

Infective endocarditis

You may have recently been diagnosed or treated for a heart condition called infective endocarditis, or you may be wondering if you are at risk of this condition.

This leaflet explains what the causes and symptoms of infective endocarditis are, and tells you what actions to take if you experience them. It describes treatments that may be appropriate for you and how you should recover after treatment. This leaflet also gives ways that you can help to avoid an episode of infective endocarditis in the future.

A list of hospital contacts and further information is also provided for easy reference. If you have any further questions or concerns, please speak to a doctor or nurse caring for you.

What is infective endocarditis?

Infective endocarditis is an infection of the inner lining or valves of the heart. It is caused by bacteria – or occasionally fungi – entering the bloodstream and sticking to heart structures.

It is quite rare, affecting 30 people in every million each year. However it can be serious, especially if complications develop, so early diagnosis, early antibiotic treatment and early surgery (if needed) are vital.

Treatment requires hospital admission and a course of antibiotics given via a drip. Up to half of people affected may need surgery to repair or replace a damaged heart valve.

Even with the highest standard of medical care, in severe cases the risk of dying can be as high as one in five.

What causes infective endocarditis?

Your heart is usually well protected against infection and most bacteria pass by harmlessly. However, if your heart valves are damaged or you have an artificial valve, it's easier for bacteria to 'sneak past' your normal immune defence and take root. This can mean that bacteria settle on the inner lining of your heart (the endocardium). These organisms are sometimes referred to as vegetations by healthcare staff. They cause inflammation of the endocardium, and that inflammation can damage your heart valves.

Clumps of cells form around the bacteria or fungi, which can break off and occasionally cause conditions such as stroke.

Ways of getting infective endocarditis

- Bacteria can enter the blood stream through the mouth during everyday activities like brushing teeth or chewing food, especially if teeth and gums are in bad condition or decayed.
- Some invasive dental procedures, like extractions or deep scaling, can increase the risk.

- Some medical conditions lower immunity to infection, for example HIV and diabetes.
- Bacteria can also enter the bloodstream through needles and tubes (for example, when you are receiving haemodialysis or chemotherapy).
- Intravenous drug abuse commonly leads to infective endocarditis.
- Gut-dwelling bacteria can sometimes enter the bloodstream via ulcers or tumours in the bowel.
- Rarely, bacteria can be introduced during heart surgery or when a pacemaker is put in.
- Occasionally, urinary catheters introduce infection into the blood via the bladder.

Who is at risk for infective endocarditis?

You are at higher risk of developing infective endocarditis if you have:

- had a previous episode of infective endocarditis
- a prosthetic (artificial) or repaired heart valve
- some types of congenital heart disease (heart defects from birth).

You are at moderately increased risk if you have:

- thickened or leaking heart valves (including bicuspid aortic valve)
- enlarged heart muscles and thickened walls (hypertrophic cardiomyopathy).

You are also at risk if:

- you have tubes (cannulas) in your veins for cancer treatment or dialysis
- you self-inject non-prescription drugs.

Symptoms and treatment

Symptoms can develop rapidly in days, or slowly over weeks. It's vital to seek medical attention at the earliest signs, so that you can have blood tests for bacterial infection and cultures (tests) to try to identify any bug. If endocarditis is a possibility, antibiotics should **not** be started before these tests have been done, unless you are very unwell.

The most common symptoms of endocarditis include:

- unexplained flu-like symptoms (fever of 38°C/100.4°F or above, sweats, chills) that are severe or last longer than a week
- weight loss, poor appetite
- general fatigue and feeling unwell
- new back pain.

Without early treatment, complications may occur. These include:

- confusion or drowsiness
- shortness of breath from severe valve damage
- stroke
- 'cold leg' from a blocked artery
- boils or black patches on the toes or fingers.

You'll need to be admitted to hospital to confirm the diagnosis where a course of antibiotics will be given through a drip.

When should I contact my GP?

You should contact your GP at the earliest sign of any of the symptoms, unless there is an obvious explanation like flu.

When you visit your GP:

- If you know you are in a higher risk category you should point this out to your GP, who may be trained to prioritise other more common conditions.
- Your GP should arrange for blood tests, including blood cultures, **before** starting antibiotics for an unknown infection. This is **very important** because antibiotics may affect your test results.
- If your GP suspects infective endocarditis, they will likely arrange a hospital visit because tests are most easily and quickly performed in hospital.

When should I seek emergency help?

If you suspect a stroke, you should dial 999 immediately to request an ambulance, whether or not you have any symptoms of endocarditis. A stroke is one of the most serious complications of endocarditis.

The most effective way to identify the symptoms of a stroke is to remember the word **FAST**, which stands for:

- **Face** – the face may have fallen on one side, the person may be unable to smile, or their mouth or eye may have drooped.
- **Arms** – the person may be unable to raise both arms and keep them there as a result of weakness or numbness.
- **Speech** – the person's speech may be slurred.
- **Time** – it's time to dial 999 immediately if there are any of these signs or symptoms.

How is infective endocarditis diagnosed?

The diagnosis is made by assessing your signs and symptoms, and by performing blood tests (including blood cultures) and echocardiography (ultrasound scanning of the heart) in hospital.

What is the treatment?

All cases of infective endocarditis initially need to be treated in hospital with high-dose antibiotics given through a drip (intravenously), usually in your arm.

Regular blood samples will be taken to see how well the treatment is working.

You will be under the care of a cardiologist with input from an infection specialist and sometimes a cardiac surgeon. They will form the endocarditis team and will discuss your case at regular meetings.

Depending on the severity of your condition, you will usually have to be given antibiotics via a drip for between two and six weeks. You may need to continue antibiotics by mouth for several weeks after this, especially if there are complications, such as an abscess in the spleen or a bone infection.

On some occasions it may be possible to finish a course of intravenous antibiotics at home. Antibiotics may be administered by yourself, a family member or a district nurse and you will usually need to return to hospital every week to be checked.

Surgery

Surgery will usually be recommended if:

- there is serious valve damage and a risk of heart failure
- the infection does not settle with antibiotics alone or the infecting organism responds poorly to antibiotics or there is an abscess in the heart
- infected tissue breaks off the valve and travels round the body despite antibiotic treatment.

Surgery consists of the repair or replacement of the damaged heart valve. If there is an abscess near your heart valve, it may be necessary to replace part of the aorta (main artery) as well with either an artificial or biological graft.

Surgery for endocarditis can be very challenging and risky, not least because a person who needs this surgery will usually be very ill to begin with.

Intravenous antibiotics will be continued after surgery until your team are satisfied that no sign of the infection remains.

How will I recover after treatment?

Infective endocarditis is a major illness and it is normal to feel weak for several weeks afterwards, even if you have had no complications.

Medication

You should find ways to remember to take your medications at the right time and at the right dose. You may wish to put a reminder on your phone, keep a diary, or use a dosette box (a plastic box with small compartments that clearly show which pills need to be taken at what time of day).

Physical and emotional wellbeing

Before you received treatment, you may have been very physically unwell. If you had surgery, you will be seen by the Cardiac Rehabilitation Team to help you cope with pain and discomfort afterwards. It is not surprising that you may have difficulty with thinking skills, such as concentration or memory, or emotional problems for a number of weeks or even months.

While not all people are affected in the same way, you may feel worry with anxiety, low mood and depression, guilt, shame and anger. If you are experiencing any of these, please consider speaking with your GP.

Return to normal activity

You will not be able to do too much while you feel physically and emotionally weakened. However, you should consider returning to normal activity as soon as you feel physically able. Not being able to do your normal activities for a long time, and perhaps being stuck in bed, can lead to problems (such as fatigue and muscle weakness) when you start to move around again.

Gradually increasing physical activity can be a good treatment for negative feelings and you should not put your life on hold because of them. You should also aim to have a good diet and a good sleep routine, and make time for enjoyable things, like hobbies and socialising. This will create a positive 'virtuous circle' of improvement.

Being too sedentary, or activities like smoking and drinking too much alcohol or caffeine, can have negative effects on your physical wellbeing even though they may seem to help in the short term.

Avoiding further episodes of infective endocarditis

Follow-up appointments

You will be seen as an outpatient by the heart team initially four to six weeks after leaving hospital.

Unfortunately, you have an increased risk of developing endocarditis again at some point in the future, but there are things you can do to minimise this risk. The most important is to look after your teeth.

Practise good oral hygiene

You should visit your dentist, usually every six months, to ensure the earliest signs of tooth or gum disease are treated. Don't let abscesses and gum disease go untreated.

You should discuss with your cardiologist whether antibiotic protection is required before invasive dental procedures (such as extractions, scaling, or any procedure that involves manipulating or cutting the gums). If antibiotic protection is thought necessary, then you will usually be given amoxicillin to take by mouth one hour before your dental treatment. If you are allergic to penicillin, the recommended alternative is clindamycin.

If you think you are allergic to penicillin, please consider asking your GP to refer you to an allergy specialist for testing. Only 1 in 10 people who think they are penicillin allergic turn out to be so after testing.

You should have been issued with an endocarditis warning card. The card explains the antibiotics you need to take. You should show this to your doctor, dentist or healthcare professional before you have any treatment (especially dental).

Take care of your skin

You should avoid any cosmetic procedure that involves breaking the skin, such as body piercing or tattooing.

Important

If you have persistent fever with no obvious cause, you should visit your GP or Emergency Department (A&E) and bring your infective endocarditis warning card with you.

Blood cultures must be taken **before** starting antibiotics for an undiagnosed illness.

Contact us

If you have any questions or concerns about infective endocarditis, please contact your GP in the first instance.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.guysandstthomas.nhs.uk/leaflets

British Heart Foundation

The British Heart Foundation funds research into all heart and circulatory diseases and their causes. The website contains a lot of helpful information on heart-related topics including: tests for heart conditions, heart valve disease, caring for someone with a heart condition, and cardiac rehabilitation.

w: www.bhf.org.uk

British Heart Valve Society

This is a professional specialty group affiliated to the British Cardiovascular Society. It includes specialists of all disciplines interested in heart valve disease, with representation from patients as well. It aims to improve the care of patients with valve disease through educational and training programmes, literature and web information, and by defining standards of care for individuals, services and hospitals. It has produced an endocarditis information and warning card that you can carry in your wallet.

w: www.bhvs.org.uk

Heart Valve Voice

Heart Valve Voice is a collection of people with real experiences of heart valve disease, including a multi-disciplinary group of experts in the field (cardiologists, cardiac surgeons, GPs), cardiac patient societies, and patients themselves. Leaflets include 'Recovering from treatment', 'Post-treatment checklist' and '10 surprising things you may not be able to do right after your treatment'.

w: www.heartvalvevoice.com

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748, Monday to Friday, 9am to 5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

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