

# Living with Heart Failure

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*People have the right to be involved in discussions and make informed decisions about their care* NICE 2018



# Living with heart failure

Heart failure, also called Congestive Heart Failure (CHF), means your heart does not pump blood as well as it should. This does not mean your heart has stopped working, but that it is not as strong as it used to be and fluid builds up in the lungs and other parts of your body. This can cause symptoms such as shortness of breath, swelling in the legs, feet, and stomach.

Like other chronic diseases (such as diabetes and asthma), chronic heart failure is a condition that will be with you for life, and it presents daily challenges. While it can be very serious and difficult to manage, the good news is that you can manage the symptoms of heart failure, avoid unnecessary hospital visits and live a long, healthy life by taking charge of your condition and working in partnership with your healthcare team.



# Heart Failure affects close to 1,000,000 people in the UK

You are not alone, it is a growing problem  
Systolic contraction and Diastolic relaxation

Many causes

Coronary heart disease – like a heart attack or angina  
Untreated long-standing hypertension (high blood pressure)  
Cardiomyopathy (your heart muscle weakens)  
Heart rhythm disturbance (like atrial fibrillation)  
Damaged heart valves  
Myocarditis (inflammation of the heart muscle maybe caused by a virus)  
Prolonged alcohol consumption  
The use of recreational drugs  
Chemotherapy treatment  
Pregnancy



# Symptoms

Trouble breathing that is worse during exercise or when lying down

Swelling in your ankles, legs, and stomach

Feeling restless, tired, or weak

Gaining weight

Feeling hungry, feeling full quickly when you eat, or having a loss of appetite

Having dry cough that does not go away

Coughing up white frothy phlegm (sputum)

Needing 2 or more pillows at night or having to sleep in the chair

Palpitations

Dizziness, collapse



# Your treatment is tailored for you

Like other chronic conditions such as diabetes, living well with chronic heart failure involves taking medicines, monitoring your symptoms daily and making some longterm lifestyle changes, as well as having regular medical check-ups. In some cases, devices such as pacemakers and defibrillators are also recommended.



# Some of the tests

These tests may include:

Consultation and examination, height and weight and BMI

Blood tests, full range NT pro BNP

Echocardiogram ultrasound to show the structure of your heart and how well it is working

Electrocardiogram (ECG) ask for a copy

**Coronary angiogram** under a local anaesthetic a thin tube (catheter) is inserted into an artery in your arm or groin and guided into the heart. Dye is then injected through the catheter into the arteries leading to the heart and X-rays are taken, giving information about the condition of these arteries.

MRI, CT scan, Chest X-ray



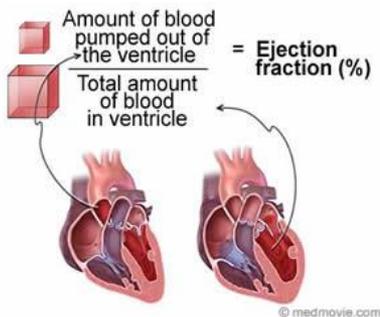
# Your numbers, what does it mean?

EF means —ejection fraction. Your EF is the percentage of blood that pumps out of the heart during each beat. It's also a measurement used to see how well your heart is functioning. A low EF is not always associated with symptoms. Your EF is an important health-related number. This number is equally important as your blood pressure and cholesterol.

50-75% heart's pumping ability is normal

36-49% heart's pumping ability is below normal

35% and below heart's pumping ability is low



# NYHA (New York Heart Association) heart failure classification

Heart failure sufferers' symptoms are classified in a standard way

NYHA Class I	No limitation of physical activity. Ordinary physical activity does not cause undue tiredness, palpitations or shortness of breath.
NYHA Class II	Slight limitation of physical activity.  Comfortable at rest, but ordinary physical activity results in tiredness, palpitations or shortness of breath.
NYHA Class III	Comfortable at rest, but less than ordinary activity causes tiredness, palpitations or shortness of breath.
NYHA Class IV	Unable to carry out any physical activity without discomfort and tired and short of breath even at rest. If any physical activity is undertaken, discomfort is increased.

Ask your Clinician which NYHA level you are.



# NICE Chronic Heart Failure Guidelines 2018 – What you need to know [www.nice.org.uk/guidance](http://www.nice.org.uk/guidance)

## 1. Your specialist team must include:

A doctor with a sub-speciality in heart failure (generally a cardiologist), Heart Failure Specialist Nurse, a healthcare professional with expertise in specialist prescribing of heart failure medicines. The specialist team must work with your primary care team

The specialist team must directly involve you if appropriate to rehabilitation services, care for older people and palliative care services.

Once you are stable and you are optimised on your drugs it is the responsibility of your primary care team to take over your management. If you go on to experience further difficulties, you should expect to be referred back into the specialist heart failure team.

## 2. Your specialist team must write you a care plan.

A care plan is a document that tells you, your carer or family member and your healthcare team how to treat and care for your needs, as described below: It must summarise your treatment and care. You must be given a copy along with your carer or family if you want, along with your healthcare team and or any other health or social care professional involved in your care

## 3. At your first consultation and then subsequent consultations your specialist team should:

Discuss your diagnosis and likely outcome, Explain your treatments and any future treatments Explain what causes your heart failure and any terminology Explain what heart failure is and the difference between a heart attack and cardiac arrest and the misconceptions around sudden death Ensure that you receive patient information to enable you to help yourself self-manage better

4. Your specialist team should prescribe medicines called Beta Blockers, ACE inhibitors or ARB's. If your symptoms remain you should be prescribed medicines called MRA's like Spironolactone or Eplerenone. Secondary medicine intervention may include Ivabradine and or Sacubitril Valsartan (Entresto)

5. If your condition is stable, you should be offered a personalised exercise rehabilitation programme in an easily accessible place

6. People with heart failure do not routinely need to restrict their salt (sodium) or fluid consumption unless instructed to by the team or primary care team. This will be constantly monitored with you



# Treating heart failure with reduced ejection fraction

To reduce symptoms, prolong life First-line treatment

**ACE, ARB** works by decreasing certain chemicals that tighten the blood vessels, so blood flows more smoothly and the heart can pump blood more efficiently. up titrate as tolerated, maximum dose

**Beta-blockers** blockade of beta adrenergic receptors improves symptoms, reduces hospitalization, and enhances survival even though acute effects are often detrimental, up titrate as tolerated, maximum dose

**Mineralocorticoid receptor antagonists** Spiro/eplerone compete with aldosterone for receptor sites in the kidneys—which increases sodium and water removal while conserving potassium

**Digoxin** It strengthens the force of the heart muscle's contractions, helps restore a normal, steady heart rhythm, and improves blood circulation.

**Hydralazine** in combination with nitrate, vasodilator relax and open up the blood vessels

**Diuretics** remove excess fluid

**Ivabradine** (HR 75 bpm, NYHA class II to IV, EF <35)

**Sacubitril valsartan** Must already be on ACE or ARB and EF <35%. Cardio specialist Well tolerated



# Other medicines & advice

Anticoagulants for people who have heart failure and atrial fibrillation, follow the recommendations on anticoagulation in the NICE guideline on atrial fibrillation.

In people with heart failure in sinus rhythm, anticoagulation should be considered for those with a history of thromboembolism, left ventricular aneurysm or intracardiac thrombus.

Amiodarone

Calcium channel blockers

Vaccinations offer flu and pneumonia vaccine

Air travel will be possible for the majority of people with heart failure, depending on their clinical condition at the time of travel

Transplantation should be considered for people with severe refractory symptoms or refractory cardiogenic shock.



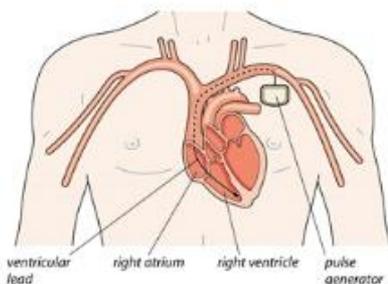
# Cardiac devices: Pacemakers, CRT, ICD's

**Pacemaker.** Patients with slow heart rhythms may require pacemaker implantation.

**Cardiac resynchronisation therapy (CRT);** In some people with heart failure, the walls of the main pumping chamber (the left ventricle) do not work together and contract out of sync with each other. CRT P is a special type of pacemaker that can correct the problem by making the walls of the left ventricle all contract at the same time. This makes the heart pump more efficiently. Most pacemakers only have one or two wires to the heart, but CRT requires an extra wire that is a bit harder to get into place than the other wires.

**Implantable cardioverter defibrillators (ICDs)** People who have, or are at high risk of developing, an abnormal heart rhythm may need an ICD fitted. This constantly monitors the heart rhythm. If the heart starts beating dangerously fast, the ICD will try to bring it back to normal by giving it a small, controlled electrical shock (defibrillation). If this fails, the ICD will deliver a larger shock. As with pacemakers, ICDs are implanted in hospital, usually under local anaesthetic. Like pacemakers, you will need to avoid things that can interfere with the way the ICD works, such as airport security systems.

**CRT-D** This is a device that does CRT and defibrillation, known as CRT D.



# Living with it

A little bit of 'attitude'

Staying positive is important in managing your heart failure. It is very important not to give up. We know it's tough but you will find your own way to manage. you'll feel better for it.

Determined – You are not going to allow your condition to rule your life

Knowledge – Understand as much about your condition as you can – you can then make the right decisions for you

Focused – Don't let the bad days spoil the show, be consistent and don't give up

Inquisitive – Always wonder what if?

Expert – You're your own expert on your condition

Self Assured – Know what you are doing is the right thing for you

Positive – Remember you have an inefficient heart not a failed heart, always remember that fact

Understand – Without understanding your condition you aren't an expert

Improve – We should be trying to improve in everything we do, so we can improve your Heart

Appointments questions, take a friend, prepare questions



# Why and what for- Medication

What are your pills?

What do they do?

Any side effects?

Make sure you take your pills as prescribed – try not to miss your dose. Use weekly pill boxes to remind you, get into the rhythm. It is important to take your pills as prescribed by your doctor or nurse because by taking them regularly you are building up their effectiveness.

Cardiologist will tell you what the best dosage is. They will probably start you off on a lower dose to get you used to it and then up the dosage. This doesn't mean you are getting worse but they are trying to get you to the most effective dose, its called "up-titration" and is very important to ensure the pills help you as much as possible.



# You are what you eat

Here are some top tips for great tasting healthy food and it's not all "eat your greens!"

What food do you like – it's a good start

On a weekly basis build up your food cupboard with Heart Failure friendly ingredients like spices, herbs, canned vegetables and fruit in natural juice, rice, pasta, olive oil and the list goes on. Always focus on no salt or very low salt, low sugar and low fat

Create a menu for the week and vary it – look on the internet for ideas

Focus on buying fresh ingredients, try not to buy processed foods.

Understand food labelling, don't add any salt, if your recipe says add salt, don't. All food has salt in it naturally so you don't need to add it. Spices can replace salt in certain foods

Watch your portion size.

If you feel like a snack pick up a piece of fruit, try new fruit or a different variety to mix it up a little



# Get active

Exercise is one of the most important things you can do to help you manage your condition and improve the quality of your life. Exercise comes in many formats and it doesn't all mean the gym, walking your dog or just simple walking will suffice. Speak to your doctor or nurse about wanting to start getting active, they may give you some pointers which will help you with what you can do and what you can't do. Ask for a referral to heart failure rehab.

We know it's not easy but if consider the below then at least you have a good start

A – Attitude – if you want to you will. You will never know how it feels if you don't do it

C – Consistent – Make time for activities in your day and week where you know you don't have an excuse to cancel – get your carer or friend to help you plan

T – Targeted – Set yourself gradual slopes to climb, don't push it. Taking part is more important than winning here. Your slopes will turn into hills and then mountains. The more you do the easier it is

I – Interesting – Interest is not just about the activity, it is also about the interest in how it is helping you. Find activities you enjoy, speak to your local council about what is on offer

V – Varied – Don't just do one activity mix it up a little – as they say variety is the spice of life

E – Enjoyable – A lot of things we do in life are enjoyable, make exercise part of your enjoyment to help improve your life

A small increase in your fitness may mean the difference between getting upstairs and not



# Fluid balance

Fluid Management used to be an important element of self-managing your Heart Failure

If a daily fluid restriction is imposed, it is so that you don't accumulate fluid.

Restricting how much fluid you take helps to control swelling of the feet and ankles, sudden weight gain, breathlessness and how effective your water tablets are.

Fluid is also liquid in a stew, canned fruit, fruit itself and ice cream etc.

If you put on more than 2 kilograms in two days, contact your doctor or heart failure nurse you may need to change meds.

Use a 500ml water bottle as a way of measuring fluids

Try adding "no added sugar" fruit squash" to your water, variety is important

Take alcohol out of your routine. Alcohol also interferes with some medication.

Handling thirst especially in hot weather is difficult, suck on frozen grapes, sugar free boiled sweets, ice cubes or ice lollies. Eat thin slices of melon, pineapple or orange.

Could try sugar free chewing gum

Use a smaller glass, remember in hot weather you will need to increase you intake therefore consult your nurse or doctor for guidance.



# Feeling sad or worried?

HF is a chronic lifelong condition, which has a significant impact on overall health and wellbeing. Symptoms of HF can cause significant disruption to people's lives on a physical level – which can, in turn, greatly impact on their quality of life

Depression is a major issue in heart failure. Depression is present in about one in five HF patients, with about 48 % of these individuals having significant depression.

It is normal for anyone to feel worried, sad or 'down' from time to time when dealing with a chronic medical condition that affects your lifestyle.

However, if you feel sad, 'down', or miserable most of the time, or if these feelings make it harder for you to go about your daily activities, you may be affected by depression. Many people with chronic heart failure experience depression at some time, affecting their work, relationships or wellbeing. If you suspect you have depression, talk to your doctor sooner rather than later because there are effective treatments. If you often feel anxious, and particularly if your anxiety makes symptoms such as shortness of breath stress management or relaxation techniques may help.



# Future Innovations in heart failure

**Sacubitril (Entresto) NICE approval for patients continuing HF.** Impressive evidence with significant improved life expectancy and avoidance of hospital

Angiotensin receptor neprilysin inhibitors (ARNIs). Combination of two drugs It works in two ways, firstly by increasing the body's natural defences against heart failure and secondly it blocks the body's natural system which as a harmful effect on the heart. clinical trial (Paradigm-HF) that improved both death rates and hospitalisation in heart failure by up to 20%.

**CardioMEMS,** is a small internal monitoring system. Small procedure to insert device which continually measures the pressure in the pulmonary artery. A rise in pressures occurs before the patients becomes symptomatic So medical intervention early results in increased meds prior to onset of symptoms. Not currently available on the NHS still undergoing trials.

**Mitacclip** For patients with leaky mitral valves, less invasive, avoids open heart surgery . All patients will be considered.

**Iron therapy** As one in every two heart failure patients has iron deficiency, that can occur without decreased haemoglobin. Measuring ferritin is a reliable indicator of iron stores, and studies are currently being carried out. effect of iron supplementation involves an improvement in exercise capacity and higher peak VO<sub>2</sub> cardiopulmonary exercise testing HF symptoms (NYHA class, fatigue score , and health related q

**Cardiac transplantation** may be considered if you have severe heart failure and medical treatments aren't helping.

**LVADS** (bridge to transplant)



# Thank you

*Your life won't stop, it will just be different.*

*There may be several adjustments to make in order to continue enjoying life, taking into consideration the lifestyle changes involved.*

Any questions??

