

YOUR GUIDE TO YOUR JOURNEY



Heart Failure



MARIA DISCOVERS SHE HAS HEART FAILURE

To her friends and family, Maria seems fit and well, despite having diabetes since childhood. Her diabetes is well controlled but she feels tired all the time, physically and emotionally exhausted, and has started taking time off work. Maria is worried that she may have cancer but her doctor suspects heart failure. Maria is surprised. She thought heart failure only happened in older people.

AN EMOTIONAL JOURNEY

Being told you have, or may have, heart failure can be frightening. However, heart failure *does not* mean that your heart has failed: failure does not mean broken. Heart failure symptoms happen because the heart does not pump enough blood and oxygen to meet the needs of your body. Some people have heart failure because their heart's structure is abnormal. In other people, the structure is normal but the heart is too weak to pump enough blood.

Heart failure treatment aims to stabilise or reduce symptoms, improve your quality of life, make you better able to do everyday activities, avoid hospital stays and help you live longer. Modern medicines when managed and sometimes when surgery is required means that most people with heart failure can live full and rewarding lives.

A COMMON PROBLEM

If you have heart failure, you are not alone. Specialists say that between 1 in 50 and 1 in 100 adults have heart failure.¹ Yet heart failure is often not noticed or is misdiagnosed.² So, these figures are likely to be underestimates.¹ In some cases, heart failure can take up to five years to be diagnosed. The delays in diagnosis can be especially long for young people with heart failure.

Heart failure can happen at any age but is more common as we get older.² As we will see, other conditions or comorbidities, such as high blood pressure, heart attacks and abnormal heart rhythms (arrhythmias), can cause heart failure. People today are now more likely to develop comorbidities and survive with them for longer.^{2,3} That is good news, but this improved survival means that more people have heart failure.²

YOUR GUIDE TO YOUR HEART FAILURE JOURNEY

This guide aims to help people with diagnosed heart failure and those currently being checked to see if they have heart failure, as well as their caregivers. This guide also aims to help people at high risk of developing heart failure because of their comorbidities. For some of these people, lifestyle changes and medicines can help stop heart failure from happening.⁴

The aim of this guide is to help you take a full and active role with your heart failure multidisciplinary care team or when talking about and agreeing treatment. The care team oversees and delivers your care. Some people want their care team to take the lead. If this sounds like you, this guide will help you understand what to expect and the reasons behind your care team's suggestions.

You can use the guide at any stage in your journey as a person with heart failure.

The guide is based on European¹ and American⁴ guidelines agreed by experts in heart failure. Also, this guide is based on discussions with representatives of patient groups worldwide. There are several other local, national and international guidelines, all of which aim to ensure people with heart failure receive the best possible care.

Every person with heart failure is an individual. So, this guide does not replace advice from your care team, which may be influenced by local and individual circumstances. For example, some treatments or diagnostic tests may not be available in every country. Your care team's advice also reflects your particular circumstances and the way heart failure affects you. If you have any questions or concerns, contact your care team or local patient group. Each section of the guide has references to more information.

DEFINITIONS

01

What is heart failure?

HEART FAILURE REFERS TO signs, symptoms or both caused by a structural and/or functional heart abnormality.⁵ Heart failure can have lots of causes. In some people, heart failure happens when the heart does not pump enough blood. In other people, heart failure follows damage to the muscles surrounding the large heart chambers (ventricles) or valves that control the blood flow around the heart.⁵ However, these changes do not always lead to heart failure. So, your medical team will also look at the results of blood and other laboratory tests, heart scans and other investigations to decide if you have heart failure.⁵

What does my heart do?

The heart is a pump that pushes blood around the body. Blood carries oxygen, nutrients, cells and antibodies that fight infection to every part of your body. Blood also helps control body temperature and brings waste to the kidneys and liver for disposal.⁶

The heart has four chambers (figure 1). In a heart with a normal structure, the right atrium receives blood that has sent oxygen around the body. Blood flows into the right ventricle. This large chamber pumps blood into the lungs, where red blood cells pick up oxygen.⁷

Blood returns to the heart into the left atrium. From here, blood passes into the left ventricle. From the left ventricle, blood is pumped to the body.⁷ This rhythmic, co-ordinated sequence during a heartbeat is called the cardiac cycle (figure 2).⁸

FIGURE 1
The four chambers of the heart

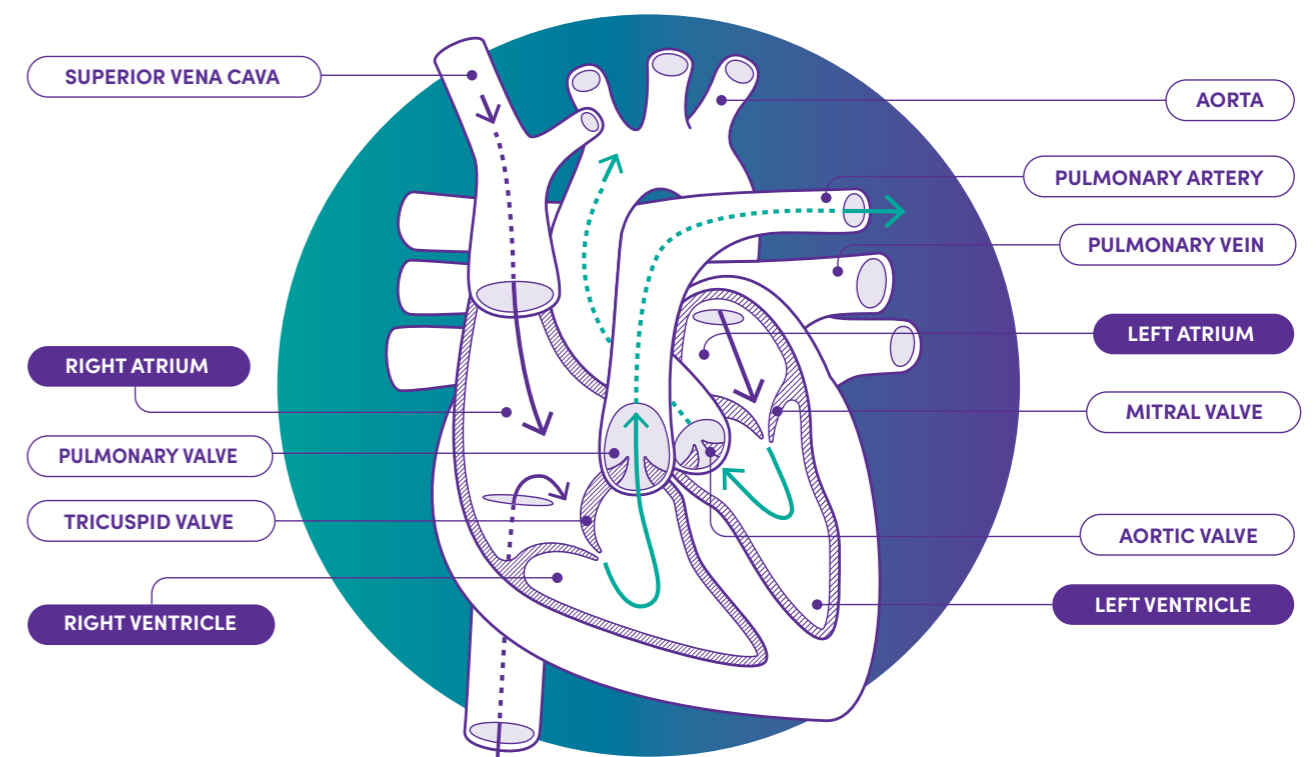
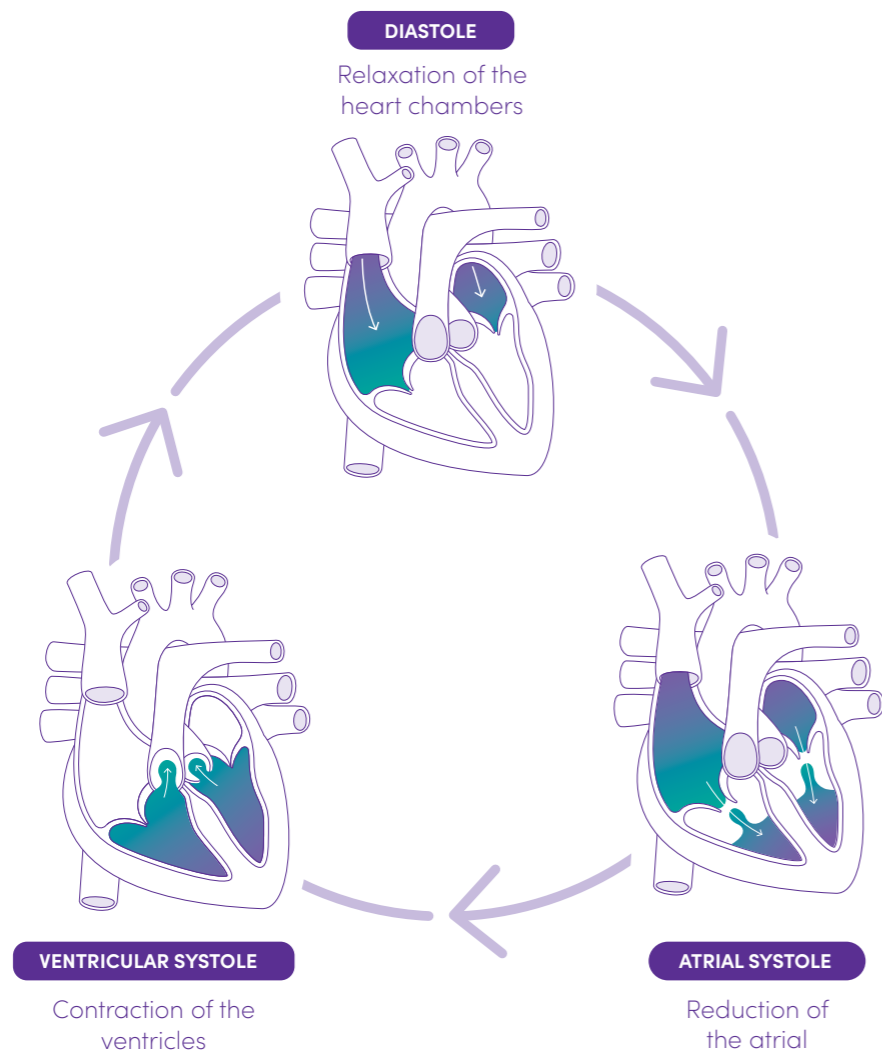


FIGURE 2
The cardiac cycle



What is the ejection fraction?

The ejection fraction is the amount of blood pumped out from the left ventricle each time this chamber contracts. Measuring your ejection fraction is one of the ways your medical team can see how well your heart is working. The amount of blood pumped by the heart depends on what the body needs: your heart pumps harder and faster if you run for a bus than while you are watching TV. However, even during exercise, a healthy heart does not push all the blood out from the left ventricle.

A normal ejection fraction is between 55% and 70%. In other words, a healthy heart pumps out between half and three-quarters of the blood in the left ventricle during each beat.⁴ In general, the lower the ejection fraction, the weaker the heart. However, people with a normal ejection fraction can have heart failure.

What are preserved and reduced ejection fractions?

Many people with heart failure have ejection fractions of about 20% to 30%. So, their hearts pump out between a fifth and a third of the normal amount. In people with heart failure, the care team calls this a 'reduced ejection fraction'. In people with heart failure they call a 'normal' ejection fraction of between 55% and 70% - a 'preserved ejection fraction'.⁴

In people with heart failure and preserved ejection fraction (HFpEF), the muscles in the left ventricle have become stiff. So, the ventricle does not relax normally and does not properly fill with blood.⁹ HFpEF accounts for more than 7 in every 10 cases of heart failure in people older than 65 years.³

In people with heart failure with reduced ejection fraction (HFrEF), the left ventricle does not contract normally. So, the heart does not pump with the force needed to push enough blood around the body.⁹ Your treatment may depend on whether the ejection fraction is preserved or reduced.¹⁴

The ejection fraction is only a guide. Some people with ejection fractions below 50% do not have heart failure. Some people with 'normal' ejection fractions have heart failure. Measuring the ejection fraction can help diagnosis, but it is not the only way to find out if you have heart failure. We will look at some of the other tests in the diagnosis section.

What is the difference between a symptom and a sign?

A symptom is a change you notice, such as being short of breath, tired all the time and having swollen ankles.¹ A sign is a change that the care team can measure, such as a faster heartbeat (tachycardia), an enlarged liver, or changes in heart sounds heard through a stethoscope.¹



What are typical signs and symptoms of heart failure?

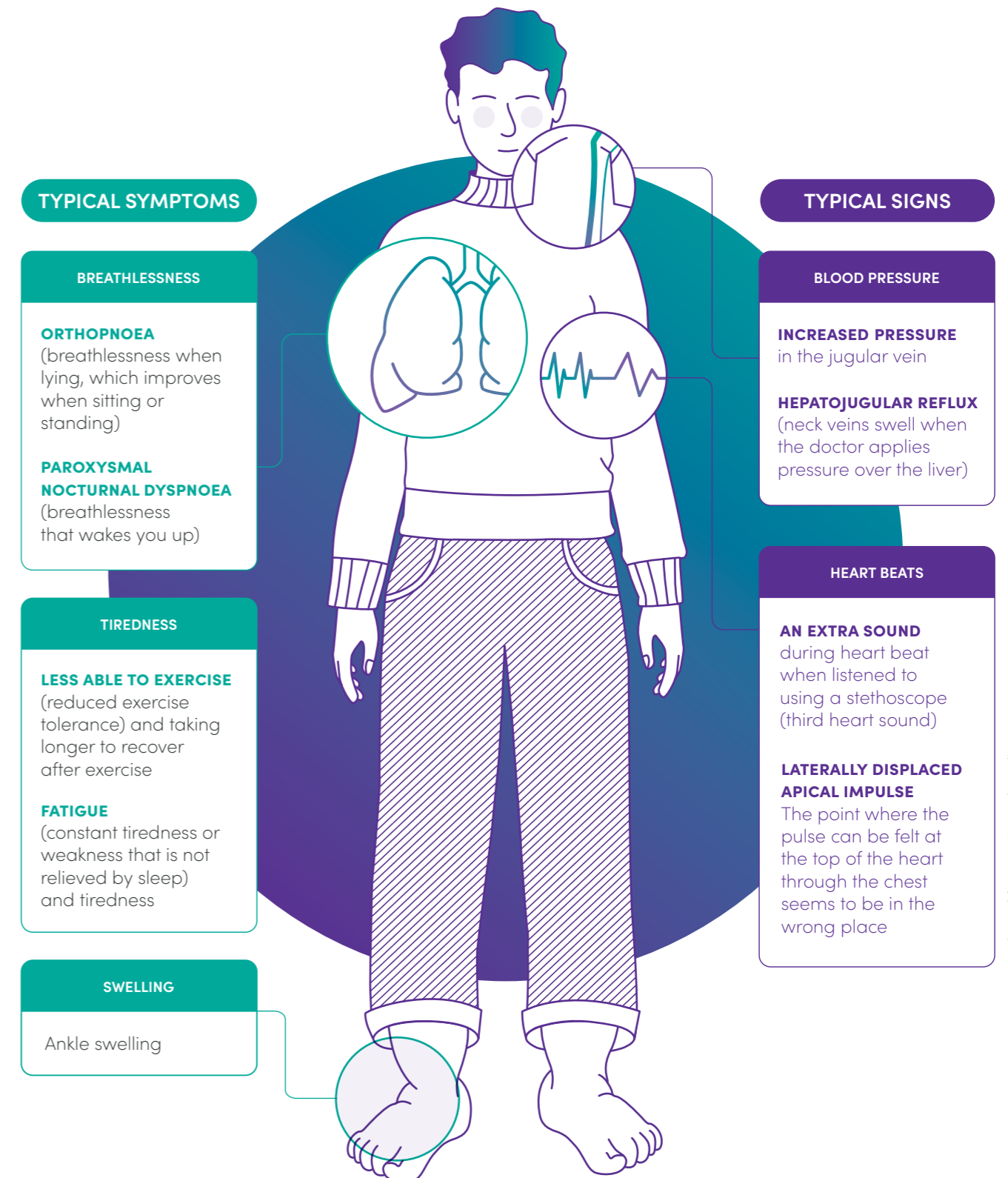
Figure 3 summarises the typical signs and symptoms of heart failure.¹ You will probably not have all of these. Your signs and symptoms and how bad they are may change during your heart failure journey.

If you have any of these signs and symptoms, make sure you mention them to your care team:



We will look at when you should contact your doctor later in the guide.

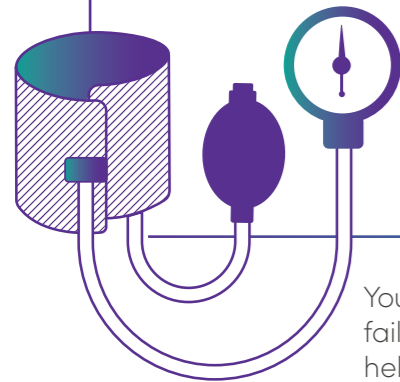
FIGURE 3
Heart failure's typical signs and symptoms¹



What causes heart failure?

Heart failure can have lots of causes. For example:

| | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>ISCHAEMIC HEART DISEASE</p> <p>Reduced blood flow to the heart muscle caused by a build-up of fatty deposits (atherosclerosis): a blood clot or a tear in wall of the blood vessels supplying the heart. A reduced blood flow can cause a heart attack or myocardial infarction which can cause damage to the heart muscle and result in heart failure.⁴</p> | <p>STRUCTURAL HEART DISEASE</p> <p>Abnormalities in the structure of the heart valves, chambers and blood vessels can cause heart failure (figure 1). In some people, these abnormalities happen over many years. One example is thickened heart valves (valvular stenosis). Sometimes people are born with these structural abnormalities (congenital heart disease).</p> | <p>OBESITY</p> <p>increases the risk of heart failure.⁴ Between 60% and 75% of people with heart failure with preserved ejection fraction are obese.³</p> |
| <p>HYPERTENSION (high blood pressure)</p> <p>can cause heart failure.⁴ Between 80% and 90% of people with heart failure with preserved ejection fraction have hypertension.³</p> | <p>Some AUTOIMMUNE DISEASES</p> <p>(the immune system attacks healthy tissue), genetic and other diseases that damage (cardiomyopathies) or inflame (myocarditis) heart muscle.</p> | <p>Certain MEDICINES</p> <p>can cause heart failure. For example, the side effects of some cancer treatments.⁴</p> |
| | | <p>DRUGS OF ABUSE</p> <p>can cause heart failure. For example, alcohol, cocaine, cannabis and methamphetamine.^{4,11}</p> |
| | | <p>Lots of OTHER CONDITIONS</p> <p>can cause heart failure or mean you are more likely to get it. For example, under- and over-active thyroid, diabetes, abnormal heart rhythms and iron deficiency.^{1,4}</p> |



Your doctor will try to help you understand what caused your heart failure. Understanding the cause may guide your treatment and help you make lifestyle changes to live a life as full and long as possible. Sometimes your medical team may not be able to find the cause.

What are the different stages of heart failure?

Your care team may use calculators or scales to help them understand the impact of heart failure on you and to discuss your treatment. The New York Heart Association (NYHA) Classification, one of the most widely used, places you into one of four classes (I-IV) based on how well you can perform the activities of daily living and four classes (A-D) based on signs of cardiovascular disease (table 1).¹²

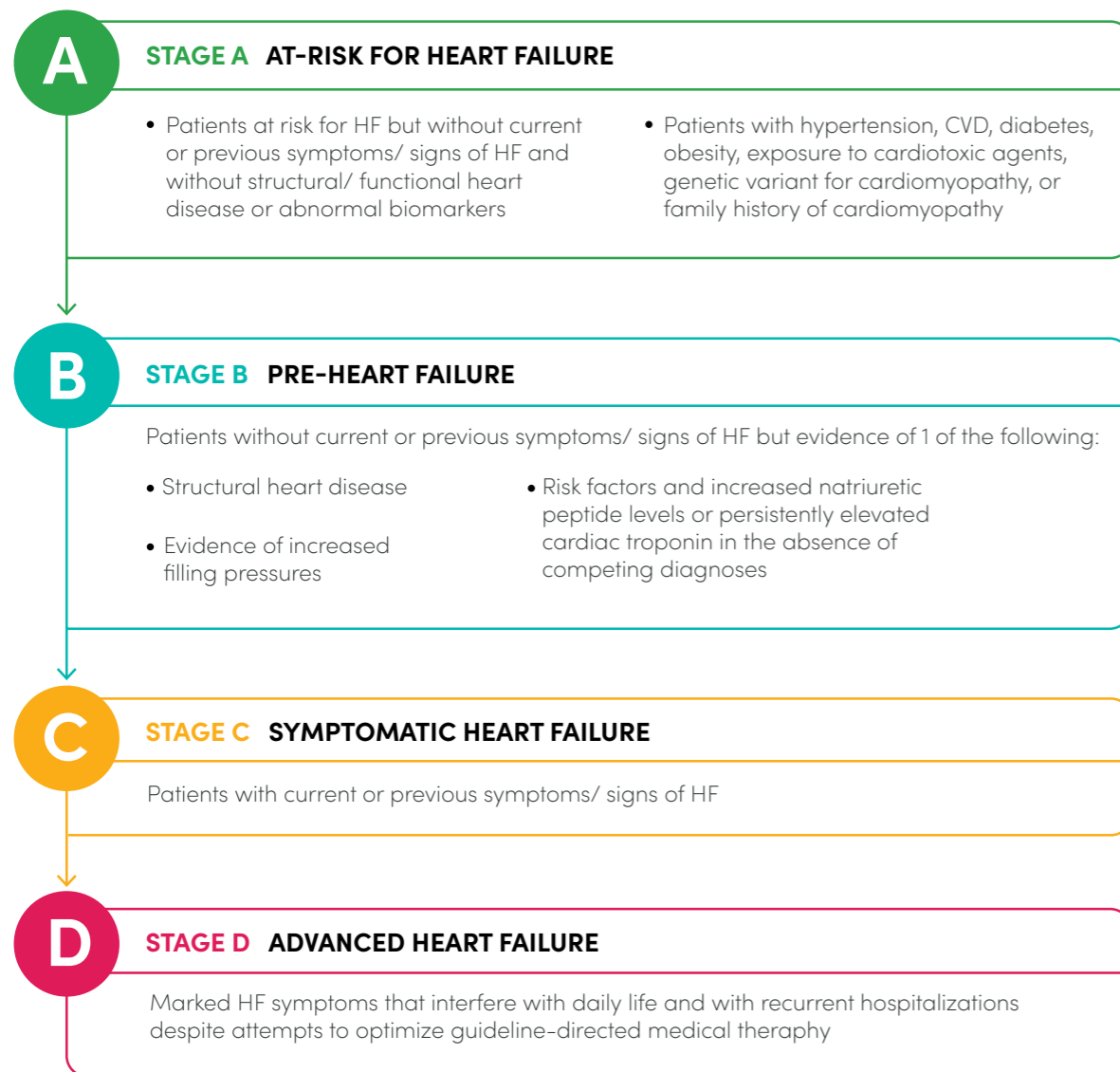
TABLE 1

The New York Heart Association (NYHA) Classification of heart failure¹²

| CLASS | PATIENT SYMPTOMS |
|-------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| I | No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations, dyspnea (shortness of breath). |
| II | Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath). |
| III | Marked limitation of physical activity. Comfortable at rest. Less than ordinary physical activity results in fatigue, palpitation, dyspnea. |
| IV | Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases. |
| CLASS | OBJECTIVE ASSESSMENT |
| A | No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity. |
| B | Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest. |
| C | Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest. |
| D | Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest. |

Breaking the heart failure journey into four stages shows how heart failure may progress and can help guide management (figure 4). People at risk stage A can change things to reduce the risk of heart disease. Once heart disease develops (stage B), treatment aims to prevent heart failure. In people with heart failure symptoms (stage C) and advanced heart failure (stage D), treatment aims to alleviate symptoms, improve the ability to do everyday activities and reduce the risk of death.⁴

FIGURE 4
Stages of heart failure⁵



Questions

that people with heart failure and caregivers can ask their care team

1 WHAT CAUSED MY HEART FAILURE?

2 IS THE CAUSE OF MY HEART FAILURE WELL CONTROLLED? IF NOT WHAT ELSE CAN WE DO?

3 ARE OTHER CONDITIONS (COMORBIDITIES) AND RISK FACTORS WELL CONTROLLED? IF NOT WHAT ELSE CAN WE DO?

How is heart failure diagnosed?

JOHN'S DIAGNOSIS

John, who survived a heart attack three years ago, tells his cardiologist that he has put on a few kilos in the past couple of weeks. His ankles seem swollen, working and other everyday activities are difficult because he is short of breath and tired all the time. A blood test shows NT-proBNP levels of 876 pg/mL. Echocardiography estimates his ejection fraction as 38%. So, he has heart failure with reduced ejection fraction. The cardiologist diagnoses NYHA stage III heart failure. John tells his cardiologist that he sometimes has palpitations, feels dizzy and faint. The blood tests also show that John has low levels of iron. The ECG is normal. The cardiologist asks John to wear a Holter monitor for two days to record his heart rhythm. This shows occasional abnormal heart rhythms (arrhythmias).

Why is early diagnosis important?

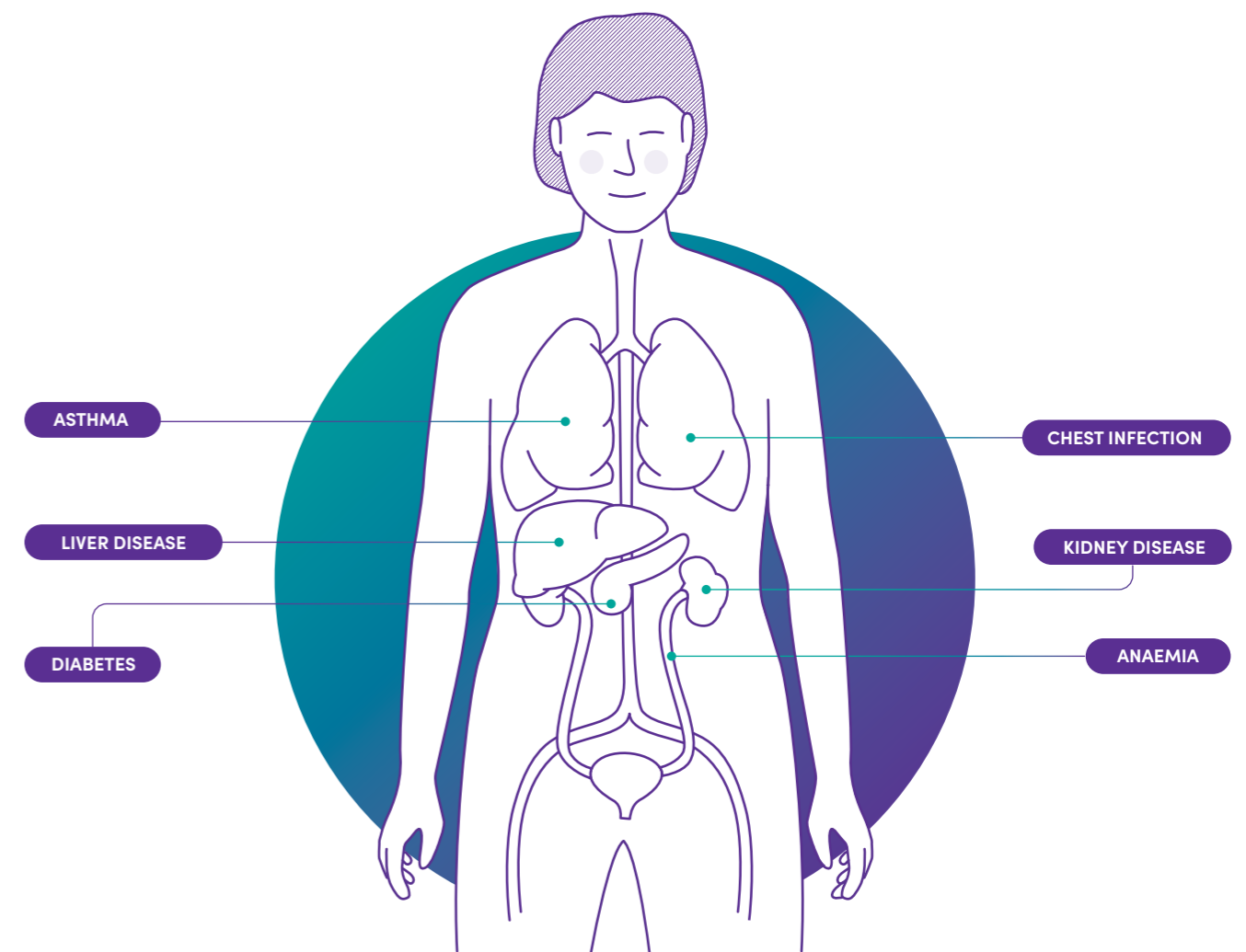
Early diagnosis lets you and your care team make lifestyle changes and use treatments to make your quality of life better and reduce the risk of life-threatening complications. People at stages A and B (figure 4) are at high risk of heart failure. In some people, this means that there may be a chance to stop heart failure of happening. For people with symptomatic (stage C) heart failure, treatment can reduce the risk of advanced (stage D) heart failure.⁴ This means that the sooner heart failure is diagnosed the better. So, if you are worried about your symptoms or your diagnosis speak to your care team. Do not be afraid to keep mentioning any worries you have.

What other conditions cause signs and symptoms similar to heart failure?

Many other conditions cause the same signs and symptoms as heart failure (figure 3). Also, people with heart failure vary widely in their signs and symptoms. Diagnosing heart failure means ruling out several other conditions (figure 5). The care team calls this the differential diagnosis.¹³

FIGURE 5

Examples of conditions that my care team need to rule out before diagnosing heart failure



What can I expect as my care team finds out if I have heart failure?

Your care team cannot just use signs and symptoms on their own to diagnose heart failure. The team also needs to check if your heart's structure or function is abnormal.⁵ Your care team can use several tests to check how well your heart works and to look for the causes of your heart failure.

For example, you may have genetic testing if your care team think a genetic or inherited cardiomyopathy could cause your heart failure.^{1,4} You may also be tested if a close relative (parent, sibling, or child) has a genetic or inherited cardiomyopathy.⁴ You should be offered counselling before and after genetic testing to help you understand the tests and what they mean, such as the risk to your children.

Laboratory tests

You may have a series of laboratory tests (table 2) to help find the cause of your heart failure, guide your treatment and check for side effects. Your care team may do laboratory tests throughout your journey to find any problems and check your progress. Things other than heart failure can affect the laboratory tests. For example, alcohol abuse can affect liver blood tests.

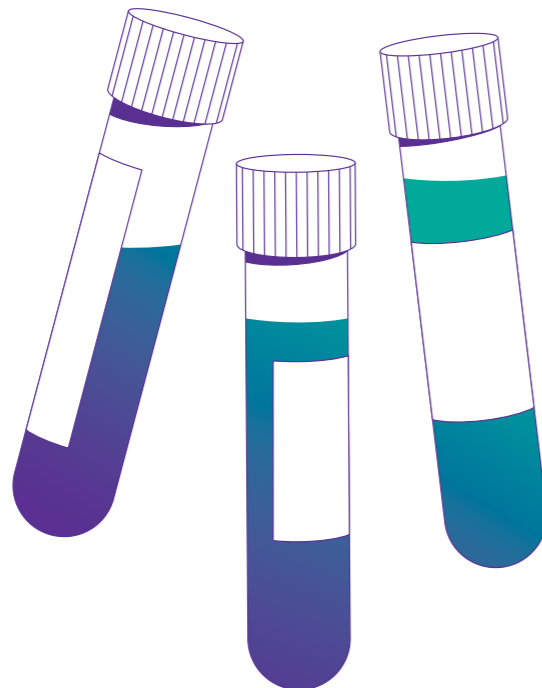


TABLE 2
Examples of laboratory tests used to help diagnose heart failure

| LABORATORY TEST | WHAT THE TEST MEANS |
|-----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Complete blood count | Analysis of the cells in your blood: helps find various diseases including infections, anaemia, immune diseases and blood cancers |
| Urinalysis | Analysis of a urine sample: helps find various diseases including urinary tract infections, kidney disease and diabetes |
| Blood electrolytes | Analysis of salts and minerals (eg sodium, potassium and chloride) in blood: levels change in certain diseases |
| Creatinine | Kidneys remove creatinine (a waste product) from your blood. Higher than normal levels of creatinine in blood or urine may show that your kidneys are not working properly |
| Glucose in urine | Urine contains little or no glucose. Levels of glucose in urine may be higher if you have diabetes |
| Lipid profile | The pattern of fats and the proteins that carry fats in your blood. Changes in the pattern may affect your risk of heart disease |
| Liver blood test | Measurements of a group of chemicals that show how well your liver is working (also called liver function tests) |
| Iron levels | Iron is part of haemoglobin, which carries oxygen in red blood cells. Low levels may mean you have anaemia |
| Thyroid-stimulating hormone (TSH) | The thyroid is a gland producing chemical messages (hormones) that control the way your body uses energy. Measuring TSH levels in blood shows if the thyroid is working properly |

Adapted from^{1,4}; Definitions based on medlineplus.gov/lab-tests/ and www.mayoclinic.org/tests-procedures accessed August 2022

→ WHAT ARE NATRIURETIC PEPTIDES?

If you have symptoms of heart failure, your healthcare professional should measure your levels of one of two small proteins: B-type natriuretic peptide (BNP) or N-terminal pro-B-type natriuretic peptide (NT-proBNP).¹⁴

Changes in pressure or the volume of blood in the heart release BNP and NT-proBNP. So, measuring levels of natriuretic peptides can help find out if you have heart failure. However, several things other than heart failure can also change natriuretic peptide levels. For example, obesity lowers natriuretic peptide levels. This means that if you are obese, measuring natriuretic peptide levels will not be as useful for diagnosis as it would be in a person with a healthy weight. Other factors that increase levels of natriuretic peptides include heart attacks, pulmonary embolism, arrhythmias, kidney disease, certain drugs used to treat cancer and bad infections.⁴ On its own, measuring natriuretic peptides does not diagnose heart failure.⁴

Measuring BNP and NT-proBNP levels can help check your progress, like using blood glucose levels to check diabetes. For example, a NT-proBNP level above 125 may suggest heart failure and should trigger more checks. So, you should know your natriuretic peptide level. Ask your medical team if you have any questions about the test or the results.

Testing for BNP and NT-proBNP may not be available in all countries. This may be because of the cost or limited resources. Testing practices may also be different between countries. Some, but not all, countries use different cut off points depending on age. So, you should ask if BNP and NT-proBNP testing is available to you.

→ WHAT IS AN ELECTROCARDIOGRAM?

An electrocardiogram (ECG) uses sensors attached to the skin to find changes in the heart's electrical signals. These changes may cause or happen because of heart failure, such as arrhythmias, ischaemic heart disease and cardiomyopathy.¹⁴ ECGs do not diagnose heart failure. However, they can provide information about the causes and tell how you are doing. So, your care team may suggest an ECG from time to time.¹

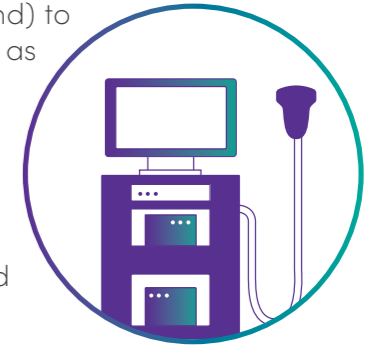
You may have an ECG taken while you are lying down or while using an exercise bike or treadmill if, for example, activity sets off your symptoms. Your care team may also suggest ambulatory ECG (wearing a Holter monitor) using a small machine worn at your waist for a few days.¹⁴ This collects your ECG as you go about everyday activities.



→ WHAT IS AN ECHOCARDIOGRAM?

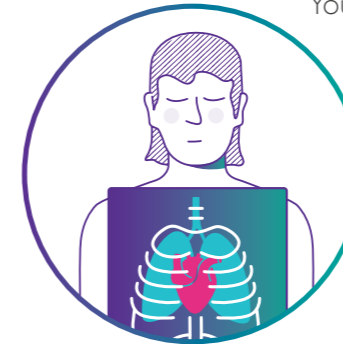
An echocardiogram uses sound waves (ultrasound) to build a picture of your heart.¹⁴ It uses the same idea as the scans done during pregnancy.

Echocardiograms allow the care team to check how well your heart is working, such as by measuring the ejection fraction.¹ Echocardiograms also show details such as the size and shape of the heart chambers, whether the heart muscles are moving properly and if the valves (figure 1) are thick or leaky.¹



→ WHAT ARE THE OTHER TYPES OF TESTS OR SCANS?

You may have a chest x-ray. This helps find other causes of breathlessness such as lung disease.¹ X-rays can find symptoms that point to a diagnosis of heart failure, such as fluid in the lungs (pulmonary congestion) or abnormal enlargement of the heart (cardiomegaly).¹



Your care team may suggest some other imaging tests, such as cardiovascular magnetic resonance (CMR) imaging, single-photon emission computerised tomography (SPECT) or cardiac computed tomography.¹ These provide more information than echocardiograms.¹ If you need one of these tests your care team will talk with you about the reasons, risks and benefits.

Questions

that people with heart failure and caregivers can ask their care team

1 WHICH LABORATORY TESTS WERE ABNORMAL? WHAT DOES THIS MEAN FOR ME AND MY TREATMENT?

2 IS TESTING FOR BNP AND NT-PROBNP AVAILABLE IN MY COUNTRY?

3 WHAT IS MY NATRIURETIC PEPTIDE NUMBER? WHAT DOES THIS MEAN FOR ME AND MY TREATMENT?

4 WHAT DID MY ECG SHOW? WHAT DOES THIS MEAN FOR ME AND MY TREATMENT?

5 WHAT DID MY ECHOCARDIOGRAM SHOW? WHAT DOES THIS MEAN FOR ME AND MY TREATMENT?

6 DO I NEED ANY OTHER TESTS OR SCANS? WHAT WOULD THE RESULTS MEAN FOR ME AND MY TREATMENT?

7 WAS MY IRON LEVEL CHECKED? HOW OFTEN SHOULD I HAVE MY IRON LEVELS CHECKED? SHOULD I TAKE AN IRON SUPPLEMENT?

8 HOW OFTEN WILL I NEED A FOLLOW-UP APPOINTMENTS? WHO SHOULD I CONTACT IF I HAVE CONCERNS IN THE MEANTIME?

Where can I get more information?

TREATMENT
& DRUGS

03

How is heart failure treated?

ANNE'S TREATMENT

Anne is overweight and almost obese. She takes diuretics and an ACE inhibitor to treat her heart failure. Her ankle swelling gets better. Anne finds she has to pass urine more often, which sometimes limits her social life. She feels 'a bit better', but still feels breathless and tired when she works or goes about her daily life. She thinks it may be her excess weight. She talks about her options with her cardiologist.

What are the elements of heart failure care?

There are three main elements of care for people with heart failure: medicines, devices and interventions, and self-care. Together these elements aim to: reduce the risk of death and hospital visits because of heart failure; make symptoms better; make it easier for you to do everyday activities also called functional capacity; and allow you to have the best possible quality of life.¹ We will consider each in turn.

What are the goals of treatment?

Treatment goals depend on the stage of heart failure (figure 4):

- Treatment goals for stages A and B are to prevent heart failure.⁴
- The goals of stage C include making symptoms better, making everyday activities easier and reducing the risk of advanced (stage D) heart failure.⁴
- At stage D, some people are suitable for advanced therapies, such as a cardiac assist device or a heart transplant; see later. Every person with heart failure at stage D should receive supportive care, sometimes called palliative care. This focuses on making symptoms better.⁴ As discussed later in the guide, palliative care does not mean treatment ends.⁴

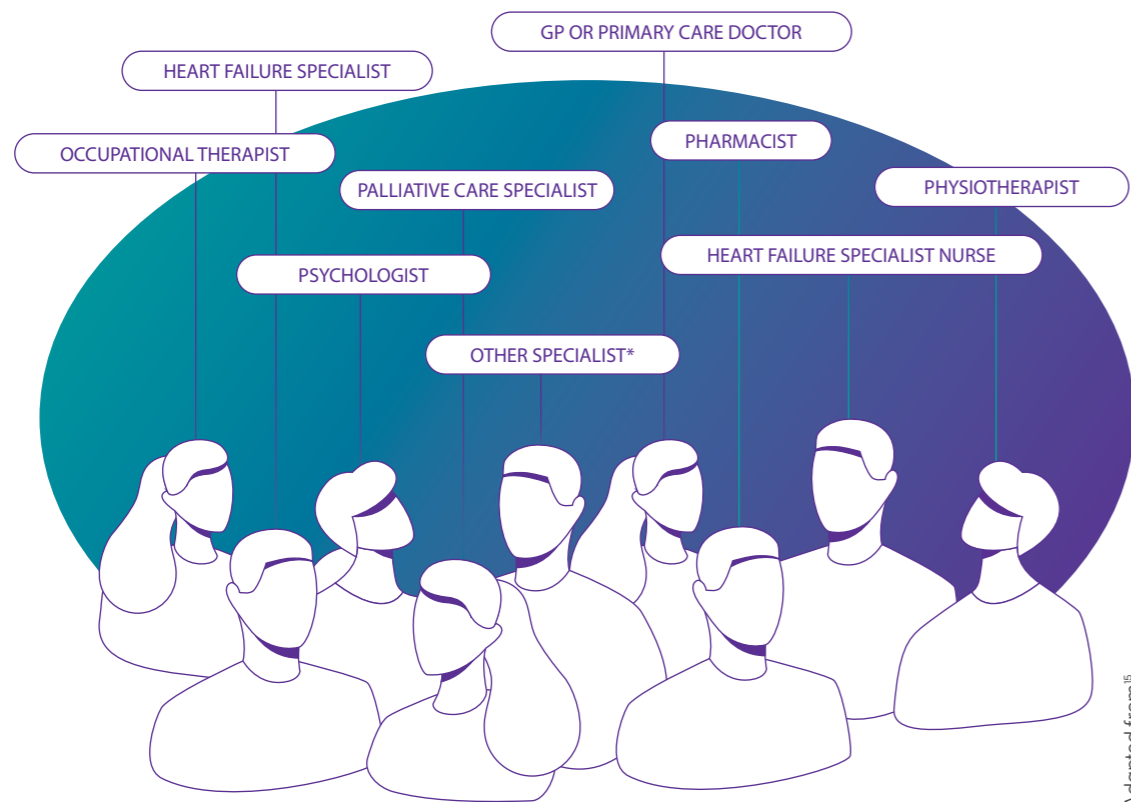
People can move between stages. People with heart failure at stage D have recurrent heart failure symptoms and hospital stays. However, treatment can improve symptoms enough for a person with heart failure to go from stage D to stage C. So, treatment goals will change along your journey. At each step, people with heart failure need to consider the balance between quality of life and quantity of life. This balance may change along the journey. You also need to consider when a treatment should be stopped, such as when it does not seem to be working or the side effects are unacceptable. It is worth talking about this before you start a treatment.

Who is involved in my care?

Every person with heart failure is different. So, the care team (figure 6) varies to meet your needs. The team usually includes a cardiologist specialising in heart failure and, in many countries, a specialist nurse, a pharmacist and your primary care doctor. There may be other professionals, such as; occupational therapists – who can suggest aids, changes to work or home to make everyday activities easier – and psychologists, if you have emotional and mental health challenges.¹⁵ Your care team may also include professionals from different areas of medicine for example, if you have comorbidities or need support to quit smoking or drug use.¹⁶

Studies show that having a care team improves the outlook for people with heart failure.¹⁵ So if you feel you need additional support, tell your care team.

FIGURE 6
Example of members of the multidisciplinary care team



*eg kidney disease, diabetes or chest disease

Adapted from¹⁵

When should I see a specialist?

You may need to see a specialist from time to time. Between appointments with your care team you should consider seeing a specialist if you have any of the issues in figure 3. You may at some point be suitable for a heart transplant or a cardiac assist device as you need more than drugs to manage your heart failure. So you should remember this as 'I NEED HELP'.¹⁷





How do I agree with my care team which medicine is right for me?

The choice of medicine depends on lots of things, including the cause, severity and stage of your heart failure, any comorbidities and other treatments (some interact with each other), your age and whether your ejection fraction is preserved or reduced. So, not every person with heart failure receives every medicine. Many of these medicines reduce hospital visits and help people with heart failure live longer.¹ Some also make people with heart failure feel better.¹

We will look at the most common medicines used to treat heart failure (figure 7), but we will not cover every aspect. So, speak to your care team if you have any worries or questions. Always read the patient information that comes with your medicine and remember that it is updated from time to time.

Before starting any medicine, make sure you understand why the drug is right for you as well as its benefits, dosing, effects and side effects. You and your care team should talk about practical things, such as the best time to take the medicine and what to do if you miss a dose.

You should also know what to do if you have a short-lived infection or illness, such as the flu, being sick or have diarrhoea. A fever, being sick or diarrhoea can lead to dehydration, worsen kidney function and lead to a drop in blood pressure. So, you may need to stop some medicines while you are ill and restart again when you feel better. Your cardiologist or pharmacist will tell you if this applies to your medicine. Never stop a drug unless your doctor or pharmacist has advised you to.

Speak to your care team or the pharmacist where you collect your prescription if you are not clear about anything.

FIGURE 7

The main medicines used to treat heart failure

When your heart has a pumping problem, the body senses that and sends a variety of 'chemical' messages to increase the pace of the heart beat (your heart works harder and faster), keep up blood pressure by constricting (tightening) blood vessels and increasing the volume of blood. This puts **EXTRA STRESS** on the heart which is already struggling to pump efficiently.



BETA BLOCKERS

Beta Blockers are used to tell the heart to stop listening to these messages and slow down.



ACE INHIBITORS

Ace Inhibitors work on your blood vessels to make them relax which helps to lower your blood pressure. Your heart is then able to pump blood to the rest of your body against less pressure, without working harder.



ALDOSTERONE ANTAGONIST

(*Spironolactone*)
Aldosterone Antagonist makes your kidneys get rid of Sodium (which likes to take water with it). This helps decrease the volume of blood the heart has to cope with.



LOOP DIURETICS

Loop Diuretics make your kidneys remove more water (making you go to the toilet more often). This helps your body get rid of excess fluid. Diuretics help symptoms caused by fluid build-up (breathlessness, swelling) and will make you feel better.



So a combination of medications is used. You will be **STARTED ON A LOW** dose that will be increased slowly until you get up to the best dose for you.

What do heart failure drugs do?

In the early stages of heart failure, heart rate increases. Blood vessels narrow to increase blood pressure. The body holds on to salt and water, which also increases blood pressure. Initially these and other changes help your heart meet your body's need. However, over a long-term, these changes can harm the heart. For this reason, the medicines used to treat heart failure target one or more of these changes. So, some medicines for heart failure lower blood pressure or heart rate. They stop or slow changes that make heart failure worse.

There is a small chance some of these medicines will cause side effects. So, your care team will check your blood pressure and your heart rate, take blood tests and consider your symptoms to make sure the benefits of a medicine outweigh the risks.

A

→ ANGIOTENSIN-CONVERTING ENZYME INHIBITORS

People with heart failure with reduced ejection fraction may receive drugs called angiotensin-converting enzyme (ACE) inhibitors. ACE inhibitors relax and open (dilate) blood vessels,¹⁸ so the heart does not have to work as hard to pump blood around the body.¹⁸ Doctors can also prescribe ACE inhibitors to treat high blood pressure (hypertension).¹⁸ Many people with heart failure need ACE inhibitors even if their blood pressure is already on the low side.

Side effects include low blood pressure (hypotension), which can cause dizziness and fainting.¹⁸ So, tell your care team if you are dizzy or feel faint after starting ACE inhibitors. ACE inhibitors can also cause a dry, irritating cough and angioedema, which is swelling underneath the skin.¹⁸

→ ANGIOTENSIN RECEPTOR BLOCKERS

The body produces a chemical called angiotensin. This strongly narrows, or constricts, blood vessels. Angiotensin receptor blockers (ARBs) stop angiotensin from working. Blood vessels then open and the heart does not have to work as hard.¹⁸

→ ANGIOTENSIN RECEPTOR BLOCKERS AND NEPRILYSIN INHIBITORS (ARNI)

Most people with heart failure with reduced ejection fraction should receive an ARNI. This combination of an ARB and a neprilysin inhibitor reduces hospital visits and makes death from heart failure less likely. Sacubitril plus valsartan is the only ARNI currently available.¹⁴ Neprilysin is a special protein, or enzyme, that destroys several chemical messages,



B

→ BETA-BLOCKERS

Beta-blockers reduce blood pressure, they slow the heart rate and help the heart relax. The heart then does not need to work as hard.¹⁸ Beta-blockers reduce hospital visits and makes death because of heart failure less likely. Beta-blockers can harm a person with heart failure whose heart function is getting worse.¹⁸ Because of this, beta-blockers are given only to people with stable heart failure.¹

Beta-blockers can narrow the airways and make asthma worse.¹⁸ So, always tell your care team if you have asthma. Other side effects include cold fingers and toes, insomnia, depression, fatigue and for men, problems getting or keeping an erection.^{18,20}

D

→ DIURETICS

People, who have heart failure with reduced ejection fraction, with signs and symptoms of congestion – fluid building up in tissues, such as the ankles and lungs – diuretics can make symptoms of heart failure better, improve how much you can exercise and reduce the hospital stays.¹

Diuretics increase excretion of sodium and water. In other words, they make you pass more urine. This reduces blood pressure. So the heart is not working as hard and excess fluid is removed from the body.¹⁸ Usually, people with heart failure receive loop diuretics, such as furosemide.¹⁸ Loop diuretics may mean you lose too much potassium.¹⁸ Your care team will monitor your potassium levels.

H

→ HYDRALAZINE PLUS ISOSORBIDE DINITRATE

The combination of hydralazine plus isosorbide dinitrate relaxes blood vessels. This reduces work the heart needs to do.¹⁸ Side effects include low blood pressure and feeling dizzy.¹⁸ The care team may suggest hydralazine plus isosorbide dinitrate for people with heart failure who cannot take other drugs such as ACE inhibitors and ARBS because of side effects or kidney disease, or who have symptoms even though they are taking other medicines as suggested in guidelines.⁴

M

→ **MINERALOCORTICOID RECEPTOR ANTAGONISTS**

Aldosterone controls levels of water and sodium in the blood. This helps keep the body healthy but in people with heart failure blood aldosterone levels are up to 60-times higher than in healthy people.²⁵ So, the body holds on to too much fluid and the heart has to work harder. High aldosterone levels can also inflame, stiffen and scar heart muscle. This contributes to heart failure.²⁵ Mineralocorticoid receptor antagonists, such as spironolactone and eplerenone, block aldosterone's harmful actions in people with heart failure with reduced ejection fraction.^{1,25} Mineralocorticoid receptor antagonists reduce hospital stays in people with heart failure with preserved ejection fraction.²⁶

Mineralocorticoid receptor antagonists can cause high levels of potassium in the blood (hyperkalaemia), which can cause symptoms including palpitations, feeling sick, muscle pain and weakness, pins and needles, or paraesthesia. These side effects happen because the high potassium levels mean that muscles or the heart do not work properly.^{25,27,28} Your care team may suggest drugs such as patiromer sorbitex calcium and sodium zirconium cyclosilicate. These bind to potassium in the gut, normalising and preventing rises of potassium levels.¹ In up to 1 in 10 men, spironolactone causes breast tenderness and enlargement called gynecomastia.²⁵ Spironolactone can also cause taste changes, or dysgeusia, such as an unpleasant metallic taste.

S

→ **SODIUM-GLUCOSE COTRANSPORTER 2 INHIBITORS**

In people with heart failure, certain sodium-glucose cotransporter 2 (SGLT2) inhibitors reduce hospital stays and make death from heart failure less likely.^{1,21-23} SGLT2 inhibitors are widely used to treat type 2 diabetes.⁴ Researchers are still trying to work out how SGLT2 inhibitors work in heart failure but people with heart failure benefit whether or not they have type 2 diabetes.⁴

SGLT2 inhibitors increase the amount of glucose in the urine. Glucose can act as an energy source for bacteria and fungi. Urinary tract infections, usually caused by thrush (yeast called *Candida*), happen in about 1 in 10 women and 1 in 20 men taking SGLT2 inhibitors.²⁴ Your care team may be able to suggest ways to make a thrush infection less likely.



What about the other conditions I have?

You and your care team may need to deal with other conditions (comorbidities) alongside your heart failure. For example, chronic kidney disease, chronic obstructive pulmonary disease or COPD. Some comorbidities can worsen heart failure, including high blood pressure, sleep disordered breathing, obstructive and central sleep apnoea, diabetes, anaemia or iron deficiency.¹

Your red blood cells use iron to carry oxygen around the body. Many people with heart failure get iron deficiency and may need iron supplements.¹⁴ Speak to your care team if you have not had your iron levels checked recently.

Make sure you let your care team know about any other condition you have, and never forget to look after them as well as your heart failure.

What do I do if I am worried about side effects?

Every medicine, even ones you can get without prescriptions, can cause side effects. Many side effects – also called adverse events – are general. You may feel ill and blame the drug when another condition or your heart failure is causing the symptom. For example, beta-blockers, heart failure and a late night can cause fatigue. Some side effects are expected or are part of the way the drug works, such as increased urination with diuretics. Others can be unexpected.

If you are worried a symptom may be a side effect, speak to your care team. There are lots of drugs available so there is often an alternative. In some cases, the team may be able to suggest ways to reduce the impact of a side effect, such as when you take diuretics. Tell your care team about any drug you have bought without a prescription, even herbal and other alternative treatments. Some of them may interact with prescription medicines.

NEVER STOP OR LOWER THE DOSE OF ANY PRESCRIBED MEDICINE WITHOUT SPEAKING TO YOUR CARE TEAM.

Questions

that people with heart failure or their caregivers can ask the care team

1 WHY IS THIS MEDICINE RIGHT FOR ME NOW?

2 WHAT DOES THE MEDICINE DO? HOW DOES IT WORK?

3 HOW DO I KNOW THAT TREATMENT IS WORKING?

4 WHAT ARE THE 'RULES' FOR STOPPING MY MEDICINE?

5 WHAT ARE THE MOST COMMON SIDE EFFECTS? WHAT SHOULD CAREGIVERS LOOK FOR?

6 CAN I DO ANYTHING TO PREVENT OR LIVE WITH THE SIDE-EFFECTS?

7 WHEN SHOULD I CONTACT MY CARE TEAM ABOUT SIDE EFFECTS?

8 WHY DOES THE MEDICINE HAVE A GENERIC AND BRAND NAME? DOES IT MATTER THAT THE SAME GENERIC DRUG SOMETIMES LOOKS DIFFERENT?

9 WHAT DO I DO IF I MISS A DOSE?

10 WHAT DO I DO IF I TAKE AN EXTRA DOSE BY MISTAKE?

11 IS THIS DRUG SAFE WITH MY OTHER MEDICINES AND ANY SUPPLEMENTS?

12 WHAT DO I DO WITH MY MEDICINE IF I AM FEELING SICK, HAVE AN INFECTION, DIARRHOEA AND SO ON?

Devices and surgery

KAI'S TREATMENT

Kai has lived with rheumatoid arthritis since he was a teenager. The arthritis recently led to heart failure. Kai's cardiologist asked him to wear a Holter monitor to record his heart rhythm. This shows occasional, but life-threatening, abnormal heart rhythms (arrhythmias). So, Kai gets an implantable cardioverter defibrillator, which treats his life threatening heart rhythm. This makes his symptoms better and he returns to work as a manager in a busy office.

Why is your care team suggesting an operation?

In most people, medicines control the signs and symptoms of heart failure. Your care team may suggest several devices or operations, if your medicines are not controlling your symptoms well enough or you have additional issues (arrhythmias; heart valve disease – see figure 3) or your heart failure continues to get worse.¹⁴

For example, an implantable cardioverter defibrillator (ICD; figure 8) is a small battery-powered device placed in your chest during an operation. It continuously checks your heartbeat. When it finds irregular heartbeats (arrhythmias), the ICD sends electric shocks to bring back a regular heartbeat. In some people with heart failure the two ventricles do not pump in time with each other. Cardiac resynchronisation therapy (figure 9) is a special pacemaker that resets the heart's pumping action.

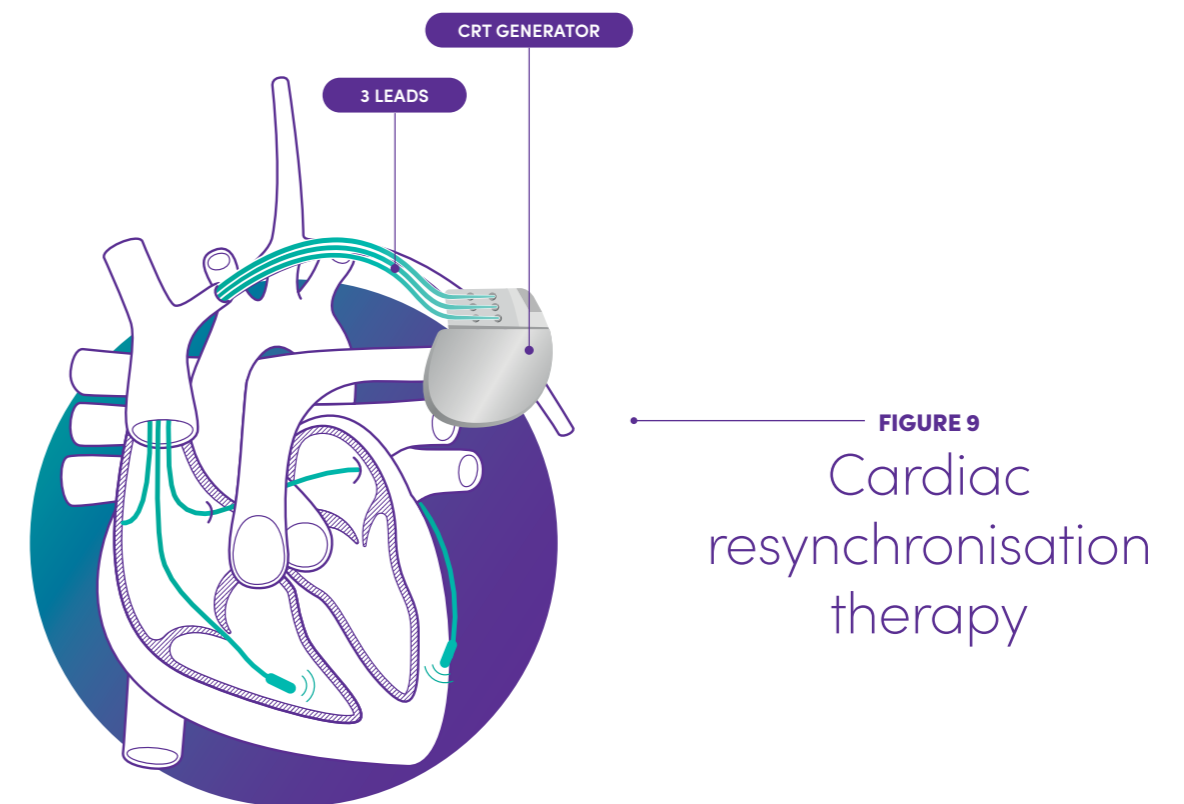
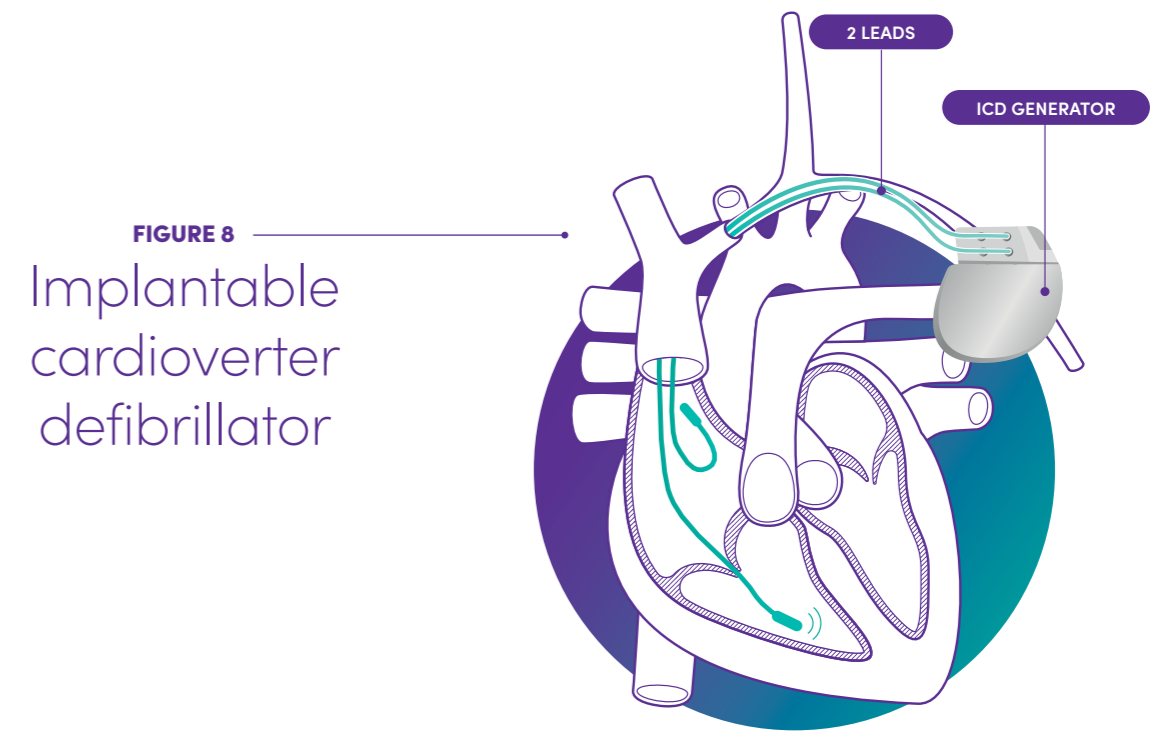


Table 3 highlights the main devices and operations used to treat heart failure but does not cover everything. You should always talk about the risks and benefits with your care team. For example, you should ask about what to expect, are there any driving restrictions and when the device may be turned off or taken out.¹ Any operation has risks, which may be higher in people with heart failure.²⁹ Your care team will suggest a device or operation only if they are sure that the benefits outweigh the risks. Always talk about the risks and benefits of any procedure with your care team.

TABLE 3

The main devices and operations used to treat heart failure

| PROCEDURE | WHAT THE PROCEDURE DOES | EXAMPLES OF POSSIBLE COMPLICATIONS |
|-----------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Implantable cardioverter defibrillator (ICD) | Corrects potentially lethal irregular heartbeats in the ventricles and treats slow heart rate (bradycardia) | Infection, bruising and bleeding; the lead may move (displacement); there is a small risk of a collapsed lung (pneumothorax) |
| Cardiac resynchronisation therapy (also called bi-ventricular pacing) | In some people with heart failure the ventricles do not pump in time with each other. A special pacemaker can coordinate the heart's pumping action and it may have a defibrillator | Same as ICD |
| Surgical revascularisation | Revascularisation widens narrowed parts of a coronary artery. Coronary artery bypass grafting (CABG) uses a vein or artery from another part of the body to bypass the blockage. Percutaneous coronary intervention (PCI) uses a metal mesh (stent) to open the vessel | CABG: heart attack during the procedure; the graft becomes blocked; low output from the heart; arrhythmias PCI: the vessel may suddenly close causing a heart attack; blood may pool in nearby tissue; the stent may perforate and rupture the coronary arteries; a blood clot may form on the stent increasing the risk of heart attacks and stroke |

| PROCEDURE | WHAT THE PROCEDURE DOES | EXAMPLES OF POSSIBLE COMPLICATIONS |
|----------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Percutaneous valvular intervention | Many people with heart failure have thick or leaky valves. In some cases, the valve can be replaced or repaired by percutaneous mitral valve repair, a type of key hole surgery. Some valves can be repaired by placing small catheters (thin, flexible tubes) in the artery at the top of the leg. A cardiologist can place a clip on the mitral valve. Some valves need to be replaced with tissue or mechanical heart valve replacements | Infections, blood clots, or infection of the inner lining of the heart (endocarditis) an abnormal rhythm in the atrium atrial fibrillation (atrial fibrillation). The risk partly depends on whether the replacement valve is mechanical or tissue. Mechanical valves need lifelong treatment with a drug called warfarin to prevent blood clots |
| Extracorporeal membrane oxygenation (ECMO) | An ECMO machine is similar to a heart-lungbypass machine used for open heart surgery. It replaces the breathing function of the heart and lungs. While potentially life-saving, ECMO has serious risks. It is used while people are seriously ill, such as waiting for an urgent heart transplant | Bleeding, blood clots, infection, kidney problems, injury to local blood vessels, stroke or loss of blood flow to hands or feet (ischaemia) |
| Left ventricular assist device (LVAD); Right ventricular assist device (RVAD); Bi-ventricular assist device (bi-VAD) | Some people with heart failure whose symptoms are severe and persistent despite medicines and other devices, may need a VAD, which is connected to the left, right or both ventricles. The VAD pumps a normal supply of blood to the body, rapidly improving heart failure symptoms | Device malfunction, blood clots in the pump, bleeding, stroke, infection, right ventricular failure, arrhythmias and abnormal blood flow through other parts of the heart (mitral regurgitation) |
| Transplantation | A healthy heart from a donor who recently died replaces a damaged or failing heart. Used in advanced heart failure that still causes severe and persistent symptoms despite medicines and other devices. Each country has clear criteria about who can have a heart transplant | The transplant may fail; the drugs used to prevent the body rejecting the organ may not work well or cause side effects including infection and some cancers (because they suppress the immune system), kidney failure, hypertension and diabetes |

Questions

that people with heart failure and their caregivers can ask their care team

1 WHY IS THIS DEVICE OR PROCEDURE THE RIGHT TREATMENT FOR ME NOW?

2 WHAT DOES THE DEVICE OR PROCEDURE DO? HOW DOES IT WORK?

3 HOW LONG WILL I TAKE TO RECOVER?

4 HOW DO I KNOW THAT DEVICE OR PROCEDURE IS WORKING?

5 WHAT ARE THE MOST COMMON COMPLICATIONS?

6 WILL THE DEVICE OR PROCEDURE AFFECT MY DAY TO DAY ACTIVITY - WORK, DRIVING OR EXERCISE?

7 WHAT SHOULD CAREGIVERS LOOK FOR?

8 CAN I DO ANYTHING TO STOP OR LIVE WITH THE COMPLICATIONS?

9 WHEN SHOULD I CONTACT MY CARE TEAM ABOUT COMPLICATIONS?

Where can I get more information?

Hospital treatment of acute heart failure

ANASTASIA IS ADMITTED TO HOSPITAL

Anastasia gains 6 kg in a couple of weeks. She notices her ankle swelling a lot and feels very breathless while resting despite breathing fast (tachypnoea). She also feels disorientated, dizzy and confused. Her husband takes her to an Accident and Emergency department. She recovers after a few days in hospital. When speaking to her care team, Anastasia says she has forgotten to take her medicines for heart failure recently and is 'fed up and bored' with her healthy lifestyle.

When should I go to hospital?

You should go to hospital if your heart failure symptoms suddenly become worse (figure 10).

FIGURE 10

An action plan for people with heart failure based on symptoms



*of more than 2-3lbs or 1kg in an 24 hours period (or 5lbs/2.5kg in a week)

What will happen if I am admitted to hospital because of heart failure?

Most patients admitted to hospital with heart failure have congestion. In other words, fluid has built up. In some cases, fluid in the respiratory systems means that the lungs do not work properly. In other cases, the blood supply to vital organs falls to dangerously low levels (cardiogenic shock).^{1,4}

Some people with heart failure have treatment to remove the excess fluid (decongestion), such as by using diuretics, which may be given through the veins. Other people with heart failure may get drugs to open the blood vessels (vasodilation). This helps clear excess fluid and improves the blood supply to vital organs.^{1,4} Other patients may need special oxygen masks that supply oxygen at high pressure and keep the airways open.

Some people with heart failure may develop cardiogenic shock. In other words, the heart suddenly cannot pump enough blood for your body's needs. Cardiogenic shock is life threatening. You may need short term support with ECMO (table 3) or a pump put into the body with a catheter to keep the blood circulating. Some people with cardiogenic shock need kidney replacement therapy. For example, dialysis.

Some people with heart failure have a higher risk of blood clots. This can increase the likelihood of heart attacks, strokes and pulmonary embolisms. Pulmonary embolisms happen when the clot lodges in the lung. These people with heart failure may be given a drug that reduces the risk of blood clots.^{1,4}

What went wrong?

There are many reasons why people with heart failure may need to go into hospital. Sometimes, people with heart failure go to hospital to have a new heart failure treatment. In other cases, the heart failure treatment is working well but an infection or another problem puts your body under stress. So, people with heart failure and their care team should talk about what may have caused the hospital stay (table 4).

You need to be honest with yourself and your care team. For example, some people struggle to take tablets or follow lifestyle advice. If this is the case, do not worry. The care team will not judge you. They know how difficult living with heart failure can be.^{1,4,37} Some cases are unavoidable, caused by other problems (figure 11). A hospital stay also offers the chance to look at underlying causes of your heart failure and review management goals.⁴ After a hospital stay with heart failure, a person with heart failure should see their care team within two weeks of leaving hospital. This allows the care team to check how well treatment is working and reduce the risk of more hospital stays. If you do not get an appointment within two weeks after the hospital stay, contact your care team.

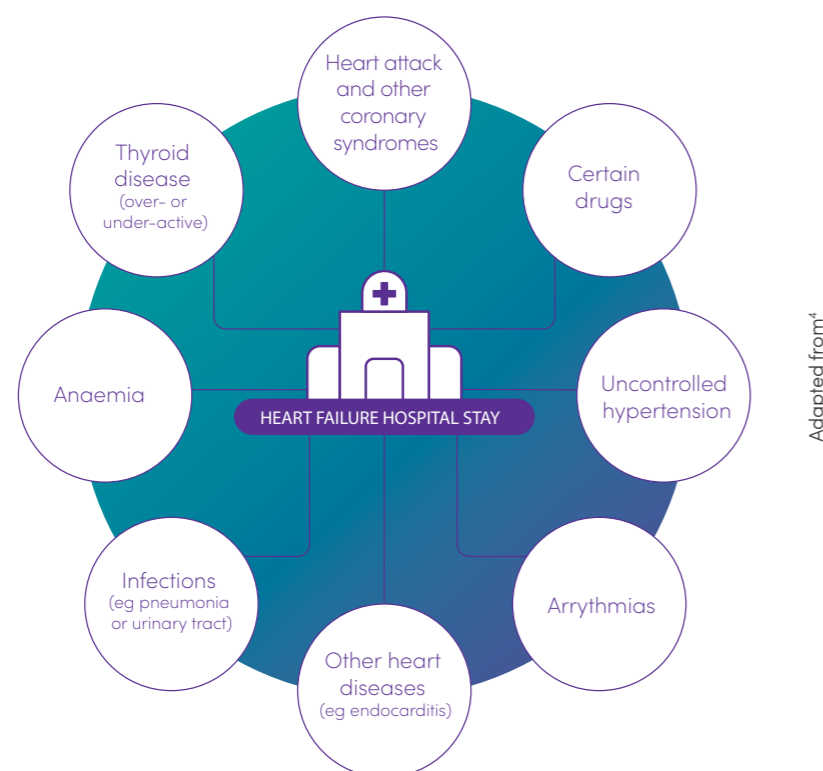
TABLE 4
Checklist of factors that may have triggered hospital treatment of heart failure



Adapted from³⁷

FIGURE 11

Examples of diseases and drugs that can trigger hospital treatment of heart failure



What is cardiac rehabilitation?

Some people with heart failure are offered cardiac rehabilitation, which is tailored to your particular condition, problems and circumstances.³⁸ However, cardiac rehabilitation services vary widely between countries. Some countries do not offer cardiac rehabilitation services. There are also different ways to deliver cardiac rehabilitation. Some people with heart failure will be offered a programme lasting for 10–12 weeks. Others will be offered a virtual (on-line) programme.

Cardiac rehabilitation usually includes a mix of exercise, education and psychological support for the anger, frustration, anxiety and depression that people with heart failure may often feel.³⁸ It also offers you the chance to meet other people with heart failure and other heart problems. They may be able to give you emotional support and help you with the practical problems of living with heart failure.³⁸ Cardiac rehabilitation also supports you to eat more healthily, quit smoking and safely increase exercise levels. Also, to talk about personal concerns with the care team, such as sexual problems.³⁸

ZIDANE CONSIDERS HIS OPTIONS

Zidane worries about the future. He struggles with his weight and his blood pressure is high despite medicines. Zidane feels anxious, admits to starting smoking again ‘occasionally’ and drinking more alcohol than he did straight after being told he had heart failure. During his cardiac rehabilitation programme, he gets counselling. Zidane starts mindfulness to help him cope with the stress of living with heart failure and other everyday stresses. He gets help to quit smoking. He decides to agree to an advance directive (a living will) with his care team and family in case his condition gets worse.

Why are my heart failure team talking about anticipatory care planning and palliative care?

→ ANTICIPATORY CARE PLANNING

Anticipatory or advanced care planning gives the people with heart failure, their caregivers and families the chance to talk about how they want to be treated, such as at the end of life. Yet, anticipatory care planning is often not done or is done poorly.³⁹

There are several reasons why, for example, people not wanting to accept a poor outlook, difficulties understanding the limitations of life-sustaining treatments and disagreements among family members. Patients and family members may not be sure about the care they want. They might prefer to focus on staying alive and feel unsure which member of the care team is responsible.³⁹ If you have any questions or are unclear, speak to your care team.

Talking about anticipatory care planning makes many people feel relieved and more in control of their care. Heart failure is often unpredictable. You may start talking about care plans long before you need to think about the end of life.³⁹

→ **WHAT IS AN ADVANCE DIRECTIVE?**

You may want to consider an advance directive, sometimes called a living will. It will reflect your personal values and your goals for future care. The advance directive also helps your care team and your family ensure they do what you would prefer if you can no longer communicate well.^{1,40}

For example, an advance directive could indicate when to deactivate devices, whether or not you want to be resuscitated or where you would like to die. An advance directive helps you safeguard your care in case you develop very advanced heart failure. You can change the advance directive at any time. Although the process can be distressing, advance care planning often improves the quality of life for people living with heart failure.^{1,40}

→ **PALLIATIVE CARE**

Palliative care aims to improve the quality of life of patients and their families who are facing challenges associated with illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well.³⁹

Palliative, sometimes called supportive care, focuses closely on the needs of the person with heart failure, their caregivers and family to make quality of life the best possible. This means thinking ahead to treat or avoid any physical, emotional, spiritual and psychological distress. The palliative care team will talk to you about your outlook (prognosis), your core values, including religious and spiritual, which treatments are reasonable to continue with and which should stop in certain circumstances.^{1,4} These talks should begin early in your illness, get more focused as your heart failure moves into the advanced stage. Talking should continue, if needed, to help caregivers and family members deal with bereavement.⁴

As mentioned, palliative care does not mean treatment ends.⁴ You may get as much, if not more, input from your care team during palliative care, which can last many months or even years. Some people prefer to call this stage supportive care. The care team may, for example, frequently check symptoms (including dyspnoea and pain) of advanced heart failure and other comorbidities. The focus is on making symptoms better, such as by using oxygen to help with breathing, treating anxiety and depression, or using painkillers and other approaches to relieve pain.¹

Where can I get more information?

Living with heart failure

What can I do to help myself?

A healthy lifestyle is important to live as full a life as possible with heart failure. Improving heart failure self-care lowers the risk that you will need hospital stays, saves lives and improves quality of life.⁴ Your care team will tailor the advice to your condition and circumstances. The following principles apply to everyone with heart failure. You should follow the lifestyle and self-care recommendations suggested by your care team. They are an important part of your treatment.

→ KEEP WATCH ON YOUR SYMPTOMS

Record your symptoms, maybe use a diary, and report them to your care team during appointments. You should contact your doctor or go to hospital if your condition gets worse (figure 10). Do not wait until your next routine appointment.

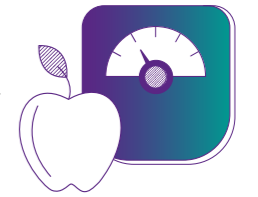
→ KEEP ACTIVE

Keeping active boosts energy and improves sleep and quality of life for people with heart failure.^{1,41} Your care team can tell you about the type and level of activity that is safe for your particular case.¹ People with heart failure should not start an exercise programme without speaking to their care team.



→ KEEP TO A HEALTHY WEIGHT AND DIET

Keeping to a healthy weight and eating a healthy balanced diet boosts your overall health and limits the strain on your heart.⁴¹ Do not eat a lot of salt, because too much sodium intake, for example, table salt, can cause fluid to build up in the body.^{1,4,41}



The care team may suggest that some people with heart failure, such as those with severe disease, limit their fluid intake. For example, 1.5 to 2 Litres a day. This can relieve symptoms and congestion. You should ask about how to adapt fluid intake to weight, heat and humidity, especially when travelling abroad, and when you are feeling or being sick.¹

→ LIMIT ALCOHOL, QUIT SMOKING AND AVOID DRUGS OF ABUSE

Limiting your alcohol intake reduces the chance of irregular heartbeats, high blood pressure, stroke, liver problems and some cancers.⁴¹ Ask your care team how much is safe for you. This will probably be less than the recommended maximum for healthy people.^{4,41}



Stop smoking, using other tobacco products and drugs of abuse such as methamphetamine, cannabis and cocaine.

This will reduce your risk of worsening heart failure and other heart and circulatory diseases.^{4,11,41} If you find this difficult, your care team can put you in touch with specialist services to help you quit.

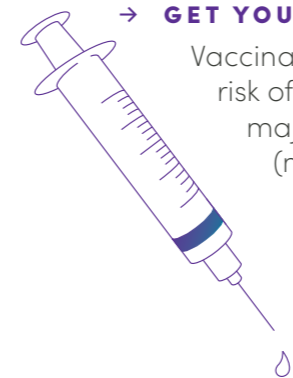
→ WEIGH YOURSELF REGULARLY

Weigh yourself regularly, even every day. Sudden weight gain may mean fluid is building up in your body.⁴¹ If you gain more than 1-1.5 kg (2-3lb) in 24 hours or 2.25 kg (5 pounds) in a week, contact your care team as soon as possible.¹⁰



→ GET YOUR JABS

Vaccination against Covid-19, flu and pneumonia reduces the risk of heart disease.^{1,4} For example, flu jabs reduce the risk of major adverse cardiovascular events such as, heart attack (myocardial infarction), stroke and even death.^{42,43}



→ **LOOK AFTER YOUR MIND**

Depression makes it harder to look after yourself. Depressed people with heart failure are more likely to need hospital visits or to die.⁴ Your care team should regularly ask you about your mental health. However, if you feel anxious, depressed or feel that you cannot cope, speak to your care team. Caregivers should also be alert for depression, anxiety and other mental health problems in people with heart failure as well as themselves.



People with heart failure and their caregivers should also strengthen their stress defences. For example, practicing mindfulness improves anxiety symptoms and quality of life in people with heart failure.⁴⁴ As a caregiver, helping yourself helps you help the person with heart failure.

People with heart failure and their caregivers should get good quality sleep. If you have trouble sleeping, speak to your care team. There are often things you can do to improve your sleep, such as adjusting the timing of your diuretics if you keep waking at night to urinate,¹ which could disturb anyone sleeping with you as well as yourself.

→ **DON'T BE ISOLATED**

Social isolation seems to increase mortality in people with heart failure.⁴ So make the effort and reach out to other people. As heart failure is common, there are likely to be many people nearby who also live with the condition. Your local heart patient group can put you and your caregiver in touch with other people with heart failure.

→ **TAKE YOUR MEDICINES AS RECOMMENDED**

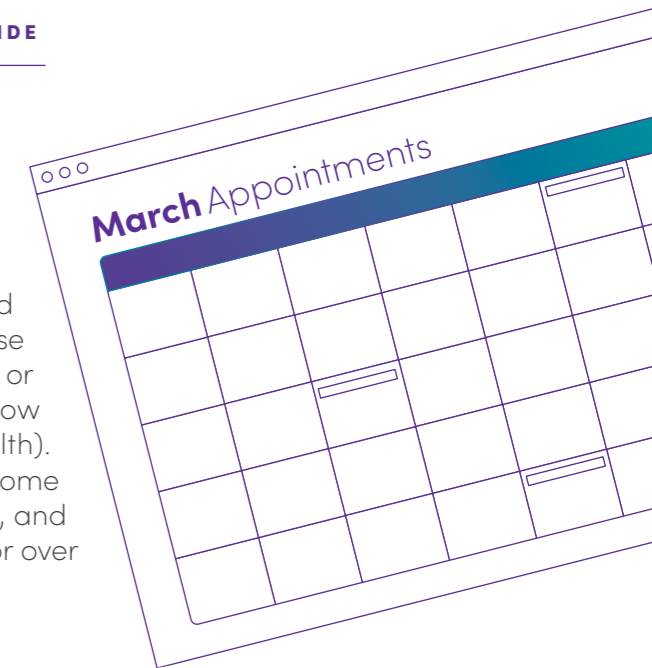
The most effective drugs will not work unless you take them as prescribed. Unfortunately, it is easy to forget. You should leave your medicine where you can see it, such as on the breakfast table. Do make sure to keep medicines out of the reach of children. You could also set an alarm as a reminder, for example, on your phone.

Your pharmacist can offer aids such as large print labels, packaging that is easier to open (if you also have arthritis for example) and boxes that allow you to divide your treatment by time and day. Your doctor may be able to suggest other ways of taking your medicine if you find it disrupts your lifestyle. For example, taking it less often.¹



→ **ATTEND YOUR APPOINTMENTS**

Follow your care team's recommendations and always attend your appointments, whether these are in a clinic, in your home, on the telephone or over the internet.¹ Some appointments are now held using video cameras (called tele health). You may also be asked to check and record some measurements, such as your blood pressure, and send these to your care team using an app or over the internet (telemonitoring).



→ **SEXUAL AND REPRODUCTIVE HEALTH**

People with heart failure can have sex. However, some medicines (such as beta-blockers), psychological distress and some symptoms can reduce desire or ability to continue or resume sexual relationships. Speak to your care team if you would like more advice.

Pregnancy with heart failure can be serious. So, women of reproductive age with heart failure should avoid unplanned pregnancy by using effective contraception. If you are thinking about a pregnancy, speak to your care team. They will be able to give you information about your particular risk in pregnancy and help you make an informed decision.

→ **WORK AND DISABILITY**

Provided you are well enough, people with heart failure can keep working for as long as they feel able. Talk to your employer as soon as you feel your heart failure is affecting your ability to do your job. You may not have to give up work. You may be able to work part-time or from home. You may be able to change or modify tasks, use special equipment or find other ways to travel to work.⁴⁵ You should find out about your employment rights and other sources of support, such as occupational therapy and disability benefits. Your local heart failure patient group should be able to help.

→ **DRIVING**

Many people with heart failure can continue to drive. You need to know the driving regulations both at home and in any country you visit.¹ Your care team will help determine if you are fit to drive and if you need to inform any authorities.

→ **TRAVELLING**

People with heart failure can travel abroad but you should discuss your travel plans with your care team. You should know where to get medical help while away from home and make sure you have the right health insurance cover. You should keep medicines in your hand luggage, carry a list of your medication and keep the contact details of your device and treatment centres.¹ It is also worth checking with the embassy of the country you are travelling to if there are any restrictions on medication. For example, certain painkillers are banned in some countries.



You may need to be particularly careful about sun exposure if you are taking amiodarone.¹ Amiodarone makes your skin highly sensitive to sunlight and you can get badly sun burnt. Cover up and wear factor 50 sun cream. You should also be especially careful to drink plenty of fluids when humidity or heat are high to avoid dehydration.¹ Levels of oxygen get less at high altitudes, which can worsen symptoms of heart failure.¹ So, always check with your care team before travelling.

→ **KNOW WHO TO CALL**

Make sure you and your caregivers know who to contact in your care team if you have questions or worries. Keep their contact details with you. Your local patient group can also help answer questions from you and your caregiver, and offer practical advice about living with heart failure.



Questions

PwHF and caregivers can ask the HF-MDT

1 HOW WILL A HEALTHY LIFESTYLE HELP WITH MANAGING MY CONDITION?

2 WHICH SYMPTOMS DO I NEED TO MONITOR?

3 WHAT LEVEL OF PHYSICAL ACTIVITY IS SAFE FOR ME, GIVEN MY CONDITION?

4 WHAT IS A SAFE LEVEL OF ALCOHOL INTAKE FOR ME, LIVING WITH HEART FAILURE?

5 WHICH VACCINES DO I NEED TO RECEIVE AND DO ANY OF THESE REQUIRE REGULAR BOOSTERS?

6 HOW REGULARLY WILL I HAVE FOLLOW-UP APPOINTMENTS WITH MY CARE TEAM?

7 HOW SHOULD I MANAGE DISTURBED SLEEP, WHICH MAY BE CAUSED BY MY DIURETICS?

8 IS MY CONDITION LIKELY TO IMPACT MY WORK? HOW SHOULD I MANAGE THIS?

9 WHAT DIET SHOULD I FOLLOW WHEN LIVING WITH HEART FAILURE?

**10 IS THERE A HEART FAILURE PATIENT COMMUNITY?
HOW I CAN CONNECT WITH ONE?**

11 HOW MAY MY CONDITION IMPACT MY SEXUAL RELATIONS?

Where can I get more information?

GLOBAL HEART HUB – Heart Failure – Your guide to your journey
<https://globalhearthub.org/hf-patient-guide/>

GLOBAL HEART HUB – International Heart Failure Patient and Caregiver Charter
<https://globalhearthub.org/hfpatientcharter/>

EUROPEAN SOCIETY OF CARDIOLOGY – 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure
www.escardio.org/Guidelines/Clinical-Practice-Guidelines/Acute-and-Chronic-Heart-Failure

EUROPEAN SOCIETY OF CARDIOLOGY – Guidelines for Patients What patients need to know
www.escardio.org/Guidelines/guidelines-for-patients

EUROPEAN SOCIETY OF CARDIOLOGY – Implantable Devices
www.heartfailurematters.org/what-your-doctor-can-do/implantable-devices/

AMERICAN COLLEGE OF CARDIOLOGY – 2022 Heart Failure Guidelines
www.acc.org/education-and-meetings/products-and-resources/features/global-cv-institute/heart-failure-guidelines

EUROPEAN HEART RHYTHM ASSOCIATION – Implantable Devices
www.myrhythmdevice.org/

HEARTLIFE FOUNDATION – Heart Failure Journey Map
<https://heartlife.ca/journey-map/>

HEARTLIFE FOUNDATION – Heartlife Toolkit
<https://heartlife.ca/toolkit/>

ITALIAN ASSOCIATION OF CARDIAC DECOMPENSATED
<https://www.associazioneaisc.org/>

ŠIRDIES NEPAKANKAMUMU SERGANČIŪJŲ ASOCIACIJA
www.sirdiesnepakankamumas.lt

Summary

BEING TOLD YOU HAVE, or may have, heart failure is frightening but heart failure treatment supports your heart to meet the needs of your body. Treatment can reduce symptoms, improve your quality of life, make you better able to do everyday activities, help you avoid hospital stays and live longer. Modern medicines, surgery and self-care mean that most people with heart failure can live full and rewarding lives. Remember that you are not alone. Your care team and local heart failure patient group are there to help you live life to the fullest possible.

We hope this guide helps make your journey a little easier and we wish you well for the future.

Our editorial advisory board

This document was developed in collaboration with an editorial advisory board made up of heart failure patients and clinicians. The Global Heart Hub wishes to acknowledge the invaluable contribution of the following members:

- **PROFESSOR JOHN AMERENA**, Director of Cardiology Research, Barwon Health
- **MARC BAINS**, Co-founder, HeartLife Foundation
- **DR JAVED BUTLER**, MD MPH MBA, Baylor Scott and White Research Institute, Dallas, TX

- **DEBORAH CHEN**, Executive Director – The Heart Foundation of Jamaica, VP InterAmerican Heart Foundation, VC Framework Convention Alliance
- **PROFESSOR AJS COATS**, Professor AJS Coats, Immediate Past-President, Heart Failure Association & Scientific Director, Heart Research Institute, Sydney, Australia
- **DR GARY DEED**, Chair, RACGP Specific Interests Diabetes, Adjunct Senior Research Fellow Monash University, HealthCare Plus Medical Centre
- **SOMANEH BOUBA DIEMÉ**, Founder, Chief Encouragement Officer, Heart of a Giant Foundation
- **DR SALVATORE DI SOMMA**, Professor of Medicine, Director Emergency Medicine, Chairman Postgraduate School of Emergency Medicine, Department of Medical-Surgery Sciences and Translational Medicine, University La Sapienza Rome, Sant'Andrea Hospital, Director Telemedicine Programme, University La Sapienza Rome-ASL Latina. Italy, President GREAT Network Italy
- **DR ANIQUE DUCHARME**, MD, MSc, Professor of Medicine, University of Montreal, University of Montreal endowed chair – Fondation Marcelle et Jean Coutu, Cal & Janine Moisan for best practices in advanced Heart Failure, Director – Heart Failure clinic, Montreal Heart Institute Research Centre; President – Canadian Heart Failure Society
- **PROFESSOR EWA A. JANKOWSKA**, MD PhD, Institute of Heart Diseases, Wroclaw Medical University, and Institute of Heart Diseases, University Hospital, Wroclaw, Poland
- **MS KRISTA JELISAVAC**, Nurse Clinician – Heart Function Clinic, Cardiosciences Outpatient Services Royal University Hospital – Saskatoon
- **NEIL JOHNSON**, Executive Director, Global Heart Hub, The International Alliance of Heart Patient Organisations
- **DR NARESH KANUMILLI**, Community Diabetes Consultant– MUF, Clinical Champion– Diabetes UK, Clinical Network Lead for Diabetes– Greater Manchester
- **DR SANDRA LAUCK**, PhD St. Paul's Hospital Professorship in Cardiovascular Nursing at UBC, Clinician Scientist at St. Paul's Hospital, Associate Professor at University of British Columbia, Vancouver Canada

- **DR ANGELA MASSOUH**, Dr Angela Massouh, Assistant Professor; Nurse Leader; and Cardiology Clinical Nurse Specialist. School of Nursing, American University of Beirut
- **PAUL PEACOCK** (MNS), CNS Heart Function, Nelson Marlborough
- **DR TAMMY PEGG**, Head of Cardiology Department, Nelson Marlborough
- **DR MARILYN PRASUN**, Clinical Nurse Specialist & Researcher, Carle BroMenn Medical Center
- **ASSOCIATE PROFESSOR DAVID SIM KHENG LENG**, National Heart Centre Singapore
- **MAGGIE SIMPSON**, Heart Failure Advanced Nurse Practitioner, NHS Greater Glasgow & Clyde Chair, Scottish Heart Failure Nurse Forum
- **AISTĚ ŠTARAITĚ**, Chair of Heart Failure Patient Council, Heart Failure Development Executive, Global Heart Hub, The International Alliance of Heart Patient Organisations

SOURCES OF FUNDING

This guide was supported by grants from industry partners including AstraZeneca, Boehringer-Ingelheim/Lilly, Medtronic, Novartis, Roche and Vifor. Our industry partners had no editorial influence or control over the content, which was written and reviewed by a fully independent editorial advisory board of the patients and clinicians listed.

References

- 1. MCDONAGH TA, METRA M, ADAMO M ET AL.** 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. *European Heart Journal* 2021;42:3599-3726
- 2. JONES NR, ROALFE AK, ADOKI I ET AL.** Survival of patients with chronic heart failure in the community: a systematic review and meta-analysis. *European Journal of Heart Failure* 2019;21:1306-1325
- 3. BORLAUG BA.** Evaluation and management of heart failure with preserved ejection fraction. *Nature Reviews Cardiology* 2020;17:559-573
- 4. HEIDENREICH PA, BOZKURT B, AGUILAR D ET AL.** 2022 AHA/ACC/HFSA Guideline for the Management of Heart Failure: A Report of the American College of Cardiology/American Heart Association Joint Committee on Clinical Practice Guidelines. *Circulation* 2022;145:e895-e1032
- 5. BOZKURT B, COATS AJS, TSUTSUI H ET AL.** Universal definition and classification of heart failure: a report of the Heart Failure Society of America, Heart Failure Association
- of the European Society of Cardiology, Japanese Heart Failure Society and Writing Committee of the Universal Definition of Heart Failure. *Journal of Cardiac Failure* 2021;27:387-413
- 6. AMERICAN SOCIETY OF HEMATOLOGY.** *Blood Basics*. Available at www.hematology.org/education/patients/blood-basics. Accessed August 2022.
- 7. JARVIS S AND SAMAN S.** Cardiac system 1: anatomy and physiology. *Nursing Times* 2018;114:
- 8. POLLOCK J AND MAKARYUS A.** Physiology, Cardiac Cycle. [Updated 2021 Oct 9]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; Available from www.ncbi.nlm.nih.gov/books/NBK459327/. Accessed August 2022.
- 9. AMERICAN HEART ASSOCIATION.** *Types of Heart Failure*. Available at www.heart.org/en/health-topics/heart-failure/what-is-heart-failure/types-of-heart-failure. Accessed August 2022.

10. AMERICAN HEART ASSOCIATION.

Symptom tracker and action plan. Available at www.heart.org/-/media/Files/Health-Topics/Heart-Failure/HF-Symptom-Tracker.pdf. Accessed August 2022.

11. KHANJI MY, JENSEN MT, KENAWYAA ET AL.

Association between recreational cannabis use and cardiac structure and function. *JACC: Cardiovascular Imaging* 2020;13:886-888

12. AMERICAN HEART ASSOCIATION.

Classes of Heart Failure. Available at www.heart.org/en/health-topics/heart-failure/what-is-heart-failure/classes-of-heart-failure. Accessed August 2022.

13. MALIK A, BRITO D, AND VAQAR S.

Congestive Heart Failure. [Updated 2022 May 22]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; Available from www.ncbi.nlm.nih.gov/books/NBK430873/. Accessed August 2022.

14. NHS.

Echocardiogram. Available at www.nhs.uk/conditions/echocardiogram/. Accessed August 2022.

15. MORTON G, MASTERS J, AND COWBURN PJ.

Multidisciplinary team approach to heart failure management. *Heart* 2018;104:1376-1382

16. ESSA H, WALKER L, MOHEE K ET AL.

Multispecialty multidisciplinary input into comorbidities along with treatment optimisation in heart failure reduces hospitalisation and clinic attendance. *Open Heart* 2022;9:e001979

17. KIDAMBI B AND SETH S.

Checklists: The road to a safer healthcare in heart failure patients. *Journal of the Practice of Cardiovascular Sciences* 2019;5:2-11

18. RITTER J, FLOWER R, HENDERSON G ET AL.,

Rang & Dale's Pharmacology. 9th ed 2020: Elsevier.

19. NICE (BNF).

Sacubitril with valsartan. Available at bnf.nice.org.uk/drugs/sacubitril-with-valsartan/. Accessed August 2022

20. MANOLIS A, DOUMAS M, FERRI C ET AL.

Erectile dysfunction and adherence to antihypertensive therapy: Focus on β -blockers. *European Journal of Internal Medicine* 2020;81:1-6

21. PACKER M, BUTLER J, ZANNAD F ET AL.

Effect of empagliflozin on worsening heart failure events in patients with heart failure and preserved ejection fraction: EMPEROR-Preserved Trial. *Circulation* 2021;144:1284-1294

22. SOLOMON SD, MCMURRAY JJV, CLAGGETT B ET AL.

Dapagliflozin in heart failure with mildly reduced or preserved ejection fraction. *New England Journal of Medicine* 2022;DOI:10.1056/NEJMoa2206286

23. VADUGANATHAN M, DOCHERTY KF, CLAGGETT BL ET AL.

SGLT-2 inhibitors in patients with heart failure: a comprehensive meta-analysis of five randomised controlled trials. *The Lancet* 2022;400:757-767

24. COWIE MR AND FISHER M.

SGLT2 inhibitors: mechanisms of cardiovascular benefit beyond glycaemic control. *Nature Reviews Cardiology* 2020;17:761-772

25. VIZZARDI E, REGAZZONI V, CARETTA G ET AL.

Mineralocorticoid receptor antagonist in heart failure: Past, present and future perspectives. *International Journal of Cardiology: Heart & Vasculature* 2014;3:6-14

26. PFEFFER MA, CLAGGETT B, ASSMANN SF ET AL.

Regional variation in patients and outcomes in the treatment of preserved cardiac function heart failure with an aldosterone antagonist (TOPCAT) trial. *Circulation* 2015;131:34-42

27. LEHNHARDT A AND KEMPER MJ.

Pathogenesis, diagnosis and management of hyperkalemia. *Pediatric Nephrology* 2011;26:377-84

28. NATIONAL KIDNEY FOUNDATION.

Best practices in managing hyperkalemia in chronic kidney disease. Available at www.kidney.org/sites/default/files/02-10-7259-DBH_Best-Practices-in-Managing-Hyperkalemia-in-CKD.pdf. Accessed August 2022.

29. LERMAN BJ, POPAT RA, ASSIMES TL ET AL.

Association of left ventricular ejection fraction and symptoms with mortality after elective noncardiac surgery among patients with heart failure. *JAMA* 2019;321:572-579

30. BRITISH HEART FOUNDATION.

Implantable Cardioverter Defibrillators (ICDs). Available at www.bhf.org.uk/information-support/publications/heart-conditions/implantable-cardioverter-defibrillators. Accessed August 2022.

31. BRITISH HEART FOUNDATION.

Living with a Pacemaker. Available at www.bhf.org.uk/information-support/publications/treatments-for-heart-conditions/pacemakers. Accessed August 2022.

32. GU D, QU J, ZHANG H ET AL.,

Revascularization for Coronary Artery Disease: Principle and Challenges, in *Coronary Artery Disease: Therapeutics and Drug Discovery*, Wang, M., Editor. 2020, Springer Singapore: Singapore. p. 75-100.

33. BRITISH HEART FOUNDATION.

How I live with Heart Valve Disease. Available at www.bhf.org.uk/information-support/publications/heart-conditions/heart-valve-disease. Accessed August 2022.

34. BRITISH HEART FOUNDATION.

Focus on: Left ventricular assist devices. Available at www.bhf.org.uk/information-support/heart-matters-magazine/medical/lvads. Accessed August 2022.

35. GREAT ORMOND STREET HOSPITAL.

Extracorporeal Membrane Oxygenation (ECMO). Available at www.gosh.nhs.uk/conditions-and-treatments/procedures-and-treatments/extracorporeal-membrane-oxygenation-ecmo/. Accessed August 2022.

36. LONG B, ROBERTSON J, KOYFMAN A ET AL.

Left ventricular assist devices and their complications: A review for emergency clinicians. *The American Journal of Emergency Medicine* 2019;37:1562-1570

37. FARMAKIS D, PARISSIS J, LEKAKIS J ET AL.

Acute heart failure: Epidemiology, risk factors, and prevention. *Revista Española de Cardiología* 2015;68:245-8

38. BRITISH HEART FOUNDATION.

Cardiac rehabilitation. Available at www.bhf.org.uk/information-support/support/practical-support/cardiac-rehabilitation. Accessed August 2022.

39. SOBANSKI PZ, ALT-EPPING B, CURROW

DC ET AL. Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement. *Cardiovascular Research* 2019;116:12-27

40. SCHICHEL M, MACARTNEY JI, WEE B ET

AL. Implementing advance care planning in heart failure: a qualitative study of primary healthcare professionals. *British Journal of General Practice* 2021;71:e550-e560

41. BRITISH HEART FOUNDATION. *Heart*

Failure. Available at www.bhf.org.uk/informationsupport/conditions/heart-failure. Accessed August 2022.

42. DIAZ-AROCUTIPA C, SAUCEDO-CHINCHAY

J, MAMAS MA ET AL. Influenza vaccine improves cardiovascular outcomes in patients with coronary artery disease: A systematic review and meta-analysis. *Travel Medicine and Infectious Disease* 2022;47:102311

43. RODRÍGUEZ-MARTÍN S, BARREIRA-

HERNÁNDEZ D, GIL M ET AL. Influenza vaccination and risk of ischemic stroke: A population-based case-control study. *Neurology* 2022;

44. RECHENBERG K, COUSIN L, AND REDWINE

L. Mindfulness, anxiety symptoms, and quality of life in heart failure. *Journal of Cardiovascular Nursing* 2020;35:358-363

45.NHS. Living with heart failure. Available at

www.nhs.uk/conditions/heart-failure/living-with/. Accessed September 2022.



FOLLOW US
WWW.GLOBALHEARTHUB.ORG



/GlobalHeartHub



Global Heart Hub



@GlobalHeartHub



@globalhearhub_org