Heart failure
Causes, diagnosis, signs and symptoms
The Heartbeat Trust is Ireland’s national heart failure charity (CHY 5938). It supports specialist clinical and research services in heart failure and heart failure prevention.

Heart failure educational resource for patients and carers.

This booklet is based on the guidelines developed by European Society of Cardiology (ESC) and the Heartbeat Trust.

Causes, diagnosis, signs and symptoms

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About this booklet
This booklet will help you, your family and your caregivers to understand heart failure. It explains the causes of heart failure, how it is diagnosed, and the signs and symptoms.

What is heart failure?

Who gets heart failure?
Up to 1 in 5 people will develop heart failure at some point during their lifetime. The term ‘heart failure’ can sound frightening, so it might be more helpful to think of it as: ‘My heart is not working as well as it should and needs some medical help’.

Like other chronic or long-standing conditions such as asthma or diabetes, heart failure is likely to be with you for life. As with any illness, it will present challenges, but you can live well with heart failure once you know and understand the condition and its treatment.

This booklet will help you to notice and report any changes in your symptoms. By working closely with your healthcare team, you can take control of your condition, avoid unnecessary hospital visits and live an active life.

How does heart failure start?
Basically, the heart is a pump. Its job is to pump blood containing oxygen and nutrients around the body. But like any pump, it can get clogged, break down and need to be repaired.

Think of your heartbeat as the heart pumping the blood around your body. Between heartbeats, the heart rests. To work at its best, the heart must be able to both pump effectively and rest (relax) properly. In heart failure, there may be a problem with either the pumping or the resting:
• the heart’s pumping chambers (the ventricles) may have become larger (dilated) and cannot pump as well as they should; or

• the walls of the heart may have thickened and cannot relax (rest) as well as they should.

You may hear the terms HF-REF and HF-PEF used to describe your condition.

• HF-REF describes a heart which does not pump well.

• HF-PEF describes a heart which does not relax well between pumping actions.
What causes heart failure?

There are many causes of heart failure and these are explained below. Some people may experience more than one. For example, a patient with high blood pressure may also have coronary heart disease. Your doctor can tell you which of these caused your heart failure.

- **Coronary heart disease and heart attack.** This is the most common cause of heart failure. Coronary heart disease causes a build-up of fatty material on the inside of the main blood vessels which supply blood to the heart, causing these vessels to narrow and become blocked. Loss of blood supply to an area of the heart results in a heart attack and this can lead to heart failure in the future.

- **High blood pressure (hypertension).** If your blood pressure is high, your heart has to work harder to pump the blood around your body. Over time, this can cause the heart muscle to get stiffer and not relax as well as it should (HF-PEF). It may also cause the heart to get weaker over time (HF-REF).

- **Heart valve function abnormality.** Sometimes one or more of the heart valves get narrower or leak. This puts extra strain on the heart and, over time, may lead to heart failure.

- **Myocarditis.** This is an infection of the heart muscle. Very rarely, people who get a bad cold or flu can develop heart failure as the body’s defence system causes inflammation and damage to the heart muscle.

- **Dilated cardiomyopathy.** This is where the heart muscle does not contract well (HF-REF) but the cause is unknown. It may be genetic and your doctor may suggest asking your relatives if they know of similar problems in the family.
• **Dilated cardiomyopathy** from the effects of toxins such as alcohol or some recreational drugs. For some people, drinking alcohol or taking other substances may damage the heart. Your doctor may advise you to reduce your drinking for a while, or to stop drinking completely. On rare occasions, some cancer treatments may cause permanent damage to the heart.

• **Abnormal heart rhythm (arrhythmia).** This causes your heart to beat too fast, creating extra work for the heart. Over time, this can weaken the heart.

• **Heart problems you are born with (congenital heart defects).** In some people, the heart doesn’t develop properly. This means the healthy parts of the heart have to work harder to pump blood. Over time, this can lead to heart failure.

• **Other diseases.** Diabetes, some lung diseases, thyroid disease, anaemia, or a build-up of iron (haemochromatosis) or protein (amyloidosis) can also cause heart failure. Very rarely, women may develop heart failure during or following pregnancy.
How is heart failure diagnosed?

Before diagnosing heart failure, your doctor will examine you, listen to your heart, and arrange some or all of the following tests.

- **Natriuretic peptide**: (often referred to as BNP or NT-proBNP). This is a blood test which measures the level of a protein called natriuretic peptide. This protein can indicate the level of difficulty that your heart is experiencing. It helps your doctor decide if your symptoms are caused by heart failure or something else.

- **Other blood tests**: Examples of blood tests include a full blood count to look for anaemia or low blood iron levels, and a renal profile to see how well your kidneys are working. It is important for your doctor to know this when prescribing certain heart failure medicines.

- **ECG (Electrocardiogram)**: An ECG is a test in which small electrodes (stickers) are placed on your chest, ankles and wrists and attached to an ECG machine. This machine records the electrical activity within your heart. It can show if you have an abnormal heart rhythm or damage to the heart muscle.

- **Echocardiogram (echo or heart ultrasound)**: In this test a small probe is rubbed over your chest and takes pictures by ultrasound of your heart. The test shows how well your heart is working and whether or not you have heart failure.

- **Coronary angiogram**: This test checks the blood supply to the heart. A problem with blood supply is a common cause of heart failure.

- **Cardiac MRI**: A cardiac MRI is another way to assess the structure and function of your heart. It is not routinely done but your doctor may recommend that you have it. An MRI involves entering a hollow tube (like a tunnel) for about 30 minutes. If you get panicky in tight spaces, tell your doctor or nurse as you may find this test difficult to do.
Once the doctor has examined you and completed the tests, they will be able to tell you if you have heart failure or not. Many of these tests are also done in patients who are known to have heart failure as a way of checking the progress of their condition over time.

Heart failure may develop slowly over time. You may notice a variety of symptoms. For example, you may become breathless on walking, or find you need an extra pillow at night because you feel breathless when lying flat. You may also notice swelling around your ankles which may increase over time.

Other symptoms such as a poor appetite and low energy levels can be related to heart failure but they are also associated with other conditions.
However, the main symptoms of heart failure relate to the build-up of water in your body (fluid retention) and tiredness. It is important that you are able to recognise the early signs of retaining fluid so that you can tell your doctor. These signs include:

• **Sudden weight gain**
  First thing every morning, after you go to the toilet but before you have breakfast, stand on your bathroom scales. Make a note of your weight. It is a good idea to keep a notebook or diary where you can record your weight each day. It is also important to weigh yourself at about the same time every day. A sudden weight gain of 2kg (4lbs) over 2 days is an early sign of retaining fluid.

• **Shortness of breath**
  Fluid building up in your lungs can make you feel breathless. There are two types of breathlessness that you need to know about:

  1. **Breathlessness on exertion**
     - means that physical effort – doing something – makes you breathless.
     - For example, if you can usually walk comfortably to your local shops but over time find this less easy to do, it might be an early sign of fluid building up on your lungs and you should tell your (GP) family doctor.

  2. **Breathlessness at rest**
     - If you find you are breathless when sitting quietly in a chair, you may be retaining fluid.
     - If you need extra pillows at night because you feel breathless when lying flat, you may be retaining fluid.
     - If you wake suddenly gasping for air, it may be a sign of fluid on your lungs. People often describe this as a feeling of suffocation or drowning.
If you get any of these forms of breathlessness at rest, contact your heart failure clinic or GP immediately.

- **Cough**
  Fluid building up in your lungs can cause a cough. If you notice a cough keeping you awake at night or if you are coughing up white frothy sputum (phlegm), there may be fluid building up in your lungs. Again, tell your doctor without delay.

- **Swollen ankles**
  You may notice that your ankles and legs become swollen during the day. If you press on your shinbone just above your ankle, you may notice your thumb leaves a dent in your flesh. This is a sign that you are retaining fluid and you should tell your GP.

- **Loss of appetite**
  Fluid can also build up in your gut and liver. This can make you feel full or bloated. It may also cause you to lose your appetite. If your gut is congested with fluid, your body may not be able to absorb your medication properly.

- **Tiredness**
  Extreme tiredness is a common symptom of heart failure as the heart is unable to supply enough blood to the muscles.

- **Palpitations**
  Some people may experience palpitations which is a feeling of your heart beating fast in your chest.

- **Dizziness**
Patients with heart failure may work with many healthcare professionals. It is important to get to know them so that you can help them to help you. Always talk openly and honestly with them about your symptoms or changes in the way you are feeling.

Your team may include:

- **your GP** who provides your routine healthcare, including physical exams and basic tests. In most cases, your GP will be in charge of your overall care and is the main person to go to if you have questions or need advice;

- a **cardiologist** who is a doctor specialising in diagnosing and treating heart problems;

- **other doctors** such as surgeons and other specialists, if your GP or cardiologist recommends them;

- **clinical nurse specialists, nurse practitioners** and other nurses who may give care, perform tests, and provide information, education and counselling;

- **physiotherapists** who will help you develop a plan for regular physical activity;

- **dietitians** who teach heart-healthy eating guidelines and help develop meal plans;

- **mental health professionals** who help patients and families deal with emotional stress, anxiety or depression;

- **pharmacists** who can give you information about your medicines.

You are an essential part of the team too! Your job is to follow the instructions and recommendations of your healthcare team, and let them know how you are doing. With good communication with your healthcare team, you can improve the quality of your life and feel better.
To access online educational resources for heart failure, please log on to www.heartbeat-trust.ie or www.croi.ie. You will find helpful tips and advice from people living with heart failure, their families, doctors, nurses, physiotherapists and dieticians.

Useful websites:
www.heartbeat-trust.ie
www.croi.ie
www.irishheart.ie
www.bhf.org.uk
www.heartfailurematters.org
www.keepitpumping.com