

Staying well with heart valve disease



Welcome

to this Heart Foundation booklet

If you have this booklet then, like many other New Zealanders, heart disease has touched your life. Whether it's you or a loved one who is looking to find out more about heart valve disease, you're 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, nurse or pharmacist about any questions or concerns you have as well.

My checklist to help me stay well with heart valve disease

- ☐ I understand my condition
- ☐ I understand my medications
- ☐ I can recognise when my symptoms are getting worse and know what action to take
- ☐ I know who to contact for care and support.

Acknowledgements

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We also wish to acknowledge everyone in the clinical community who provided input into the design of this booklet.

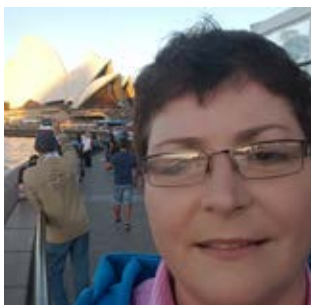
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You're not alone

There is support available to help you stay well with heart valve disease. Your family/whānau, your loved ones, health professionals and the Heart Foundation are here to help you through your journey.

Although your journey will be unique, you're not the first person to face heart valve disease. Remember there are many others in New Zealand who have walked a similar road before you.



When **Julie** found it harder to climb the 75 steps to her house in Wellington, she thought her childhood asthma was coming back.

Tests revealed that her aortic and mitral valves weren't closing properly (regurgitation), the result of rheumatic fever, and she was going to need surgery.

Anne had been getting very breathless, and started going regularly to a doctor.

"She thought she could hear a heart murmur, and referred me to cardiology. One of my valves was severely leaking and the other one was not bad, but not in good shape."



Pete recently celebrated the 11th anniversary of his heart valve replacement with a 101km bike race.

Back in 2005, Pete noticed that his heart 'went nuts' when he cycled uphill, forcing him to rest. A regular check-up with his GP revealed a severely leaking mitral valve.

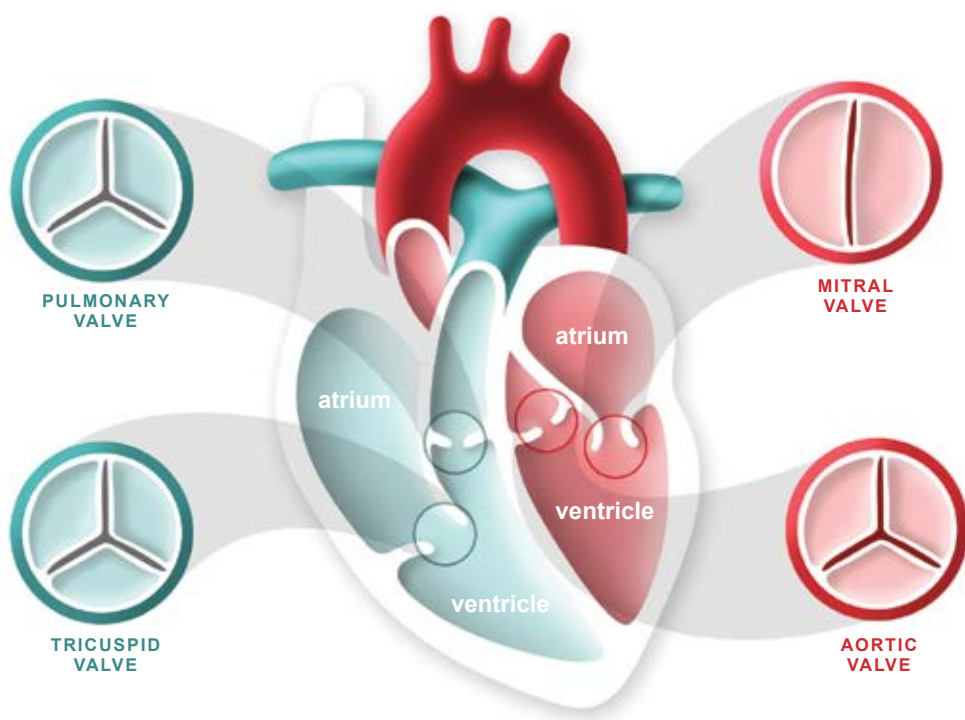


To read the full stories visit
heartfoundation.org.nz/journeys

About heart valves

Your heart is a pump with four chambers and four valves. Each valve is a flap that acts like a one-way door to make sure enough blood flows to every part of the body, including the heart muscle.

There are four valves in the heart. The mitral and tricuspid valves control blood flow from the collecting chambers (each called an atrium) to the pumping chambers (ventricles). The aortic and pulmonary valves control blood flowing out of the heart.



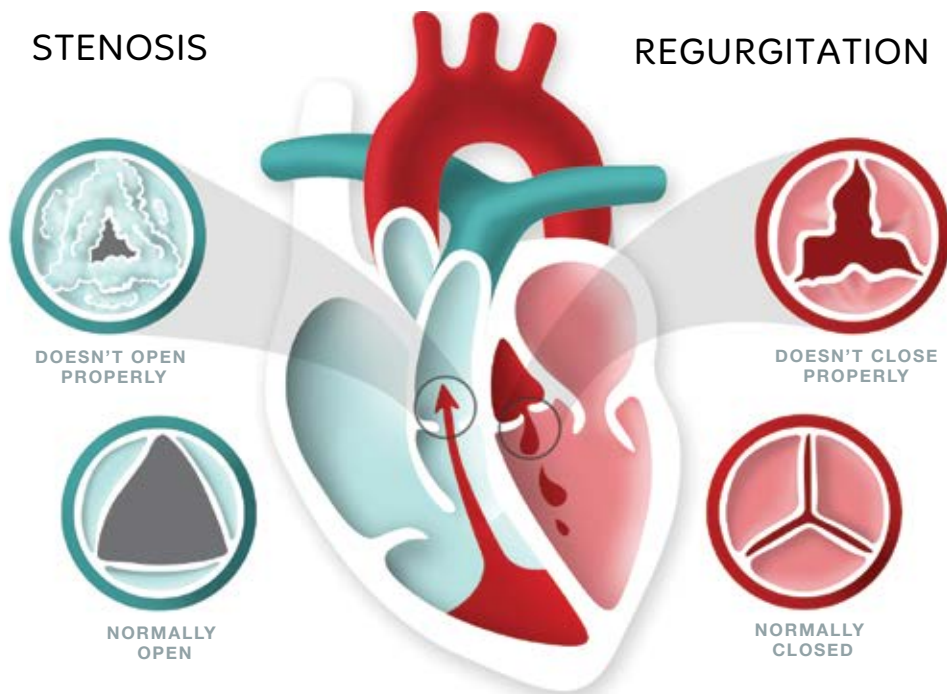
A **murmur** is a sound that can occur when blood flows through a heart valve that doesn't open or close properly.

Types of heart valve disease

When a valve is damaged, it means your heart has to work harder to deliver oxygen-rich blood around your body. There are two common types of heart valve disease: stenosis and regurgitation. Some people may have a combination of both.

Stenosis is when your valve **doesn't open** properly. This means pressure and blood can back up, causing strain on your heart.

Regurgitation is when your valve **doesn't close** properly (insufficiency). This lets blood leak back through your valve, rather than forcing it in one direction only.



Symptoms of heart valve disease

Tiredness



Heart palpitations



Shortness of breath



Swollen ankles



Chest pain



Dizziness



The strain on your heart from leaky or narrowed valves can cause further complications such as **heart failure**, where your heart muscle is weak or stiff and doesn't pump or fill normally. If you notice increased shortness of breath, ankle swelling or sudden weight gain, contact your doctor or nurse for a heart check-up.

Kerri was used to being breathless, but after the doctor heard a heart murmur, she was put on the waiting list to see a cardiologist.

"My legs started swelling and when they stayed swollen overnight I went to hospital. They said I was in the final stages of heart failure, and I had two weak heart valves."



Causes of heart valve disease

We are not always sure what has caused your heart valve disease, but common causes are:

- congenital heart disease (being born with a damaged valve)
- valvular damage and scarring due to rheumatic fever
- ageing of the heart valves
- infection of the heart valves (endocarditis).

Heart tests

You're likely to need some tests to find out more about the condition of your heart. Common tests include:



using a stethoscope to listen for a heart murmur



electrocardiograph or an ECG (looking at the electrical activity of your heart)



chest x-ray



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



coronary angiogram (using dye to get special x-ray pictures of your arteries).

You may also need a CT scan of your chest (looking at size and shape of your aorta, the main blood vessel leaving the heart).

Jeanette had thought she was just getting older when doctors diagnosed her with several heart problems.

“I had an enlarged heart and a heart murmur. Tests showed that my mitral valve wasn't functioning properly and 60% of the blood was leaking back through my valve.”



Treatments for valve disease

Many people with heart valve disease need little or no treatment and can have a good quality of life for many years. Regular check-ups including an echocardiogram may be all you need.

The sort of treatment you need depends on:

- which valve(s) is affected
- how many valves are affected
- how badly the valve(s) is affected
- how well your heart muscle is coping
- your symptoms and general health.

Common treatments

Common treatments for heart valve disease include:

- taking medications
- open heart surgery to repair or replace a valve
- transcatheter aortic valve implantation (TAVI).

Sometimes you may need a combination of these treatments.

Your heart specialist may recommend that you have a procedure even if your symptoms seem mild or if you don't have any symptoms. This may help prevent further damage to your heart muscle.

A note about pregnancy

Did you know that when you're pregnant, your heart has to work 50% harder all day every day? The heart's hard work starts very early in pregnancy and keeps increasing until about seven months pregnant. Ten extra beats a minute doesn't sound very much but that is 14,000 extra beats a day. That's a lot!

If you know you have heart valve disease, you should have a heart check-up before you get pregnant. Make sure you tell your midwife and doctor about your heart condition. Depending on how badly your heart valves are damaged or if you have had surgery, you may need extra monitoring and sometimes treatment to make sure you and your baby stay healthy throughout the pregnancy.

Sometimes it's only after you're pregnant that valve disease is discovered. In these cases, it's usually possible to continue with the pregnancy under close medical supervision. If needed, you may have valve surgery while you're pregnant.

Your plans for the future may impact on your choice of treatment. For example, if you would need to be on anticoagulant medication in the long-term it would make any bleeding harder to stop, meaning any pregnancy would be higher risk.



Kerri had mitral stenosis and tricuspid regurgitation so ended up having two valve replacements.

“My tissue valves only last 10-15 years. The main reason I chose to have the tissue valves was because if we decide to have another child, it would have been a bit too hard if I were on warfarin.”

Preparing for a valve procedure

In heart valve surgery your surgeon repairs or replaces the affected heart valve(s). Many surgical procedures may be used to repair or replace heart valves including open heart surgery or minimally invasive heart surgery.

Open heart surgery to repair or replace a valve is performed under a general anaesthetic. A small cut is made down the middle of your chest, through the sternum, to reach the heart. From here, either the damaged valve is repaired or it's removed and an artificial valve is sewn into its place. The entire surgery usually takes between two to six hours.

Minimally invasive procedures like transcatheter aortic valve replacement (TAVI) make smaller incisions, involve shorter hospital stays and have quicker recovery times.

Before surgery

To lower your risk of developing an infection in the lining of your heart (endocarditis), you need healthy teeth and gums with no sign of infection. You will have a full assessment of your teeth and gums and any necessary dental work completed before your heart valve surgery. This helps to prevent bacteria and fungi from entering your bloodstream and reaching your heart.

Following surgery

You will usually stay in hospital for five to seven days after your surgery. Your doctors and nurses will advise you when you can go home.

Before returning home after open heart surgery, make sure someone can look after you for between seven to ten days after discharge. If there is no one to take care of you, tell the nurses and they will arrange for someone to talk to you about care options.

Heart valve repair

Valve repair is most often used for leaking mitral valves but other valves can also be repaired. A repair is recommended only if the surgeon believes the procedure is likely to restore acceptable, long-term function.

“By lunchtime, the team had opened me up, tried to repair my valve, tested it, found it still didn’t pass the pressure and leakage tests, removed and replaced it with a new valve and stitched me up. Not a bad morning’s work.”

Pete



Whether you’re offered a valve repair or replacement depends on the type of valve affected and how badly it’s affected. You may be referred to a larger hospital for the right treatment for you.

Transcatheter aortic valve implantation (TAVI)

A transcatheter aortic valve implantation is a way of putting in a new valve without removing the old damaged valve. This procedure is currently used when open heart surgery may be too risky for an individual. It is likely that this procedure will be used more frequently.

The TAVI approach delivers a fully expandable replacement valve to the valve site through a catheter, usually inserted into the artery in the groin. Once the new valve is expanded, it pushes the old valve out of the way and the tissue in the replacement valve takes over working as a valve.

Heart valve replacement

Valve replacement is when a diseased valve is replaced with another valve. There are two main types of replacement valves.

Mechanical valves are usually made of special ultra-smooth carbon.

These valves tend to last longer, but there is a risk of blood clots developing on the surface of the valve. To help prevent this, you will need to take an anticoagulant medication e.g. Warfarin for the rest of your life. You may also be on low dose aspirin.

Tissue valves are human or animal valves.

Valves taken from a pig or cow are mounted on a cloth-covered metal or plastic frame to make them easier to insert. Human valves are from a donated human heart.

Because these valves are made from natural tissue, you won't need to take anticoagulants for life, although you're likely to need them for a short period after surgery until the valve has settled in.

Your surgeon or cardiologist will discuss the benefits and risks of a mechanical or tissue valve with you, taking into account your age and other medical history.



Julie has noticed that her mechanical valves make quite a bit of noise.

“They tick, it sounds like a cheap watch, and you hear this tick, tick, tick, constantly...”

“I had a bit of trouble in the beginning getting used to the sound, but I got used to it over time. I would tell myself that it's ticking, so that's a good thing.”

Risks of a valve procedure

As with all medical procedures, there are both benefits and risks associated with having heart valve repair or replacement surgery. It's possible that during or shortly after the procedure, you may experience complications.

Major complications may include heart attack, stroke, an infection in the lining of your heart (endocarditis), wound infection or death.

Occasionally after heart surgery you may experience some complications. If you experience any of the following, please contact your doctor immediately:

- temperature higher than 38°C, chills, flu-like symptoms, feeling hot and cold, heavy or night sweats
- irregular heartbeats
- increased shortness of breath, ankle or leg swelling, or sudden weight gain
- wound infection
- pain that's getting worse.

You may also end up needing:

- a blood transfusion
- a permanent pacemaker implanted to correct slow or irregular heartbeats
- fluid to be drained from around the heart or lungs
- to return to the operating theatre due to bleeding.

Other complications may include:

- blood clots (more likely on mechanical valves)
- further valve damage (more likely with tissue valves)
- high blood pressure.

Your surgeon or cardiologist will discuss with you the possible risks from a procedure, taking into account your age and medical history. There may be other risks depending on your medical condition.

Medications

There are medications that can help manage heart valve disease without needing a surgical procedure. These medications help to control symptoms and prevent further damage.

Medications are used:

- to control symptoms
- after heart valve surgery, medications can help prevent a clot forming on your heart valve.

Key points about your medication

- Keep taking your medications regularly and make sure you don't run out - ask your GP for repeat prescriptions. If you do forget to take your medication, don't try to 'catch up' by taking extra tablets next time.
- Keep a list of your medications with you. You'll need this at hand when you go to see your doctor, specialist, pharmacist, dentist or to the hospital.

Make sure you feel confident with how best to take each of your medications. If you're unsure, keep asking until you understand.



If you have concerns about what your medications might be doing to you, talk to your doctor, nurse or pharmacist. Don't suddenly stop taking your medication as this may make your condition worse.

Medication	Why take it?	How does it work?
Anticoagulant e.g. warfarin, aspirin	Helps to prevent a heart attack or stroke	Helps to prevent clotting on the valve
Diuretic e.g. frusemide, bumetanide	Helps improve symptoms like shortness of breath and swelling	Helps your body get rid of excess fluid
ACE inhibitor e.g. cilazapril, enalapril	Improves heart function Helps improve symptoms Lowers blood pressure	Makes it easier for your heart to pump blood
Beta blocker e.g. metoprolol, carvedilol, bisoprolol	Improves heart function Helps control irregular heart rate Lowers blood pressure	Makes your heart beat slower and work more efficiently

If you're taking warfarin, please ask your doctor or nurse about alcohol and any foods that can interfere with this medication.



To learn more about your medication, search:
heartfoundation.org.nz

Recovering after valve surgery

Returning home

Following surgery, recovery will take four to six weeks. Your sternum takes six to twelve weeks to heal completely. **Avoid lifting heavy objects and doing movements that place stress on your chest area.** Supporting your chest with a small cushion while coughing or moving can reduce the physical strain on your chest.

To help you recover at home, your cardiac rehabilitation nurse will help you set realistic goals for resuming household chores, exercise, driving, employment, eating well and taking your medications. A cardiac specialist nurse will contact you either whilst you're still in hospital, or once you're home.

Metal detectors and electronic equipment

The amount of metal used in mechanical and tissue valves is very small. Normally, if you pass through a metal detector it shouldn't set off the alarm. Metal detectors will not harm your heart valve.

Mechanical heart valves are made of materials that will not be affected by CT scans, X-rays or MRI equipment. Other devices such as microwave ovens and mobile phones will not affect your new heart valve.

Follow-up care is important

About six weeks after your surgery, you will have a check-up with your doctor and/or cardiologist including an echocardiogram (ECG) to test how well your heart valves are functioning. This check-up is a chance for you to ask any questions you may have. If at this stage you haven't yet been contacted by a cardiac rehabilitation nurse specialist, ask your cardiologist for their contact details so you can follow up with them.



Ask your doctor or nurse for information about cardiac rehabilitation. You can also find contact details at heartfoundation.org.nz/cardiac-rehab or by calling the Heart Line on 0800 863 375.

Talk to your doctor or nurse about cardiac rehabilitation

Cardiac rehabilitation can involve education, exercise, emotional support and information on medications and medical treatments.

Taking part in cardiac rehabilitation will help you understand what has happened to you and help your recovery. It will help you adjust to life after hospital, learn more about what you can expect in the near future, and give you the chance to ask any questions you may have.

Your cardiac rehabilitation classes are a good chance to ask about examples of the sorts of physical activity that are right for you as you progress through your recovery.

Evidence suggests that doing cardiac rehabilitation can help you get fitter, return to work and other activities sooner, and lower your chances of having chest pain and anxiety.

There are usually three phases of cardiac rehabilitation:



in hospital (phase one)



at home (phase two)



community support (phase three).

Note that unfortunately, phase two and three cardiac rehabilitation are not always available in all areas.

“I joined a cardiac rehab group. I was the youngest by a good thirty years, but it was helpful for me to see where I was at and to realise that everyone recovers at a different pace.”

Anne



Getting active again

The first few days, and even weeks, at home after a heart valve procedure may be difficult. You may wonder what is safe to do, whether you should be going out and about, and when you can start exercising.

There are no hard and fast rules to answer these questions – each person will feel differently, it depends on your heart condition and what life was like for you before your surgery. Full recovery can take between six to eight weeks, but the sooner you start getting active again, the sooner you will be able to return to your normal work and leisure activities.

Activity improves your physical and mental health and will give you more energy. It will help train your heart muscle to pump more efficiently and can improve your circulation and cardiovascular fitness.



Together with your doctor, nurse or physiotherapist, talk about the types of activity you like to do and work out an activity plan that is right for you. Progress at your own rate, and try to get a good balance between rest and activity.

Warning: NO HEAVY LIFTING

If your sternum has been surgically broken and rewired together, it takes six to twelve weeks to heal completely. Supporting your chest with a small cushion while coughing or moving can reduce the physical strain on your chest wall.

Exercise is an important part of your recovery. It should feel light, and you should stop for a break if you're tired. A good place to start is with gentle lower-body exercise like walking. It's just as effective to do several short walks in a day to start you off, rather than one long walk. Gradually increase your distance, time, frequency and intensity over several weeks, working toward 30 minutes a day.

What about general housework?

Light housework that doesn't put any strain on the healing breastbone is fine. Preparing meals, doing dishes and light dusting is a good starting point. Family or friends are recommended to assist with vacuuming, hanging out the washing etc. Your GP can arrange assistance if there is no one to help at home.

When can I play sport?

Check with your cardiologist before doing contact sport or sports that require severe loads on the heart (e.g. squash, weight lifting, rugby), as these activities are not usually recommended in the recovery phase.



“You feel like you want to do a lot of things. In your mind you think you can. It's pretty tough taking it as quiet as you're told, but you soon learn that the advice is correct. You just have to help yourself slowly build up without overdoing it, and remember to stay active.”

Pete

Sex after heart valve surgery

Most people can safely return to sexual activity after heart surgery. Many people worry that sex will put too much stress on their heart and cause damage.

It's important to discuss your feelings and concerns with your partner.

If you can climb two flights of stairs without getting chest pain or shortness of breath, you will probably be able to cope with the amount of energy needed for sex.

Find a position that is comfortable and avoid positions where your arms are supporting your body weight.

Tablets for erectile dysfunction should not be used with GTN spray. Taken within 24 hours of each other, this combination of medications can cause a large drop in blood pressure resulting in dizziness, fainting or even a heart attack.

Mental and emotional recovery

You may experience the ‘cardiac blues’ after leaving hospital, with uncertainty, fear and other negative thoughts and feelings. This is a common part of recovery, especially when you first arrive home from hospital. The negative thoughts and feelings tend to pass within three months or so.

At the start of your recovery you may also notice extreme emotional highs and lows, but after about six weeks these emotions tend to balance out again to little highs and lows.



“One of the things I had to deal with on a spiritual and emotional level, was that I’d had my chest split open and someone has held my heart in their hands.

“These thoughts were soon dispelled with the reality that the hands that had held my heart, had saved my life.”

Julie

“I had the heart valve repair and all went well, but I did struggle with my recovery.

“I try to be active by joining different groups. It’s very easy to think, I can’t be bothered doing something. Sometimes you can get into a big black hole. You’ve really got to work hard at getting out of that. You’ve just got to get out and about and be with people.”

Jeanette



Stress, worry and feeling sad

One of the best ways to manage worry and to prevent the build-up of stress, is to regain balance in your life.

You may like to make a list of things that will keep you busy. Set time aside for them and do them, even if you can't see the point right now.

Each day, make sure you:



Do some form of physical activity



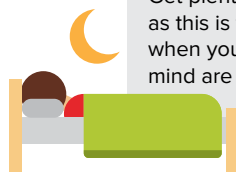
Have some rest and relaxation time



Include some enjoyable activities, especially those that make you laugh



Do some form of work where you feel useful, productive and gain a sense of achievement



Get plenty of sleep as this is the time when your body and mind are restored



It also helps to talk with others – your family, whānau or people who have gone through a similar experience. Sharing the experience helps to remind you that you are not alone



If you still aren't feeling right three months after leaving hospital, ask your doctor or nurse about what support is available.

“At first I found the scar terrifying. Quickly though I owned it as part of who I was now. That mind shift was important.

“I am no longer the athlete I once was - it’s been a huge identity shift for me. I’m a different person. And that’s okay. It’s just taking some time to realise acceptance.”

Anne



Regaining confidence

Sometimes it takes time for you to regain your former confidence. A good way to get started is to use goal setting.

For example, if you’re anxious about going out for a walk on your own, start with a small goal like walking to the edge of your garden, or to the letterbox. Once you have done that a few times, set a larger goal like walking to the end of the street.

Gradually increasing your goal can help you to build up your confidence again.



Getting behind the wheel

You can be a passenger in a car straight away, but it will be at least four weeks before you can drive again after valve surgery. Different rules may apply depending on the treatment you have had, if you hold a vocational licence and if you drive passenger vehicles, trucks, forklifts, courier vans, fly aeroplanes or skipper boats.

You may need to have an assessment by a specialist before returning to driving. It also pays to check with your insurance company to ensure that you're fully covered.

Anyone who holds a commercial licence must check their medical legal requirements are satisfied before returning to work.



Returning to work

How soon you can return to work depends on the nature of your job and your personal rate of recovery. Talk to your doctor about the timing that will work best for you.

Generally people return to work between six to twelve weeks after surgery.

It's worth taking some time to think about how your heart condition will affect you in the workplace. Will you be able to do exactly the same sort of work you used to do? Will you need to work fewer hours? Will you need to learn new skills?

It's normal to feel tired when you get back to work after your heart surgery. One way to reduce fatigue is to include the type of activity you do at work into your home physical activity programme. You may also wish to speak with your employer or occupational health team about other options, such as a gradual return-to-work programme.

Staying well

Preventing heart valve infection

Endocarditis is a rare but serious condition, where the lining of the heart becomes infected after bacteria enter your bloodstream. It often affects the tissue surrounding a new heart valve.

Avoiding endocarditis

- Look after your teeth. Make sure you have regular six-monthly dental checks and brush your teeth with toothpaste twice a day.
- Avoid body piercing and tattooing.
- Don't inject any drugs that have not been prescribed.
- If you have any signs of infection, report it to your doctor straight away so you can get treatment quickly.

How to recognise endocarditis

If you experience flu-like symptoms with a high temperature, you should see your GP as soon as possible and tell them you have had a heart valve procedure. If not treated quickly, endocarditis can be life-threatening but with early diagnosis, most people recover well with antibiotics.

Dental and other procedures and testing

Heart valves can sometimes get infected during certain types of dental work and operations. You may need extra antibiotics to help protect your heart (from infections like endocarditis). This is why, before having any medical or dental testing or procedures, **you need to tell your doctor, dentist, dental therapist or dental hygienist that you have had heart valve surgery.**

Recognising depression

Often after valve surgery, people do not recognise the warning signs of depression in themselves. These include:

- lack of energy
- lack of motivation
- lack of enthusiasm to do anything.

In the short-term, these can be common effects of surgery, but if you notice any of these warning signs lasting longer than twelve weeks, it's time to ask your doctor about additional support that may be available.



"I can empathise with people who experience some depression. There have been times after open heart surgery when I've thought that life isn't going to be the same again and my best years are behind me.

"But I've now done more Forrest Graperides with my new valve than I ever did with my old one."

Pete



For information and support, visit: **depression.org.nz** or **mentalhealth.org.nz**

Stopping 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

What about e-cigarettes?

Current research suggests vaping (or using e-cigarettes) is a less harmful alternative than conventional cigarettes and can help you quit.



Phone Quitline on **0800 778 778** or visit **quit.org.nz** for more information about support to stop smoking.



“I’ve really learnt to eat healthy, and exercise – I’m more of a leisure walker, my husband helps motivate me. We do a lot of outdoor things as a family.

“I used to smoke, but it’s been four years now since I’ve given up smoking.

“It’s a change for the good. I suppose you sometimes need a scare to give you a bit of life perspective.”

Kerri

Make heart-healthy eating and drinking choices

Heart-healthy eating is all about balancing the different types of food you eat to get a range of nutrients. Try balancing your day's eating like this:

**eat
most**
vegetables
& fruit

eat some
grain foods &
starchy vegetables

legumes, fish, seafood,
eggs, poultry & meat

milk, yoghurt
& cheese

healthy oils,
nuts & seeds

CUT BACK ON junk foods, takeaways & foods or drinks high in sugar, salt or saturated & trans fats

Follow these simple steps to help you make realistic changes to what you eat and to improve your heart health.

1

Share and enjoy meals with family and friends that focus mostly on foods close to how they are found in nature.



2



Include plenty of colourful non-starchy* vegetables and/or fruit at every meal and for most snacks.

3

Choose whole grain foods in place of refined grains.



4



Include some legumes, fish or seafood, eggs, skinless chicken or lean meat at one or two meals each day.



5

Use mostly reduced-fat or low-fat milk and milk products (or non-dairy options with calcium added).



6



Choose healthy oils, nuts and seeds instead of animal and coconut fats.



7

Drink water to quench thirst, and limit sugary drinks and alcohol.

8



When preparing meals, snacks or drinks, use pepper, herbs, spices or fruit to add flavour rather than using salt or sugar.

9

Cut back on junk foods, takeaways and foods high in sugar, salt or saturated and trans fats.



*Does not include starchy vegetables like potatoes, Māori potatoes, kūmara, corn, parsnip, yams, cassava/tapioca, green banana and taro

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 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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