



Your guide to living with heart failure

Adult community services in Bexley and Greenwich

oxleas.nhs.uk



This guide is intended to provide you with information about living with heart failure and help you to manage your condition at home. It contains charts for you to record information about your weight and medication and a section for your heart failure nurse to record notes from your appointments. Please bring it with you to appointments with your heart failure nurse.

What is heart failure?

Heart failure is a condition in which the heart is unable to pump blood around the body effectively. It does not mean the heart is about to stop, but rather, if left untreated, the heart muscle would continue to weaken. It is one of the most common heart problems in the UK.

If you have heart failure, you may experience shortness of breath, weakness, tiredness and swelling of the ankles. However some people experience very few symptoms and their heart failure may have only been discovered by a special heart scan known as an echocardiogram.

Heart failure can lead to symptoms of:

- tiredness
- breathlessness
- feet and ankle swelling
- ‘bloated’ feeling
- reduced appetite.

There are various cases of heart failure, including:

- a history of heart attacks
- coronary artery disease
- heart valve disease
- viral illness
- excessive alcohol intake
- high blood pressure.

Sometimes a specific cause of the heart failure cannot be found.

Although rarely completely curable, there are effective treatments for heart failure. A range of medications can assist the heart, help to control and improve symptoms and increase life expectancy. Many of these drugs need to be started at low doses and increased slowly. Once started most treatments need to be continued indefinitely.

Your Heart Failure Nursing Team

Your Heart Failure Nursing Team is run by Oxleas NHS Foundation Trust. Our goal is to support people to better manage their condition in their own home and avoid unnecessary hospital admissions and A&E attendances.

The team consists of:

- a consultant cardiologist
- heart failure specialist nurses (4 each in Bexley and Greenwich)
- healthcare assistant to take bloods and perform ECGs
- an administrator
- input from a psychologist.

We run five heart failure clinics a week and visit patients in their own homes who are unable to attend a clinic.

In the heart failure clinic and when you are visited at home you will be seen by a nurse who specialises in the care and treatment of people with heart failure. Each time you will be examined and your weight, pulse and blood pressure recorded. From time to time you may also need an ECG (electrocardiogram) and blood tests.

Your nurse will make sure that you are prescribed the right medication to work most effectively for you. Everyone reacts differently to medicine, so to ensure you are on the best dose for you, your nurse may adjust drug doses quite often at first. They may also talk to your GP about how the medication is working and discuss alternatives.

Your nurse will also explain the things you can do to keep yourself as well as possible and answer any questions you may have about your condition.

Monitoring your weight

It is a good idea for people with heart failure to weigh themselves regularly, as this gives an indication of how much fluid the body is retaining. For example, if your weight goes up by four pounds, you may be retaining around three pints of fluid. The more fluid you retain, the more your ankles may swell and your breathing will feel worse (particularly when you lie down, or try to do things).

Weigh yourself every day.

Most people find it easiest to weigh themselves first thing in the morning, after going to the toilet, in their night-wear before breakfast.

You can record your weight on the following pages if you want to.

When weighing yourself, follow these guidelines.

- Always use the same scales.
- Always weigh yourself at the same time of day.
- Always weigh yourself wearing the same sort of clothes/shoes.
- Always use the same units, ie pounds and ounces or kilograms.

If your weight goes up by two to three pounds in one day, make sure you weigh yourself the next day and if it is still raised, particularly if you have noticed an increase in breathlessness or ankle swelling, contact your doctor or heart failure nurse for advice.

If your weight has increased very quickly it is likely to be due to fluid retention and it is likely that you will need to take an extra dose of your diuretic (water) tablets for a day or two. Your doctor or nurse will advise you about this.

Medication

It is very important that you take your medication regularly, as if you miss doses or muddle your tablets up, your heart failure may get worse and you may get more side effects.

You need to devise a system that ensures that you take your medication as it is prescribed. You can use the form on page 10 to help you organise when to take your tablets. Talk to your pharmacist or nurse if you feel that you need extra help in coping with your tablets.

It is likely that you will be prescribed a combination of tablets (see the following pages for the types of medication used) and your condition will be monitored closely as each new tablet is introduced. The medications listed in this booklet are the most commonly used in the treatment of heart failure, but there are others that can be used if you are not able to take those listed.

Important

- Make sure you take your medications every day.
- Always have a supply of medication so you never run out.
- Bring all of your tablets (in their original containers) with you when you see the doctor or nurse.
- Keep taking the tablets unless your doctor or nurse tells you to stop.
- If you are bothered by side effects, please discuss this with your nurse or doctor.
- Do not take any 'over the counter' medicines without checking with your doctor, nurse or pharmacist first.
- For minor aches and pains, such as a headache, you can take Paracetamol, up to eight tablets in 24 hours.
- Do not take any non-steroidal anti-inflammatory drugs (NSAIDs), including Nurofen, Brufen, Ibuprofen, Indomethacin, Diclofenac, Naproxen, Voltarol or Arthrotec.

Here are some of the most common heart failure medications. Your nurse will write the name of the drugs you are taking into the relevant spaces below so you can read about how they work and why you are on them.

ACE (Angiotensin Converting Enzyme) inhibitors

Name of drug:

These work by relaxing your blood vessels, making it easier for your heart to pump blood through them. The dose is always started very low and increased over time.

When you are on an ACE inhibitor, your blood pressure will need to be monitored and you will need regular blood tests to monitor your kidney function.

Possible side effects include: dry irritating cough; low blood pressure; and dizziness.

Angiotensin-II receptor antagonists

Name of drug:

These have a similar effect as ACE inhibitors described above, but are less likely to cause a dry cough as a side effect.

Diuretics (water tablets)

Name of drug:

These help your body to get rid of excess fluid by making your kidneys lose extra water so you pass urine more frequently. They help to reduce ankle swelling and make you feel less breathless. You should notice that you pass more urine after taking your tablets.

It doesn't matter what time of day you take the tablet, although most people take it first thing in the morning.

If you are worried about having to find toilets when you are out shopping, on a car journey or at a special occasion, it is OK to delay taking the tablet until later in the day (but try not to leave it out altogether). It is recommended that you do not take it later than 3pm as it may continue to work into your bed time and lead to a disturbed night's sleep.

Occasionally, diuretics may make you lose essential substances (called electrolytes) from your blood. You will need to have blood tests to monitor your electrolyte levels.

Digoxin

Current dose of Digoxin:

This drug can help your heart beat more strongly and ensures that it doesn't beat too fast. This is especially important if you are in an irregular heart rhythm such as atrial fibrillation.

Side effects include: nausea; loss of appetite; visual disturbances; and diarrhoea. If this occurs please see your doctor or nurse as soon as possible.

Beta Blockers

Name of drug:

Beta blockers work by slowing down your heartbeat so your heart doesn't work so hard. Some also relax your blood vessels, making it easier for the heart to pump blood through them. The dose is always started off at a low level and built up slowly depending on how you feel, your pulse and blood pressure. You will be closely monitored each time the dose is increased.

Possible side effects include: feeling tired; cold hands and feet; vivid dreams; and impotence. Contact lens wearers may notice dry eyes.

Aldosterone Antagonists

Name of drug:

These drugs reduce salt and water retention and may make the heart muscle less stiff. They are useful in controlling symptoms in people with moderate to severe heart failure. Blood tests to measure the amount of potassium are required occasionally.

Possible side effects include: enlargement of breast tissue (men); painful or sensitive nipples; and impotence.

Use the table to record the details of your medication and when you should take it.

Angiotensin Receptor Nprilysin Inhibitor

Name of drug:

These are new medications which help improve the heart's ability to pump blood around the body. It blocks the body's natural system which has a harmful effect on the heart.

Medication	AM	Midday	PM	Bed time	Extra Information

Dietary advice

Keep your weight under control.

Your heart has to work harder if you are overweight. The usual advice to people who are trying to lose weight is to increase the amount of exercise that they are doing and reduce the amount of calories (from excess sugar and fat) they are eating. When you have heart failure it can be difficult to increase your exercise levels, although it is important to keep as active as your condition allows (this may vary from day to day). It is therefore particularly important that you try to eat as healthy a diet as possible.

- Try to eat less fat – choose lean meat, fish and poultry. Avoid fried foods and pastry.
- Dairy foods (milk, butter, cream and cheese) are an important source of calcium. Use low fat versions (semi-skimmed milk, half fat cheese, low fat spreads) as they contain the same amount of calcium and other nutrients but less fat.
- Eat more high fibre foods such as wholemeal bread, pasta and cereals.

- Try to eat five portions of fruit and vegetables per day (use fresh or frozen – avoid tinned vegetables if possible as they contain a high level of salt – see below).
- Try to eat fewer biscuits, cakes and sweet things.

If your appetite is low, you are troubled by nausea or vomiting, or you have recently been in hospital, please talk to your nurse or doctor about how to increase your energy intake as this can be very important.

Reduce your salt intake

If you eat too much salt (which contains sodium) it may affect the amount of fluid in your body, making you retain fluid. This will make your ankles swell and breathing worse. Try to reduce the amount of salt you eat as much as possible.

Most foods contain low levels of salt naturally and this is usually enough for our needs. Therefore do not add any salt to your food during the cooking process, or at the table. There is hidden salt in items such as packet soups, stock cubes, sauce mixes, gravy granules, cheese, bacon and smoked meats, crisps, salted

nuts and sausages. Also there can be high levels in processed foods such as tinned vegetables, sauces and 'ready meals'. It is better to avoid these items altogether, but if this is not possible, try to keep levels as low as possible, and use less of these items, eg: use half a stock cube or make your own stock and use less gravy.

It is alright to use vinegar, lemon juice, garlic, pepper and other herbs to make your food more interesting, especially if you have lost some of your sense of taste (a common problem in heart failure patients).

Do not use any 'salt alternative' products such as Lo Salt, as they contain high levels of potassium, which can react with your medication.

Alcohol

If you have been told not to drink, don't.

If you have been told you can have alcohol, then keep your consumption to no more than three units per day if you are a man and two units per day if you are a woman. You should have at least two alcohol free days a week.

One unit of alcohol is equivalent to:

- half a pint of normal strength beer
- a pub measure glass of wine
- a pub measure of spirits.

Fluid intake

The more you drink, the more your heart has to work to eliminate fluid. On the other hand it is very important not to drink so little that you become dehydrated. It is recommended that you drink about two to three pints (1.0-1.7 litres) of fluid every day in total (tea, coffee, fruit juice, squash, low calorie fizzy drinks, etc). In warm weather add a further pint (0.6 litres) unless you have been given specific advice by your doctor or nurse. If you find that you have a dry mouth try using refreshing mouthwashes or suck frozen fruit juice ice cubes.

Exercise

If your heart failure has made you inactive, you may gradually feel weaker and less able to do things. Try to keep as active as possible (what you feel able to do may change from day to day). Many people with heart failure have said that they

feel better when they exercise regularly. Whatever you do (walking, swimming, cycling, dancing, golf) you must always be able to feel that you have enough breath to be able to talk to someone while you are doing it. If you feel that you are having difficulty talking, you must slow down a bit until you are able to hold a conversation.

Please talk to your nurse about exercise levels specific to you. If you wish, you can be referred to an appropriate exercise class.

Smoking

Smoking can damage your heart and lungs. If you smoke we would advise you to stop now. You should also avoid passive smoking as much as possible. If you need help to stop please talk to your nurse who can refer you to a local stop smoking service.

Get immunised

People with heart failure can quickly become very unwell with flu or pneumonia. Therefore we suggest you see your doctor to get the appropriate immunisations each autumn.

Date	Appointment notes	Initials

Date	Appointment notes (cont.)	Initials

Contact us

Our team is based at the following address.

Heart Failure Nursing Team

151-153 Goldie Leigh

Lodge Hill

Abbey Wood

SE2 0AY

We are available Monday to Friday from 8am to 6pm.



@oxleasNHS



facebook.com/oxleasNHS

oxleas.nhs.uk

Confidentiality

All staff abide by a strict code of conduct on confidentiality and only share information in order to provide good quality care. We usually discuss this with you first.

Your opinion matters

We welcome your views on the services we provide. PALS is a free, confidential service which helps patients, families and carers deal with any concerns about our treatment and care.

Monday to Friday 9am to 5pm
(answerphone available)

Email: oxl-tr.pals@nhs.net

Tel: 0800 9177159 (freephone)
(not free from mobile phones)

Raising concerns

Your complaints, comments and suggestions help us improve the services we provide.

Email: oxl-tr.complaints@nhs.net

Tel: 01322 625751

Accessible information

If you'd like information in your own language, large print, audio or other formats, we can arrange this. Please speak to a member of staff.

Oxleas NHS Foundation Trust

Pinewood House

Pinewood Place

Dartford

Kent DA2 7WG

Tel: 01322 625700