

If you start to feel unwell when your GP surgery is closed, phone NHS 24 on **0845 4 24 24 24**.

Chest pain is a symptom of a heart attack. If you start to feel severe chest pain you should phone **999** (or **112** from a mobile phone).

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what is this booklet about?

This booklet is for people with chronic heart failure and for their families and friends. It is based on the recommendations from a national clinical guideline on how to look after patients with chronic heart failure. The booklet will help to make patients aware of the tests and treatment they should expect to receive from the NHS.

The booklet explains:

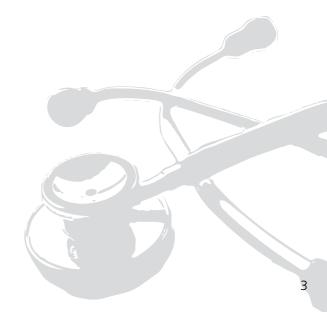
- what chronic heart failure is;
- · what causes it;
- what the symptoms are;
- how it is diagnosed;
- how it is treated; and
- what you can do to help yourself.

We have listed a number of support organisations at the end of the booklet where you can get more information.

We have explained the medical terms used in this booklet on page 25.

what is chronic heart failure?

Chronic heart failure describes what happens when your heart is not able to pump blood around the rest of your body as well as it should. People with heart failure can get short of breath and tired very easily.



causes

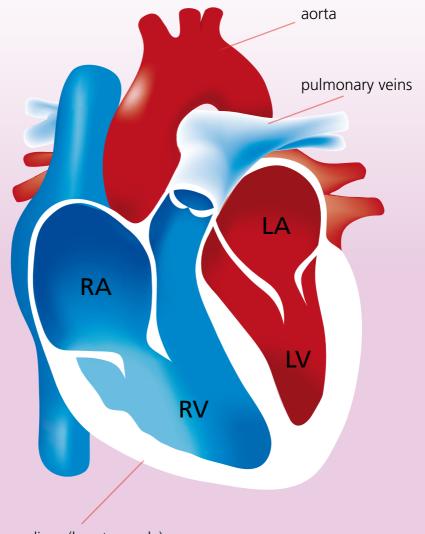
What causes chronic heart failure?

The most common cause of chronic heart failure is a heart attack, which causes damage to the muscle of the **left ventricle** (see diagram opposite).

But there are other possible causes. For example:

- narrowing of the arteries that supply blood to the heart muscle.
 This is called coronary artery disease;
- a previous heart attack (sometimes called myocardial infarction), which has left scar tissue that stops the heart muscle working normally;
- high blood pressure (hypertension);
- diseased or damaged heart valves can affect the flow of blood in the heart;
- a disease of the heart muscle itself, called **cardiomyopathy**;
- **congenital heart defects** (these are heart defects that were present at birth); and
- infection of the heart valves and/or heart muscle itself (known as **endocarditis** or **myocarditis**).

Sometimes the cause of chronic heart failure is unknown.



myocardium (heart muscle)

RA: right atrium LA: left atrium RV: right ventricle LV: left ventricle

symptoms

What are the symptoms of chronic heart failure?

The main symptoms of chronic heart failure are:

- severe tiredness or fatigue;
- shortness of breath, sometimes known as **dyspnoea**; and
- swelling of the ankles.

These symptoms can also be caused by other conditions. Your doctors will do some tests to find out if you have heart failure. They will look at your symptoms to find out how serious it is.

Doctors will use your symptoms to classify the severity of your heart failure. The table opposite shows how they do this.

class of heart failure

No limitations. Ordinary physical exercise does not cause undue fatigue, breathing difficulties or palpitations. Slight limitation of physical activity. Comfortable at rest but ordinary activity Ш results in fatigue, palpitations or breathing difficulties. Marked limitation of physical activity. Ш Comfortable at rest but less than ordinary activity results in symptoms. Unable to carry out any physical activity without discomfort. Symptoms of heart failure are present even at rest with increased discomfort with any physical activity.

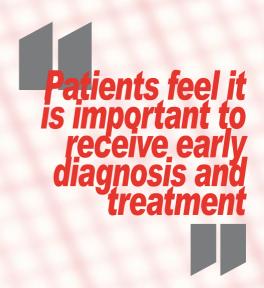
Classifying the severity of heart failure (I-IV) using the New York Heart Association (NYHA) scale.

diagnosis

What tests will the doctors do?

Your doctor will:

- measure your pulse rate;
- measure your blood pressure;
- take some blood and urine to find out if you have anaemia, liver damage, kidney damage or thyroid disease; and
- take an x-ray of your chest.



If your doctor thinks that you have heart failure after these tests, you will then have the following tests:

- electrocardiogram (also known as an ECG) electrodes are placed on your body and connected to a recording machine to measure the rhythm and electrical activity of your heart.
- brain natriuretic peptide monitoring (BNP) despite its name, this is not a test to monitor your brain functioning. This is a blood test to measure the levels of this hormone in your blood. If you have heart failure the level of BNP in your blood is increased.

If your doctor thinks you have heart failure after doing these tests, you may also be referred for an **echocardiogram**. This is when a recorder is put on your chest wall and ultrasound is passed through your chest to your heart. The recorder monitors the echoes from your heart and displays them on a screen to show doctors how your heart is working.

lifestyle changes

How can I help myself?

As a patient there are some steps you can take to slow down the progression of your heart failure. The table shows you some of the things you could try.

Drink less alcohol

Stop smoking

Be more physically active

Cut down on salt

Reduce your fluid intake

Watch your weight

Avoid: St John's Wort cranberry juice grapefruit juice

Steps for a healthier heart

You should try not to drink too much alcohol. If your heart failure has been caused by drinking too much alcohol your doctor will encourage you to stop.
If you are a smoker you should give up. Your doctor should offer you advice and support to do this.
You should try some low intensity physical activity such as walking. Even just a few minutes a day can help.
You should aim to eat less than 6 grams of salt per day. This will improve your blood pressure which helps to reduce your heart failure. But don't use "low salt" substitutes, as they have high potassium content, which your body may not be able to cope with. A high level of potassium in your blood can cause stomach cramps, diarrhoea, generalised weakness and skeletal muscle spasms.
Reducing your fluid intake will help improve any swelling you have and will make you feel less tired. Your doctor will give you advice on how much fluid you should drink each day.
Weigh yourself every day and let your GP know if your weight changes by more than 1.5-2kg (3-4 lbs) in two days.
Don't take St John's Wort or cranberry juice as they interact with medications such as warfarin and digoxin. If you are taking the statins called atorvastatin or simvastatin, grapefruit juice can affect how well these drugs work.

how will I feel?

It is common for patients with heart failure to experience depression. You may wish to discuss this with your doctor or clinical nurse specialist.

> Patients identified a need fo



medicines for chronic heart failure

What drugs will I be given to treat my heart failure?

You may receive some of the following drug treatments:

Angiotensin converting enzyme inhibitors (ACE inhibitor)

You should be given an ACE inhibitor no matter how severe your heart failure is. You will be started on a low dose and your blood pressure will be monitored regularly.

ACE inhibitors lower your blood pressure and reduce the work your heart has to do to pump blood around your body. Your symptoms should improve within a few weeks to a few months of starting treatment.

Side-effects of ACE inhibitors can include:

- cough
- low blood pressure/dizziness (hypotension)
- kidney problems (renal impairment)
- high levels of potassium in the blood (hyperkalaemia)

A rare side-effect is swelling under the skin around eyes, lips and throat (called **angio-oedema**). This can be dangerous and if this happens your ACE inhibitor will be stopped and you will be prescribed a different medication

Aldosterone antagonists – spironolactone and eplerenone

If you have moderate to severe heart failure, you may be given a drug called spironolactone. This belongs to a class of drugs known as an aldosterone antagonists.

Side effects of spironolactone can include:

- development of breasts in men (gynaecomastia)
- high levels of potassium in the blood (hyperkalaemia)
- kidney problems (renal dysfunction)

If you develop gynaecomastia you should stop taking spironolactone. You will be prescribed another aldosterone antagonist called eplerenone.

If you have suffered from a heart attack and have diabetes or signs of heart failure, you should be offered **eplerenone**.

To reduce the risk of side effects your blood will be monitored while you are taking spironolactone or eplerenone.

You cannot be given spironolactone or eplerenone if you have signs of renal impairment or high levels of potassium in your blood.

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Angiotensin receptor blocker (ARB)

If you experience side effects from an ACE inhibitor you should be given an angiotensin receptor blocker (ARB) instead. The doctor will start you on a low dose and will monitor your blood pressure and blood chemistry.

Beta blockers

As soon as your condition is stable you should receive beta blocker therapy. If you have a history of asthma, heart block (**abnormal electrical activity**) or low blood pressure (**hypotension**) you should not be started on beta blocker therapy.

Beta blockers block the action of hormones called **noradrenaline** and **adrenaline**, which normally increase your heart rate (make your heart beat faster). Using beta blockers slows down your heart rate and lowers your blood pressure.

Symptoms may take 3-6 months or longer to improve. In the short term, your symptoms may briefly worsen after starting a beta blocker. It is important that you monitor your health during this time and if it gets worse tell your doctor, for example, tiredness, fatigue, breathlessness. These symptoms can usually be managed by adjusting your medication.

You should not stop taking your beta blocker without speaking to your doctor first.

a need for doctors to give appropriate ation and provide patients with a clear ave been given these drugs. They also scribed drugs are frequently reviewed.

Candesartan

This is an angiotensin receptor blocker (ARB) that is given to people who still have symptoms of chronic heart failure after they have been on ACF inhibitors and a beta blocker.

Digoxin

If you have heart failure and a normal, regular heart rhythm (known as **sinus rhythm**) and are still suffering from the symptoms of heart failure despite treatment, you may be given digoxin in addition to your other treatment (an **add-on therapy**).

If you experience a slow heart rate (**bradycardia**) when taking digoxin and a beta blocker, then the digoxin should be stopped.

You should not take St John's Wort or cranberry juice if you are taking digoxin as they can interact with this medication.



Diuretics

Diuretic therapy, sometimes known as water tablets, is used to reduce the build up of fluid in your ankles and lungs. This swelling is common in people with heart failure.

Water tablets act by increasing the amount of water and salt in your urine. The dose you receive will depend on your individual needs and will balance the need to reduce your fluid retention without producing dehydration or kidney problems

Sometimes diuretics can cause gout in patients with heart failure. Unfortunately the diuretics are vital to the treatment of heart failure and it is not possible to stop them, even if they cause gout. You should be offered pain killers called **non-steroidal anti-inflammatory drugs** (NSAIDs, eg **ibuprofen**) or a drug called **colchicine** to reduce the inflammation.

Hydralazine and isosorbide dinitrate

These drugs are used in the same way as ACE inhibitors but they are not as effective. You may be given these drugs if you are intolerant to ACE or ARB.



other treatments

What other treatments are available?

Assisted ventilation

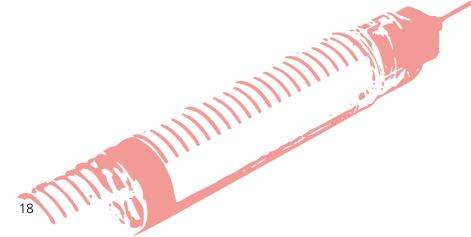
A very small number of patients may have such severe breathing difficulties that they cannot sleep. This can be treated safely with **continuous positive airway pressure** (CPAP). By placing a mask over your nose, CPAP takes air into your airways, helping you to breathe more easily when you are asleep.

Exercise training programme

If your heart failure has been classified as NYHA II and III (see table on page 7) you should be considered for a moderate intensity supervised exercise training programme. This will help to improve your exercise tolerance and your quality of life.

You should be encouraged to take exercise within limits dictated by your symptoms. This means exercise such as walking, climbing stairs, swimming, dancing or running.

Your exercise programme should be tailored to you, based on your needs.



Cardiac resynchronisation

Patients who are severely ill with a specific type of heart failure should be considered for cardiac resynchronisation.

In this procedure, a very special pacemaker system will be fitted. This will help to co-ordinate the contractions of the left and right sides of your heart muscle.

Cardiac transplantation

If you have severe heart failure and your drug treatment is not working you should be referred to an advanced heart failure centre. At this centre specialist doctors will assess you to find out if you are suitable for a heart transplant.

Immunisation

If you have chronic heart failure you are at greater risk of developing a more serious illness from infections such as flu. It is recommended that you are given vaccinations for flu and pneumococcal infection. Your doctor should offer you this.

Preoperative intra-aortic balloon counterpulsation

If you need an operation to bypass a narrowed section or sections of coronary arteries to improve blood supply to the heart (known as **coronary artery bypass surgery**) you should be given intra-aortic balloon counterpulsation before you have this surgery. Intra-aortic balloon pump counterpulsation is used to increase blood flow to your heart muscle and to reduce the workload for your heart. The pump will be placed inside your aorta, which is the main artery that carries oxygen-rich blood to the rest of your body.

leaving hospital

What happens to me when I leave hospital?

When you are discharged from hospital, the healthcare staff should make arrangements for you to receive ongoing support. This may include:

- attending a heart clinic;
- home visits from nurses;
- telephone follow-up by a heart failure nurse; and
- treatment advice from a pharmacist.

Your doctor or practice nurse should give you information on support groups and refer you to your nearest group if you feel this would be useful. There are cardiac support groups across Scotland supported by Chest Heart and Stroke Scotland (CHSS). These self help groups are run by lay people with experience of heart disease. You and your family may find it helpful to meet and talk to people who have gone through similar experiences. You can refer yourself to one of these support groups if your healthcare team hasn't already done so (details of CHSS are listed on page 23). Support groups can give you and your family/friends:

- emotional and social support;
- help with rehabilitation (through a structured exercise programme);
- advice on preventing further heart problems; and
- information and education.

Is palliative care available?

When you are living with heart failure you may start to think about the risk of dying. You may have concerns and unanswered questions. You should be put in touch with a palliative care team who will listen to your concerns and talk to you about these issues.

Your palliative care team will offer you a patient-centred approach to end-of-life care, providing you with:

- emotional support;
- symptom management; and
- the opportunity to discuss stopping treatments.

If your breathlessness is becoming very difficult to cope with your palliative care team may give you low dose **opioids** to help.

Your medication should be reviewed regularly and the decision to adjust or stop any treatments should be based on how effective the treatments are and how you feel.

You have the right to refuse any medical treatment or request withdrawal of treatment, including pacemakers and other ICDs (**implanted arrhythmia control devices**). Your palliative care team will talk to you about any concerns you have with your treatments.

Where can I find out more?

British Cardiac Patients Association

BCPA Head Office 2 Station Road Swavesey Cambridge CB4 5QJ

Phone: 0800 479 2800 • Fax: 01954 202 022 Email: enquiries@bcpa.co.uk • www.bcpa.co.uk

The British Cardiac Patients Association is a charitable organisation run by volunteers providing support, advice and information to cardiac patients and their carers.

British Heart Foundation (Scotland)

4 Shore Place Edinburgh EH6 6WW

Phone: 0131 555 5891 • Email: scotland@bhf.org.uk

Heart Information line: 08450 70 80 70 (available Mon-Fri 9am-5pm)

www.bhf.org.uk

The British Heart Foundation provides a free telephone information service for those seeking information on heart health issues. Also provides a range of written materials offering advice and information to CHD patients and carers. Topics include physical activity, smoking and diabetes

information and support

Chest Heart and Stroke Scotland

65 North Castle Street Edinburgh EH2 3LT

Phone: 0131 225 6963 • Freephone helpline: 0845 0776000

Email: admin@chss.org.uk • www.chss.org.uk

Chest Heart and Stroke Scotland provides a 24 hour advice line offering confidential, independent advice on all aspects of chest, heart and stroke illness. A series of information booklets, factsheets and videos are available free of charge to patients and carers. There are over 30 cardiac support groups in Scotland which are affiliated to CHSS, patients can contact CHSS for details of their nearest local support group.

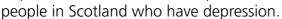
Depression Alliance Scotland

3 Grosvenor Gardens Edinburgh EH12 5JU

Phone: 0131 467 3050 • E-mail: info@dascot.org

www.depressionalliance.org

Depression Alliance Scotland provides information and support for





NHS Health Scotland

Woodburn House Canaan Lane Edinburgh FH10 4SG

Phone: 0131 536 5500 • Textphone: 0131 535 5503

Fax: 0131 535 5501

Email: publications@health.scot.org.uk (information on obtaining Health Scotland publications); library.enquiries@health.scot.nhs.uk

(help with general health information enquiries)

www.hebs.com

NHS Health Scotland is a special health board within NHS Scotland. The organisation provides information on projects, publications, support groups and information leaflets relating to CHD.

NHS 24

Phone: 0845 4 24 24 24

www.nhs24.com

NHS 24 is a nurse led service for members of the public. It is a free helpline offering health information, advice and help over the phone.

glossary

Aldosterone antagonist a drug used to treat heart failure

Angiotensin converting enzyme inhibitor (ACE inhibitor) a drug used to lower blood pressure

Angiotensin receptor blocker (ARB) a drug used to lower blood pressure

Beta blocker a drug which blocks the action of hormones called noradrenaline and adrenaline which normally increase your heart rate (make your heart beat faster). Using beta blockers slows down your heart rate and lowers your blood pressure

brain natriuretic peptide monitoring (BNP) a blood test to measure the levels of this hormone in your blood. The levels of BNP released by your heart muscle increase if you have heart failure

Candesartan a drug given to people who still have symptoms of chronic heart failure after they have been on ACE inhibitors and a beta blocker Cardiac resynchronisation a procedure where a special pacemaker is fitted to help coordinate the left and right sides of your heart muscle

Coronary artery bypass grafting (CABG) an operation to bypass a narrowed section or sections of coronary arteries and improve the blood supply to the heart

Digoxin a drug used to treat heart failure

Diuretic a water tablet used to reduce the build up of fluid in ankles and lungs

Dyspnoea shortness of breath

Echocardiogram (ECG) a test where a recorder is put on your chest wall and ultrasound sent to your heart. The recorder monitors the echoes from your heart and displays them on a screen to show doctors how your heart is working

Electrocardiogram a test which records the rhythm and electrical activity of your heart by putting electrodes on your body and connecting these to a recording machine Flu a viral infection of the respiratory system

High blood pressure occurs when the smaller blood vessels in the body become narrow and cause pressure to build up. Also known as hypertension

Hydralazine a drug used to lower blood pressure

Hypertension high blood pressure Hypotension low blood pressure

ICD (implanted arrhythmia control device) a device which monitors your heart rhythm and sends out an electrical shock if your heart rhythm becomes abnormal

Isosorbide dinitrate a drug used to lower blood pressure

Opioids drugs used to help control pain. Can be given to heart failure patients to help control breathlessness

Palliative care is given to improve quality of life for patients who have a life threatening illness

Peripheral arterial disease is a disease of the arteries which supply blood to the arms and legs

Pneumococcal infection a bacterial infection which can cause pneumonia, bloodstream infections and meningitis

Revascularisation any procedure that restores blood flow to a part of the body

Simvastatin this is a type of statin that is sometimes given to patients with heart failure. A statin is a drug that helps to lower your cholesterol level

Statin therapy drugs used to reduce cholesterol levels (a fatty material made in the body by the liver)

Warfarin a drug which helps to prevent your blood from clotting. You may be given this to prevent blood clots forming and blocking your arteries

References:

British Heart Foundation (BHF). The heart – technical terms explained: Heart Information Series Number 18; BHF; London; 2004.

notes

notes

What is SIGN?

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice to doctors, nurses, physiotherapists, occupational therapists, other healthcare staff and patients about the best treatments that are available. We write them by working with doctors, nurses and other NHS staff and with patients, carers and members of the public. The guidelines are based on the most up to date medical evidence.

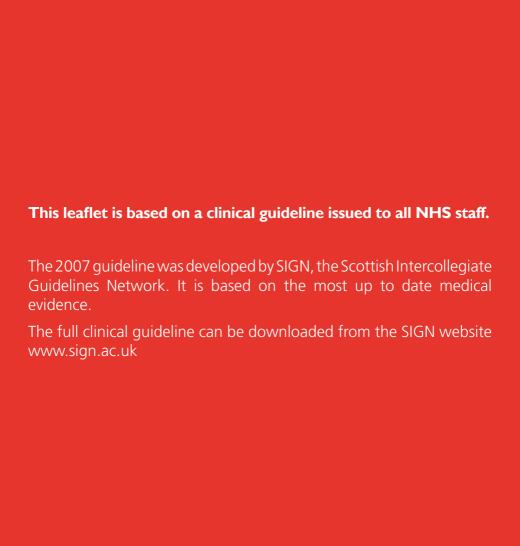
Alternative formats

If you would like a copy of this leaflet in an alternative language or format such as large print, please contact

Karen Graham Patient Involvement Co-ordinator

Phone: 0131 718 5108 • Email: karen.graham2@nhs.net





SIGN

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