

Chest
Heart &
Stroke
Scotland



LIVING WITH HEART FAILURE



H5

**NO LIFE
HALF LIVED**



NO LIFE HALF LIVED

The information contained in this booklet is based on guidelines and practice and is correct at time of printing. The content has undergone peer, patient and expert review.

Living with HEART FAILURE

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ABOUT THIS BOOKLET

Who is this booklet for?

The booklet is for people who have heart failure. You may also find it useful if you are a friend, relative or carer of someone who has heart failure. The booklet is not for people who have acute heart failure (a rapid onset of new or worsening symptoms of heart failure).

What is this booklet about?

The booklet explains what heart failure is, its causes and symptoms. It explains how heart failure is diagnosed and managed and what you can do to help control your symptoms and keep yourself well. The booklet also addresses some of the concerns you may have about living day-to-day with heart failure and offers practical advice to help you continue to do the things that you enjoy.

How to use the booklet

The booklet is divided into different sections. These are outlined in the contents list. You do not have to read all of the sections at once. Some sections may be useful to you now, other sections you may want to come back to and read at a later time.

Further information

If you would like more information, Chest Heart & Stroke Scotland have a range of easy-to-read 'essential guides' on a number of different topics discussed in the booklet. This includes guides on breathlessness, tiredness and fatigue, mental wellbeing, physical activity and healthy eating. To see the full list of guides and other resources and to order, view or download them, go to: **www.chss.org.uk/publications** or call the Advice Line nurses for more information on 0808 801 0899.

WHAT IS HEART FAILURE?

The term 'heart failure' can sound a bit scary – as if your heart is going to give up. This is not the case. The term 'heart failure' means that your heart cannot pump blood around your body as well as it should.

Heart failure is a long-term condition that tends to gradually get worse over time. However, with the right treatment and support, symptoms can be managed well and many people continue to have a good quality of life. It is very difficult to tell how symptoms will progress from person to person. Lots of people with heart failure remain stable for many years but for some people symptoms may worsen more quickly.

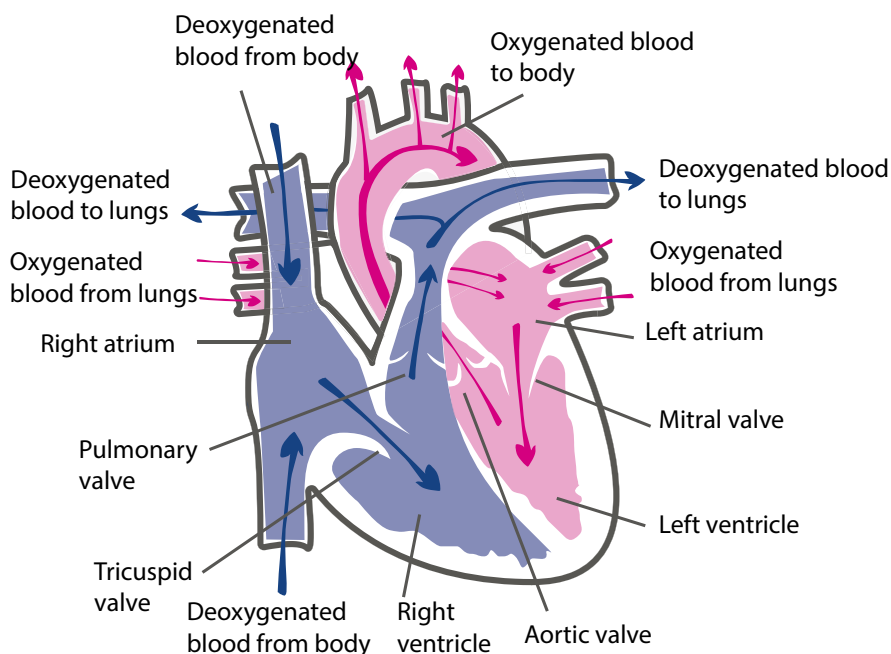
To understand what heart failure is and why it happens, it is useful to know a little bit about how your heart works.

How does your heart work?

Your heart is a muscular pump that pushes blood around your body through your blood vessels. The blood provides your body with the oxygen and nutrients it needs.

The heart is made up of four chambers. These are the left and right atria (the upper chambers) and the left and right ventricles (the lower chambers). The chambers are attached to blood vessels (arteries and veins) which either take blood to or take it away from your heart.

Your heart has a built-in electrical system that sends signals to your heart to tell it when to pump or beat. On the right side of the heart, the right atrium and ventricle work together to pump deoxygenated blood (blood low in oxygen) out to the lungs to collect oxygen. The blood then returns to the left side of the heart and the left atrium and ventricle work together to pump oxygenated blood (blood rich in oxygen) out to the rest of your body. Valves between the chambers of your heart keep the blood flowing in the right direction.



What causes heart failure?

It is important to understand the cause of your heart failure so that this can be treated and help prevent your heart failure from getting worse. There are a number of conditions that weaken the heart and cause heart failure.

A **heart attack** is the most common cause of heart failure. During a heart attack the blood vessels that supply blood to the heart muscles become blocked. This prevents the heart muscle getting the oxygen that it needs to pump properly and can cause permanent damage.

Other possible causes of heart failure include:

- **Coronary heart disease** (a build-up of fatty deposits in the blood vessels that supply blood to the heart)
- **High blood pressure** or hypertension
- **Cardiomyopathy** (a disease of the heart muscle itself, this can be hereditary)
- Diseased or damaged **heart valves** (for example, aortic stenosis)
- Heart defects that develop before birth (**congenital heart defects**)
- **Infection** of the heart valves or heart muscle itself (endocarditis or myocarditis)
- **Severe anaemia**
- An uncontrolled or irregular heart rate (such as **atrial fibrillation**)
- **Alcohol** or recreational **drug misuse**

Sometimes the cause of heart failure is not known.

**“There are different reasons for heart failure.
Everyone has a different story to tell.”**

What are the symptoms of heart failure?

If you have heart failure, your heart cannot pump blood around your body as well as it needs to.

Heart failure symptoms may come on suddenly (for example, after a heart attack). Usually, however, symptoms develop over weeks and months as the heart becomes weaker and less able to pump. At first, you may notice these symptoms when doing something active but the condition can progress so that you notice them even when you are resting.

The most common symptoms of heart failure include:

- Shortness of breath — this may happen after activity or when you are resting; it is often worse when you are lying flat
- Swelling of ankles and legs, caused by a build-up of fluid
- Severe tiredness or fatigue

These symptoms can also be caused by other medical conditions so tests will usually be needed to find out if heart failure is the cause.

How does my doctor know I have heart failure?

To work out whether you have heart failure, your doctor will ask you about your symptoms and will do some initial tests.

Initial tests may include:

- Checking your **pulse**
- Measuring your **blood pressure**
- Taking **blood tests** and a **urine sample** to check your kidney, liver and thyroid function and check for diabetes and anaemia
- Taking a **chest x-ray** to identify any signs of heart failure and other possible causes of your symptoms

If, after the initial tests, your doctor thinks that you may have heart failure, further tests will usually be needed to confirm or exclude a diagnosis of heart failure.

Further tests may include:

- **An electrocardiogram (ECG).** An ECG measures the electrical activity and rhythm of your heart (the pattern that your heart beats at). An ECG can help to detect a previous heart attack.
- **B-type natriuretic peptides (BNP) tests.** This is a blood test that measures the levels of the hormone B-type natriuretic peptide in your blood. If you have unstable heart failure, the level of BNP in your blood will be increased.

- **An echocardiogram.** Also referred to as an ‘echo’, this is an ultrasound of your heart. A recorder is put on your chest and sound waves are passed through your chest to your heart.

The recorder monitors the sound waves as they bounce back from your heart and displays them on a screen. This provides information about:

- o The size of your heart
- o How well your heart muscle is working
- o How well your heart valves are working

“It is important to receive early diagnosis and treatment.”

How severe is my heart failure?

The severity of heart failure is determined by your symptoms. It is classified on a scale of 1 to 4 called the New York Heart Association (NYHA) scale.

Class	Limitations	Symptoms
Class 1	No limitation of physical activity	Ordinary physical exercise does not cause undue tiredness, breathing difficulties or palpitations
Class 2	Slight limitation of physical activity	Comfortable at rest but ordinary physical activity results in fatigue, palpitations or breathing difficulties
Class 3	Marked limitation of physical activity	Comfortable at rest but less than ordinary activity results in symptoms
Class 4	Unable to carry out any physical activity without discomfort	Symptoms are present even at rest; discomfort increases with any physical activity

Use the space below to note down any symptoms you have when you do any physical activity. Where do you think you are on the NYHA scale?



Note that you may move up or down on the scale as your condition and treatments change.

The classification of your heart failure can be used to help determine the best treatment for you at the correct time. As your heart failure progresses, you may be offered a different treatment, additional medication or a change in the dose of your medication.

HOW IS HEART FAILURE TREATED?

Treatment for heart failure aims to relieve your symptoms and make your heart stronger to improve your quality of life.

A number of different treatment options will be considered for you. These include medication, devices to help your heart pump normally and surgery. Deciding what treatment is right for you will be based on a number of factors including the severity of your heart failure, your symptoms, any other conditions you have and potential side effects of treatment.

Medication



There are lots of medicines that can help with heart failure. The cause of heart failure will not be the same for everyone and so different people will be on different medication at different doses.

It may take a bit of time before the right medication is found for you.

“You can get side effects but be patient while your doctor finds the right balance for you. This can take time.”

Listed below are some of the most commonly used medicines for heart failure. Medicines are often referred to by their brand name. The generic, non-brand alternatives have the same active ingredients and will work in the same way.

More information about these medicines can be found on page 51.

- Diuretics (sometimes known as water tablets)
- Angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs)
- Beta-blockers (e.g. bisoprolol, carvedilol)
- Mineralocorticoid receptor antagonist (e.g. spironolactone, eplerenone)
- Sacubitril/valsartan
- Ivabradine
- Digoxin
- Hydralazine/isosorbide dinitrate

You may be on several different medicines. It can be helpful to keep a note of when you started each one and what dose you are on. Using a pill organiser or dosette box can help to keep track of what medication you are taking and when.

“If I’m tired, I need to be careful that I don’t take the wrong thing at the wrong time so the dosette box from my pharmacist has been ideal.”

Implantable devices & surgery

If your symptoms worsen they may not always respond to medical treatment. If this is the case, other options will be considered. These include:

- Inserting a pacemaker
- Cardiac resynchronisation therapy
- Inserting an implantable cardioverter defibrillator
- Inserting a left ventricular assist device (LVAD)
- Having a heart transplant

Pacemaker

A pacemaker is a small device that is implanted into your chest and sends an electrical signal to your heart to keep it beating regularly. Fitting a pacemaker is a very common procedure and most people are able to leave hospital within 24 hours of having it fitted.

Cardiac resynchronisation therapy (CRT)

CRT is a special type of pacemaker that helps to co-ordinate the contractions of the left and right sides of the heart.

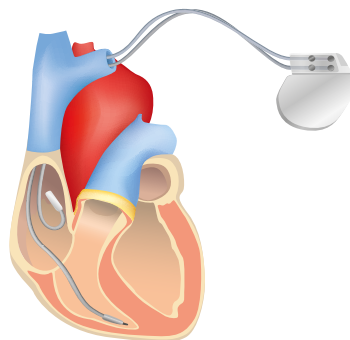
There are two types of CRT devices.

The first is a CRT-P (P is for pacing). This works as a normal pacemaker while also delivering small electrical pulses to your heart to help the left and right sides pump more effectively.

The second is a CRT-D (D is for defibrillator). This also works as a normal pacemaker while delivering small electrical pulses to your heart to help the left and right sides pump more effectively. A CRT-D also delivers an electrical shock if your heart rhythm becomes abnormal.

Implantable cardioverter defibrillator (ICD)

An ICD is placed in your chest. It monitors and corrects any abnormal heart rhythms by delivering either a series of electrical pulses or an electrical shock that restores a normal rhythm.

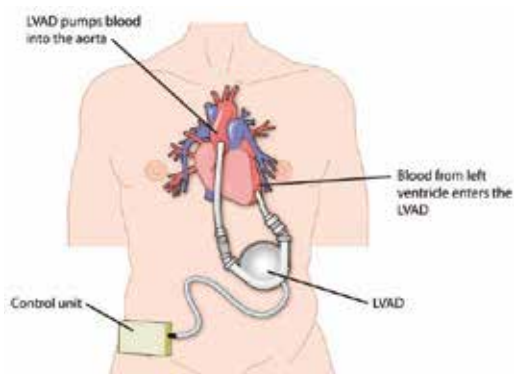


Left Ventricular Assist Device (LVAD)

An LVAD is a mechanical pump that helps the left ventricle pump blood around the body. An LVAD is used for people with severe heart failure and

in some cases for those

waiting for a heart transplant. Open heart surgery is required to implant an LVAD.



Heart Transplant

If you have severe (class 4) heart failure and your medication is not working, you should be referred to specialist heart doctors who will assess whether you are suitable for a heart transplant.

If you are considered for any of the procedures listed above you will receive full and detailed information about them from your doctor.

Who will be involved in my care?

To ensure you receive the right treatment for your heart failure you will be supported by your GP and a specialist team (sometimes called a multidisciplinary team or MDT). The team may include a cardiologist (heart doctor), a heart failure nurse, a pharmacist and a psychologist.

Your MDT will discuss your treatment options with you. You will be involved in any decision-making regarding your treatment.

WHAT CAN I DO TO KEEP MYSELF WELL?

If you have heart failure, there are a number of things you can do to keep yourself well and help you live life to the full.

These include:

- Monitoring your symptoms and knowing when to get help
- Taking your heart failure medication as prescribed
- Cutting down on salt
- Limiting your fluid intake
- Keeping as active as you can
- Making sure your vaccinations are up to date
- Controlling your blood pressure
- Limiting your alcohol intake
- Stopping smoking
- Eating a healthy, balanced diet and maintaining a healthy weight
- Looking after yourself emotionally

Know when to get help

One of the most important things you can do to help with your heart failure is monitor your symptoms.

It is important you know what symptoms are 'normal' for you and how to recognise if things are getting worse. Early treatment can stop you becoming more unwell. A sudden increase in symptoms over a day or two may mean that your body is holding on to too much fluid. This happens when your heart is not pumping properly and your body cannot get rid of the extra fluid. An increase in symptoms can be a sign that your heart failure is getting worse. It is important to know how to recognise fluid build-up because the earlier you notice, the sooner you can deal with it. Warning signs include:

- Sudden weight gain
- Swelling of your feet, ankles, legs or stomach
- Increased breathlessness (at rest or lying down)
- Coughing or wheezing
- Feeling more tired than usual

Your heart failure specialist should develop a self-management plan with you. This is sometimes referred to as the 'traffic light' model. This is a plan that helps you to identify any changes in your symptoms and what action you should take. You may also be given a 'Sick Day Rules' card that tells you what to do if you become dehydrated due to sickness or diarrhoea .

Actions may include restricting how much you drink or adjusting the dose of your diuretic (water tablet).

Traffic Light Model:



Green = I feel OK, my symptoms are stable, there is no change to my weight and I am able to carry out my normal daily activities. **No action necessary.**



Amber = I feel I am getting worse and I don't feel OK, my weight has increased and/or other symptoms are becoming worse. **Action may be required.**



Red = I feel much worse, my weight has increased suddenly and/or I can't do my normal activities without symptoms or feeling extremely tired. **Immediate action required.**

Take your heart failure medication as prescribed

Taking the right medication properly can help to:

- Control the symptoms of your heart failure and help to improve quality of life
- Prevent your condition from getting worse
- Improve your life expectancy
- Treat the cause of your heart failure

Keep track of your medication

- Make a list of the medicines that you are taking and take it to all of your appointments
- Understand what you are taking each medicine for

See page 51 for more information about some of the commonly used medicines for heart failure.

Monitor your weight on a daily basis

It is important to monitor your weight. A sudden increase may mean that your body is holding on to too much fluid.

Ideally weigh yourself when you get up each morning after going to the toilet. If possible, weigh yourself without shoes or clothes on to get a consistent reading. Write down your weight and compare it to the day before.

Let your GP or heart failure nurse know if your weight increases by more than 3 to 4lbs (1.5 to 2kg) over 2 days. Weight that is put on rapidly is probably due to fluid build-up. Weight put on over several weeks is more likely to be due to increased body mass.

Cut down on salt

Too much salt causes your body to retain fluid. It also increases your blood pressure. If you have heart failure, you should aim to reduce your salt intake as much as possible. This will help to reduce your blood pressure and avoid the risk of developing other health conditions.

Adults with heart failure should have **less than 6g** of salt per day. This includes salt already present in the food you buy and salt added to food (in cooking or at the table). 6g of salt is about the same as 1 level teaspoonful.

Do not use 'low salt' substitutes as they contain high levels of potassium which your body may not be able to cope with if you have heart failure.

**Each of these
contains**

$\frac{1}{4}$ teaspoon salt*

- 1 individual pork pie
- 1 sausage roll
- 60g cornflakes with milk



**Each of these
contains**

$\frac{1}{2}$ teaspoon salt*

- 2 noodle sachets
- 1 tin cream of tomato soup
- 3 rashers bacon



**Each of these
contains 1 teaspoon
salt***

- 3-4 slices meat pizza
- 12 slices bread
- 3 tablespoons soy sauce



** All figures are approximations*

Limit your fluid intake

Some people with heart failure will benefit from limiting the amount of fluid they take in each day. If you are not sure whether you should reduce your fluid intake, ask your doctor or heart failure nurse.

“I take half a cup of coffee instead of a whole, so I can still have it but just a smaller amount.”

“My mouth was like a desert when I had to cut my fluids! My heart failure nurse advised me to try ice lollies or chewing gum.”

Keep as active as you can

Because being physically active can bring on symptoms of breathlessness and fatigue, it may surprise you to learn that increasing the amount of activity you do can actually help improve your heart failure.

Regular physical activity can:

- Help you manage your symptoms
- Slow down the progression of your heart failure
- Increase your energy levels
- Improve your overall quality of life
- Reduce hospital admissions

Is it OK for me to do exercise?

Unless you have been told to rest completely, regular physical activity will help strengthen your heart, control your symptoms and make you feel better.

For most people with heart failure it is perfectly safe to do regular physical activity. Before you start, however, you might want to discuss with your doctor what types of exercise are best for you. They will take into account your symptoms and personal preferences. There are no specific recommendations on the best type of exercise for people with heart failure and you will be the best judge of what will or won't work for you.

What type of activity can I do?

If your heart failure impacts on your ability to undertake normal activities you should be offered a referral to a supervised exercise programme.

The amount you will be able to do will depend on your current level of fitness. It is best to start with a low intensity activity, such as walking. Even just taking a short walk can help. Start slowly and gradually build up the amount and intensity of exercise you do; it is important not to overdo it. If you are not able to walk, there are other ways to stay active such as yoga or tai chi. There are also many chair-based exercise programmes that you can be referred to, just ask your GP or specialist.

Think about any questions or concerns you would like to discuss with your GP or heart specialist.

Some helpful questions are listed in the table on the next page.

Question	Answer
How much exercise can I do each day?	
How often can/should I exercise each week?	
What types of activities are good for me to do?	
Does it matter if I take my medication before or after I exercise?	
Should I be monitoring my pulse when I exercise and what pulse rate should I aim for?	
What warning signs do I need to look out for?	
What should I do if I experience any warning signs?	

“I was advised about what exercise to do. For me, it helped to reduce my weight and improved my mood. With medical advice I’ve even managed to reduce my medication dose.”

How to exercise safely

- Pay attention to your body. When you first start exercising, your muscles may feel sore. This is normal and any soreness will fade as your body gets used to exercising.
- Wait at least an hour after eating a meal before exercising.
- Make sure you warm up before exercising and cool down after exercising.
- Look out for symptoms during exercise. If you feel any pain, feel faint or are extremely breathless, stop exercising immediately.
- If you are (or have been) unwell, do a lower level of activity.
- Exercising with others can cause you to go too fast or push yourself too hard. Go at your own pace.

Make sure your vaccinations are up-to-date

If you have heart failure it is important to protect yourself from infections such as colds, flu and other chest infections. This includes avoiding contact with people who are unwell and making sure that you are vaccinated against pneumonia and flu. Being vaccinated will reduce your risk of getting these infections and it will reduce the severity if you do get infected.

You should be offered:

- **A pneumococcal vaccine** to protect you against pneumonia – you will only need this once in your lifetime
- **A flu vaccine** - you will need this every year

Limit your alcohol intake

If your heart failure has been caused by drinking too much alcohol, it is best to stop drinking alcohol altogether. You should be offered support to help you stop.

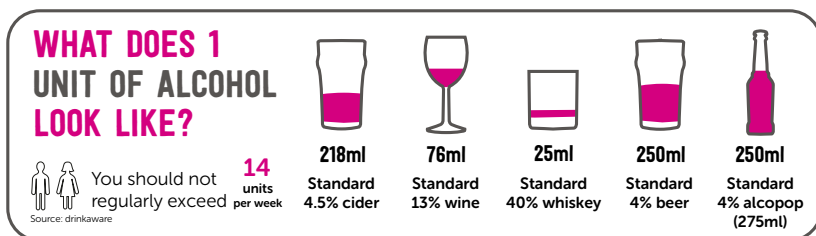
Drinking more than the recommended amount can:

- Increase your blood pressure
- Damage your heart muscle
- Affect your fluid balance
- Cause weight gain

Remember that alcoholic drinks form part of your fluid allowance if you are fluid-restricted.

There is no safe level of alcohol to drink. If you do choose to drink alcohol, try to stay within the recommended limits:

- Men and women should not regularly drink more than 14 units per week. 14 units of alcohol is the equivalent of around 6 pints of beer or 7 medium glasses of wine.
- If you choose to drink as much as 14 units a week, don't save it all up to drink in one session.
- Aim to spread the amount you drink over three days or more and have at least two alcohol-free days each week.
- Avoid binge drinking (drinking large amounts of alcohol over a short period of time). Binge drinking is particularly harmful and can increase your risk of heart attack and stroke.



Stop smoking

Smoking increases your risk of developing or worsening your heart failure. If you smoke, stopping smoking is an important part of managing your heart failure and can be as effective as medical treatment.

You are more than 4 times more likely to succeed at stopping if you have specialist support.

For more information about the support available in your local area, call a Quit Your Way Scotland advisor free on 0800 848484 or visit www.nhsinform.scot/healthy-living/stopping-smoking.

For more information about the support available in your local area, call a Quit Your Way Scotland advisor free on 0800 848484 or visit: www.canstopsmoking.com.

Eat a healthy, balanced diet and maintain a healthy weight

Maintaining a healthy weight and shape will help with your symptoms and can help prevent other health problems. Controlling how much you eat, as well as what you eat, will help with your weight. It is important to have a healthy diet.

Your weight may go down because your appetite is poor and you are not eating enough or it may be because your body is not able to absorb nutrients properly. If you have lost weight your doctor will want to investigate the cause of your weight loss and may refer you to a dietician.

Managing low mood and depression

It is common for people with heart failure to feel 'low' or 'down'. This is a natural reaction as you come to terms and learn to live with your condition. However, if you are feeling low a lot of the time, you may be suffering from depression.

Depression is common in people with long-term health conditions. It can make it more difficult for you to look after yourself. You may feel as if you don't want to get up in the morning or go out and see friends. The most important thing is that there is help available and lots of things you can do to help yourself feel better.

If you think you might be depressed, you should talk to your doctor as soon as possible. They will provide you with advice on what help is available.

“I hadn’t associated my feeling low with my heart failure. My specialist helped me to see that this was a normal reaction to my diagnosis and that help was available.”

LIVING WITH HEART FAILURE

“It’s hidden so people can’t tell that you are ill”

It is important to know how your heart failure may affect your day-to-day life. This section provides information on how to manage your breathlessness and coping with tiredness to help you go through your day as well as you can. It also provides information on driving, travel, work, financial support that may be available to you, relationships and sex.

Managing your breathlessness

Shortness of breath in heart failure is caused by fluid build-up in the lungs. This makes it difficult for your body to take in oxygen. In early heart failure you may only notice breathlessness after exercise. As your heart failure progresses, you may start noticing it more frequently during everyday activities. You may also feel breathless at night when lying flat. This can affect your sleep.

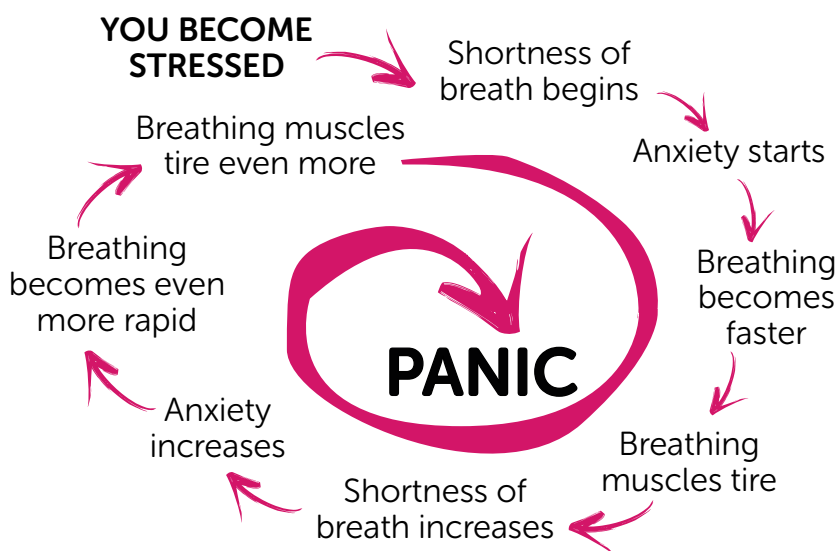
- Listen to your body. Learn to recognise when symptoms start and next time stop at the first sign of them. Exercising regularly improves the performance of the heart so it’s good to find a level of activity that you can maintain.
- If you become breathless when doing everyday tasks like climbing the stairs or taking a shower, talk to your doctor or heart failure nurse about whether your treatment is working properly and/or exercises that may help your breathing.

- If you become breathless when resting it's a good idea to talk to your doctor or heart failure nurse about how to manage this. Adjustment to your current treatment may be needed.
- If you feel breathless when lying down, try supporting yourself with several pillows so that you are lying in a more upright position.

For many people finding it hard to breathe can be quite frightening. This, in turn, can make symptoms of breathlessness worse.

How to stay calm when feeling breathless

When you feel short of breath, your neck, shoulders and chest muscles tense. You can become anxious and so begin to breathe faster. Your breathing muscles tire and trap air in your lungs. Your chest may feel tight. Anxiety increases and you may start to panic.



The key to controlling breathlessness and panic is to break the cycle before it starts:

- Learn and practice breathing control techniques and positions
- Learn techniques to control anxiety
- Manage your weight, cut down your salt intake and monitor your fluids
- Keep physically active
- Develop your own self-management strategies by recognising what causes your breathlessness and slowing down before it starts

Breathing control techniques

You can use breathing control techniques to regain your breath after an activity or during an episode of breathlessness. For example, you can use breathing control techniques to help you if you are out for a walk and need to stop for a rest. The techniques encourage a more normal breathing pattern and help to get air into the lower part of the lungs.

Breathing control techniques involve gentle breathing using your upper chest, shoulders and stomach.

Examples of breathing control techniques include:

- **Relaxed, slow, deep breathing:** make sure you are in a comfortable position, relax your shoulders and breathe in gently through your nose and out through your mouth.
- **Blow as you go:** breathe out hard when you are doing an activity that needs a big effort such as bending down, stretching, standing up, as you push and pull a vacuum cleaner or going up or down steps.

- **Pursed-lips breathing:** breathe out with your lips pursed as if you are whistling. This helps to slow breathing down and make it more effective.
- **Paced breathing:** breathe in and out in time with the activity you are doing, such as climbing stairs. Tune in to your breathing rate as you walk or climb.

Breathing positions

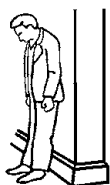
Below are different breathing positions to help control your breathing. Try them all until you find the one that works best for you depending on where you are and what you are doing.



Sit on a chair leaning forward with both arms resting on your thighs, or sit upright against the back of the chair with your hands resting on your thighs. Relax your hands and wrists.



Stand leaning forward with your arms resting on a ledge, for example a windowsill, bench or banister rail.



Lean back against a wall with your shoulders relaxed and arms resting down by your side. Your feet should be about 30cm away from the wall (or as far as is comfortable) and slightly apart.

Breathlessness at night

Some people with heart failure experience breathlessness at night when lying flat. You can ease your breathing in this case by using extra pillows to prop you up. If this is constantly happening, or you need more pillows, it may be a sign that your heart failure is getting worse. Remember to discuss any concerns with your doctor or heart failure nurse.

Coping with tiredness

Extreme tiredness or fatigue is common in people with heart failure. It can be a symptom of the disease itself due to a reduced oxygen supply to your muscles. However, it can also happen because you are not getting enough exercise or you are not sleeping properly.

There are some things that may help you to manage your tiredness:

- **Try to keep active**

Being physically active can be difficult if you are limited by how much you can do, but keeping physically active can increase the blood flow around your body and the amount of oxygen that gets to your muscles. Physical activity can also help you sleep.

TIP: If you're performing an activity, take regular breaks, even if you don't feel you need to. This may help you to achieve your goal without getting too tired or feeling exhausted the next day.

- **Get a good night's sleep**

Up to half of people with moderate to severe heart failure have a sleep disorder called sleep apnoea. Sleep apnoea is a condition that may cause you to take shallow breaths or briefly stop breathing at night. You may find that your partner or carer hears you snoring loudly or that you have heavy, interrupted breathing. If you think you may be experiencing sleep problems discuss this with your GP.

Many people with heart failure wake up frequently through the night, often due to breathlessness. If you are frequently woken at night feeling short of breath, speak to a member of your specialist heart failure team.

Other tips to help cope with tiredness are to:

- Save energy when you can
- Organise your time and space
- Eat healthily and drink plenty of fluids
- Lose weight if you are overweight
- Cut out caffeine and alcohol
- Find time to rest and relax
- Pace yourself

Driving

Most people are still able to drive after a diagnosis of heart failure. In some cases you will be required to report your condition to the DVLA. To do this you need to complete a form that can be found online (www.gov.uk), or you can request one directly from the DVLA.

Car or motorcycle licence

Most people with heart failure can continue to drive safely. As long as your symptoms are stable and do not affect your ability to drive or do not distract you, you do not need to notify the DVLA.

If you have Class 4 (severe) heart failure and have symptoms when you are not doing any activity ('at rest'), you need to tell the DVLA and will not be allowed to drive unless your symptoms improve.

Speak to your doctor about whether you are able to continue driving and/or need to notify the DVLA about your condition.

"If you're concerned, just don't drive. It's not worth the risk."

Bus, coach or lorry licence

If you have a bus, coach or lorry licence you must tell the DVLA about your heart failure.

Depending on your symptoms, you may be required to stop driving. In some cases, you may be allowed to start driving again if your symptoms improve. You should discuss your symptoms with your doctor who will be able to advise you.

Travel

Unless your doctor has told you not to, you should be OK to travel if you feel well enough. However, there are some things you might want to think about before you go.

The key is to **be prepared**.

- Discuss your plans with a member of your healthcare team before you make any arrangements
- Travel to high altitudes or very hot and humid climates is not recommended for people with symptomatic heart failure.
- Colder climates can increase your need for oxygen.
- For long journeys, air travel is usually better than other means of transport.
- If you are flying, make sure you request special assistance in advance so you don't have to walk long distances or lift heavy luggage.
- Ask your healthcare professional about wearing flight socks on long flights to reduce the risk of developing blood clots.
- Medication
 - Take extra medication with you and keep a list of your medication in each piece of luggage.
 - If you are travelling across time zones, make sure you know how to adjust the timing of your medication.

- Fluid balance
 - Maintain your normal fluid balance and remember to weigh yourself every day.
 - Monitor your fluid intake carefully, especially during flights and in hot climates.
 - You may need to adjust the time that you take your diuretics during travel, depending on the availability of a toilet.
- Insurance
 - Make sure your travel insurance will cover your trip. You may also want to check if it includes cover for anyone travelling with you if they have to change their travel plans if you become unwell.

“Although my insurance company paid out on our expenses, I had to pay the hospital bills when I was there. Make sure you have the contact details of your insurance company. Make sure you have phone credit.”

Work

As long as you feel well enough, you should be able to continue to work.

The decision to continue to work should take into account how well you feel, how your symptoms are managed and what kind of job you do. If you are not sure about the impact that your heart failure might have on your ability to work, talk to your doctor or heart failure nurse. For example, if you are in a manual job you may be restricted in what you can do; if you have a pacemaker you will not be able to work with certain types of machinery.

If part of your job involves driving make sure you check with your doctor, the DVLA and your employer to ensure you are still safe to drive.

Talk to your employer if you feel that your heart failure is affecting your ability to do your job. It may be possible to make adjustments such as working shorter hours or taking on a different role.

You may also wish to discuss your condition with your employer and any support that your workplace can offer you. This may include time off to attend appointments or providing special equipment to support you in your role. Employers can get advice on how they can support you from NHS Scotland Healthy Working Lives (tel: 0800 019 2211 or visit www.healthyworkinglives.scot).

Financial support

If you are unable to return to work or you have had to reduce your hours as a result of heart failure, you may be able to claim disability and incapacity benefits:

- People over the age of 65 who are severely disabled may qualify for a type of disability benefit called Attendance Allowance.
- If you are between the ages of 16 and 64 you can consider applying for Personal Independence Payment.
- If you have been unable to work for at least 28 weeks in a row because of illness or disability, the Severe Disablement Allowance may be available to support you.

There are also a number of disability-related discounts that may be worth considering:

- The Blue Badge Scheme
- Concessionary bus travel
- Disabled Student Allowance
- Motability Scheme

If you have a carer, they may also be entitled to financial support under the Carer's Allowance scheme.

The CHSS Advice Line nurses can provide independent financial advice and support to people affected by a chest, heart or stroke condition. Call FREE on 0808 801 0899.

Relationships

Your heart failure diagnosis can impact on your close relationships. This can be a worrying time and it is common to feel shock, anger and fear. Remember that your friends and relatives will be feeling these emotions too. Try to be open about how you're feeling and make sure you speak to your heart specialist team about your worries and anxieties.

You may also want to consider joining a support group. Speaking to other people in a similar situation can make a huge difference for some people and can help provide you with advice and support in a number of areas. CHSS has support groups across Scotland. To find out if there is a support group that might be suitable for you in your area, call the Advice Line nurses on 0808 801 0899.

Planning for the end of life (the final weeks of life when death is near) should not be seen as giving up on life. Instead, it can be seen as a positive way to help ease worries you may have about what might happen to you if you are unable to make decisions about your own care or about death and dying. Getting answers to your questions and letting people know what you want can help you feel more in control and give you peace of mind.

Sex

Sexual problems are common in both men and women with heart failure. People with heart failure can experience sexual dysfunction or a loss of sex drive. This may be due to the physical effects of heart failure, emotional stress or as a result of medication. Make the most of rested time. Trying out different positions may help to make things easier.

You should be able to resume sexual activity once your symptoms are stable and well-managed. Symptoms such as shortness of breath, palpitations and angina are unlikely to occur during sex unless similar symptoms are experienced after, for example, walking up two to three flights of stairs reasonably quickly, gardening or general housework.

If you are of childbearing age you should discuss contraception and pre-conception planning with your heart failure specialist before getting pregnant.

PLANNING FOR THE FUTURE

Heart failure is a long-term condition for which there is currently no cure. Although symptoms can usually be well controlled with treatment, it is likely that your heart failure will gradually worsen over time. It is difficult to predict if or when your condition will get worse.

It is a good idea for you and your family to start talking now about what kind of care you would or would not want in the future if your heart failure does worsen and you are not able to make decisions about your care at that time. This is often referred to as **anticipatory care planning**.

Anticipatory care planning helps people and their families make decisions about their health care when things may become difficult. It can help you to manage your condition, improve your health and have a better quality of life. It can also help to reduce some of the stress related to increased symptoms, poorer quality of life, physical, emotional and financial worries. This can become increasingly important if things start to change.

What is an Anticipatory Care Plan?

An Anticipatory Care Plan (ACP) is where you record your future plans and wishes. For example, you may wish to consider where you would like to be cared for and other important issues in the months or years before approaching the end of your life. You may not wish to do this just now and that is absolutely fine.

Remember, you can change your mind about anything you have written in your plan at any time. Remember to write any changes in your plan and let the relevant people know so they are aware of them.

An ACP is not legally binding, but having a plan helps the people looking after you to know what is important to you now and in the future. If this time comes, anything you have written in your care plan will be carefully considered and respected. After making an ACP keep it in your possession and share it with anyone involved in your care. Take it with you if you go into hospital so that the people involved in your care are aware of your plan and can carry out your wishes.

It may eventually reach a point when your heart failure becomes very severe and stops responding to treatment.

Palliative care will usually begin when heart failure reaches this stage. Palliative care is the phase of an illness when care focuses on quality of life. The aim of palliative care is to help you feel as comfortable as possible, as well as providing psychological, spiritual and social support for you and your family.

At this stage, it can be helpful to let others know what your wishes are. The period of time palliative care can last varies but it can be many weeks, months or years.

End of life care usually refers to the last few days of life. It can be difficult to think ahead to this time, but it may also give you peace of mind to know that your thoughts and wishes have been recorded, if you would like to do so.

Planning for the end of life (the final weeks of life when death is near) should not be seen as giving up on life. Instead, it can be seen as a positive way to help ease worries you may have about what might happen to you if you are unable to make decisions about your own care or about death and dying. Getting answers to your questions and letting people know what you want can help you feel more in control and give you peace of mind.

What happens if I have an implanted device?

You may have had a device such as a pacemaker or defibrillator fitted to help manage your heart failure. If you have advanced heart failure and you are nearing the end of your life, it may come to the point when continuing to have the device switched on is not the best thing for you.

Your cardiology and palliative care team will discuss with you and your family when the right time might be to turn the device off. This should be discussed as part of the planning ahead process.

The decision about when to switch off your device can be a difficult one and it is important to ensure that all of your questions are answered fully. Turning the device off may not mean that you will pass away any earlier but it may mean that you stop experiencing any unnecessary discomfort associated with your device.

SUPPORTING SOMEONE WITH HEART FAILURE

If you are a family member or friend of someone with heart failure, the support you can provide can be of great help. For example, through providing emotional support or encouraging positive health choices. Such choices can reduce hospital admissions and keep the person living with heart failure healthier for longer. However, it can be difficult to find a balance between showing support and concern and being over-protective. It is important to be supportive, but not critical, and to respect the individual's right to make their own choices.

Some of the things you can do to support someone with heart failure include:

- **Symptom management**

You can help the person living with heart failure to recognise and take action when their symptoms are worsening and support them with any actions that may help. For example, if they become breathless, you can help them to keep calm and reassure them.

- **Support to ask questions**

Hospital appointments can be overwhelming and a bit intimidating. Having support at clinic appointments, if that's what the person living with heart failure wishes, may be useful to ensure that their questions (and your own questions) are answered. You may wish to discuss and note down what questions you both feel need asked. You may find writing down the answers to these is a useful reminder of what was said.

- **Care giving**

There may come a point where the person living with heart failure requires some more support from others. You may find yourself referred to as a 'carer'. This term can be quite conflicting for some. It is important for you to recognize that you may need your own emotional and practical support in this new role.

- **Talk & Listen**

It is really important to talk about what is happening and how you feel about it and listen to how the person living with heart failure feels. Ask them how they want you to behave towards them and explore ways of how you can help. Even the smallest things can help, for example reminding them to take tablets, doing the washing or encouraging healthy lifestyle changes.

FURTHER INFORMATION ON MEDICATIONS

Diuretics (water tablets)

Bendroflumethiazide, Bumetanide, Furosemide, Metolazone

People with heart failure often develop swelling (edema) in their legs and fluid in their lungs. A diuretic (sometimes called a 'water pill') helps your kidneys get rid of this excess fluid. This helps to reduce the swelling and improve breathlessness.

Your dose of diuretic may need to be adjusted until the right level is found for you. Some people are prescribed more than one diuretic. If you are prescribed diuretics you will need to have regular blood tests to check your kidney function and potassium levels.

Your body gets rid of this excess fluid in your urine so you will find you may need to go to the toilet more frequently. You may be advised to take your diuretic in the morning to avoid having to get up to go to the toilet through the night.

Diuretics can also increase your blood sugar level and you should tell your doctor if you have diabetes.

Other possible side effects include feeling thirsty, dizzy or weak, muscle cramps and headaches. Tell your doctor if you experience any side effects. You should also tell your doctor if you have an episode of vomiting or diarrhoea lasting more than 24 hours.

Angiotensin Converting Enzyme (ACE) inhibitors

Ramipril, Lisinopril, Enalapril, Perindopril

ACE inhibitors help relax and widen your blood vessels. This lowers your blood pressure and reduces the work that your heart has to do to pump blood around your body.

If you are prescribed ACE inhibitors you will need to have regular blood tests to check your kidney function and potassium levels. Your blood pressure will also be monitored. ACE inhibitors may increase the level of potassium in your blood so you should avoid salt substitutes as these also contain potassium.

Some people who take an ACE inhibitor develop a dry cough. Speak to your doctor if you experience this or any other side effects.

ACE inhibitors are not suitable for everyone and your doctor will decide whether they are right for you depending on your symptoms and the cause of your heart failure.

Angiotensin Receptor Blockers (ARBs)

Losartan, Candesartan, Valsartan, Irbesartan, Telmisartan

ARBs work in a similar way to ACE inhibitors. However, they are less likely to cause the persistent dry cough that some people get with an ACE inhibitor. As with an ACE inhibitor, you will need to have regular blood tests if you are taking an ARB.

Side effects may include dizziness or headaches. Discuss any side effects with your doctor.

Beta Blockers

Atenolol, Bisoprolol, Carvedilol, Metoprolol, Nebivolol.

Beta blockers work by slowing your heart rate and lowering your blood pressure so your heart doesn't have to work so hard. You will be started on a low dose to begin with. This may be adjusted until the right dose is found for you.

Beta blockers are not usually recommended for people who have asthma or low blood pressure as they can worsen these conditions. Other side effects include tiredness or fatigue, cold hands and feet, erectile dysfunction (impotence), dizziness, and disturbed sleep or nightmares. These will usually improve over time and it is important that you do not stop taking your beta blockers suddenly. If you do experience side effects, speak to your doctor, pharmacist or nurse as they may be able to reduce the dose or prescribe another beta blocker.

Digoxin

Digoxin helps to reduce the strain on your heart and helps it to beat in a normal, steady, strong rhythm.

Side effects of digoxin can include loss of appetite, heart palpitations and nausea. Discuss any side effects with your doctor. St John's Wort and cranberry juice can interact with digoxin and should not be taken if taking digoxin. You may be given digoxin along with other heart failure medication(s).

Hydralazine and isosorbide dinitrate

Hydralazine and isosorbide dinitrate helps widen your veins and arteries making it easier for your heart to pump.

You may experience headaches when you first start taking this medication. If you do, discuss this with your doctor who may suggest taking a painkiller to help. Do not stop taking hydralazine and isosorbide dinitrate suddenly.

Other side effects of hydralazine and isosorbide dinitrate may include dizziness, blurred vision, dry mouth and numbness or tingling in your arms and legs.

Ivabradine

Ivabradine is used to help lower your heart rate. It can be used alongside a beta blocker or as an alternative to them. Your heart failure should be stable before being prescribed ivabradine. It should not be prescribed if your heart rate is already low.

Possible side effects include tiredness, dizziness and problems with your vision. Discuss any side effects with your doctor.

Mineralocorticoid receptor antagonist (MRA)

Eplerenone, Spironolactone.

MRAs lower your blood pressure and help your body get rid of excess fluid without preventing the loss of too much potassium. They are a mild diuretic and you may find you need to go to the toilet more frequently.

If you are prescribed an MRA you will need to have regular blood tests to check your kidney function and potassium levels.

In rare cases, spironolactone can cause enlarged breasts in men, and breast tenderness and increased hair growth in women. If you experience these side effects, you should talk to your doctor and may be prescribed a different MRA.

The MRA eplerenone can cause sleeping difficulties, dizziness and headaches. St John's Wort may interact with eplerenone and should not be taken at the same time.

Sacubitril/valsartan

Sacubitril/valsartan is a relatively new heart failure medication recommended for use in people with more severe heart failure. It works by widening your blood vessels, increasing your blood flow and lowering your blood pressure. It comes in the form of a single tablet that combines an angiotensin receptor blocker (ARB) and a medication called a neprilysin inhibitor.

If you are prescribed sacubitril/valsartan you will need to have regular blood tests to check your kidney function and potassium levels. Your blood pressure will also be checked.

Before starting on this medication you will be given advice on when to start it if you have already been on an ACE inhibitor. This is to reduce the risk of developing angioedema, a condition that causes swelling under the skin.

Sacubitril/valsartan is not suitable for everyone and your doctor will decide whether it is right for you depending on your symptoms and cause of your heart failure.

Remember:

- Read the information leaflet that comes with your medication and always take medication the way you have been instructed by your doctor.
- Never change the dose of your medication or stop taking your medication suddenly unless instructed by your doctor.
- Keep a list of each medication you are taking, when you started it, what dose you are on and when you should take it.
- It may be helpful to organise your medications using a dosette box (a pill organiser) that has separate compartments for days of the week and/or times of day. These are available at pharmacies.
- With starting any new medication tell your doctor if you have any signs of an intolerance or allergic reaction. Signs may include itchy skin or a rash, nausea, vomiting or diarrhoea, difficulty breathing or swelling of the face or eyelids.
- Most heart failure medications require regular monitoring to ensure they are working efficiently and not causing any unwanted side effects. Monitoring will usually involve blood tests and blood pressure checks. It is important that you regularly attend these appointments.
- Check with your doctor or pharmacist before taking any over-the-counter medications or herbal remedies such as St. John's Wort as these can interfere with your heart failure medication.
- Ask about a self management 'traffic light' plan to help support you with your treatment.

HELP AND SUPPORT FROM CHSS

For information on any of our services across Scotland, contact the Advice Line nurses on 0808 801 0899.

CHSS offers a range of support for people living with heart failure and their families including:

Support groups

Hearing how other people are living with heart failure can be a life-line for some people. CHSS has heart support groups all over Scotland. To find out if there is a heart support group in your area, call the Advice Line nurses

Advice Line

For confidential, independent advice on all aspects of living with a heart condition call the CHSS Advice Line on 0808 801 0899 or email advice@chss.org.uk. Staffed by nurses, the Advice Line is open Monday to Friday 9.30am – 4.00pm. Whether you need someone to talk to, information about your treatment or you are looking for details of local services, the Advice Line nurses will help with any information you or your family needs. All calls are FREE from landlines and mobiles.

Health Information

CHSS have a range of booklets and easy-to-read 'essential guides'. To see the full list of guides and other resources and to order, view or download them, go to:

www.chss.org.uk/publications or call the Advice Line nurses for more information on 0808 801 0899.

USEFUL RESOURCES

Chest Heart & Stroke Scotland

www.chss.org.uk

Tel: 0131 225 6963

E-mail: advice@chss.org.uk

Advice Line: 0808 801 0899 (Mon to Fri 9.30am-4pm)

Chest Heart & Stroke Scotland supports people in Scotland affected by chest, heart and stroke conditions. We do this by working to ensure there is help and support in every community for anyone who needs it.

Breathing Space

www.breathingspace.scot

Tel: 0800 83 85 87

Weekdays: Mon-Thurs, 6pm-2am

Weekend: Fri 6pm-Mon 6am

Breathing Space is a free confidential phone and web-based service for anyone who is experiencing low mood or depression.

Drinkaware

www.drinkaware.co.uk

Tel: 020 7766 9900

Email: contact@drinkaware.co.uk

Provides advice about how to reduce your alcohol intake and how to calculate how many units you are drinking.

NHS 24

Tel: free on: 111

This phone service is designed to help you get the right help from the right people at the right time and GP out-of-hours advice.

NHS Inform

www.nhsinform.scot

NHS inform is Scotland's national health information service.

Quit Your Way Scotland

www.canstopsmoking.com

Tel: 0800 84 84 84 (8am-10pm, Mon-Sun)

Quit Your Way Scotland offers initial and ongoing telephone support and encouragement to callers wishing to stop smoking or who have recently stopped and want to stay stopped. Quit Your Way Scotland can provide you with the location of your nearest free stop-smoking service, give you access to specialist counsellors and send you further information.

MONITORING YOUR WEIGHT

- Weigh yourself every morning and write it down on this card
- Make sure you weigh yourself after going to the toilet but before your breakfast or getting dressed
- Always use the same scales
- If you gain weight 2-3 days in a row or you gain 3-4 lbs (1.5-2kg) in a week, you **MUST** report this to your nurse or doctor
- A small change in your medication could avoid an acute attack and a hospital admission
- Write down any changes in symptoms you notice at the time such as shortness of breath, increased ankle swelling, etc.

Date	Weight	How you feel

HAVE YOUR SAY...

Chest Heart & Stroke Scotland welcomes your comments and feedback on this resource to help us to develop the best information for you and others living with heart failure.

If you have any comments regarding this booklet or any of our other publications you can contact us through:



www.chss.org.uk



healthinformation@chss.org.uk



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Edinburgh EH1 2 5EZ

PERSONAL STORIES

We would also like to hear from you if you would like to tell us about your experience of living with heart failure.

Chest
Heart &
Stroke
Scotland



Advice Line Nurses



For confidential help, support and advice,
call our specialist nurses or visit

www.chss.org.uk

Chest Heart & Stroke Scotland (CHSS) is a wholly Scottish charity
Scottish Charity Number SC018761

Helplines
STANDARD

OUR PUBLICATIONS

We hope this information has been useful to you.

Our publications are free to anyone in Scotland who needs them.

To view, download or order any of our resources, visit **www.chss.org.uk/publications**

If you'd like more information about our publications, please contact our Health Information team:



www.chss.org.uk



healthinformation@chss.org.uk



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Chest Heart & Stroke Scotland is a Scottish charity. Our ambition is to make sure that there is no life half lived in Scotland.

After a diagnosis of a chest or heart condition or a stroke, many people experience fear and isolation and struggle with the impact on their lives. **Chest Heart & Stroke Scotland** won't stand for that. The care and support we deliver every day ensures everyone can live the life they want to.

We offer our resources free of charge to anyone in Scotland who needs them. To help us to continue to do this, and to help provide vital services to people in Scotland affected by chest, heart and stroke conditions, you can donate at:

www.chss.org.uk/supportus/donations

CONTACT US

**For confidential advice, support and information
call the CHSS Advice Line nurses on:**

Freephone 0808 801 0899 or email adviceline@chss.org.uk

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