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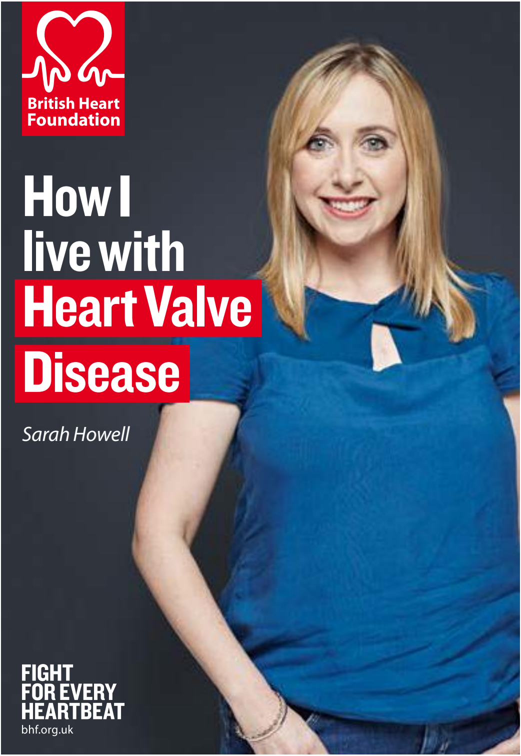

How I live with Heart Valve Disease

Sarah Howell

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FOR EVERY
HEARTBEAT**
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ABOUT THE BRITISH HEART FOUNDATION

As the nation's heart charity, we've been funding cutting-edge research that has made a big difference to people's lives.

But the landscape of heart and circulatory disease is changing. More people survive a heart attack than ever before, and that means more people are now living with heart and circulatory disease and need our help.

Our research is powered by your support. Every pound raised, every minute of your time, and every donation to our shops will help make a difference to people's lives.

If you would like to make a donation, please:

- call our donation hotline on **0300 330 3322**
- visit **bhf.org.uk/donate** or
- post it to us at BHF Customer Services, Lyndon Place, 2096 Coventry Road, Birmingham B26 3YU.

For more information, see **bhf.org.uk**

Find out more about our life saving heart research at bhf.org.uk/research

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ABOUT THIS BOOKLET

This booklet is for people who have a problem with one or more of their heart valves. It also provides useful information for family and friends. It explains:

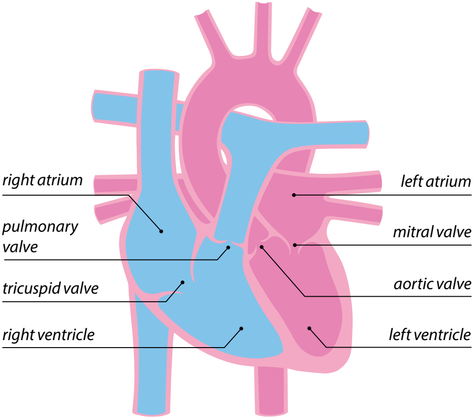
- what heart valve disease is
- how heart valve disease is diagnosed
- what types of treatment are available, and
- what you can do to help yourself.

This booklet doesn't replace the advice your doctor or cardiologist (heart specialist) may give you, but it should help you to understand what they tell you.

WHAT ARE THE HEART VALVES?

Your heart is a muscle that pumps blood around your body. It's made up of four connected chambers (sections). These are the left atrium, the right atrium, the left ventricle and the right ventricle.

There are four valves in your heart, guarding the exits of the four chambers. They are called the mitral, aortic, tricuspid and pulmonary valves.



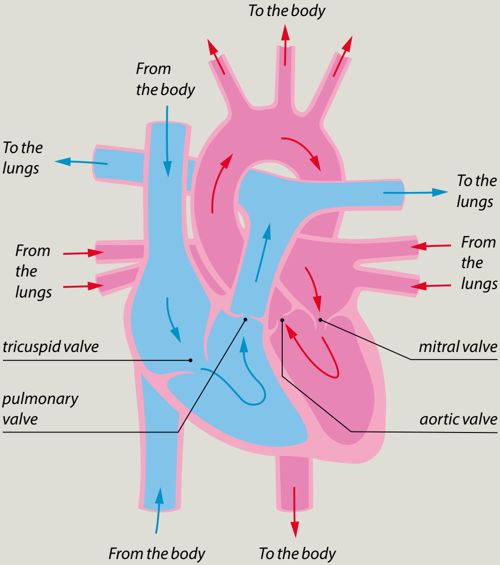
How does my blood flow?

Each heart valve has either two or three ‘leaflets’ or ‘cusps’. These are very small flaps of skin which cover the valve. The flaps open and close to let blood flow through in the correct direction, and to stop it from flowing backwards.

This is the journey that blood takes through your heart and around your body:

- Blood containing oxygen arrives from your lungs into the left atrium of your heart, and passes through the **mitral valve** into the left ventricle.
- It then passes back out of the heart through the **aortic valve**, to provide oxygen-filled blood around your body.
- Once this blood has travelled around your body, providing oxygen and nutrients to your cells, it returns to the heart. It arrives into the right atrium.
- Next, it passes through the **tricuspid valve** into the right ventricle.
- Finally, the blood leaves the heart through the **pulmonary valve**, travelling back to the lungs where it takes in more oxygen.

Blood flowing through the heart



The valves in your heart can become diseased or damaged for different reasons (see pages 12-15). It may be something that you're born with, or that develops during your life.

Problems with your heart valves can make it difficult for blood to flow through your heart properly. There are two ways this can happen:

- The valve doesn't open fully or it becomes stiff. This is called **valve stenosis.** It means that the valve becomes narrow, so blood can't flow through as easily as it would through a healthy valve.
- The valve doesn't close properly, which causes some blood to leak backwards. This is called **valve regurgitation** or **valve incompetence**. Doctors may call this a 'leaky valve'.

Both stenosis and regurgitation can put extra strain on your heart.

If you have valve stenosis, the stiff, narrowed valve can limit the flow of blood, so your heart will have to pump harder to force blood through the valve.

If you have valve regurgitation, your heart will have to work extra hard to pump enough blood forward against the blood that leaks back through the valve.

The blood behind an affected valve will be under increased pressure too. This is called 'back pressure', and it can cause a build-up of fluid in your lungs, ankles or legs, depending on the valve affected.

The most common problems that people have are different for each valve:

Valve	Most common problem
Mitral	The leaflets (flaps) stretch and become 'floppy', leading to blood leaking backwards (regurgitation). Or, the valve becomes deformed, causing it to leak blood. This is **mitral valve prolapse** – it can cause a heart murmur (see page 18), but will not usually need treatment.
Aortic	Becomes stiff and narrow, making it difficult for blood to leave the heart.
Tricuspid	Problems are less common than the mitral or aortic valves. Problems with the left side of the heart can cause the tricuspid valve to leak.
Pulmonary	Problems are rare, and usually caused by congenital defects (problems a baby develops while in their mother's womb).

LEADING THE FIGHT...

against heart valve disease

The BHF is the UK's largest independent funder of research into heart and circulatory disease. Some highlights of our research into heart valve disease include:

1. Developing new replacement heart valves out of materials that last longer and improve the quality of life for those who need them. These valves could help reduce the number of repeat surgeries and avoid the need for anticoagulants.
2. Researching how the heart valves form when a baby is in the womb, to identify why some babies are born with heart valve abnormalities, and understand why problems related to these abnormalities can develop later in life.

Our life saving research is powered by your support. If you'd like to make a donation, please see the inside front cover for more details.

For more information on the BHF's research successes, visit bhf.org.uk/research

The symptoms of heart valve disease vary, depending on which valve is affected and how badly it has been damaged. People with mild heart valve disease (see pages 22-23) might not notice any symptoms, or may have very few symptoms.

But others can experience several common symptoms, caused by problems related to heart valve disease:

Problem	Symptom
Increased strain on the heart (see pages 06-07)	• **Tiredness** • **Palpitations (uncomfortable pounding in the chest)**
'Back pressure' (see page 07) causing build-up of fluid in the lungs and legs	• **Shortness of breath** • **Swelling of ankles and legs**
Blood not flowing correctly to the coronary arteries (the blood vessels which supply the heart muscle with oxygen)	• **Chest pain**
Forward flow of blood severely obstructed, blocking enough blood from reaching the brain	• **Dizziness** • **Fainting**

Abnormal heart rhythms (atrial fibrillation)

Your heart's normal pumping action is controlled by tiny electrical messages, sent out to make sure your heart pumps blood around your body in a normal, regular rhythm.

Some people with heart valve disease may develop an abnormal heart rhythm called **atrial fibrillation**. This is when different places in and around the atria (the two upper chambers of the heart – see page 03) fire off electrical impulses in an uncoordinated, disorganised way. This makes the atria twitch or quiver, causing an irregular and sometimes fast heart rate, or pulse.

The symptoms of atrial fibrillation may include palpitations, dizziness or light-headedness, and shortness of breath.

The treatment for atrial fibrillation may be one or more of the medicines listed on page 28, and might include an anticoagulant medicine (see pages 48-53).

For more information about atrial fibrillation, its symptoms and treatments, see our booklet Atrial fibrillation.

The main causes of heart valve disease are:

- ageing of the heart
- congenital heart disease (being born with an abnormal heart valve or valves)
- coronary heart disease
- cardiomyopathy
- a previous infection with endocarditis, and
- rheumatic fever.

Ageing of the heart

As you get older, your heart valves can become thicker because of wear and tear or high blood pressure. This means that your blood has a narrower space to flow through. This is most common with the aortic valve.

Your symptoms will depend on how serious this narrowing is. For example, calcium deposits from the blood may settle on the aortic valve, causing it to harden and become stiff.

For many people this doesn't cause a problem, but others may get some of the symptoms as described on pages 10-11.

Congenital heart disease

A congenital condition is a condition which develops when a baby is in the womb. Some people are born with an abnormal heart valve or valves.

Most of these people will never experience any symptoms. But for some people, their condition can get worse over time. The valve may become stiff or leaky and require treatment.

For example, a child could be born with a **bicuspid aortic valve**, with two cusps (flaps) on their aortic valve, rather than the usual three.

This condition is unlikely to cause issues for a child, but problems may develop in later life. Serious cases may need surgery.

Coronary heart disease

Coronary heart disease is when your heart muscle isn't getting a good supply of oxygen, because the arteries that supply your heart with oxygen-containing blood are blocked by fatty deposits.

This can make your heart muscle pump less efficiently, which may cause problems with the mitral valve.

Cardiomyopathy

Cardiomyopathy is a disease of the heart muscle. If you have this disease, your heart may not contract (tighten) properly because the heart muscle has become stretched, which can affect one or more of your heart valves.

The most common problem linked to cardiomyopathy is the mitral valve leaking blood. This is because the valve's opening has become stretched and the valve can no longer close properly.

An infection with endocarditis

Endocarditis is an infection of the lining of the heart. If you have had endocarditis before, it may have damaged one of your heart valves.

If this is the case, you may need to have the affected valve replaced or repaired. See pages 54-57 for more information about endocarditis.

Rheumatic fever

Only a very small number of people in the UK get rheumatic fever, so related heart valve problems are rare. It’s more common in other parts of the world, such as South America.

People affected by rheumatic fever as children might develop symptoms of heart valve disease as adults. Rheumatic fever can cause stiffness or leaking, or both. It usually affects the aortic and mitral valves.

See page 74 for details of how to order additional information about these causes, or visit bhf.org.uk to find information online.

SARAH'S STORY

"I was born with a heart defect but it wasn't diagnosed until I was aged two. As a baby, I was blue in colour and had no energy. I had open heart surgery twice, but doctors told my mum that the repairs wouldn't last forever.

Everything was normal until I went to university. At an annual check-up I was told I'd need a valve replacement. It wasn't until I was 25, when I'd started to get breathless, that they decided to operate. I had an MRI scan of my heart to figure out the best time for my surgery. I was given two options for my valve replacement – a mechanical valve, which would mean taking warfarin, or a pig valve. The pig valve was best for me as I didn't have to take ongoing medication.

I hadn't realised how bad I'd been feeling until my valve was replaced. I could breathe more deeply, had more energy and found things like climbing stairs much easier. I consider myself really lucky to live in an age where these sorts of operations can take place and conditions like mine can be drastically improved."

Heart valve problems are often noticed at a routine medical examination when your doctor listens to the heart with a stethoscope and hears an extra noise called a ‘murmur’.

Murmurs can also be heard in hearts that are otherwise completely normal. Depending on the type of murmur your doctor hears, you may be sent for further tests.

Even after a heart valve condition has been diagnosed, it can be 10 or 20 years before you experience symptoms.

It’s therefore important to have your heart checked regularly. Your doctor or cardiologist will tell you how often to do this.

What tests might I have?

If you have symptoms that may be caused by a faulty valve, or if you have a murmur that doesn’t sound normal, your doctor will arrange for you to have the following tests:

- an **echocardiogram**, which produces an ultrasound picture of the heart and its valves (see pages 20-21)
- an electrocardiogram or **ECG**, which records the rhythm and electrical activity of your heart
- a **chest X-ray**, which can show anything unusual with the size and shape of your heart, or show the build-up of calcium within the heart, and
- a **CT (computerised tomography)** scan, which produces multiple X-ray images to show the heart in detail.

You may also have a **coronary angiogram** to check for the condition of your heart, and the blood supply to your heart. If it shows any problems, you might need to have heart bypass surgery.

This may be done at the same time as valve surgery, if you also have heart valve problems (see pages 30-39 for information about heart surgery).

Echocardiogram

A **transthoracic echocardiogram** is the name for a standard echocardiogram, or 'echo':

- This non-invasive test uses a probe placed on your chest to send sound waves through your skin and to your heart.
- These waves echo off your heart and are picked up again by the probe.
- The signal from these waves is then converted into an image on a screen, showing a detailed picture of your heart.
- The image helps your doctors look for any problems with how your heart and its valves are working.

There are other types of echo which use different methods to create an image showing how your heart and its valves are working.

A **stress echocardiogram** is a standard, non-invasive echo test, but it is done while the heart is put under 'stress'. This is done by safely increasing your heart rate with exercise or medication. The test helps to see how your heart reacts to an increased workload.

A **transoesophageal echocardiogram** (T.O.E.) is an invasive echo test, during which you 'swallow' a small echo probe.

The probe goes down your oesophagus (the tube connecting your mouth and stomach) until it sits just behind your heart.

Putting the probe in this position helps to get a closer and more detailed picture from the echoes

This test can feel unpleasant, so anaesthetic and sometimes a light sedative can be used to help you relax.

Visit bhf.org.uk/tests to find more information about these tests, including videos showing what happens during the tests.

How serious is my condition?

Your doctor may describe your condition as mild, moderate or severe, based on the results of your tests. Treatment is different for each level:

Mild

If you’re diagnosed with mild heart valve disease, you may not need to see a specialist doctor straight after diagnosis. Your GP will organise an echocardiogram 12 to 18 months after your diagnosis, to review your condition.

Most people with mild heart valve disease will be able to carry on with their daily activities. And, for a lot of people, the disease might not get worse.

But you may need to take medicines such as beta-blockers and ACE inhibitors (see page 28) to reduce the workload of your heart.

Moderate

People with moderate heart valve disease are likely to need more frequent echocardiogram tests, and to keep in close contact with their GP about their condition.

If you’re diagnosed with moderate heart valve disease and have certain symptoms, your GP may advise that you see a specialist doctor.

Severe

If you're diagnosed with severe heart valve disease then you will need to see a specialist doctor, even if you have no symptoms. Although you may feel well, you’ll still need to have treatment for the condition, otherwise it will get worse.

Most people with severe heart valve disease will need medication, and many will be referred for surgery.

There are many factors involved in finding out how serious your condition is. Your doctors will tell you their opinion based on your test results, and they may recommend that you have treatment for your condition, **but this is ultimately your decision**.

See pages 26-45 for information about treatments for heart valve disease.

WHAT HAPPENS AFTER MY DIAGNOSIS?

Most people with heart valve disease will have regular check-ups with a cardiologist or their GP. How often you need a check-up will depend on your condition and your symptoms.

These check-ups are important, even if you feel well overall. The check-up will usually include having an echocardiogram to find out if there have been any changes to your condition. In many cases, treatment will not be needed for many years, if ever.

Careful monitoring of your condition will make sure you get the treatment you need. You should see your GP at least once a year to review your health and any medication you're taking.

It is a good idea to have an echocardiogram at least every two years - your GP can advise you how often is best for you.

> **If you're diagnosed with heart valve disease, it's important to have your heart checked regularly, even if you feel well.**

Many people with heart valve disease can live a normal life for many years, with little treatment.

If you're offered treatment for heart valve disease, you can discuss the advantages and disadvantages of each treatment with your medical team. **The final decision over which type of treatment you wish to have will always be yours.**

Your medical team will recommend a treatment based on the following factors:

- which valve or valves are affected
- how badly the valve or valves are affected
- how badly the heart's ventricles (lower chambers) are affected
- your symptoms, and
- your general health.

The main treatment options are:

- **medicines** (pages 28-29)
- **valve surgery**, either repairing or replacing the valve (pages 30-39)
- **percutaneous mitral valve leaflet repair** (page 42)
- **transcatheter aortic valve implantation (TAVI)** (pages 43-44)
- **valvuloplasty** (page 44), or
- a combination of medicines with one of these procedures.

Even if your symptoms appear mild or you don't have any symptoms, your specialist doctor may still recommend surgery or another procedure.

This is because your heart muscle may be showing signs of strain. The treatment options aim to ensure that the faulty valve doesn't cause any further damage to your heart muscle.

Medicines

Most people with heart valve disease will need to take medicines to control their symptoms.

These may include:

Type of medicine	What does it do?
ACE (angiotensin-converting enzyme) inhibitors	Relaxes the blood vessels and reduces the strain on the heart
Anti-arrhythmics	Treats irregular heart rhythms
Anticoagulants	Lowers the chance of blood clots forming, especially on a replacement mechanical heart valve (see pages 48-53)
Beta-blockers	Slows the heart rate and reduces the strain on the heart
Diuretics	Encourages the body to produce urine, and can reduce the build-up of fluid in the lungs, ankles and legs
Nitrates	Dilates (widen) the blood vessels, making it easier for the heart to pump blood around the body, lowering the strain on the heart

Different medicines are used for different types of heart valve disease – your cardiologist will prescribe medicines that are suitable for you.

Often, if your condition has been found in its early stages, it can be controlled for many years just by taking medicines.

For more information about medicines, see our booklet *Medicines for my heart*.

If a valve is severely affected, you may be advised to have **open heart valve surgery**.

Your doctor or cardiologist may recommend having surgery even if you don't have any symptoms, as it can prevent other serious heart problems from developing in the future.

Repairing and replacing valves

There are two main types of valve surgery, called valve repair and valve replacement:

- **Valve repair** is most often used to repair leaking mitral valves, although the other valves can also be repaired.
- **Valve replacement** is when the diseased valve is replaced with another valve. This is most common with the aortic valve.

There are two main types of replacement valves: mechanical valves (usually made of ultra-smooth carbon), and tissue valves (human valves, or valves made from synthetic material).

See pages 34-37 for more information about the different types of replacement valve.

Dental care before heart surgery

It is essential to have your teeth and gums checked before you're due to have your surgery, to reduce the risk of endocarditis (an infection of the lining of the heart). See pages 54-57 for more about endocarditis.

Your dentist will check that:

- your teeth and gums are healthy
- there's no sign of infection, and
- any treatment is completed before your surgery.

Some hospitals won't carry out your surgery unless this is done. Ask at your pre-assessment clinic how long before surgery these checks should be done.

What happens during surgery?

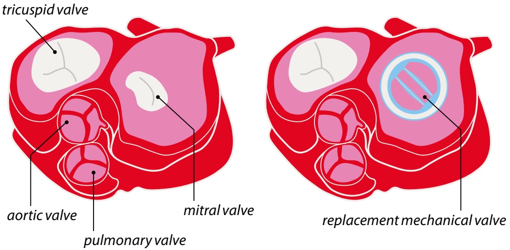
Open heart valve surgery is done under general anaesthetic, which means medicine is used to send you to sleep shortly before the operation.

The surgeon makes an incision (cut) down the middle of the breastbone, at the centre of the chest, to access your heart.

The surgeon then connects a heart-lung machine to divert blood from your heart and circulate it around your body. This means that the surgeon can stop your heart to operate on it, while your body still gets the oxygen and nutrients it needs.

The surgeon then cuts open your heart and either repairs the faulty valve, or removes the diseased valve and sews a replacement valve in its place. Once the repair or replacement is finished, your heart is then closed and re-started, and your breastbone closed.

Inside view of your heart from above, before and after valve replacement



Before

After

Minimal access surgery

With minimal access surgery – also called minimally invasive surgery – the surgeon makes one or more small cuts in the skin on the chest.

The cuts are smaller than those used for open heart surgery, so either the breastbone is not cut at all, or only part of it is cut. This may reduce your level of discomfort after the operation.

The surgery is done using special equipment, including very small cameras, so the surgeon can access the heart through these small cuts and see the heart on a screen while they operate.

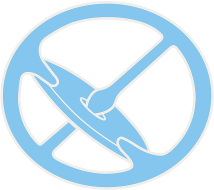
Minimal access surgery is increasingly used to treat aortic and mitral valve disease, but it is still very specialised and only available in a few centres in the UK. For most people, the main option for valve repair or replacement is open heart surgery.

For more information about having a heart operation, see our booklet Heart surgery. It covers every stage of surgery, from preparing for your operation to returning home from hospital.

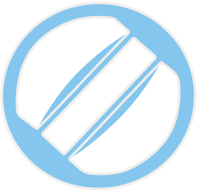
There are two main types of replacement valve used in valve replacement surgery – mechanical valves and tissue valves.

Mechanical valves

Tilting disk valve



Bileaflet valve



Mechanical valves are man-made, from a special ultra-smooth carbon. There are many different types of mechanical valves and all have been tested for function and wear. This is important, as the valves will open and close around 40 million times a year.

Tissue valves

Preserved human valves (also called **homografts**) and synthetic tissue valves are the most commonly used replacement valves. In a small number of cases, valves taken from animals such as pigs may be used.

Which type of valve is best for me?

There are a few different things to think about when choosing which type of valve is most suitable for your condition and lifestyle:

Mechanical valves – advantages and disadvantages

Mechanical valves are made from high-quality materials and are designed to last a lifetime, even if you're young when you have your valve replaced.

But there is a risk of a blood clot developing on the surface of mechanical valves. To help prevent this, you'll have to take **anticoagulant** medicines, such as warfarin, for the rest of your life.

This could be especially significant if you like playing contact sports, or you're a woman planning to have a baby in the future.

We explain more about anticoagulants on pages 48-53, and have information about pregnancy and heart valve disease on pages 46-47.

A mechanical valve can make a light clicking sound. Although you may find this disturbing at first, most people soon get used it. If you have a partner, they may find that they are also aware of the clicking sound at night.

Tissue valves - advantages and disadvantages

If you're young and do a lot of physical activity, the stresses placed on the tissue valve may cause it to wear out more quickly.

As a result, you might need a second replacement operation in the future. In older people, a tissue valve will often last a lifetime.

These valves are made from natural tissue rather than man-made materials, so you won't need to take anticoagulants for life.

Anticoagulants may be recommended for the first few weeks or months after surgery, until the valve has settled in your heart. After that, you may need to take aspirin to reduce the risk of blood clots forming.

Choosing your valve

You can discuss with your surgeon which type of valve would be most suitable for you.

Your conversation will take into account your views and preferences, your condition and your lifestyle, including how your life may be affected into the future. **It is always your final decision to choose the type of valve that is best for you**.

Pulmonary valves

In some cases, a person's own pulmonary valve may be used to replace an aortic valve. The pulmonary valve is then replaced with a new tissue valve. This is known as **pulmonary autografting**, or the **Ross procedure**.

Valve surgery is generally very successful, and it can have many benefits. It can help to relieve symptoms, or get rid of them completely. It could help you live longer and improve your quality of life.

But, like any other surgery, there are risks. There is a small risk of having a heart attack or stroke, or dying, either during or soon after the operation.

Your risk will depend on:

- your age
- your current state of health
- the level of your condition (see pages 22-23)
- which valve is affected
- if you're having a valve replaced or repaired, and
- whether you're having coronary artery bypass surgery at the same time as the valve surgery.

Before you have surgery, you should discuss these risk factors with your surgeon.

For a few weeks after surgery, you may experience pain and soreness where the cut or cuts were made. You may also find it difficult to lift, push or pull anything heavy for some time after your operation.

After your operation

Once you've recovered from your operation, problems are rare. But the following issues could occur:

- There's a small risk of mechanical and tissue valves becoming **infected**.
- **Blood clots** may form, especially if this has been difficult to control with anticoagulant medicines (see pages 48-53). This is more common with mechanical valves.
- Any type of replacement valve can become **damaged**. This could happen because of uncontrolled **high blood pressure** or **endocarditis** (see pages 54-57), for example. Damage is more likely with tissue valves.
- Some people may experience **atrial fibrillation** (an abnormal heart rhythm) after heart valve surgery. This usually gets better within a few weeks or months, with treatment. See page 11 for more information about atrial fibrillation.

For more information about recovering from a heart operation, see our booklet Heart surgery.

JOHN'S STORY

In 2014, John had an aortic valve replacement after suffering a cardiac arrest.

"In 2004, I found out I had heart valve disease. I didn't experience any symptoms until six years later when I developed an arrhythmia. I had regular check-ups and scans for my condition, but generally I felt fine.

One day, while I was driving down the M25, I went into cardiac arrest. Thankfully, my wife was with me and performed CPR until the paramedics took over. After several defibrillator shocks, I was taken to hospital where I had surgery to replace my aortic valve.

My surgeon believed my cardiac arrest was because of my arrhythmia, which was caused by heart valve disease. I'd been told several years ago that surgery would be needed at some point, but I'd put it to the back of my mind and continued my very active life.

Even though this was a traumatic experience, I'm thankful to be doing everything I was able to do previously, including cycling up to 150 miles a week!"

Open-heart surgery is still the most common treatment for repairing or replacing heart valves. But in some cases, different techniques may be used. These include:

- percutaneous mitral valve leaflet repair
- transcatheter aortic valve implantation, and
- valvuloplasty.

Percutaneous mitral valve leaflet repair

This procedure is for people who are too ill to have mitral valve surgery, and it is performed under general anaesthetic. Percutaneous means 'through the skin'.

A catheter (a thin, flexible tube) containing a special clip is passed through a small cut in your groin into an artery, and up into the heart and to the mitral valve.

The clip is then used to hold together the two 'leaflets' (flaps) which cover the mitral valve, to reduce the amount of leaking from the valve.

Percutaneous mitral valve leaflet repair is a new procedure, so its long-term benefits aren't yet known. But it is not suitable for everyone. Your cardiologist will discuss the risks of the treatment with you.

Transcatheter aortic valve implantation (TAVI)

TAVI is used to replace aortic valves in adults who aren't well enough to have open heart valve surgery. TAVI carries the same level of risk as surgery, but recovery should be quicker.

You may require a CT scan before the procedure to determine the size and type of replacement valve you need. TAVI may be performed under general or local anaesthetic.

In a TAVI procedure, a catheter with a small balloon at its tip is inserted into an artery through a cut in the groin or under the collarbone. The catheter is passed into the heart and placed within the aortic valve.

The balloon is gently inflated to flatten the valve, making room for a new tissue valve in its place. Once in position, the new valve either expands on its own or is expanded using the balloon.

The balloon is then let down and removed with the catheter. The new valve will now sit in place of the damaged valve.

Because TAVI uses a replacement tissue valve, you won't need to take anticoagulants for more than a few weeks after surgery. But you'll need to take a blood-thinning medicine, such as aspirin or clopidogrel, for the rest of your life.

You can watch a video of a TAVI procedure by visiting bhf.org.uk/tavi

Valvuloplasty

Valvuloplasty is a very rare treatment for heart valve disease. It's also called balloon treatment or balloon valvuloplasty, and is used to treat valve stenosis.

The procedure is similar to TAVI, but the small balloon is only used to stretch a stiff, narrow valve, rather than to implant a replacement valve. The procedure avoids the need for surgery, but in future the valve may become narrow again or start leaking.

New types of surgery

Sutureless aortic valve replacement for aortic stenosis

This new procedure is for people who have aortic stenosis. It may be offered if you can't have standard valve replacement surgery or a TAVI procedure. It is currently only available in specialist hospitals.

It is a similar process to standard open heart valve surgery, but the replacement valve doesn't need to be sewn into place. This means the operation is quicker, so you need less time on a heart-lung bypass machine during the procedure. Your stay in hospital and recovery time afterwards should also be shorter.

The long-term effects of this procedure are being monitored by NICE (the National Institute for Health and Care Excellence), an organisation that provides national guidance and advice on healthcare.

Transapical transcatheter mitral valve-in-valve implantation

This new procedure is going through clinical trials. It is performed through one or more small cuts on the chest wall, so there's no need to cut the breastbone. A new heart valve is placed into the damaged mitral valve and expanded into place with a small balloon.

People who have this type of surgery will have a general anaesthetic, but they may not need to go on a heart-lung bypass machine. This means recovery time from the procedure is likely to be quicker than with standard valve surgery.

Most women with mild or moderate heart valve disease don't experience heart problems during pregnancy, although careful medical supervision is always recommended.

But if the heart valve disease is severe, there are more risks involved with getting pregnant, for both the mother and the baby.

If you have severe heart valve disease and are planning to have a baby, your cardiologist may advise you to have valve surgery before you get pregnant.

If you need your valve replaced, you may want to think about which type of valve you want (see pages 34-37).

This is because pregnant women are usually advised not to take warfarin (a common type of anticoagulant medicine - see pages 47-53), as warfarin can cause harm to a developing baby.

So if you need to have a valve replaced you may want to choose a tissue valve, as this usually requires taking warfarin for only the first few weeks after surgery.

Sometimes, heart valve disease is diagnosed during pregnancy. If this happens, it is usually possible to continue with the pregnancy under strict medical supervision. If necessary, you can have valve surgery or a valvuloplasty procedure while you're pregnant.

If you have a replacement heart valve, you'll probably need to take **anticoagulants**. Anticoagulants are medicines that reduce the chances of a blood clot forming. How long you take them will depend on the type of replacement valve you have:

- If you have a **mechanical valve replacement**, you'll need to take anticoagulants for the rest of your life. This is because if a blood clot forms on a mechanical valve, it can block the valve and stop it working properly. Also, a blood clot could break away into your blood circulation, causing a stroke if it reaches your brain. Taking anticoagulants can help prevent both problems.
- If you have a **tissue valve replacement**, you may need to take anticoagulants for the first few weeks after surgery, but not for the rest of your life.

The most common type of anticoagulant is **warfarin**. You may also be offered **direct oral anticoagulants**, or DOACs. These would only be offered after a tissue valve replacement, as they aren't safe to use with mechanical heart valves.

If you're taking anticoagulants and suffer a head injury, such as falling and hitting your head, or you experience a blow to the head, **seek medical help without delay** to rule out internal bleeding – which may not be immediately obvious.

Blood tests

If you take warfarin, it's important to make sure you're taking the correct dose. This is because too much can lead to bleeding, and too little could increase the risk of blood clots forming. To check this, you will need to have regular blood tests at your local anticoagulant clinic or with your GP.

These blood tests are a way of measuring your **international normalised ratio**, or INR. This is a measure of the time it takes for your blood to clot. The clinic, or your GP, can change your dose to keep your INR at the right level.

When you first start taking anticoagulants, your INR will be checked once or twice a week. As your condition becomes more stable, you should only need it checked every six to eight weeks.

How can I tell if my dose is too high?

The following symptoms might suggest that your dose of anticoagulants is too high:

- cuts which bleed for longer than usual
- bleeding that doesn’t stop by itself
- nose bleeds that last for more than a few minutes
- bleeding gums
- red or dark brown urine
- red or black bowel movements
- unexplained bruises
- for women, heavier bleeding during periods, or other vaginal bleeding.

If you’re worried, contact your GP or clinic, or go to the A&E department at your local hospital. Take your anticoagulant card or booklet and any medicines with you.

Anticoagulant card and booklet

When you start taking anticoagulants, you'll receive an anticoagulant alert card. If you take warfarin, you'll also receive a booklet in which your INR test results will be recorded. You should always carry your card or booklet with you, and remember to tell anyone treating you that you're taking anticoagulants.

You can also choose to wear a medical alert bracelet or necklace, showing which anticoagulant medicine you’re taking, and why.

Taking other medicines

Oral anticoagulants can interact with many other medicines. This means that they might not work properly if you take them at the same time.

If you're taking anticoagulants, check with your doctor or pharmacist before taking other medicines. This includes over-the-counter and prescription medicines, and homeopathic preparations.

Sports

If you take part in contact sports with a risk of injury and you are taking anticoagulants, speak to your doctor. This is even if only minor injuries are likely.

Food and drink

Certain foods and drinks can affect how anticoagulants will work in your bloodstream.

If you're taking warfarin, this includes foods that are high in vitamin K. This includes liver and green, leafy vegetables, such as broccoli, Brussels sprouts, cabbage, kale and spinach.

You don't need to avoid these foods completely, but if you do normally eat them you should try to eat a similar amount every day. If you don't usually eat them, do not suddenly consume a large amount. A normal portion of these foods is around 80 grams (3 ounces), which is roughly a handful.

It is also best to avoid drinking cranberry juice and eating cranberries if you're taking warfarin. There are no foods or soft drinks that you need to avoid if you're taking DOACs.

But for all types of anticoagulant, you should also follow the recommendations for sensible levels of alcohol drinking, and especially avoid binge drinking (having a large amount of alcohol in one session). Your clinic will offer more detailed advice about this.

TOP TIPS...

for taking anticoagulants

1. **Always carry your anticoagulant card or booklet, giving details of your treatment.**
2. **Avoid playing contact sports, even if the injuries are usually only minor.**
3. **Make sure to have regular blood tests to check your INR level (how thin your blood is).**
4. **Try to avoid drinking cranberry juice or eating large amounts of food containing vitamin K if you take warfarin, or drinking alcohol beyond sensible limits if you take any anticoagulants.**

Endocarditis is a rare but serious condition, when the lining of the heart is infected. Those at risk of getting endocarditis are people who have:

- an abnormal heart valve
- had a heart valve replacement, or
- previously had endocarditis.

What causes endocarditis?

Endocarditis is caused by bacteria (or rarely another type of infection) entering your bloodstream and travelling to your heart, infecting your heart's lining.

These bacteria are most likely to grow on your heart valves because the valves don't have a direct supply of blood. This means there is no supply of white blood cells which would normally help to fight infections.

An abnormal heart valve has more risk of becoming infected than a normal valve. This is because bacteria carried in the blood are more likely to stick to the uneven surface of an abnormal valve, even if the abnormality is mild.

Bacteria are also more likely to stick to a replacement valve than a normal valve. The bacteria then grow and the infection can spread to the lining of the heart.

What are the symptoms of endocarditis?

The early symptoms of endocarditis are often subtle, so can be hard to notice and diagnose. The most common symptoms include:

- flu-like symptoms with a high temperature – these include tiredness, headaches, chills, a cough and a sore throat
- unexplained weight loss
- pale skin
- aching muscles and joints
- a heart murmur.

If you’re at high risk of getting endocarditis and you have flu-like symptoms with a high temperature, see your GP or cardiologist as soon as possible, and make sure to tell them that you’re at risk.

How is endocarditis treated?

Endocarditis can be life-threatening if it isn't treated quickly. But if it's diagnosed early, most people recover well with antibiotics.

If you develop endocarditis, you'll need to go into hospital to have antibiotics intravenously (through a vein). How long you stay in hospital will depend on how serious the infection is, and on the type of antibiotics you need to take.

You'll also be given a course of antibiotic tablets to take at home for another four to six weeks, after you leave hospital.

If the infection does not respond to the antibiotics, or if a heart valve becomes damaged because of the infection, you may need to have surgery to repair or replace the valve.

What can you do to help prevent endocarditis?

It isn't possible to stop all bacteria from getting into the bloodstream. But there are things you can do to prevent infections in your mouth or through your skin, to reduce the risk of bacteria spreading to your heart and causing endocarditis:

- Maintain good oral hygiene and have regular check-ups of your teeth and gums with your dentist.
- Avoid body piercing and tattooing.
- Don't inject any drugs that aren't prescribed.
- If you have an infection, report it to your GP immediately so that you can have tests and treatment as soon as possible.

Endocarditis warning card

If you know that you're at increased risk of developing endocarditis, carry an endocarditis warning card to show to your GP and any other health professionals who may need to treat you.

You can order one of these cards by calling the BHF Orderline on **0300 200 2222**.

Many people with heart valve disease can live a healthy life. But it is perfectly normal if you feel worried about your condition.

Many people with heart valve disease can live a normal, healthy life. But for others, it may be more difficult. It can have an impact on daily life in many ways, sometimes over a number of years.

Some people may struggle with taking medicine on a regular basis, or not recovering from an operation as quickly as they might hope. Other, more day-to-day worries, could include:

- driving
- work and money concerns
- having sex
- drinking alcohol, and
- going on holiday and flying.

We offer many resources that can help you deal with these everyday matters, as well as many other issues relating to your condition and its impact on your life and the people around you.

To find a range of information that may help, visit **bhf.org.uk/living-with** or see page 74 for details of ordering our resources about living with a heart condition.

Your emotional wellbeing

Living with heart valve disease might make you feel low or sad from time to time. This is perfectly normal.

It's also normal to feel worried or stressed about your condition, and its effect on your life and the people around you.

If you feel like you are struggling with your emotions, our booklet *Heart to heart – heart disease and your emotional wellbeing* may have information which can help you.

Our print and online magazine *Heart Matters* also provides information, inspiration and support for people living with a heart condition. Sign up for free by visiting **bhf.org.uk/heart-matters**

You can also call our Heart Helpline on **0300 330 3311** (similar cost to 01 or 02 numbers), to chat to one of our Cardiac Nurses who can offer support.

Or you could visit one of our local Heart Support Groups (see page 77) to speak to others about your feelings and experiences.

If you prefer speaking to people online, you can connect with others for advice, support or a chat through our online community. To sign up, visit **bhf.org.uk/community**

How can I help myself?

It's vital to keep your heart healthy if you have a heart condition, such as heart valve disease. This will help to reduce your risk of future problems. Your doctors can give you advice on how to keep healthy with your specific condition. But doing these things should help:

- if you smoke, **stop smoking**
- keep physically active
- keep to a healthy weight and body shape
- keep your cholesterol level and your blood pressure under control. It's important to have these checked regularly at your GP surgery
- if you have diabetes, make sure you control your blood glucose level.

For more detailed information and help with these, see our booklet Keep your heart healthy or visit bhf.org.uk/prevention

Air pollution

Being exposed to high levels of air pollution can make heart conditions worse. The level of pollution varies each day, depending on the weather and season.

Pollution levels are classed as low, moderate, high or very high. You can check the daily air pollution level in your area by visiting **uk-air.defra.gov.uk**

If you have heart valve disease, you may want to avoid spending long periods of time in places where there are high levels of pollution. For example, avoid walking near busy roads.

For most people, the benefits of exercising outdoors outweigh the risks associated with air pollution, but it is good to be aware of the potential risk. The risk for you may depend on the level of your condition – you can speak to your GP for more information about this.

For more information about how air pollution can affect your heart, visit bhf.org.uk/airpollution

Caring for someone with heart valve disease

Caring for someone with a heart condition can be immensely rewarding. But it can be hard work too, both emotionally and physically.

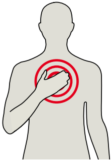
If you care for someone, it's important that you take the time to look after yourself too, and there is plenty of support available.

For more information for carers, see our booklet Caring for someone with a heart condition.

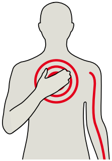
HEART ATTACK? THE SYMPTOMS... AND WHAT TO DO

A heart attack is when a part of the heart muscle suddenly loses its blood supply. This is usually due to coronary heart disease.

The symptoms of a heart attack

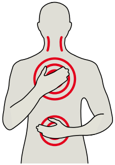


Pain or discomfort in the chest that doesn't go away.



The pain may spread to the left or right arm...

...or may spread to the neck and jaw.



You may feel sick or short of breath.

Think quick… act fast. Call 999 immediately.

ACT FAST...

What to do if you think someone is having a heart attack

1. Send someone to call 999 for an ambulance immediately.

   If you are alone, go and call 999 immediately and then come straight back to the person.

2. Get the person to sit in a comfortable position, stay with them and keep them calm.

3. Give the person an adult aspirin tablet (300mg) to chew if one is easily available, unless they're allergic to aspirin or they've been told not to take it.

   If you don't have an aspirin next to you, or if you don't know if the person is allergic to aspirin, just get them to stay resting until the ambulance arrives.

A **cardiac arrest** is when a person's heart stops pumping blood round their body and they become unconscious and stop breathing or stop breathing normally.

A person who is having a cardiac arrest may develop a dangerously fast heart rhythm which can be fatal. It is sometimes possible to shock the heart back into a normal heart rhythm by giving **defibrillation**. This means giving the heart an electrical shock using a defibrillator.

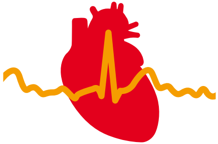
There are now **public access defibrillators** – or **PADs** for short – in many workplaces, shopping centres, train stations, leisure centres and village halls. It's very easy to use a PAD. The machine gives clear, spoken instructions and you don't need training to use one.

Once switched on, the PAD will instruct you how to attach the pads, whether or not a shock is needed and how to deliver it.

For more information, go to **bhf.org.uk/defibs**

The most important thing you can do to help save a person's life is **CPR – cardiopulmonary resuscitation**. This, along with defibrillation, can double someone's chance of survival in some cases. We explain how to do this on the next pages.

CARDIAC ARREST is an **ELECTRICAL** problem

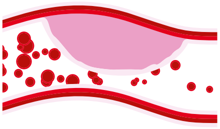


The person will be

UNCONSCIOUS

■ Call 999 ■ Start CPR

A HEART ATTACK is a **CIRCULATION** problem



The person will probably be

CONSCIOUS

■ Call 999 ■ Keep them calm

CALL PUSH RESCUE

If someone has had a cardiac arrest, they will be unconscious, and either not breathing or not breathing normally. The person needs immediate help or they will die within minutes.

First check that it is safe to approach the person.

To find out if the person is conscious, gently shake him or her, and shout loudly, 'Are you all right?' If there is no response, the person is unconscious.

You will need to assess the person's **airway** and **breathing.**

Open the person's airway by tilting their head back and lifting their chin.

Look, listen and feel for signs of normal breathing. Only do this for up to ten seconds. Don't confuse gasps with normal breathing. If you're not sure if their breathing is normal, act as if it is not normal.

Now remember: **Call Push Rescue**

CALL...

Call for help.

If the person is unconscious and is either not breathing or not breathing normally, they are in cardiac arrest.

Call 999 immediately.

- Send someone else to call 999 for an ambulance while you start CPR.
- **Or, if you are alone with the person, call 999 before you start CPR.**

9 9 9

PUSH...

Push hard and fast on the centre of the chest.

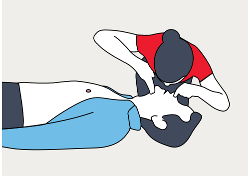
Start chest compressions.

- Place the heel of one hand in the centre of the person's chest.
- Place the heel of your other hand on top of your first hand and interlock your fingers.
- Press down firmly and smoothly on the chest 30 times, so that the chest is pressed down between five and six centimetres each time. Do this at a rate of about 100 to 120 times a minute. That's about two each second.

RESCUE...

Give rescue breaths.

After 30 compressions, open the airway again by tilting the head back and lifting the chin, and give two of your own breaths to the person. These are called rescue breaths.



To do this, pinch the soft parts of the person's nose closed. Take a normal breath, make a seal around their mouth with your mouth, and then breathe out steadily. The person's chest should rise and fall with each breath. It should take no more than five seconds to give the two rescue breaths.

Then give another 30 chest compressions and then two rescue breaths.

Keep doing the 30 chest compressions followed by two rescue breaths until:

- the ambulance crew arrives and takes over, or

- the person starts to show signs of regaining consciousness, such as coughing, opening their eyes, speaking, or moving purposefully **and** starts to breathe normally, or
- you become exhausted.

If you prefer not to give rescue breaths

If you'd rather not give rescue breaths, call 999 and then deliver **hands-only CPR**. Keep doing the chest compressions – at a rate of about 100 to 120 times a minute.

For more on this, see **bhf.org.uk/handsonly**

ℹ **For more information about training in how to do CPR, see page 76.**

British Heart Foundation website

bhf.org.uk

For up-to-date information about heart and circulatory disease, the BHF and its services.

Genetic Information Service

0300 456 8383

(A similar cost to 01 or 02 numbers.)

For information and support on inherited heart conditions.

Online community

community.bhf.org.uk

Share your experiences, stories, tips and ideas with other people like you in our online community.

Heart Helpline

0300 330 3311

(A similar cost to 01 or 02 numbers.)

For information and support about your heart condition and keeping your heart healthy.

Twitter

@TheBHF

Get our latest news and views directly into your Twitter feed.

Facebook

facebook.com/bhf

Join the conversation and get our latest news and updates on Facebook.

Booklets and DVDs

To order our booklets or DVDs:

- call the BHF Orderline on **0300 200 2222**
- email **orderline@bhf.org.uk** or
- visit **bhf.org.uk/publications**

You can also download many of our publications from our website.

Our resources and services are free of charge, but we rely on donations to continue our vital work. If you'd like to make a donation, please call our donation hotline on **0300 330 3322** or visit our website at **bhf.org.uk/donate**

Heart Information Series

This booklet is part of the *Heart Information Series*. The booklets in this series are:

- Angina
- Atrial fibrillation (AF)
- Blood pressure
- Cardiac rehabilitation
- Caring for someone with a heart condition
- Coronary angioplasty
- Diabetes and your heart
- Heart attack
- Heart failure
- Heart rhythms
- Heart surgery
- Heart transplant
- Heart valve disease
- Implantable cardioverter defibrillators (ICDs)
- Keep your heart healthy
- Living with a pacemaker
- Medicines for my heart
- Peripheral arterial disease
- Reducing my blood cholesterol
- Returning to work
- Tests

Our services

For more information about any of our services, contact the BHF on **0300 330 3322** or visit **bhf.org.uk**

Nation of life savers

The BHF has a vision to create a nation of life savers. As part of that vision, we're doing everything we can to make sure the UK public know CPR and can use public access defibrillators. Help us save the lives of thousands of people across the UK each year. Find out more at **bhf.org.uk/cpr**

- **Heartstart** is a free, two-hour course where you can learn CPR and other emergency life saving skills.
- Our **Call Push Rescue** training kit is available free to eligible secondary schools, and for a small fee to workplaces and community groups. It has everything you need to learn CPR, including a training DVD.

Heart Matters

Heart Matters is the BHF's free, personalised service offering information to help you lead a heart-healthy lifestyle. Join today and enjoy the benefits, including *Heart Matters* magazine and access to online tools. Call the **Heart Matters Helpline** on **0300 330 3300**, or join online at **bhf.org.uk/heartmatters**

Heart Support Groups

Local Heart Support Groups give you the chance to talk about your own experience with other heart patients and their carers. They may also include exercise classes, talks by guest speakers, and social get-togethers. To find out if there is a Heart Support Group in your area, contact the **Heart Helpline** on **0300 330 3311**.

Help shape the BHF – Heart Voices

Heart Voices is a growing network of heart patients who use their experiences to make sure our work meets the needs of patients. By signing up, you'll get the chance to shape the BHF by getting involved with anything from helping us to make new resources to informing our research. Visit **bhf.org.uk/heartvoices** for more information and to sign up.

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HAVE YOUR SAY

We would welcome your comments to help us produce the best information for you. Why not let us know what you think? Contact us through our website **bhf.org.uk/contact**. Or, write to us at:

BHF Customer Services
Lyndon Place
2096 Coventry Road
Birmingham B26 3YU.

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Particular thanks for their work on this booklet are due to:

- **Dr Rajan Sharma**, Consultant Cardiologist and Head of Clinical Services, Cardiology Clinical Academic Group, St. George's Hospital.

THANK YOU

This booklet is part of the *Heart Information Series*. We distribute 2 million booklets from this series each year. Without your hard work and support the British Heart Foundation wouldn’t be able to provide this vital information for people living with heart and circulatory conditions.

Donate to the fight at **bhf.org.uk/donate** or text **FIGHT** to **70080** to donate £3 to fund our life saving research.

British Heart
Foundation

For over 50 years our research has saved lives.

We've broken new ground, revolutionised treatments and transformed care.

But heart and circulatory disease still kills one in four people in the UK.

That's why we need you.

With your support, your time, your donations, our research will beat heart disease for good.

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

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