



Patient Information

Infective Endocarditis

This booklet has been created and provided for you by
The Sussex Heart Charity
(Registered Charity No. 1120998)

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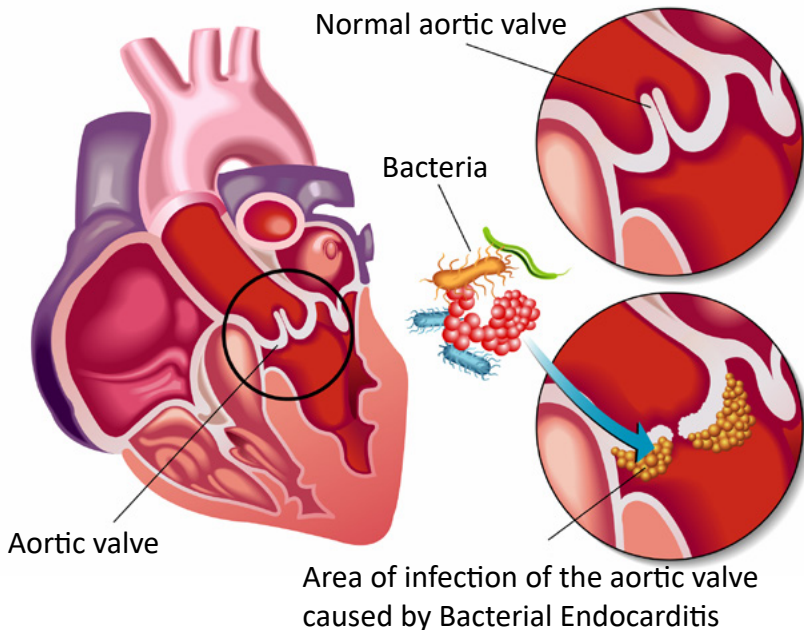
Audio Version Available

For those who prefer to listen, scan the QR code with your smartphone to access an audiobook version of this booklet.



What is Infective Endocarditis?

Endocarditis is a rare condition when the inner lining (the endocardium) of the heart becomes infected. The infection is usually due to bacteria but occasionally can be due to a fungal infection and usually involves one or more of the heart valves. Heart valves control the flow of blood through the chambers of the heart by opening and closing. Endocarditis is a serious condition and is potentially life-threatening but it can be treated and cured. Infection of pacemaker or internal defibrillator leads inside the heart are covered by this information booklet.



How many people get Infective Endocarditis?

In the UK endocarditis affects an estimated 3-10 people per 100,000 of the population. Endocarditis can happen to anybody, but it is more common in men and in people who have one or more risk factor (see page 8). Endocarditis is more common after the age of 50.

How does Infective Endocarditis happen?

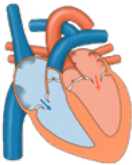
Infective Endocarditis is due to bacteria (very rarely fungi) infecting the bloodstream. The bacteria travel around the body and can attach themselves onto the heart valves or pacemaker leads inside the heart. Bacteria find it easiest to attach themselves to an area that where the lining of the heart is abnormal e.g. the surface of a narrowed valve or where there is manmade (prosthetic) material present e.g. a valve replacement. Once bacteria attach to the heart valves, it is very difficult for your own immune system to clear the infection. The collection of bacteria and your own cells trying to fight the infection is called a vegetation.

Bacteria that cause such infection can come from different areas of your body: approximately 30% of endocarditis is due to bacteria found in our mouths. Sometimes endocarditis can be associated with bacteria or infections from the bowel or your back (e.g. discitis).

Factors which increase your risk of getting Infective Endocarditis include:



Mouth – if your teeth and gums aren't healthy this increases the risk of bacteria getting into the bloodstream



Abnormal heart valves – e.g. a narrowed valve (stenosis) or a leaky valve (regurgitation)



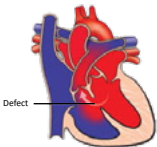
Previous heart surgery - Having an artificial heart valve, repaired valve or heart transplant.



A poor immune system – e.g. from chemotherapy



Needles and lines – e.g. injecting recreational drugs or lines which are inserted long term for medical reasons



Congenital heart problems - e.g. being born with a hole in the heart

A previous episode of endocarditis – having endocarditis before – increases your risk of further infection

What are the symptoms?

The symptoms of endocarditis are often non-specific and may come on gradually (over weeks to months), but they can develop suddenly depending on the type of bacterial infection.

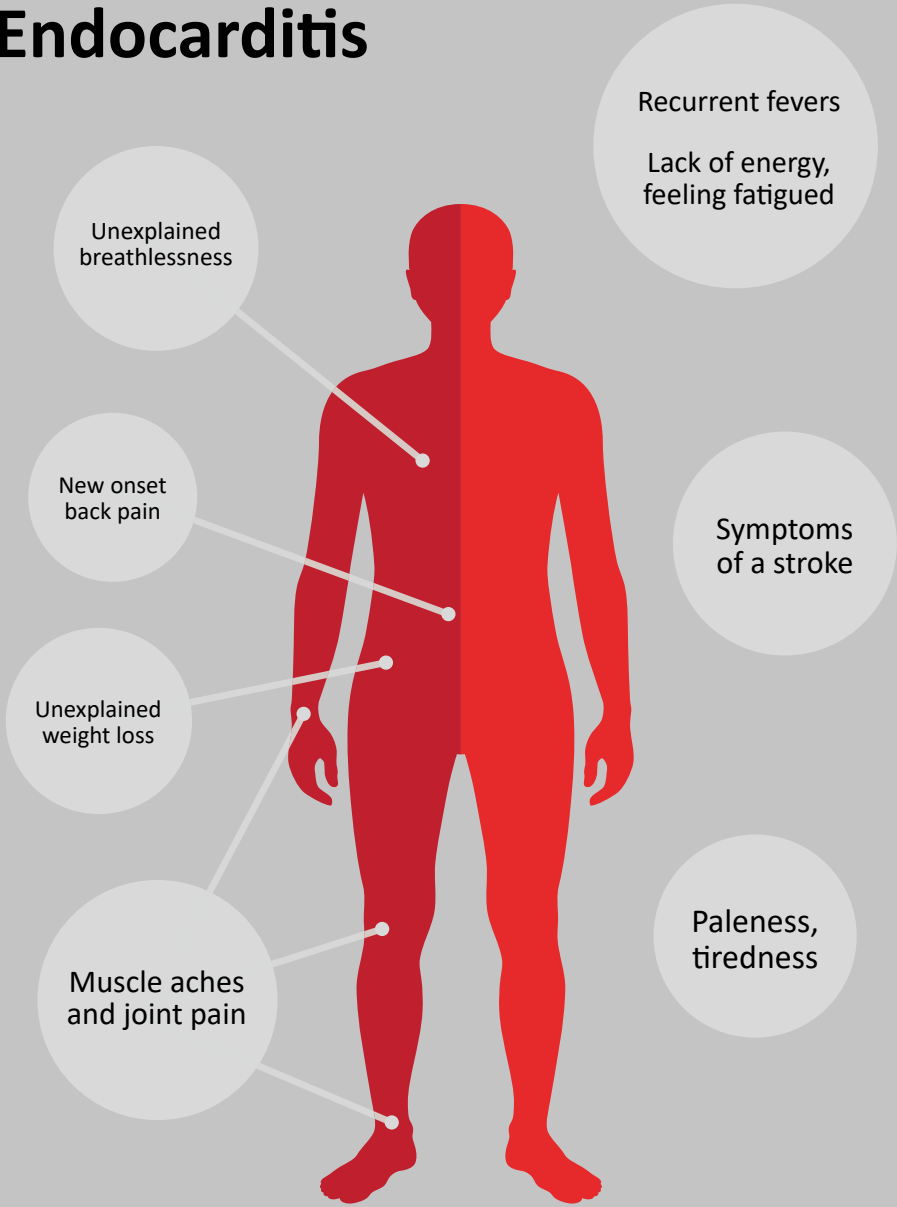
Typical symptoms include:

- Feeling generally unwell with listlessness and feeling fatigued
- Experiencing recurrent fevers and sweating
- Tiredness
- Breathlessness – particularly when lying flat or if you exert yourself
- Muscle aches and joint pains

These may be accompanied by:

- Weight loss
- Skin rashes
- Painful purple spots on the pads of your fingers and toes
- Symptoms of a stroke with weakness on one side of the body or difficulty in speaking

Symptoms of Endocarditis



How is Infective Endocarditis diagnosed?

Generally, endocarditis needs to be suspected to be diagnosed. It is important for patients who are at increased risk to know about the symptoms and to report them to their doctor. If you are suspected of having endocarditis, you will need a range of tests to confirm the diagnosis. These will include:

- **Blood tests** – to look for evidence of infection including culture of the blood (blood cultures) to see if the infecting bacteria can be grown in the lab to find the most effective antibiotic treatment for you
- **ECG (electrocardiogram)**– to assess the rhythm of your heart
- **Chest X-ray**
- **Urine test**

Echocardiogram or 'echo' for short - This is an ultrasound scan of your heart. It uses high frequency sound waves that reflect against structures in your heart to build up a detailed picture. This allows the function of the heart valves and pump of your heart to be assessed.

Transoesophageal echocardiogram or 'TOE' for short. This is a specialised ultrasound scan where pictures of the heart are taken from the inside by swallowing a small probe which is mounted on the end of a flexible tube. The probe sits in the food pipe or oesophagus and the procedure is performed using local anaesthetic spray onto the back of your throat and sedation. It allows a more detailed view of your heart.

Treatment of Infective Endocarditis

Your Care

During your time in hospital you will be looked after by your ward team who will see you daily, as well as being visited by the specialist Endocarditis Team. The Endocarditis Team involves a consultant cardiologist, a consultant microbiologist (infection specialist), junior doctor and specialist pharmacist. The Endocarditis Team work closely with the cardiac surgeons, cardiologists specialising in pacemakers and stroke consultants.

Antibiotics

Infective Endocarditis requires high dose antibiotics for several weeks. In most cases the antibiotics are given intravenously (via a vein). The type of antibiotic will depend on the infection you have and which antibiotic the bacteria are most susceptible to. Rare infections caused by fungi are treated with anti-fungal medicine.

Blood tests

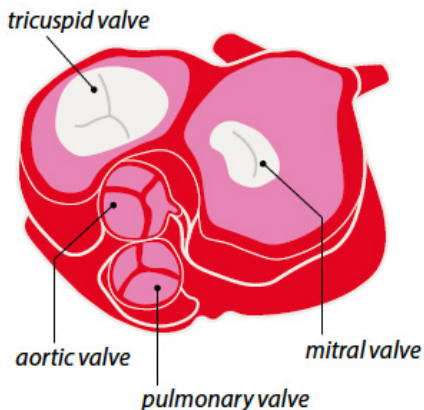
You will require regular blood tests during your treatment to ensure the antibiotics are effective in

treating the infection and depending on the antibiotics you are prescribed, to measure the level of antibiotic in the blood and to check the function of other organs in the body e.g. the kidneys. This is important if you are taking antibiotics called Gentamicin and Vancomycin.

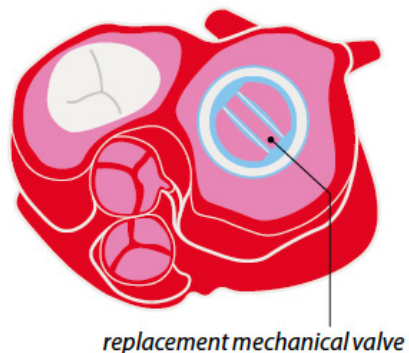
Surgery

In addition to antibiotics, approximately 50% of patients with endocarditis (50 in 100) require heart surgery. Surgery may be required to remove the infection if it is not responding to the antibiotics or to repair or replace a damaged heart valve. In general pacemakers or internal defibrillators are also removed if they are infected.

Before



After



Pacemaker

Some patients may require a pacemaker if the conduction system of the heart has been damaged by the infection. A pacemaker is also more common after heart surgery.

Intensive Care

Some patients who become very unwell may need help with breathing or dialysis and require specialist care on the intensive care unit (ICU). All patients requiring heart surgery have a period of care on cardiac intensive care (CICU).

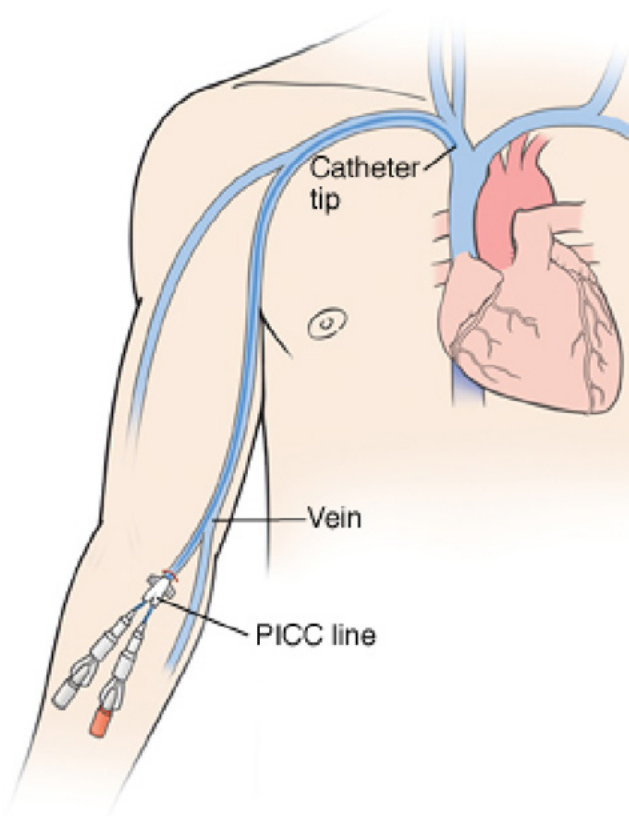
Duration of treatment

The majority of people require antibiotic treatment for 4-6 weeks depending on the bacterial infection, whether surgery has been necessary and whether other areas of the body are infected e.g. the back (discitis). We try to match your treatment to the specific bacteria causing your infection to provide the most effective and time efficient treatment.

You will need to have an intravenous line inserted into your arm to give the antibiotics. This is initially done via a cannula however, most people have a PICC line (peripherally inserted catheter – see diagram). A PICC line is a line that goes into the vein under your bicep muscle in your upper arm to provide the antibiotics directly to where they are needed. The PICC line can usually stay in place for the duration of your treatment. It can also be used for antibiotics at home for some patients who are suitable to complete treatment.

When patients are medically stable and recovered from heart surgery or a pacemaker extraction, if this has been necessary, we usually organise for nurses to come to your home to administer the antibiotics to complete the course.

Diagram of a PICC line



What is the outlook?

Many people recover from Infective Endocarditis but it is a serious condition and 50% of people require heart surgery. Endocarditis can progress to an advanced stage before the diagnosis is made and treatment is started. In this case it may have already caused serious damage to the heart and unfortunately some people may die from the complications or overwhelming infection.

The sooner the diagnosis is made and the infection is detected and treated, the better the prognosis.

What are the possible complications?

Given the severity of endocarditis, there are some potential complications to be aware of. These tend to develop if the infection is not treated or treatment has been delayed. They include:

- Damage to the heart valves – this can lead to impaired pumping of the heart
- Bits of the infective material, the vegetation, can break off into the bloodstream and travel to other parts of the body. This is called embolisation, and can lead to a stroke
- Infection can spread to other parts of the body, for example the back (discitis) – this may require additional treatment. This is usually in the form of a longer course of antibiotics (typically at least 8 weeks in total), and in some cases, surgery.

How will I recover after treatment?

Infective Endocarditis is a major illness and it is common to feel tired or fatigued for several weeks after finishing treatment, even if you have had no complications or haven't required heart surgery.

Return to normal activities

Whilst not all people are affected in the same way it is normal to have mixed emotions after being diagnosed with a serious heart problem. You may be relieved that you have had treatment to address the condition, but it is normal to feel concerned that you might not be able to do as much as you were before or feel anxious about further heart problems. You may feel low, bad tempered or even angry that it has occurred in the first place. All of this is natural.

It is important to talk about these feelings with your friends, family, the endocarditis team or the cardiac rehab team.

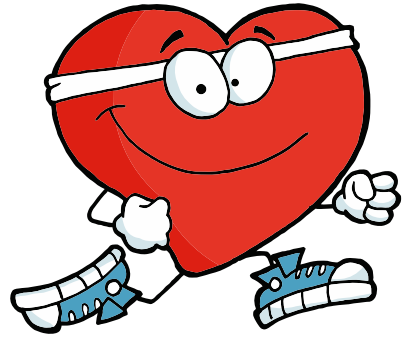
If you continue to feel low or depressed, please arrange to see your GP. He or she will be able to provide additional support if necessary.

Regular physical activity can help you recover and become independent more quickly. It is also a good treatment for anxiety and negative feelings that you might be experiencing.

Although you may not be able to do the same amount you were able to before your illness, you should aim to do a little bit more activity each day and build up how long you exercise for and how often.

Rest is also important for your recovery. It is normal to feel tired after such a serious heart condition. If you are feeling tired, make sure to rest properly on your bed rather than just dozing in a chair. You should also aim to have a good diet and make time for things you enjoy, like hobbies and socialising.

Cardiac Rehabilitation



The aim of cardiac rehabilitation is to help you recover and get back to living a full life as possible after a cardiac event such as infective endocarditis, heart attack or undergoing heart surgery.

Cardiac rehabilitation involves a combination of exercise, education, relaxation and psychological support. It is an important part of your treatment and rehabilitation aims to give you the information you need both to look after your heart health and to keep you well in the future.

A member of the cardiac rehabilitation team will see you on the ward if you are due to have surgery as part of your treatment. You can expect to be invited to go on a cardiac rehab programme after you have left hospital and completed your treatment.

Avoiding future episodes of Infective Endocarditis

Unfortunately, people who have had one episode of infective endocarditis are at an increased risk of developing a further episode. Fortunately, there are things you can do to minimise the risk:

Attending follow up appointments

You will be seen by a cardiologist in the outpatient department usually four to six weeks after leaving the hospital. If you have had heart surgery, generally your surgeon will also see you.

You will have another echocardiogram (heart scan), to check the heart valve function

Look after your teeth

One of the most important things to do is look after your teeth and practice good oral hygiene. Visit your dentist regularly (usually every six

months) to ensure that tooth or gum disease is caught early and treated.

Avoid body tattoos or body piercings

We advise avoiding having a piercing in areas of the body difficult to keep clean such as the tongue or other areas of the mouth and to avoid body tattooing.

Take care of your skin

Take care of any cuts or grazes; be sure to wash them as soon as you notice them to prevent the chance of infection. If you develop any symptoms of skin infection contact your GP for further advice.

Symptoms of a skin infection include:

- redness and swelling of the affected area
- the skin may feel tender and warm to touch
- discharge of pus from the affected area

Antibiotic Prophylaxis

We continue to recommend that anyone who has had endocarditis (or who has a heart valve replacement or repair) has antibiotic treatment before invasive dental procedures or treatment from the hygienist.

This is called antibiotic prophylaxis and you should be given an antibiotic prophylaxis card which explains the single dose of antibiotics you need to take 30-60 minutes before the planned procedure.

You should show the card to your dentist or hygienist before you have any dental treatment.

Sussex Cardiac Centre

Antibiotic prophylaxis is recommended in the following:

- Patients with prosthetic valves including TAVI, or prosthetic material used for cardiac valve repair
- Patients with previous infective endocarditis
- Patients with cyanotic congenital heart disease

- 2g Amoxicillin or if allergic to penicillin Cephalexin 2g or Doxycycline 100mg
- Single dose 30-60 minutes prior to high-risk dental procedures



This card was funded by the Sussex Heart Charity
www.sussexheartcharity.org

Be aware of symptoms

Remember to report an unexplained fever or flu like illness that persists for more than a week. You will be given an endocarditis warning card to help you.

IMPORTANT

If you have a persistent fever with no obvious cause you should arrange to see your GP. Don't forget to bring your endocarditis warning card.



Endocarditis

What is it?

It is an infection of the lining of the heart, typically the heart valves

Symptoms

Unexplained fever or flu like symptoms for longer than a week

Reducing your risk



- Good dental hygiene and regular check-ups with a dentist
- Avoid body piercing or tattooing
- Don't inject recreational drugs

Gentamicin

Gentamicin is an important antibiotic, commonly used to treat Infective Endocarditis. It is given via a vein (intravenously) through a cannula or a PICC line.

What are the possible side effects of Gentamicin?

Gentamicin is a very effective antibiotic but unfortunately like all medicines, it can cause side effects, although not everyone gets them. It is extremely important that you tell your doctor, nurse or pharmacist if you experience any of these side effects at any time as they could be serious or long term.

- Reduced kidney function – you may have no symptoms, but you may notice passing less urine
- Allergic reactions – rash, itch, fever, shortness of breath, chest tightness or wheeze
- Hearing or balance problems – these may include:
 - Hearing impairment – you may experience ringing in your ears or hearing loss
 - Disturbances of balance – feeling dizzy or difficulty keeping your balance
 - Visual disturbances – jerking or bouncing of vision

You are unable to take gentamicin if you have the neurological condition myasthenia gravis, as this may make your condition worse.

The harmful effects of Gentamicin are more common if your kidneys do not work normally. A Gentamicin patient information leaflet is available. If you have any concerns please discuss them with your doctor or pharmacist.

Tests required during Gentamicin injection courses

Gentamicin levels in the blood have to be measured at specific times depending on whether you are prescribed it twice a day or once a day. The monitoring allows the dose of Gentamicin to be increased or decreased or the interval between doses to be varied so that you gain the maximum benefit from the treatment with minimal side effects.

We are indebted to the endocarditis patients who kindly gave us important insight into the condition and feedback in writing this information leaflet

James Smethurst, Matija Taušan, Rachael James
January 2023

Useful Phone Numbers and Web Links

Albion Ward	01273 523175
Lewes Ward	01273 523176
Cardiac Care Unit Level 8A West	01273 664484 or 01273 523177
The Sussex Heart Charity	01273 523026 www.sussexheartcharity.org
NHS Direct - health advice	0845 46 47
NHS Smoking Helpline	0300 1231044
Alcoholics Anonymous	0800 9177650
Somerville Foundation	01473 252007
The British Heart Foundation	0300 3303311 hearthelpline@bhf.org.uk
Cardiomyopathy UK Helpline	0800 018 1024
Peer Support Volunteers Live Chat	01494 791224 www.cardiomyopathy.org
ICU Steps	www.icusteps.org
Heart Valve Voice	www.heartvalvevoice.com
Society for Cardiothoracic Surgery	www.scts.org
Aortic Dissection Awareness	www.aorticdissectionawareness.org



University Hospitals Sussex
NHS Foundation Trust

Cardiac Patients Improvements Group

We are a group of cardiac patients who share their experiences of care in order to inform clinicians and improve the cardiac patient experience in the short, medium and long term.

New members are always very welcome and membership is free.

We meet every 3 months in a relaxed and informal environment.

Mondays between 4:30 and 6:00 pm at the Royal Sussex County Hospital, Brighton.

What does the Cardiac Patients Improvements Group do?

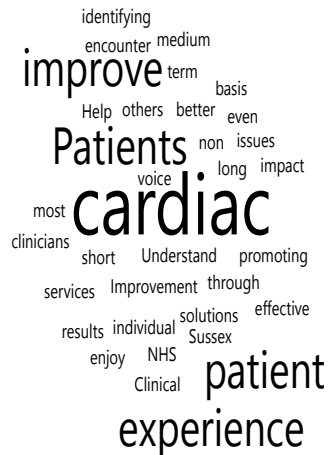
Facilitates Communication:

Provides a platform for staff at the Sussex Cardiac Centre to actively listen to patient perspectives. This includes reviewing patient information, soliciting feedback through questionnaires, and conducting focus groups.

Addresses Patient Concerns:

Offers patients a forum to raise and discuss issues that are significant to them. This could involve matters such as accessing information and support when needed or addressing privacy or dignity concerns.

Your voice matters to us. Through our discussions, we can drive meaningful changes that benefit all patients.



If you are interested and would like further information please contact:

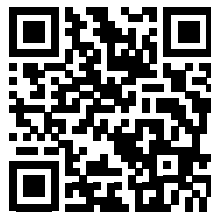
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Scan to donate.



This booklet was designed and published by:

The Sussex Heart Charity

Founded in 1987, the Sussex Heart Charity is dedicated to improving the lives of people with heart conditions in Sussex.

We fund cutting-edge treatments, specialist training for healthcare professionals and essential equipment for hospitals and community settings. Our support also drives pioneering research and new approaches to cardiac care, ensuring patients receive the highest standard of treatment.

As a charity funded entirely by donations, we rely on the generosity of our supporters—many of whom have experienced the exceptional care of the Sussex Cardiac Centre firsthand. Their gratitude and commitment help us continue our vital work, ensuring that more people across Sussex receive the best possible cardiac care when they need it most.

Your support makes this possible.

With your help, we can continue funding innovation, equipping healthcare teams and improving the lives of people with heart conditions across Sussex.

Your generosity can make a real difference. You can donate by scanning the QR code or by visiting our website at:

www.sussexheartcharity.org

Every contribution, no matter the size, helps us provide life-saving care and support to those in need.

Together, we can save lives.

Thank you!

THE SUSSEX HEART CHARITY Annual Sponsored Walk



Each year, the Sussex Heart Charity hosts a sponsored walk along Brighton's seafront, bringing together heart patients, families, healthcare professionals and supporters to raise funds for vital cardiac care.

Whether you're walking to celebrate your heart health journey, support a loved one, or champion heart health in Sussex, every step makes a difference

How to Get Involved:

Date: The event takes place annually—check our website for the latest details.

Location: Brighton Seafront

Who Can Join? Everyone is welcome!

For more information, speak to your Cardiac Rehabilitation Team or visit:
www.sussexheartcharity.org for details of our next walk.

MAP OF RSCH SHOWING CARDIAC CENTRE



Getting to the Royal Sussex County Hospital by Bus

Bus services **1, 1X, 7, 14B, 14C, 23, 27C, 47, 52, 71, 73, 94A** and **N7** all stop at the hospital.

Timetable details are available from Brighton & Hove Bus Company by calling **01273 886 200**, visiting www.buses.co.uk or downloading the **Brighton & Hove Buses** app.

Getting to the Royal Sussex County Hospital by Train

Brighton has a mainline railway station.

For timetable details please call: **03457 48 49 50**, visit the website at www.nationalrail.co.uk or download the **National Rail** app.

PLEASE HELP THE SUSSEX HEART CHARITY

FIND US ONLINE - WWW.SUSSEXHEARTCHARITY.ORG
GIVE US A CALL - 01273 523 026

YOUR DETAILS

PLEASE COMPLETE THIS FORM IN BLOCK CAPITALS

TITLE:

FIRST NAME:

SURNAME:

EMAIL: _____

ADDRESS: _____

TOWN:

POSTCODE:

TELEPHONE:

MOBILE:

SET UP A STANDING ORDER YOURSELF

The following details can be used to set up a standing order via your own online banking.
Please let us know so we can tell you how we use your generous donations.

ACCOUNT The Sussex Heart Charity

SORT CODE - -

ACCOUNT NUMBER

OR YOU CAN PROVIDE US WITH INSTRUCTIONS TO CONTACT YOUR BANK AND SET UP A STANDING ORDER FOR YOU

I / WE WOULD LIKE TO DONATE: £ PER MONTH £ PER QUARTER £ PER YEAR

BANK NAME _____

BANK ADDRESS _____

ACCOUNT NAME(S) _____

SORT CODE - -

ACCOUNT NUMBER



STARTING / /

SINGLE ONE-OFF DONATION

Please don't send cash in the post
Payable to: The Sussex Heart Charity

I HAVE INCLUDED A DONATION OF £ _____

GIFT AID

Yes I would like you to claim Gift Aid on my donation
I want all donations I've made to you in the past four years and all donations in future to be treated as Gift Aid donations until I notify you otherwise.
I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.
We will claim 25p on every £1 you donate.

SIGNATURE _____

DATE / /

PLEASE CONTACT ME ABOUT YOUR WORK AND EVENTS

In line with General Data Protection Regulation (GDPR) we are NOT allowed to contact you unless you give us permission.
Please choose your preferred method of contact.

PHONE TEXT EMAIL POST

PLEASE RETURN YOUR COMPLETED FORM TO:

FREEPOST: THE SUSSEX HEART CHARITY (No need to write anything else on the envelope but please use capitals)



Improving the lives of people with heart conditions in Sussex



The Sussex Heart Charity is vital for patients with heart conditions and essential for development and education of staff looking after them.

J Paice – Arrhythmia Specialist Nurse

A fantastic local charity which makes such a positive impact for cardiac patients in Sussex, both directly funding equipment and posts, and indirectly through supporting education of staff.

S Young – Nurse Consultant Cardiology

The SHC does so much work to help our patients and helps us deliver the best care that we can to them, for which we are very grateful.

C Huggett – Cardiac Rehabilitation Cardiac Nurse Specialist

An incredible charity making a huge impact on both patients and the professionals that look after the patients lives.

A Frappell – Heart Failure Clinical Nurse Specialist

The Sussex Heart Charity has provided so much support over the years to my professional development, and to the provision of resources for my patients. It is a huge asset to the local population, and we are extremely grateful for the work that the charity do.

J McQueen – Heart Failure Nurse Specialist

The Sussex Heart Charity has supported the nurses by providing funds for various courses and conferences. This support has a huge impact on the standard of care that the patients receive...

S Senith – Junior Sister



The Sussex Heart Charity

www.sussexheartcharity.org

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