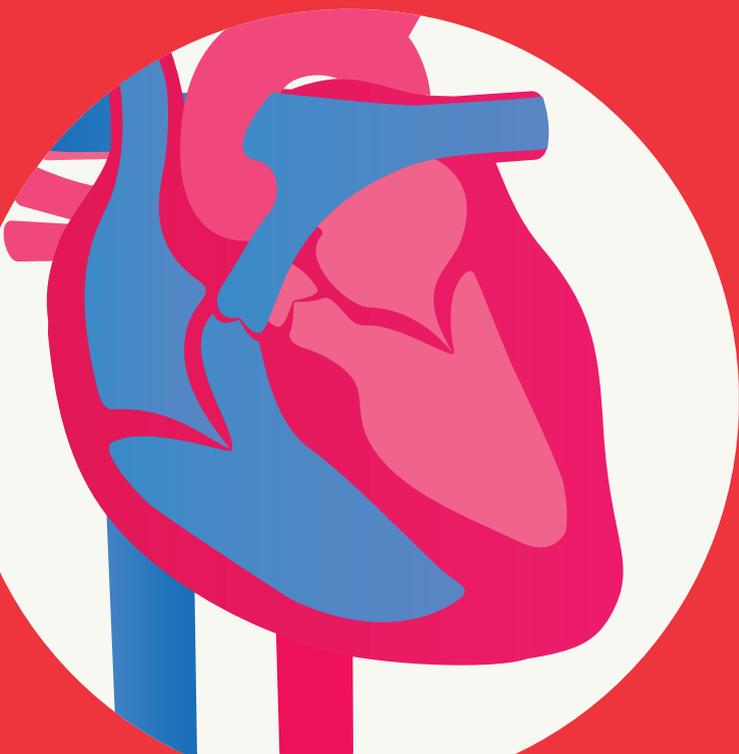


bhf.org.uk



Understanding heart valve disease



Large print

About this booklet

Being diagnosed with heart valve disease can be scary for you and your loved ones.

This booklet can help you find out:

- what it means to have heart valve disease
- how heart valve disease is diagnosed and treated
- how to live with a heart condition and where to get support.

It can feel overwhelming to be given lots of information about your heart. Please use this booklet when you're ready. There's no need to read it all at once.



Call 0808 802 1234 (freephone)
to speak to a cardiac nurse.
Our helpline is open weekdays
9am to 5pm (excluding bank
holidays).

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What is heart valve disease?

Heart valve disease is when one or more of your heart valves do not work like they should. This affects how blood flows around your heart and means your heart has to work harder than normal.

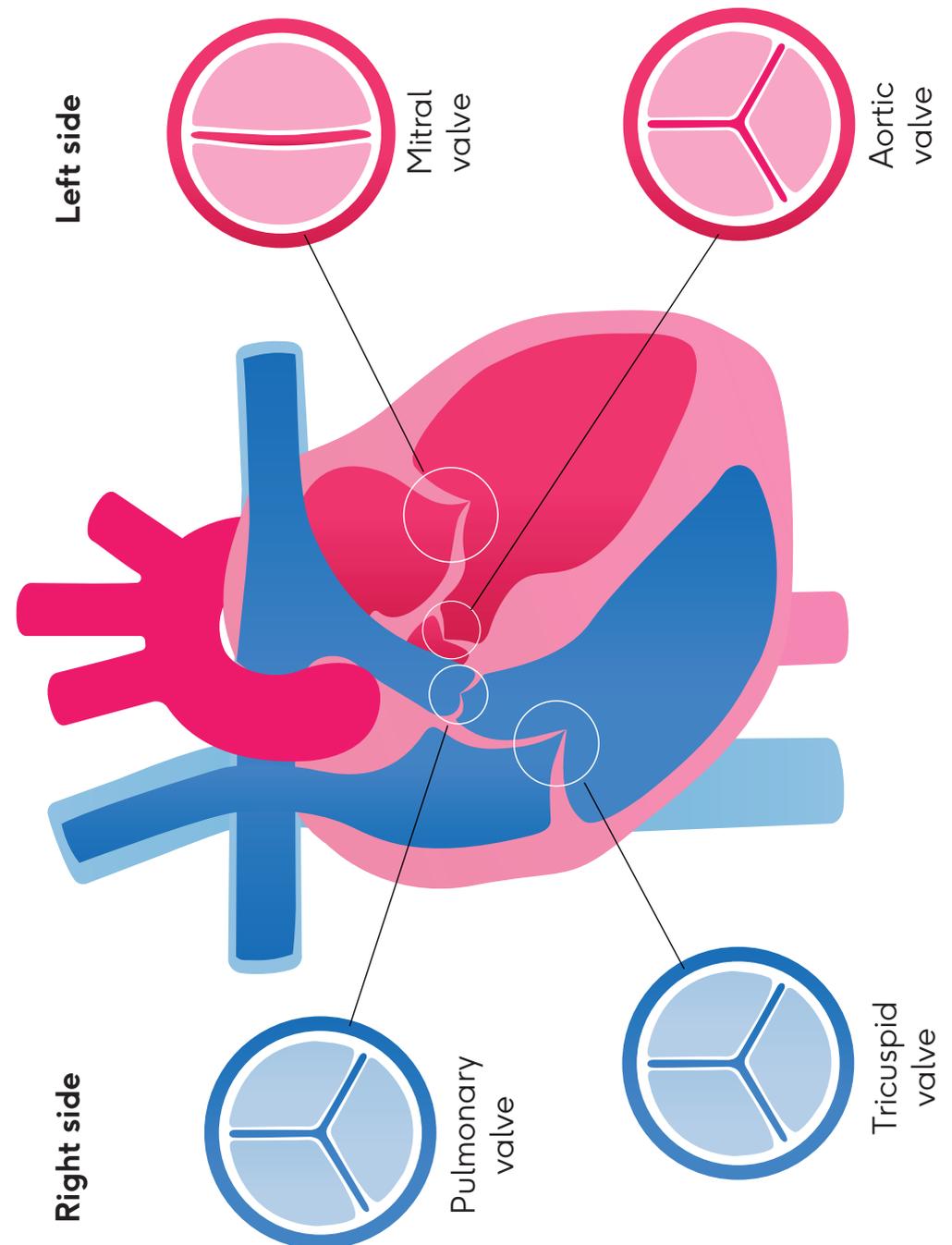
What do your heart valves do?

Your blood flows around your heart and the rest of your body in one direction, like a one-way traffic system.

Your heart valves control the direction of your blood flow. They have very small flaps of tissue (called leaflets or cusps) that open and close like doors with every heartbeat.

They stop the blood flowing backwards.

There are four valves in your heart (see page 5).



What can go wrong with my heart valves?

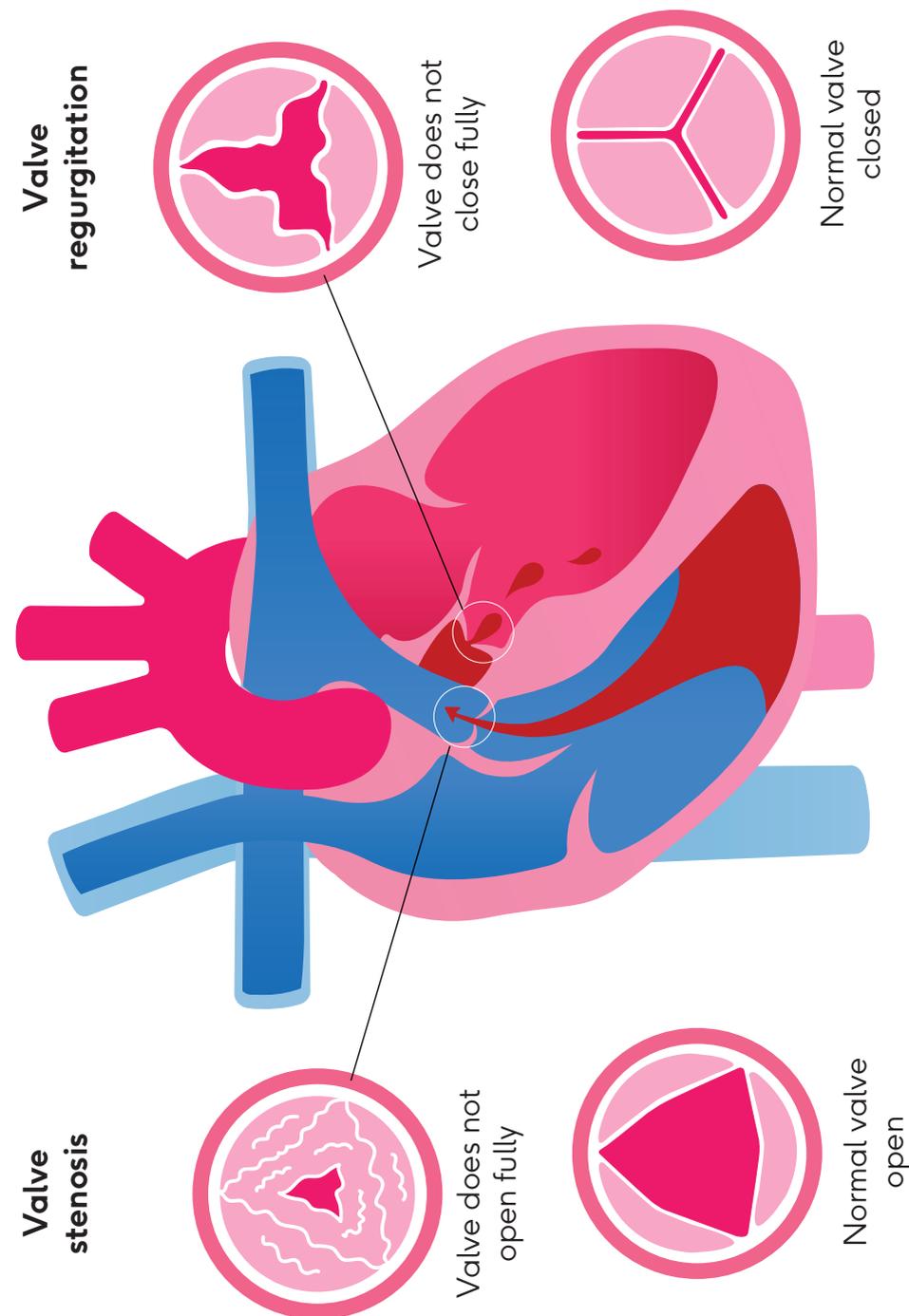
There are different types of heart valve disease.

The main problems are caused by the valve not opening or closing properly.

- **Valve stenosis or narrowing** means the valve does not open fully and it can block or restrict the flow of blood.
- **Valve regurgitation, incompetence or a leaky valve**, means the valve does not close fully and the blood can flow backwards into the heart instead of forwards into the body.
- **Valve prolapse** means the valve becomes floppy and does not close fully.

It's more common to have problems with your aortic or mitral valves.

These problems can put extra strain on your heart and make your heart work harder.



What is my heart valve disease level?

When you're diagnosed with heart valve disease, you may hear your doctor describe it as mild, moderate or severe.

- **Mild** – you may not need treatment but you should have a cardiology appointment and a scan of your heart every three to five years. You may be given medicine to help your heart work better and improve any symptoms.
- **Moderate or severe** – you may have treatment. You'll also have a cardiology appointment and a scan of your heart every 6 to 12 months. If you have ongoing symptoms, you may have appointments more regularly.

Talk to your doctor about what level your heart valve disease is and what this means for you.

Can heart valve disease lead to other problems?

Having heart valve disease puts extra strain on your heart and it means your heart has to work harder.

Over time, it can increase your risk of having:

- a heart attack
- a stroke
- heart failure
- arrhythmias (abnormal heart rhythms).

Find more information on these conditions on our website: [bhf.org.uk/conditions](https://www.bhf.org.uk/conditions)

What causes heart valve disease?

The main causes of heart valve disease are:

- getting older
- damage to your heart muscle from a heart attack
- conditions that affect your heart, like rheumatic fever, cardiomyopathy (disease of your heart muscle) and endocarditis (an infection in the lining of your heart and valves)
- being born with congenital heart disease.

Find out more about heart valve disease and its causes at [bhf.org.uk/heartvalvedisease](https://www.bhf.org.uk/heartvalvedisease)

Congenital heart valve disease

Some people can be born with problems with their heart valves. This is called congenital heart valve disease.

You should be managed by a hospital specialist or congenital heart disease team.

Find out more about congenital heart disease at [bhf.org.uk/congen](https://www.bhf.org.uk/congen)

What are the symptoms of heart valve disease?

Some people with heart valve disease have no symptoms. Other people may have one or more symptoms.

Doctors may hear a heart murmur (a swishing sound) when they listen to your heart with a stethoscope. This could be a sign that you have a heart valve problem.

Common symptoms include:

- feeling breathless
- chest pain or discomfort
- feeling weak or dizzy
- swollen ankles and feet
- being more tired than usual
- a fluttering or pounding feeling in your chest or neck (palpitations)
- getting more tired when exercising, for example walking up stairs can get more difficult.

Symptoms can be mild, moderate or severe.

When to get help

Call 999 if you:

- have chest pain that does not go away when you rest
- feel like you cannot breathe, even when you rest
- faint and lose consciousness.

Contact your doctor for an appointment if you have:

- symptoms that are getting worse
- new symptoms
- a high temperature (38°C or above) and there's no obvious reason why
- been sweating more than usual, especially at night
- lost weight and there's no obvious reason why
- been feeling unwell for two to three weeks.

How is heart valve disease diagnosed?

The most common test to diagnose heart valve disease is an echocardiogram (echo). There are different types of echocardiograms, and you may have more than one.

You may also have other tests or scans, such as:

- a chest X-ray
- an electrocardiogram (ECG)
- blood tests
- a cardiac CT scan
- a cardiac MRI
- an angiogram.

Read about these tests and what to expect at [bhf.org.uk/tests](https://www.bhf.org.uk/tests)

Ask your doctor about the tests they're recommending you have. They can answer any questions or concerns.

When you're having a test or scan, ask when and how you'll get your results.

If the tests show heart valve disease, you will usually be referred to a cardiology team for a specialist assessment.

Get support with your diagnosis

It's normal to feel anxious, sad or scared when you're diagnosed with a heart condition. Many people have good and bad days following a diagnosis.

Talking it through and finding out what to expect can help you and your loved ones to feel prepared. It might help to know you are not alone and there is support available.

Call the Heart Helpline

If you want someone to talk to, you can speak to our cardiac nurses. Your friends and family can also call if they want to understand what's happening or have questions.

Call **0808 802 1234** (freephone) or email **hearthelpline@bhf.org.uk**
Our helpline is open weekdays, 9am to 5pm (excluding bank holidays).

Find an online community

Our community on HealthUnlocked is a free online space for people with heart and circulatory conditions to share experiences and get support from one another.

Visit **healthunlocked.com**

How often should I have a cardiology appointment?

How often you have an appointment with your cardiology team depends on the level of heart valve disease you have, if you're having treatment and if you have any symptoms.

Generally:

- **Mild** – you should have a cardiology appointment and a scan of your heart every three to five years.
- **Moderate or severe** – you should have a cardiology appointment and a scan of your heart every 6 to 12 months.

It's important to go to your appointments even if you feel well so your doctor can check how your heart is working.

Contact your cardiology team or your GP if you have new symptoms, or your symptoms are getting worse.

How is heart valve disease treated?

Many people with heart valve disease need little or no treatment and can have a good quality of life for many years.

Treatments for heart valve disease can include:

- medicines
- surgery or a procedure to replace or repair your heart valve.

Talk to your doctor about the treatment they're recommending and why. You can be involved in the decisions about your treatment and care. Your doctors will help you choose the best option for you.

Medicines

Medicine, also called medical management, can be used to help reduce the workload of your heart. It can help your heart to pump enough blood and oxygen around your body.

Medicine can help:

- reduce your blood pressure
- keep your heart rate steady
- stop extra fluid building up in your body.

They also reduce the risk of your heart being damaged and improve any symptoms you have.

You may be offered medicine if your heart valve disease is mild or getting worse, or if surgery is not an option for you.

Your doctor will discuss what medicines they're recommending and why.

Find more information on medicines for heart conditions at [bhf.org.uk/medication](https://www.bhf.org.uk/medication)

Many people find it hard to take medicine every day. Try our simple steps to make taking medicine easier:

- Get into a routine and take it at the same time each day.
- Ask your pharmacist for a medicine organiser to help you remember to take them.
- Give your body time to get used to the medicine.
- Make sure you have enough medicine if you're going on holiday.
- Speak to your doctor or pharmacist about any other medicines you're taking.

If you're struggling with the side effects of your medicine, it's important not to stop taking it before speaking to a healthcare professional. Speak to your GP or a pharmacist.

You can also talk to one of our cardiac nurses (see page 56).

Surgery and procedures (interventions)

If your heart valve is not working properly, you may need surgery or a procedure. This could be to repair your heart valve or replace it.

You may hear surgery or a procedure being called an intervention.

The surgery or procedure you're offered can depend on:

- your age
- which heart valve is affected
- how well your heart is working
- any other medical conditions
- recovery time and how it will affect your daily life
- if you need other surgeries or procedures.

Your doctor can explain what surgery they're recommending and why.

Find more information on heart surgery in our booklet **Understanding heart surgery**. It contains tips to help you prepare and support for your recovery.

Order your free copy at **bhf.org.uk/publications**

You can also read more information on our website: **bhf.org.uk/heartsurgery**

Heart valve repair

There are different types of surgery to repair a heart valve.

- Making the heart valve stronger using a man-made ring to stop it leaking (**annuloplasty**).
- Clipping parts of the heart valve together to stop it leaking (**clip repair**).
- Repairing the chords that help support your heart valve to work properly (**chord repair**).
- Widening the heart valve if it's become narrow (**valvuloplasty**).

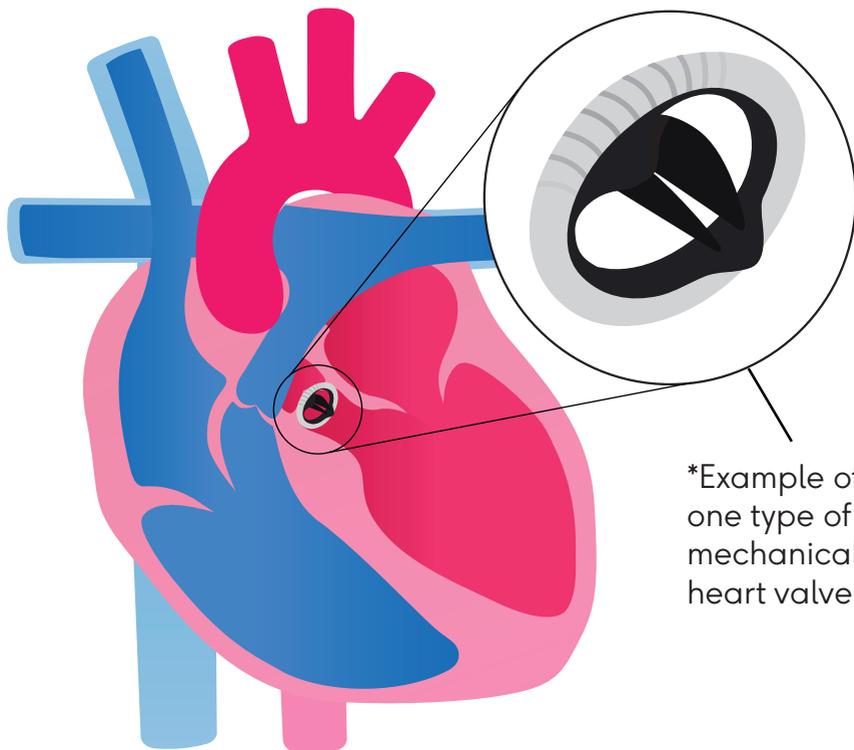
In some cases, during your surgery, your surgeon may find that your heart valve cannot be repaired, and it may need to be replaced. Your surgeon will talk to you about this before you have surgery.

Heart valve replacement

If you need heart valve replacement surgery, you'll usually have either a tissue (biological) or mechanical valve.

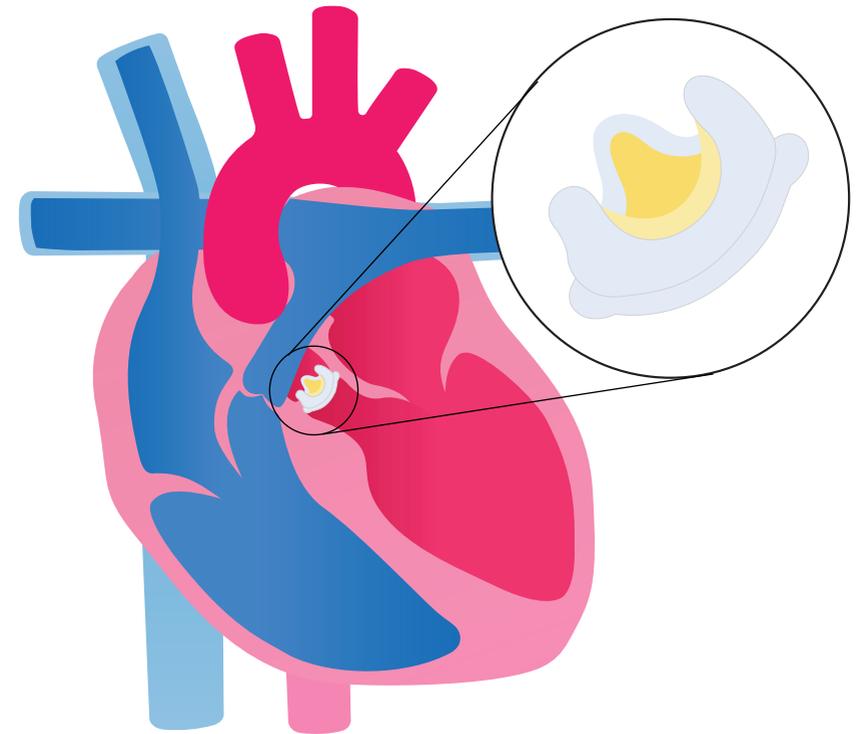
There are different types of tissue and mechanical valves. Find out the main differences between the two types of valves on page 28.

Mechanical valve



*Example of one type of mechanical heart valve

Tissue (biological) valve



Heart valve replacement is usually done as heart surgery, but some types of replacement can be done as a procedure (see page 36).

The difference between tissue and mechanical valves

Tissue (biological)

- Made from animal tissue, like the heart tissue from a pig or cow.
- Usually offered if you're over 60 years old.
- In most cases, you will not need to take a blood thinning medicine (anticoagulants) for the rest of your life.
- Can last an average of 10 to 20 years, but it can be shorter or longer.

Mechanical

- Made from carbon, a light and strong material.
- Usually offered if you're younger because it can last longer.
- You'll need to take blood thinning medicine (anticoagulants) for the rest of your life. This is because a mechanical valve can increase your chances of having a blood clot.
- Can last your lifetime.
- Can cause a clicking sound in your chest (see page 54).

Are there other types of replacement surgery?

You may hear about other types of surgery or procedures to replace your heart valve. For example:

- **Ross procedure** – your surgeon will replace your aortic valve with your own pulmonary valve. Your pulmonary valve is then replaced with a donated human tissue valve.
- **Transcatheter aortic valve implantation (TAVI)** – you will have a new tissue (biological) valve put in your heart to improve blood flow. Your old aortic valve is left in place, so you have the old valve and your new tissue valve.

Some other types of replacement surgery are only available at specialist centres. Your doctor or surgeon can speak to you about whether you have this option.

Read more about Ross procedure at [bhf.org.uk/valverepacement](https://www.bhf.org.uk/valverepacement)

Read more about TAVI at [bhf.org.uk/tavi](https://www.bhf.org.uk/tavi)

How long will my heart valve last?

These timings are just a guide. Everyone is different.

- Tissue valves usually last 10 to 20 years.
- Mechanical valves can last for your lifetime.

How long your valve lasts and when it needs replacing will depend on your individual situation. Speak to your doctor for more information.

Which heart valve should I have?

If you're offered the choice between a mechanical or tissue valve, it's your personal choice which one you have. Some people may not be offered the choice if one valve is more suitable.

Things you may want to consider when choosing:

- **Age** – if you're younger, a mechanical valve will last longer. However, you will need to take blood thinning medicines for the rest of your life. If you're older, you may prefer a tissue valve as it can last your lifetime.
- **Clicking noise** – the mechanical valve makes a clicking noise when it's working. Some people find this reassuring to know it's working, but for other people it can be quite disruptive until they get used to it (see page 54).

- **Blood thinning medicines (anticoagulants)** – if you have a mechanical valve, you'll need to take blood thinning medicines for the rest of your life. You may also need regular appointments, usually weekly, to check your blood (see page 41).

There are certain medicines you cannot take with blood thinning medicines (see page 43). Speak to your doctor about the impact this may have on your life.

- **Your lifestyle** – if you're young and do a lot of physical activity, a tissue valve can wear out quicker. This may mean you need another surgery in the future.

It can help to talk things through with someone. You can ask your doctor about the advantages and disadvantages of each valve. You could also speak to friends and family.

If you need someone to talk to, you can call our cardiac nurses.



Call 0808 802 1234 (freephone)
or email hearthelpline@bhf.org.uk
Our helpline is open weekdays,
9am to 5pm (excluding
bank holidays).

Different surgical approaches

Whether you're having your heart valve repaired or replaced, there are different ways the surgeon will do this.

- **Minimally invasive procedures** – normally done using smaller cuts and less cuts on your body. Your recovery time is usually quicker.
- **Heart surgery** – a surgeon opens your chest to work directly on your heart. Your recovery time is usually longer than minimally invasive surgery or procedures.

Your doctor or surgeon can discuss which approach is best for you.

Being told you need to have surgery, or a procedure can be scary. It's normal to feel nervous about what's going to happen.

You can find out what to expect before, during and after surgery in our booklet **Understanding heart surgery**.

It contains tips for your recovery that may also be useful if you're having a heart procedure. Order your free copy at **bhf.org.uk/publications**

You can also read about heart surgery and what to expect at **bhf.org.uk/heartsurgery**

Recovery

Everyone recovers at different times. Some people find they feel much better quite quickly after surgery while other people find it takes longer.

It can be scary waking up after surgery. Many people feel disorientated for a little while.

Heart procedure

You'll usually stay in hospital for at least two to five days.

You should be able to do most of your normal activities after six weeks, including working, driving and exercise. You may also have an appointment with your surgeon at this time.

Heart surgery

You'll usually stay in hospital for at least 5 to 10 days.

You should be able to do most of your normal activities after 12 weeks, including working, driving and exercise.

Everyone's recovery times are different. Your doctor or surgeon can give you more information on your recovery and what to expect.

Blood thinning medicines after surgery

You'll need to take blood thinning medicines (called anticoagulants) for the rest of your life if you've had a mechanical heart valve fitted. If you've had a tissue heart valve, you do not usually need to take blood thinning medicines.

Most people will be given warfarin. You'll be given an alert card that you should carry with you at all times. It lets other healthcare professionals know that you're taking blood thinning medicines.

It's very important to take your medicine as your doctor advises. It helps to stop blood clots forming on your new valve which can stop it from working properly. If you do not take them, you may be at higher risk of a heart attack or stroke.

Appointments when you're taking warfarin

Blood thinning medicines do not make your blood thinner. They make your blood clot more slowly and you'll need regular blood tests.

The blood test measures how long it takes your blood to clot, called your international normalised ratio (INR). It helps doctors work out what dose of medicine to give you.

Your blood test will usually be once a week at your GP surgery or local clinic until your levels are stable (similar each time you're tested).

Some people can check their INR levels at home. Speak to your doctor to find out if this is possible for you.

If you're taking warfarin, your doctor or local clinic will give you a way to track your treatment and the dose you're taking. This may be a yellow book or a way to track it online.

If you're on a new type of blood thinning medicine, you may not need regular appointments to check your blood.

If you have questions about medicines you're taking, talk to our cardiac nurses.



Call 0808 802 1234 (freephone)
or email hearthelpline@bhf.org.uk
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bank holidays).

Medicines to avoid if you're taking warfarin

Some medicines can stop blood thinning medicines working or can make you bleed more, which can be dangerous.

This includes:

- medicines that reduce pain and inflammation (called NSAIDs) – such as ibuprofen, naproxen, diclofenac and higher-dose aspirin
- some antibiotics.

Your GP or pharmacist can give you more information on medicines you need to avoid. Speak to your GP if you need pain relief about what you can take.

Cardiac rehabilitation

You should be offered cardiac rehabilitation (cardiac rehab) to help you recover.

Cardiac rehab is a programme of exercise and education sessions. It can be done online, in person or a mix of both. It's a vital part of your recovery, helping you get back to as full a life as possible.

Speak to your hospital team if you have not been offered cardiac rehab. You can also get in touch with your local cardiac rehab team at **www.cardiac-rehabilitation.net**

Find out more in our **Understanding cardiac rehabilitation** booklet. Order your free copy at **bhf.org.uk/publications**

Will I need another surgery in the future?

It's normal to worry about your heart valve and if you'll need another surgery in the future.

You may have regular appointments with your cardiology team if you have symptoms or other heart conditions. You can ask them about your heart valve and whether you'll need surgery in the future.

If you do not have appointments with your cardiology team and you're worried about your heart valve, or you have new or worsening symptoms (see page 12) contact your GP.

Living with heart valve disease

It's normal to feel anxious after being diagnosed. You may feel worried about your condition and how it will affect your life. Many people live well with heart valve disease.

You can support your overall health and wellbeing by making healthy lifestyle choices. This can help prevent your condition getting worse and help you to live well.

You can find lots of information about healthy lifestyle choices in our booklet, **Understanding your heart health**. Order your free copy at [bhf.org.uk/publications](https://www.bhf.org.uk/publications)

Exercise

Exercise is important for your overall health and wellbeing. However, it's important to check what exercise is safe for you.

You may need to avoid activities where you strain or hold your breath, for example heavy lifting, weight training or swimming.

You may be asked to not exercise or do lighter exercise, like gentle walking, until your valve is repaired, replaced, or your symptoms have stopped.

Speak to your doctor about your diagnosis. They can explain what you can do or if there's anything you need to avoid.

Find more information on exercising with a heart condition at [bhf.org.uk/activity](https://www.bhf.org.uk/activity)

Sex

Most people with heart valve disease can have sex.

Sometimes you may want to find other ways of being intimate if you're struggling with symptoms or you've just had surgery. But you can continue to enjoy a healthy sex life once you've recovered from surgery and your symptoms are controlled.

If you have a heart condition, some types of contraception may be more suitable than others. Speak to your doctor about what contraception you can have.

Your doctor will have talked to lots of other people about sex. It may not be easy to talk about at first, but most people say they feel reassured when they do.

Read more on our website at [bhf.org.uk/sex](https://www.bhf.org.uk/sex)

Pregnancy

If you're pregnant or planning to have a family, it's important to let your doctor know.

With planning, most people with heart valve disease will not have any complications during pregnancy.

You may need to see a specialist cardiologist if you're thinking about having children and you:

- have moderate or severe heart valve disease
- have bicuspid aortic valve disease
- have a mechanical valve
- take blood thinning medicines (anticoagulants).

If you have heart valve disease and are considering starting a family, talk to your GP or hospital doctor before getting pregnant.

They can help make sure you get the care and support you need. Find out more at [bhf.org.uk/contraception-pregnancy](https://www.bhf.org.uk/contraception-pregnancy)

Driving

Many people with heart valve disease will be able to drive.

If you have symptoms that affect your ability to drive safely, you'll need to stop driving. You should talk to your doctor, the DVLA and your car insurance provider.

Symptoms that affect your ability to drive safely include being breathless when resting and finding any movement or physical activity difficult.

You'll need to stop driving for a short time after heart surgery or a procedure. Your surgical team can answer any questions you have about driving.

Speak to your doctor if you're not sure, or you start having new symptoms.

Find out more about driving at [bhf.org.uk/driving](https://www.bhf.org.uk/driving)

Holidays and flying

Most people with heart valve disease can go on holiday.

If your condition is controlled and you feel well, it should be ok. You should check with your doctor that you are fit enough to travel.

If you've recently had surgery, speak to your doctor or surgeon about when you'll be fit enough to travel.

Tips for holidays and flying:

- Take enough medicine to last your holiday.
- Pack medicines you need in your hand luggage.
- Take a list of medicines you're taking in case you need to replace any.

Get more information on holidays and flying at [bhf.org.uk/holidays](https://www.bhf.org.uk/holidays)

Travel and life insurance

If you're diagnosed with heart valve disease, you need to tell your life and travel insurance provider.

Many people can live well with heart valve disease if you've had treatment or it's mild. But it's important to make sure your insurance provider knows about your condition in case you need to claim in the future.

Find out more about travel and life insurance at [bhf.org.uk/practicalsupport](https://www.bhf.org.uk/practicalsupport)

Scanners and your heart valve

Airport scanners and metal detectors should not affect your mechanical heart valve.

If you have a health scan, like an MRI, X-ray or mammogram, let the healthcare professional know you have a mechanical heart valve before you have the test.

Most heart valves are compatible with health scans but it's important to let the person doing the test know.

Mechanical valve clicking

If you have a mechanical heart valve you may hear a clicking sound from your chest after surgery. This is normal and is the sound of your valve working.

Some people find it reassuring to hear it working. But for other people it can affect their daily activities and sleep for a while.

It can sound louder when you first have your valve fitted. Sometimes people close to you may be able to hear it. But over time you'll get used to the noise and many people say they hear it less.

At the start, you could try listening to music or a podcast to help you fall asleep.

Worries about your health

It's normal to feel worried or anxious about your health. But sometimes, this can get in the way of living your life.

If you feel anxious and sad a lot of the time, and it's affecting your daily life, talk to your GP.

Do not be afraid to ask for help. Sometimes you need to put yourself first.

You can also refer yourself to the NHS for talking therapies, like cognitive behavioural therapy (CBT) or counselling. Search '**NHS talking therapies**' for more information.

You can also get in touch with Mind, a charity offering support to anyone affected by their mental health. Visit **mind.org.uk**

Get support

Being diagnosed with a heart condition can be scary. Many people with heart valve disease can live well with their condition.

There are places you can go to ask questions and get support.

Call the Heart Helpline

If you or your family are affected by heart valve disease, our cardiac nurses can help you with your questions or concerns.

Call **0808 802 1234** (freephone) or email **hearthelpline@bhf.org.uk**
Our helpline is open weekdays, 9am to 5pm (excluding bank holidays).

You can also speak to our nurses using the live chat feature. Find out more at **bhf.org.uk/helpline**

Join Heart Matters

Discover the benefits of Heart Matters, your free heart-health membership.

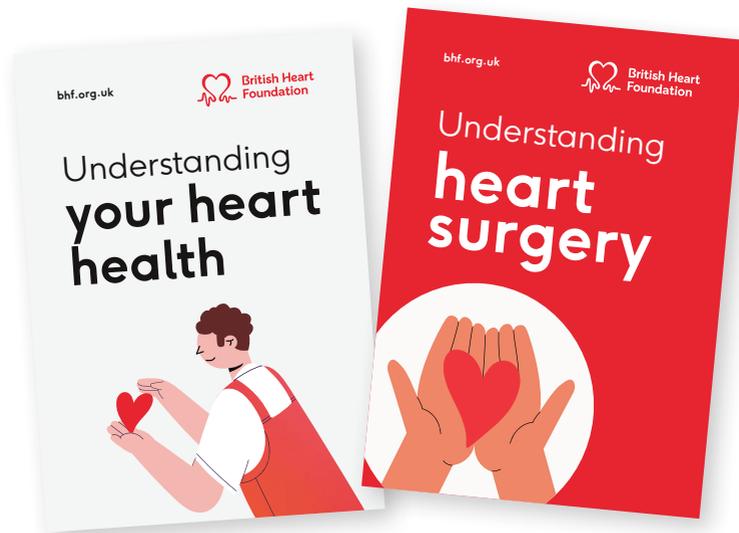
Join to receive our free magazine or email newsletter, featuring expert tips, heart-healthy recipes, inspiring stories, and the latest updates backed by BHF-funded science.

Guided by our team of experts, Heart Matters helps you to make small changes for a healthier heart.

bhf.org.uk/heartmatters

Order our information

We have lots of information about living with a heart condition and looking after your heart health.



You can read and order our booklets for free at bhf.org.uk/publications

We also have information in audio, easy read, braille and other languages. Read or listen to our information online at bhf.org.uk/infoforall

Have your say

We want people with lived experience of heart and circulatory conditions to be involved in everything we do.

Join Heart Voices, our patient and public involvement (PPI) network. The network can connect you with opportunities to take part in our lifesaving work.

By getting involved, you'll have the chance to share your insights with us and build connections with people who have been through similar experiences as you.

Join the network at bhf.org.uk/heart-voices

We are British Heart Foundation



Through research, information and support we're here for everyone affected by heart and circulatory conditions.

Get help

Speak to one of our experienced cardiac nurses for more information and support. They can help answer your questions, big or small.

You can call **0808 802 1234** (freephone). Our helpline is open weekdays, 9am to 5pm (excluding bank holidays).

Support our work

If you've found this information helpful and would like to support our work, please scan the QR code or visit bhf.org.uk/support-us



Scan here with
the camera
on your phone

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