful for you to learn more about your condition and you may be able to identify patterns in behaviour triggering an episode of atrial fibrillation. For example, some people find that drinking alcohol can trigger their atrial fibrillation.



“My AF seems to come about once a month, but too much vigorous exercise can trigger it for me. I remember once I was on a walk and I went the wrong way. I climbed up a big hill and I was really puffing and when I came home I got quite bad AF that night.”

Ralph

Think about applying for a MedicAlert bracelet

Making sure that the people around you are prepared with as much information about your condition and what to look out for is a good way to ensure you will get prompt attention if you have an atrial fibrillation episode.

Make the most of your time with your healthcare team

You'll have limited time with your doctor or nurse, so make a list of anything you want to ask before your appointment. During the appointment, ask questions if you don't understand what the doctor's saying or request a drawing if that would help. Before you leave, write down anything you are going to do next.

Planning for 'bad days'

You may find that there are days when, for one reason or another, your symptoms feel worse. It helps to plan strategies ahead of time to deal with these symptoms and to help get you through the day.

Problem solving

Think about what frustrates you about your bad days. What could you do to help solve the problem?

For example, when dealing with dizziness:

- find somewhere to sit down and take slow breaths. Ask someone to get you some water (or always carry a small bottle of water with you). Take your time and rest for as long as you need to feel better.

To help you deal with exhaustion:

- have frozen meals prepared so that you can simply reheat them.
- enlist family and friends to help you with chores or child care.

To help you deal with atrial fibrillation symptoms:

- sit down or lie down when you notice symptoms. Many episodes pass spontaneously.
- you may like to try putting some headphones on and listening to music to settle you down.

“When I went overseas last year with some friends, I made them cards with the phone number for the local ambulance and my travel insurance details, so they'd know what to do if anything happened.”

Nikki



Lowering my risk and staying well

AF is a common heart rhythm condition, which can increase the risk of stroke and heart failure. For many it is a life-long condition, there are choices you can make to reduce the impact on your wellbeing and reduce your risk of other heart events.

There are a number of factors that are known to increase your risk of heart disease. These are called risk factors. The more risk factors you have, the greater your chance of developing further heart disease. Some risk factors you can't do anything about, including age, ethnicity, gender, personal or family history of heart attack or stroke. But there are other risk factors that you can change.

Choices you can make to lower your risk of further heart disease



Stop smoking



Take medications



Lose weight



Make heart healthy eating and drinking choices



Move more

Stop smoking

Becoming smokefree is the best thing you can do for your heart.



You are more likely to successfully stop smoking if you get help. Using stop smoking services and medications can double your chances of being smokefree in the long-term. Talk to your doctor, nurse or pharmacist about options to help you quit.



Phone, online and text-to-quit



Local one-on-one or group support programme



Patches, lozenges and/or gum



Other medications

Take medications

Remember to ask questions about the medications you are taking.



There are things you can do to help you remember when you need to take your medications.



Set reminders on your cellphone



Talk to your pharmacist about a blister pack

Lose weight

Losing weight can help you to manage your atrial fibrillation symptoms.



There's increasing evidence that if you're overweight, weight reduction can reduce the frequency and severity of your AF symptoms.



Use a small plate rather than a big one



Swap a can of fizzy to water



Keep a food diary to help you keep on track



Cut down on alcohol



Try walking or biking to work one day rather than driving



For more ideas, check out the tips for heart healthy eating and moving more on page 30

"I used to eat a lot of rubbish, pies and fish and chips and stuff like that. I'm into real good tucker now. I think that's made quite a difference to me, I've lost about five kilograms." - **Ralph**

Move more

Getting more active can be simple. Why not try one of these ideas each day?



Take the stairs not the elevator



Get off the bus one stop early and walk



Talk to your doctor or nurse about a green prescription



Deliver a message to a co-worker in person instead of sending an email



Catch up with friends during a walk instead of by phone



Turn up the music and dance while doing household chores

Make heart healthy eating and drinking choices

Healthier eating can be easy. Why not start by taking one simple step?



Add one piece of fruit to breakfast or lunch



Add one more vege to dinner



Switch to lite blue, green or yellow top milk



Swap from white bread to whole grain



Cut the fat off meat and skin off chicken



Swap butter or ghee to oils or margarine

"I'm a little more conscious about what I'm eating, and make sure I read food labels. I also watch how much I drink, because I enjoy a drink so I've got to be careful about that." - **Bill**

Stroke warning signs

**AT ANY SIGN OF STROKE
CALL 111**



STROKE HEART FOUNDATION 50 years of prevention 50 years of research stroke.org.nz

If you see any of these signs, call 111 immediately. Getting help fast means a better chance of recovery.

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Questions or concerns?

The Heart Foundation has a heart health enquiry service. If you have any questions or concerns about atrial fibrillation, please get in touch with us:

- email hearthealthinfo@heartfoundation.org.nz
- or phone **0800 863 375**

For videos, stories and more information about staying well with atrial fibrillation, visit our website

www.heartfoundation.org.nz/af

Hearts fit for life

The Heart Foundation is the charity that works to stop all people in New Zealand dying prematurely from heart disease and enable people with heart disease to live full lives.

Visit our website **heartfoundation.org.nz** to find out how to:

- join information and support sessions
- share your story
- ask questions.

If you would like to help people in New Zealand who are living with heart disease, please consider donating.

To donate:

Visit: heartfoundation.org.nz/donate

Phone: 0800 830 100

Heart Foundation, PO Box 17160, Greenlane, Auckland 1546

T 0800 863 375 **F** 09 571 9190 **E** info@heartfoundation.org.nz

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As a charity, we thank our generous donors for helping bring this resource to life.

