British Heart Valve Society
For Education and Best Practice in Heart Valve Disease

Infective endocarditis

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

This leaflet explains the causes and symptoms of infective endocarditis, and 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.

- Infective endocarditis is an infection of the inner lining or valves of the heart. It is caused by bacteria 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 via a drip.
- Many patients (up to 50%) may need surgery to repair or replace a damaged heart valve.
- Even with the highest standard of medical care the risk of dying can be as high as 1 in 5 in severe cases.

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 - or occasionally fungi – settle on the inner lining of your heart (the endocardium). These organisms can sometimes be referred to as vegetations by the professionals.
- They cause inflammation of the lining, 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 blood stream 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 blood stream from 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 (cannulae) in your veins for cancer treatment or dialysis
- If 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 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 38C (100.4F) or above, sweats or chills) that are severe or last longer than about 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 the most common cause for not growing bacteria in a blood culture (even if you have endocarditis) is being given antibiotics before the culture is taken
- 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 from the symptoms and signs elicited by your doctor, aided by blood tests (including blood cultures) and echocardiography (ultrasound scan of the heart) performed 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 - usually in your arm (intravenously).

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. These professionals form the endocarditis team and will discuss your case at regular meetings.

Depending on the severity of your condition, you will usually have to take antibiotics via a drip for between 2-6 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 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 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 emotional feelings and you should not put your life on hold because of them. You should also aim for a good diet, a good sleep routine and making time for enjoyable things, like hobbies and socialising. This will create a positive ‘virtuous circle’ of improvement.

Being too sedentary, or activities like smoking, 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 4 to 6 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 6 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 (e.g. extractions, scaling, or any procedure that involves manipulation or cutting the gums). If antibiotic protection is thought necessary, then usually this is with amoxicillin 3 grams taken orally one hour before dental treatment. If you are allergic to penicillin, the recommended alternative is clindamycin 600 milligrams orally.

If you think you are allergic to penicillin, please consider asking your GP to refer you to an allergy specialist for testing. Only one in 10 patients who thinks they are penicillin allergic turns 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, and you should show this to your doctor, dentist or healthcare professional before any treatment (especially dental).

Take care of your skin

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

Final key message

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

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

British Heart Valve Society
For Education and Best Practice in Heart Valve Disease

Useful sources of information

British Heart Foundation – www.bhf.org.uk

The British Heart Foundation funds research into all heart and circulatory diseases and the things that cause them. The website contains a lot of helpful information, including:

- Tests for heart conditions
- Heart valve disease
- Caring for someone with a heart condition
- Cardiac rehabilitation

British Heart Valve Society – www.bhvs.org.uk

This is a professional specialty group affiliated to the British Cardiovascular Society. It includes people 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 via 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 you can carry in your wallet.

Heart Valve Voice – www.heartvalvevoice.com

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.

This information has been developed by the South London Cardiac Operational Delivery Network, in conjunction with NHS trust clinicians across the region for a consistent approach to patient information for infective endocarditis.