

# MY HEART FAILURE HANDBOOK



Name: .....

Emergency contact: .....

Doctor: .....  
name, address, phone number

Heart Failure Nurse: .....  
name, address, phone number



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## About this booklet



- Heart failure is a condition that affects around 64 million people worldwide.
- It is one of the leading causes of hospitalization in people aged 75 years and over.
- Being told that you have heart failure can be very frightening. There are large healthcare teams dedicated to helping you manage your heart failure. They will help you to maintain a healthy lifestyle and emotional well-being, monitor your symptoms and manage your treatment.

**This booklet is for adults of all ages who have heart failure, and for their families and caregivers. It explains:**

- the normal function of the heart**
- what heart failure is**
- how it is diagnosed**
- the symptoms of heart failure**
- the complications that happen and why heart failure needs to be controlled and treated**
- the medicines and treatments you may be given, including implantable devices or invasive and surgical procedures that may be used**
- the importance of co-morbidities in heart failure treatment**

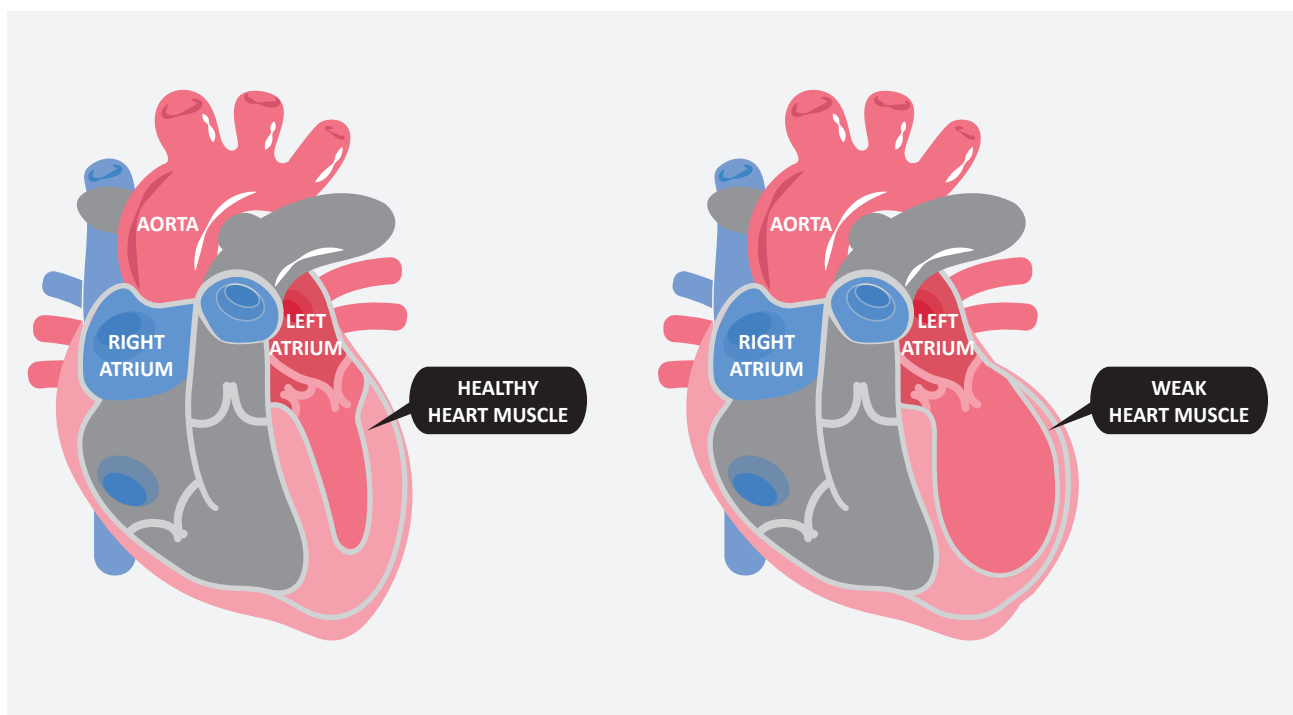
- ✓ **how you can help maintain your health and monitor and manage your heart failure during everyday life**
- ✓ **how your family and caregivers can help you**
- ✓ **how your treatment team will help you**
- ✓ **how to cope with difficult situations.**

- This booklet does not replace the advice that your doctor or heart failure nurse may give you, but it should help you to understand what they tell you.
- This booklet also contains sections for you to note down important information about your heart failure.

## About heart failure

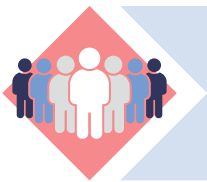
### What is heart failure?

The heart is a powerful muscular pump that delivers blood and oxygen around your body. Heart failure is a condition that affects the ability of your heart to pump blood and oxygen around your body properly. It does not mean your heart has stopped working, only that it is not working as well as it should. There are many reasons why this might happen, including damage to the heart muscle, heart weakness or stiffness, or problems with blood vessels or heart valves. Sometimes heart failure may be something that you are born with (congenital heart failure). In a healthy heart, during each heartbeat blood enters the heart then is pumped around the body to other organs. In heart failure, your heart can't pump enough blood to meet the demands of the other organs and has to start working harder and harder to keep up.

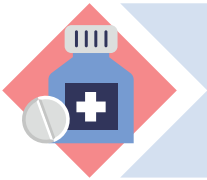


Heart failure can involve the left side of the heart, which is made up of the left atrium and left ventricle. In left-sided heart failure, the heart has trouble pumping blood, oxygenated in the lungs, around the body. This leads to fluid retention in the lungs and manifests as a feeling of shortness of breath. Right-sided heart failure involves the right side of the heart, which is made up of the right atrium and right ventricle. In right-sided heart failure, there is a problem pumping deoxygenated blood from the body to the lungs for oxygenation. This leads to fluid retention in the body and manifests as swelling around the ankles, feet or abdomen.

In the developed world, around 1–2% of adults have heart failure and around 1 in 5 will develop heart failure during their lifetime. It is most common in elderly people.



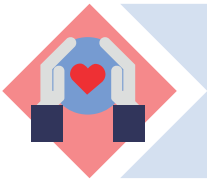
**Worldwide, more than 64 million people have heart failure**



**Medicines can reduce the symptoms associated with heart failure**



**It is important to take your medication as prescribed because doing this will greatly reduce the risk of heart failure causing a hospitalization**



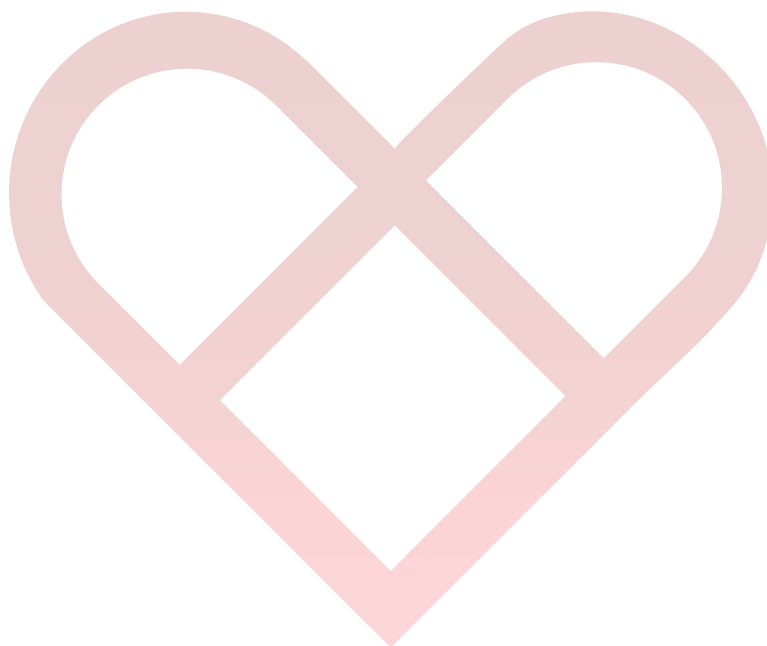
**Self-care is essential for long-term management of your heart failure**

Heart failure may be classified in several different ways by your healthcare providers. A term you may hear is **'left ventricular ejection fraction' (LVEF)**. LVEF is the amount of blood pumped out of your left ventricle with each

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heartbeat, given as a percentage. No one has 100% LVEF – between 50 and 65% is normal. There are two main types of heart failure: one type in which your heart cannot fill properly, known as **heart failure with preserved ejection fraction (HFpEF)**, and another type in which your heart cannot pump properly, known as **heart failure with reduced ejection fraction (HFrEF)**. In HFpEF, the heart walls become thicker and stiffer so that the heart doesn't fill with blood properly between heartbeats. In HFrEF, the heart walls become thinner and weaker so that the heart can't pump enough blood around the body when it beats. There is a third type of heart failure called **heart failure with mid-range ejection fraction (HFmrEF)**, which is in between the two.

Heart failure can affect many aspects of your life, including your ability to work and socialize as you usually would. It can also lead to long and recurring stays in hospital. Heart failure is a progressive condition that can get worse with time. However, medication and medical devices like pacemakers can slow down this progression and improve your symptoms so that you are able to function well in your day-to-day life.





## What causes heart failure?

There are **many causes of heart failure**. For most people, their heart failure is caused by a combination of factors. The most common causes are:

- **high blood pressure**
- **heart attack**
- **problems with your heart muscle (cardiomyopathy) in the past.**

Other health conditions that can cause heart failure include:

- **coronary artery disease**
- **congenital heart defects**
- **inflammation of the heart**
- **diabetes**
- **some infections.**

Certain lifestyle factors also increase your risk of developing heart failure, including:

- **smoking**
- **stress**
- **some medications**
- **drinking too much alcohol**
- **not getting enough exercise**
- **eating a diet with lots of salt or fat.**



## How does my doctor know if I have heart failure?

The typical **symptoms of heart failure** are:

- **breathlessness after activity or during rest**
- **coughing fits or breathlessness at night (paroxysmal nocturnal dyspnea)**
- **exacerbation of breathlessness when lying down and relief after sitting**
- **feeling tired most of the time**
- **reduced exercise tolerance or inability to exercise**
- **shortness of breath when bending down, tying shoelaces, putting on socks**
- **swollen legs, ankles, feet or abdomen.**



Less common symptoms of heart failure that may occur include:

- **dizziness or fainting**
- **cough that gets worse at night**
- **fast or irregular heartbeat**
- **wheezing**
- **bloating**
- **feeling full after eating**
- **loss of appetite**
- **rapid changes in weight**
- **confusion or memory problems**
- **depression.**

You may also have difficulty sleeping because of a persistent cough when you lie down or have a frequent need to empty your bladder.

Many of the symptoms of heart failure can also be caused by other medical conditions, so tests are usually used to confirm a diagnosis. Some of the tests you may have include:

- **a natriuretic peptide blood test** to measure your levels of hormones related to heart failure, such as N-terminal-pro-brain natriuretic peptide (NT-proBNP)
- **an electrocardiogram (ECG)** to check the electrical activity of your heart
- **an echocardiogram (a type of ultrasound scan, sometimes called an 'echo')** to produce an image of your heart and look at how well it is beating
- **other tests** like chest X-rays, cardiac magnetic resonance scans, cardiac computer tomography scans, coronary angiography and genetic testing that may be useful in diagnosing heart failure.

If symptoms appear or get much worse at rest, you may have **decompensated heart failure**. **This is a medical emergency, and you should call an ambulance or visit a hospital emergency department.**

If symptoms have been going on for some time and are not getting worse rapidly, it is called **stable heart failure**.

## How bad is my heart failure?

Heart failure is divided into four symptom classes using the New York Heart Association (NYHA) classification (Table 1).

Table 1. New York Heart Association (NYHA) functional classification.

PATIENTS SYMPTOMS	
class I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitations (a feeling that your heart has skipped or added a beat), or shortness of breath.
class II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitations or shortness of breath.
class III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitations or shortness of breath.
class IV	Unable to carry out any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

Heart failure can also be classified as being **'stable'** or **'acute'**. If you have stable heart failure you may not notice any problems because your heart is still working well enough or your body is adjusting well enough that you can manage symptoms easily. In acute/decompensated heart failure, your body cannot compensate for the reduction in heart function, meaning that you have symptoms that require therapeutic intervention.

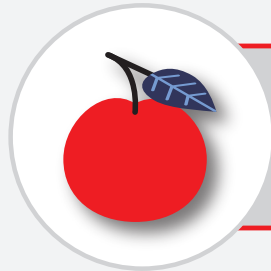
## Can heart failure be cured?

Heart failure is a treatable condition. If your heart failure was caused by high blood pressure or heart valve problems, heart function may return to normal if managed well or treated with surgery. However, if your heart failure was caused by a heart attack (in which your heart muscle became damaged) you can only control and manage symptoms. Remember, with implementation of appropriate management and treatment you will be able to achieve improvements in heart failure symptoms, functional and exercise capacity, and your quality of life.



## How is heart failure treated?

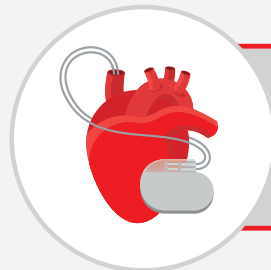
Treatment of heart failure is based on the following aspects:



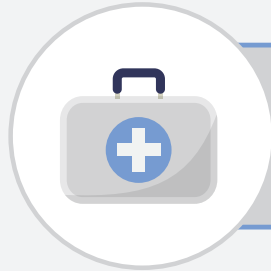
Lifestyle changes



Drugs



Implantable devices



Treatment of co-morbidities

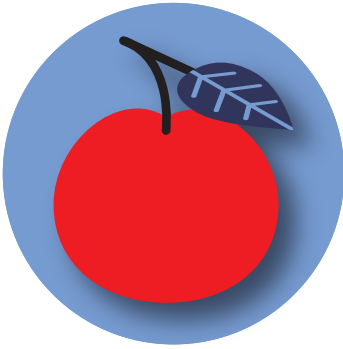


Invasive and surgical procedures

## Lifestyle changes

### Your dietary choices

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What you eat and how you eat undoubtedly affects the condition of your heart. Following a healthy diet improves your mood and helps you to manage the symptoms of heart failure. A ‘heart-healthy’ diet is rich in fruits and vegetables, whole grains, legumes, skinless poultry meat, fish and low-fat dairy products. In your dietary choices remember to do the following.

#### Practical advices:

- **Eat four or five meals a day in small portions.**
- **Eat regularly**, preferably at regular times throughout the day.
- **Keep fluid intake between 1.5–2 L** (include coffee, tea and soups in your fluid intake). You will always need to reduce your fluid intake if your symptoms worsen. You can increase fluid intake in hot and humid weather. It is best to ask your doctor or heart failure nurse how much fluid you can consume a day.
- **Reduce salt** (sodium) in your diet. Excessive salt intake promotes a build-up of water in the body, which leads to oedema and worsens heart failure symptoms. Keep your total salt intake to less than 5 g (one teaspoon) a day by not eating processed foods and not adding salt to food during or after cooking. Remove the saltshaker from the table or do without it altogether. Use herbs to enhance the flavour of prepared foods. Avoid hidden sources of salt. Most of us take in more salt than we need. Learn to read the nutrition label. This can help you choose foods with less salt. Always look for products in the shop that say ‘low-salt’,

'low-sodium' or 'no added salt' on the label. Products that contain high amounts of salt include: powdered soups, canned meat and fish, ham, sausage, salted nuts, salted butter and margarine, ready-made dishes, salty snacks, cheese, salad dressings and fast food.

- **Ask your doctor or heart failure nurse about your potassium intake** because both potassium excess and potassium deficiency are unfavourable. You must be aware that diuretics cause potassium loss, while other medications can cause potassium to build up in your body. Impaired kidney function can also cause potassium to build up in your body. Foods rich in potassium include apricots, bananas, strawberries, peaches, watermelon, oranges, tomatoes, potatoes, spinach and peas.
- **Limit your intake of saturated fats.** These are usually found in animal products, particularly meat and full-fat dairy products. They are also found in coconut oil and palm oil.
- **Limit your intake of trans fats,** which are often found in hard margarines, vegetable starches, packaged foods, commercial baked goods, and prepared foods such as French fries.
- **Limit your intake of sugars** that are added to foods during processing and preparation, or that are served at the table. Examples include sucrose, glucose, fructose, maltose, dextrose, corn syrups, high-fructose corn syrup, concentrated fruit juice and honey.
- **You should not drink more than two units of alcohol a day if you are a man or more than one unit a day if you are a woman.** Avoid binge drinking. If your heart failure was thought to be caused by alcohol or your symptoms become worse when you drink alcohol, you should not drink it at all.
- **Minimize your intake of caffeinated drinks,** such as coffee, black tea and caffeinated sodas. Caffeine is a stimulant that can put more stress on your heart.



➔ **Get advice from a dietician** who will help you to plan a healthy and nutritionally complete diet.

## Your healthy weight (sarcopenia, frailty syndrome, cachexia)

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Try to maintain a healthy weight. If you are overweight or obese, talk to your doctor or heart failure nurse about how you can safely work on reducing your weight. Remember that a healthy, well-balanced diet and regular physical activity are important for weight loss. However, if you have experienced unintentional weight loss in the past 6–12 months (unrelated to fluid restriction or diuretics), you should always report this to your doctor or heart failure nurse. Weight loss may be associated with loss of muscle mass (sarcopenia), which leads to weakened muscle strength and decreased mobility. It may also indicate the presence of frailty syndrome, which means a decrease in your body’s physiological reserves. It may also be associated with the development of cardiac cachexia, which is usually characteristic in advanced heart failure. Identifying sarcopenia, frailty syndrome and cachexia is important for early intervention to optimize your nutritional or functional status.

**Sarcopenia** – the loss of muscle mass and function, which is often manifested by decreased muscle strength and mobility. Heart failure patients with sarcopenia require hospitalizations more often than those without sarcopenia.

**Frailty syndrome** – the decline in reserve and function across multiple physiologic systems resulting in physical, cognitive and social impairments that increase patient’s vulnerability to stressors and predispose them to morbidity. Frailty syndrome is an independent predictor of early disability, long-term mortality and readmission to hospital.

**Cachexia** – unintentional, oedema-free weight loss of more than 5–7.5% of body weight over 6–12 months or BMI less than 20 kg/m<sup>2</sup> with high C-reactive protein and low albumin levels. Cachexia may be associated with increased symptoms, decreased exercise capacity and more frequent hospitalizations.

## Smoking

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It is very important to stop any form of smoking (including cigarettes, e-cigarettes and waterpipes). Smoking may cause irreversible damage to your heart. You will be unable to obtain a heart transplant, if needed, if you smoke. If you feel you need more help to quit smoking, talk to your doctor. There are medicines that can help you to quit smoking. Find out if one of these may be right for you. Nicotine replacement medications are available in several forms, including chewing gum, patches, inhalers and prescription pills. These must be always prescribed by a doctor.

## Exercise

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Heart failure is not a contraindication for physical activity. Don't be afraid to take up physical activity. Regular physical training is a form of treatment and contributes to many beneficial changes in the cardiovascular system. People with heart failure need regular, moderate physical activity to help strengthen their heart. Exercise can help to reduce your symptoms, improve your mood and manage your weight. The extent and type of activity will always depend on the health of your heart. A physiotherapist can help you to choose the right form of activity

for you. Walking, swimming or cycling are aerobic exercises that may be recommended by physiotherapists for heart failure. The most important thing is that the physical activity is tailored to your individual needs, consistent with your interests.

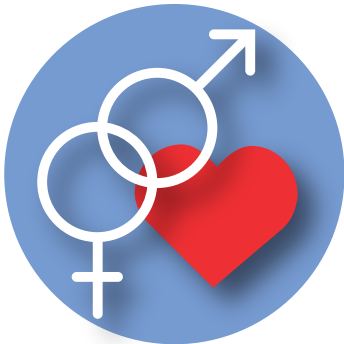
Ask your heart failure nurse which exercises may work best for you. Make a list of weekly physical activities and how many times you need to do them. Exercise daily and try to stay physically active throughout the day. If possible, exercise regularly at a level that causes mild or moderate breathlessness.

### Practical advice:

- Work with your therapeutic team to determine how much activity is safe for you. The best solution is to consult a physiotherapist to adjust your exercise sessions to your exercise tolerance.
- Aerobic exercise, such as walking, swimming or cycling, is effective and safe for patients with stable heart failure so find time each day for this form of physical activity.
- Record your activity in a heart failure journal.
- If your health is stable, it is recommended to do aerobic exercise 3–5 times a week for 20–60 minutes each time.
- Doing upper and lower body strength exercises 2–3 times a week can help to strengthen your muscles. Ask your physiotherapist what strength exercises you can do.
- Monitor your heart rate and blood pressure not only at rest but also during exercise. If your blood pressure is too low or too high, or if you notice symptoms of worsening heart failure such as shortness of breath at rest or during minimal exertion, do not undertake physical activity. Instead, you should contact your doctor or heart failure nurse. You will be able to return to physical activity later, but only after your heart failure symptoms have stabilized.

## Sexual activity

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If your heart failure is stable, it is OK to have sex, providing sexual activity does not worsen your symptoms. Having sex can improve your mental health and help you to stay physically and emotionally close to your partner.

### Practical advice

- Wait and choose a time when you are rested, relaxed and free of stressful feelings. It's OK if you're not ready to have sex right away.
- Avoid engaging in sexual activity after eating a heavy meal.
- Choose a familiar, quiet place.
- If you begin to feel uncomfortable or tired during sexual activity, stop and rest for a short time.
- If erectile dysfunction is a problem, ask your heart failure nurse for advice on possible treatment.

## Sleep and mental health

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Your heart failure symptoms may affect your sleep. Try to relax before sleep and avoid watching TV or using your mobile phone or computer. Avoid caffeine late in the day. Make sure you have enough pillows to support you in a comfortable position. Tell your heart failure nurse if you have shortness of breath, have a bad cough when you lie down, wake up frequently

during the night or think you might have sleep apnoea (a condition in which your breathing temporarily stops during sleep), because they may be able to recommend treatment.

Stress and anxiety about your heart failure may affect your sleep, and being unable to sleep may also affect your mood. It can help to discuss your thoughts and feelings with family and friends. You might consider attending a heart failure support group, where you can talk to people going through the same thing as you. You should remember that it is normal to feel sad or depressed when you are diagnosed with a chronic illness. If these feelings accompany you for a long time or interfere with your normal activities, you may have depression.

If you've been feeling depressed or hopeless in the past few weeks, talk to your doctor or heart failure nurse right away. Don't be afraid to talk about your feelings about heart failure. Depression is a common condition that can be treated. If necessary, you may be referred to a clinical psychologist for help.

## Travel and leisure

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Air travel is usually safe for patients with stable heart failure who have had no recent changes in symptoms or medications. However, you may be more likely than usual to develop clots on long-distance flights. Wear compression socks or consider train travel. Be sure to take out travel insurance and check airline information on health conditions. Pack your medication in your hand luggage and the same amount in your checked-in luggage, if possible. If you have severe, worsening symptoms, it is not advisable to travel by air.

Travelling may bring changes in diet and climate. If you know you will be drinking more alcohol and eating more salty foods, talk to your care provider about how you may adjust your diuretic medication.

If the climate is hot or humid, you may sweat more, which may lead to dehydration, particularly if you also have gastro-intestinal upset. In this case, increase intake of fluids and talk to your care provider about temporarily reducing your diuretics. Be aware that some medications may cause you to have adverse reactions to sun exposure, so check with your heart failure nurse.

## Driving

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You may be able to drive with your condition, but talk to your heart failure nurse about your heart failure symptoms and confidence in driving. If travelling, check international regulations on driving with heart failure/with an ICD (implantable cardioverter defibrillator).

You should still be able to drive as part of your job or drive heavy vehicles, unless you have NYHA class III or IV heart failure. If you have NYHA class IV heart failure, you will not be able to drive at all.

## Immunization and preventing infections

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Influenza, pneumonia and COVID-19 infection pose a greater risk to people with heart failure than to healthy people. Ask your doctor about the annual flu vaccine, the one-time pneumococcal vaccine and the COVID-19 vaccine. These vaccines are generally safe and rarely cause serious reactions. It is much riskier not to have them.

### Practical advice

- If possible, avoid anyone with a cold or flu symptoms or COVID-19.
- Stay away from crowds during peak flu season (usually October to March).
- Follow the COVID-19 sanitation regime. Maintain an appropriate social distance. Wear protective masks.
- Wash your hands well and often, especially after using the toilet and before eating, and ask caregivers to do the same.
- Keep your hands away from your face.

## Drugs: what heart failure medications are you taking?

Heart failure is a treatable condition. There are many medications available that can control your symptoms and help strengthen your heart.

### The main goals of heart failure treatment are to:

- » alleviate symptoms
- » reduce the risk of hospitalization
- » improve quality of life
- » reduce mortality.

Remember, your medications will not do their job if you do not take them as directed. You should take your medication as prescribed by your doctor, in the correct dose and at the correct time. Never stop taking your medications without first consulting your doctor or heart failure nurse.

Make sure that you are aware of the common side effects of your medications. The most common side effects of heart failure medications are listed in the table below (Table 2). You should contact your doctor or heart failure

nurse if you experience any side effects of your medication. Sometimes you may need to modify your pharmacotherapy, such as by changing the dose of a medication, replacing one medication with another medication, or eliminating a medication.

Table 2. Possible side effects of heart failure medications.

Medication	Possible side effects				
	Hypotonia	Bradycardia	Dizziness	Renal impairment	Other
Angiotensin-converting enzyme inhibitors (ACEIs) <i>Captopril, enalapril, lisinopril, ramipril, trandolapril</i>	Yes	-	Yes	Yes	Dry cough, skin allergies
Angiotensin receptor blockers (ARBs) <i>Candesartan, losartan, valsartan</i>	Yes	-	Yes	Yes	-
Angiotensin receptor neprilysin inhibitors (ARNIs) <i>Sacubitril/valsartan</i>	Yes	-	Yes	Yes	-
Beta-blockers <i>Bisoprolol, carvedilol, metoprolol succinate CR/XL, nebivolol</i>	Yes	Yes	Yes	-	Headache, cold hands and feet
Mineralocorticoid receptor antagonists (MRAs) <i>Eplerenone, spironolactone</i>	-	-	-	Yes	Spironolactone may cause gynecomastia
Sodium-glucose co-transporter-2 inhibitors (SGLT2Is) <i>Dapagliflozin, empagliflozin, canagliflozin</i>	-	-	Yes	-	Glucose in urine, urinary tract infections
Diuretics <i>Furosemide, bumetanide, torasemide, hydrochlorothiazide, metolazone, indapamide</i>	Yes	-	Yes	Yes	Thirst, loss of appetite
If-channel inhibitors <i>Ivabradine</i>	Yes	Yes	Yes	Yes	Luminous phenomena as flashing lights
Digitalis glycosides <i>Digoxin</i>	-	Yes	Yes	-	Nausea or vomiting, loss of appetite, vision changes (such as blurred or yellow/green vision)
Hydralazine and isosorbide dinitrate	Yes	-	Yes	-	Nausea or vomiting



### Practical advice

- Remember, medications are an important part of treatment, so be sure to bring a list of your medications to each doctor's appointment. It is important that you know what your medicines are for and how to take them safely!
- Always tell your doctor about all medicines you take, including over-the-counter medicines, supplements or herbal medicines. Also, inform your doctor or heart failure nurse about any medications you have stopped taking.
- Some of your medications will lower your heart rate and blood pressure so you should monitor and record them every day.
- If your heart rate or blood pressure are not accurate, contact your doctor or heart failure nurse.
- Some of your medications may impair your kidney function or affect the potassium levels in your blood, so your doctor will regularly order blood tests for this.
- Diuretics will increase your urine output so be sure to monitor and note your weight daily. They may cause a loss of electrolytes (potassium, sodium, magnesium). Your doctor may sometimes prescribe supplementation of these electrolytes.
- You should know that SGLT2Is (sodium-glucose co-transporter-2 inhibitors) cause glucose excretion in the urine. SGLT2Is may cause urinary tract infections, so you should take care of your intimate hygiene. Tell your doctor or heart failure nurse if you have any discomfort or burning sensation when you urinate.
- You should avoid using non-steroidal anti-inflammatory drugs, such as ibuprofen, ketoprofen and diclofenac, because they may interact with your medication. If you have pain, take paracetamol or ask your doctor or heart failure nurse about appropriate medicine.

- If you are taking anticoagulants (warfarin, acenocoumarol, dabigatran, rivaroxaban or apixaban) and experience bleeding, vomiting or coughing blood, notice blood in your stool (black stool), or have a headache or dizziness, contact your doctor or heart failure nurse straight away.
- If you are taking warfarin or acenocoumarol, remember to dose according to your INR (International Normalized Ratio) measurement. This measurement is used to monitor blood clotting and you will need to check it regularly. Ask your doctor what INR you should maintain during your anticoagulation treatment. The usual range is 2.0–3.0. Too low an INR means that too low a dose of anticoagulant was used and the treatment is not effective. Exceeding your target INR indicates an overdose of anticoagulant drug and a risk of serious bleeding. Vitamin K affects how blood clots form and may affect INR results. Remember that this vitamin is found in many foods, including leafy green vegetables, parsley, asparagus, broccoli and Brussels sprouts. You should limit these foods in your diet.
- If you are taking statins, always inform your doctor or heart failure nurse if you experience muscle pain, liver damage, memory loss, nausea, gassiness diarrhoea and/or constipation, or a rash while taking these medications.
- Lay out your medications in a weekly organizer. This is a box with spaces for the medicines you will take on each day of the week. They also usually have a time-of-day breakdown for morning, afternoon and evening.

## Implantable devices

Some patients with heart failure may need additional treatments such as implantable devices to prevent serious heart problems. Patients with heart failure may have the following devices implanted.

**Standard pacemaker** – implanted to prevent heart from slowing down.

**CRT**, *cardiac resynchronization therapy* also known as ‘biventricular pacing’ – used to make the heart chambers contract simultaneously.

**ICD**, *implantable cardioverter-defibrillator* needed to prevent sudden cardiac death. An ICD detects and terminates life-threatening heart rhythm disturbances.

**CRT-D** – a device that combines CRT and ICD functions.

**VAD**, *ventricular assist device* also known as a ‘mechanical circulatory support device’ – a mechanical pump that helps to pump blood from the ventricles to the rest of the body. VADs can be placed in the left, right or both chambers of the heart. A VAD is most commonly placed in the left ventricle, where it is known as a LVAD or a left-ventricular mechanical circulatory support. For a heart that is unable to pump blood on its own, mechanical circulatory support may be an option. Some people use this device permanently, but it is most often used as a ‘bridge to recovery’ or as a short-term aid when surgery or a heart transplant is needed.

## Invasive and surgical procedures

Sometimes heart failure needs to be treated with surgery, especially if it is severe enough that it cannot be treated with medication and lifestyle changes. There are several invasive procedures that may be considered as follows.

**PCI**, *percutaneous coronary intervention* – aims to unclog the coronary arteries.

**Ablation** – the destruction of a group of cells in the heart that are responsible for causing arrhythmias.

**Heart valve procedures** (surgical replacement or percutaneous implantation) – if the failure is caused by a defective or diseased heart valve.

**CABG**, *coronary artery bypass grafting* – a blood vessel, usually taken from a lower limb or the chest, is attached to allow blood flow, bypassing the narrowed area.

**Heart transplantation** – if none of the available treatments is the right solution for heart failure, a heart transplant may be necessary.


## Treatment of co-morbidities

Most patients with heart failure have co-morbidities. The identification, control and appropriate treatment of cardiovascular and/or non-cardiovascular co-morbidities are critical in the management of heart failure. Poor control of co-morbidities may exacerbate heart failure symptoms and increase your risk of hospitalization.

If you have any of the conditions listed in the table below (Table 3), remember that you should strictly follow the therapeutic recommendations in order to control your co-morbidities. Talk to your doctor or heart failure nurse about how your co-morbidities affect your heart and what you should do to control them.

Table 3. Common co-morbidities in heart failure patients.

Cardiovascular co-morbidities	Non-cardiovascular co-morbidities
Angina Coronary artery disease Stroke or transient ischemic attack Hypertension Valvular heart disease Atrial fibrillation	Diabetes Chronic kidney disease Asthma Chronic obstructive pulmonary disease Sleep-disordered breathing Cancer Iron deficiency and anaemia Hyperlipidaemia Hypokalaemia and hyperkalaemia Obesity Sarcopenia, frailty syndrome, cachexia Erectile dysfunction Gout Arthritis Depression Cognitive disorders



## Your role: heart failure self-care

### What is self-care?

Self-care is a number of steps you can take at home to improve your health and manage your symptoms. Self-care will improve your quality of life and help to prevent hospitalization. There are three aspects of self-care for heart failure: maintenance, monitoring and management (Figure 1). Maintenance includes things you can do to maintain your physical and emotional health. Monitoring involves watching for changes in your symptoms. Management is the steps you can take in response to any new symptoms that you have, such as increasing your medications.



## Maintenance

**Those behaviours used by persons with a chronic illness to maintain physical and emotional stability.**

- Restrict sodium when needed
- Restrict fluids when needed
- Limit/refrain from alcohol
- When nutritionally deficient, consider food supplements
- Get vaccinated
- Be physically active
- Take medication as prescribed
- Recognize mood disturbances
- Maintain healthy sleep
- Don't smoke or take drugs
- Adapt travel and leisure if needed

## Monitoring

**The process of observing oneself for changes in signs and symptoms.**

- Shortness of breath/dyspnea
- Oedema
- Chest pain
- Decreased appetite/nausea
- Fatigue, tiredness
- Cough, wheezing
- Thirst
- Palpitations
- Dizziness
- Activity level
- Body mass
- Pulse, blood pressure
- Need for support
- Nutritional status
- Fever, diarrhoea, vomiting
- Feelings of depression, low mood

## Management

**Response to signs and symptoms when they occur.**

- Adjust diuretics
- Adjust other medications
- Adapt activity level
- Adap diet
- Ask for support
- Consult a healthcare professional

Figure 1. Self-care maintenance, monitoring and management of heart failure. Adapted from Jaarsma et al. 2020.

## How do I monitor my symptoms?

It is important to be able to recognize the symptoms of heart failure. If you notice any symptoms of heart failure, or a sudden increase in your current symptoms, contact your doctor or heart failure nurse. To identify early increases in heart failure symptoms, remember to check and regularly record your heart rate, blood pressure, body weight and fluid intake.

### Heart rate and blood pressure monitoring

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You should check your pulse and blood pressure every morning after taking your medication and record the measurements in your heart failure diary. Do not measure your blood pressure after exercising, smoking or consuming a heavy meal, coffee or alcohol. Always check with your doctor to determine the best values for your heart rate and blood pressure. Remember that a heart rate over 100 beats/minute (bpm)

is a sign of worsening heart failure, while a low heart rate of less than 50 bpm may be bad for your heart. An irregular heartbeat may also be indicative of worsening heart failure symptoms. Remember, all sudden changes in vital signs are a reason to consult your doctor or heart failure nurse.

### Body mass monitoring

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When you have heart failure, you need to know how much you currently weigh, what weight you should maintain, and, most importantly, monitor your weight daily and record your measurements. Sudden changes in body mass can be a sign of worsening heart failure symptoms. A weight gain of 2 kg in 2 days may be the first sign of fluid build-up in your body.





Weigh yourself every day, preferably every morning after urinating and before eating and drinking. Always wear the same type of clothing and weigh yourself without shoes. This will help you see the actual changes in your weight from day to day. Keep a record of your weight in your heart failure diary. If you start to gain weight, tell your doctor or heart failure nurse right away. Even if you feel well, your doctor or heart

failure nurse needs to know about changes in your weight so that he or she can adjust your diuretics if necessary. This may help you avoid hospitalization for worsening heart failure.

### **Fluid intake monitoring**

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Diuretics are often used in heart failure to get rid of excess water and sodium from the body, thereby reducing the strain on the heart. Your doctor or heart failure nurse will probably advise you to limit your fluid intake to about 1.5–2 litres/day. Ask them how much fluid you can drink each day.

Keep in mind that you will often feel thirsty, although your body will not need more fluids. If you are thirsty and have been advised to limit your fluid intake, try sucking on sugar-free hard sweets. Note that the water in some foods counts as fluid. To keep track of your fluid intake, pay attention to foods that contain a lot of fluid such as yogurt, ice cream, fruits and vegetables.

## How can I manage heart failure at home?

You can help monitor your condition at home by staying alert to any changes in your health, symptoms or side effects. Noticing changes in symptoms early may reduce your risk of needing to be admitted to hospital. You can help manage your condition at home by responding appropriately to any changes you notice in your symptoms. To help relieve worsening symptoms at home, you can adjust your diuretic dose as advised by your healthcare provider and temporarily decrease your activity level and salt and fluid intake. These steps may be enough to relieve your symptoms; however, if you are not comfortable making these decisions, or are in any doubt, please contact your healthcare provider. Your healthcare provider will also be able to give you further advice on what you can do at home to help relieve your individual symptoms. Your symptoms may be side effects of your medication. You can use the section in this booklet, 'I'm in control of my heart failure', to record your symptoms.

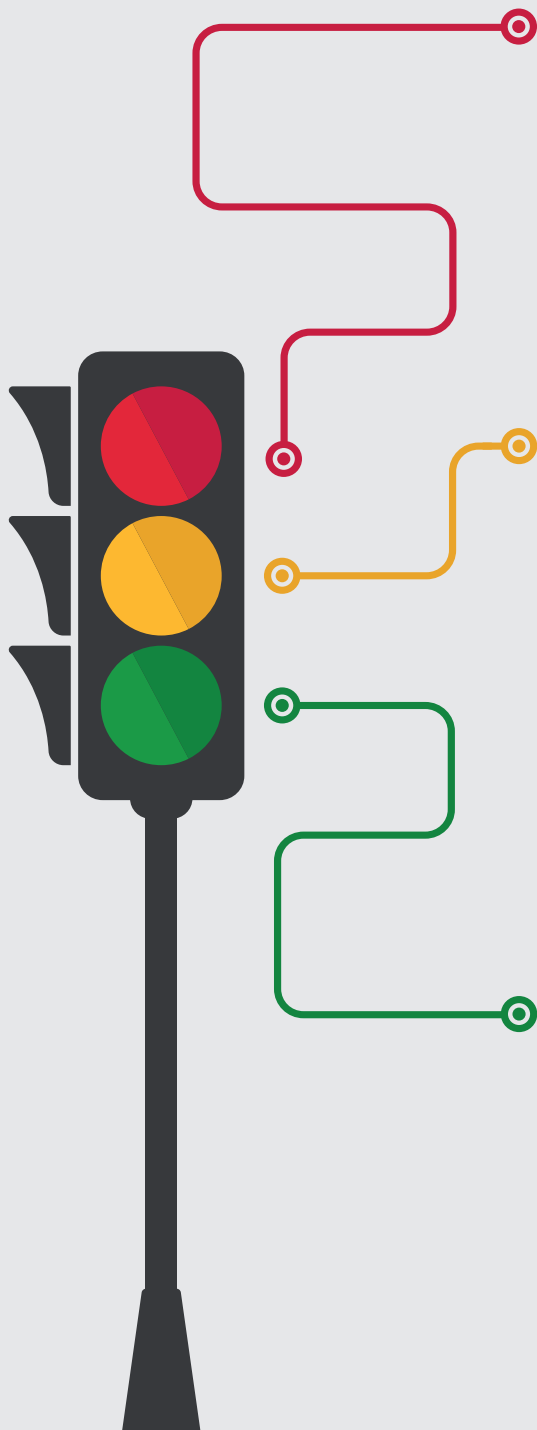
An easy guide to help you to monitor and manage changes in your symptoms is shown in Figure 2.

There are three zones to help you to respond appropriately to the symptoms you are experiencing:

- 🔊 a green **'Safety Zone'**, in which there are no changes in your symptoms and you can continue to monitor your health as normal;
- 🔊 an amber **'Warning Zone'**, in which your symptoms have worsened, and you should contact your heart failure nurse for advice and take steps to relieve your symptoms at home;
- 🔊 a red **'Alert Zone'**, in which you should contact your heart failure nurse or go to the emergency department immediately.

**Tips for you and your family.**

**When you can feel safe and when you should react immediately**



If you have persistent dry, wheezing cough, shortness of breath at rest, increased discomfort and swelling in your lower body, sudden weight gain (2-3 pounds in the last 24 hours), dizziness, feeling confused, feeling sad or having depressive symptoms, loss of appetite, having increasing trouble sleeping, and not being able to lie flat, then you need to see your doctor immediately or call the emergency number;

If you have a dry, wheezing cough, have trouble breathing during physical activity, notice increased swelling in the lower extremities, feet, ankles, sudden weight gain (2-3 kg in the last 24 hours), abdominal enlargement, trouble sleeping, then watch these symptoms vigilantly and be extra careful. Keep your head up, as you may just need a change in medication dosage. Contact your doctor or heart failure nurse;

If your breathing is normal, you feel good during physical activity, you don't notice any swelling, your weight is normal, you don't have any chest pain or discomfort, that's GREAT, continue to monitor yourself properly: check your heart rate, blood pressure, and weight daily, take your medications as directed, eat a low-sodium diet, and keep your follow-up appointments;

Figure 2. Guidance to help you decide how to respond to your heart failure symptoms

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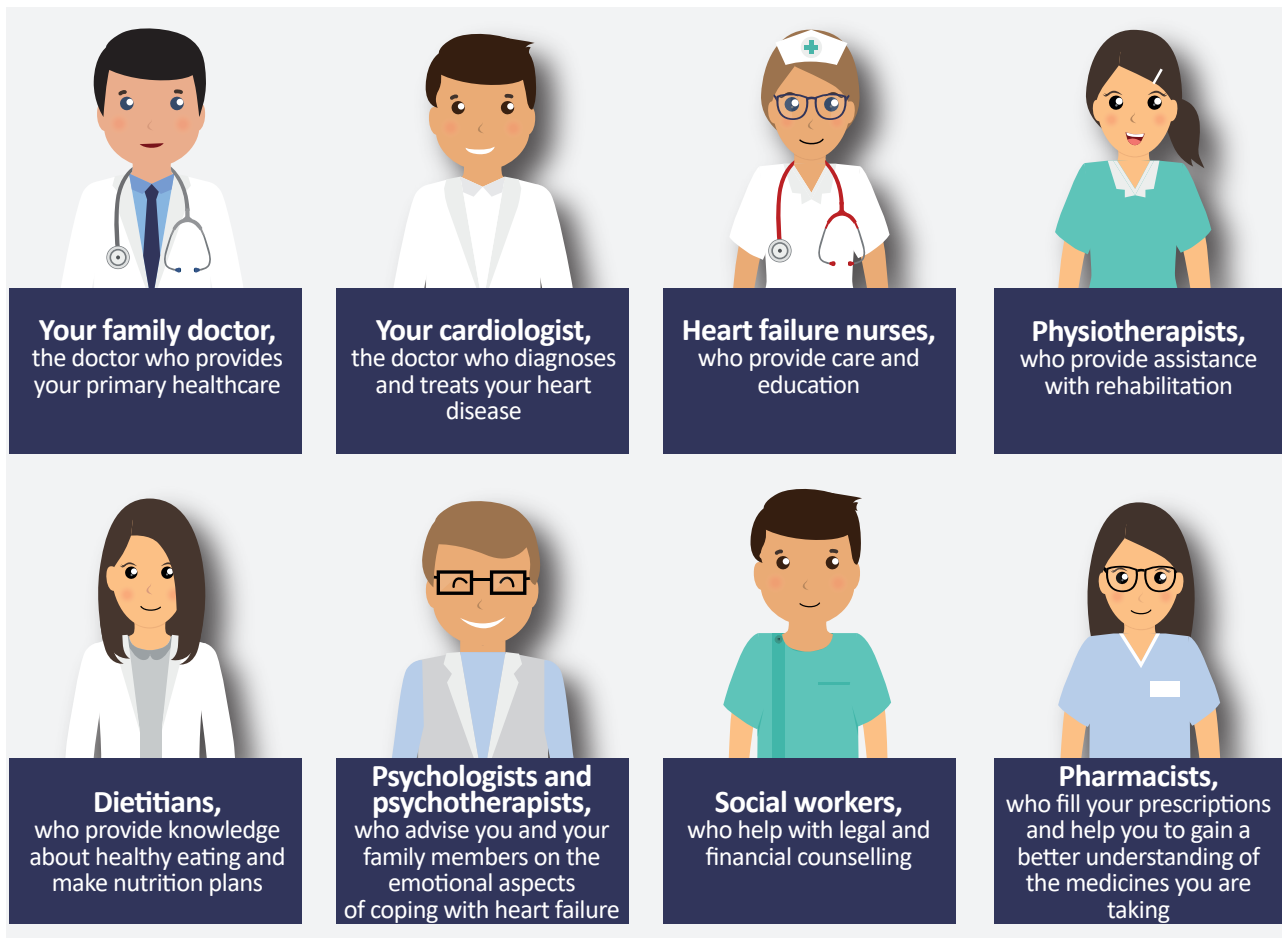
## The role of your family and caregivers

Your family and informal caregivers can provide a vital network of physical and emotional support. Positive support from people around you may lead to better self-care, improved well-being and mental health, and a better prognosis (how long you stay well for). Family and informal caregivers may be able to help you with feelings of anxiety and help you to cope with any loss of independence or any social isolation and troubling symptoms, should they arise. Family and other informal caregivers may also be able to help you with aspects of self-care, such as helping you to monitor your symptoms. The role of your family and caregivers may change throughout the progression of your illness; for example, in more advanced stages of heart failure family and caregivers will often contribute to treatment decisions and may take responsibility for your medication and devices if you are unable to do this yourself.



## The role of your treatment team

Throughout your treatment journey, you will be supported by many different healthcare professionals, including:

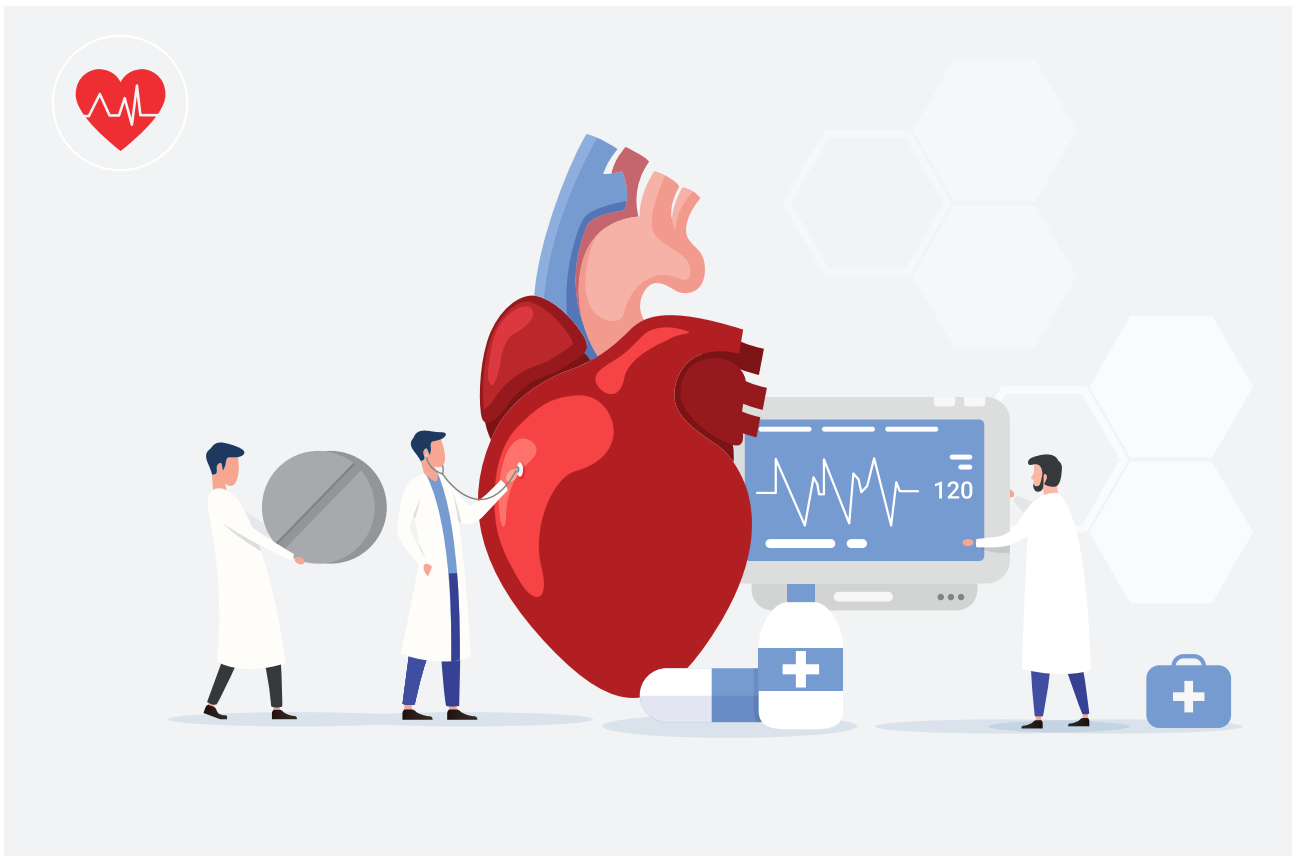


These healthcare professionals make up your multidisciplinary care team and will help you to manage different aspects of your disease. If you receive recommendations from your doctor, nurse or other member of your treatment team, make sure you understand everything. You can also ask to have the instructions written down for you on a piece of paper or for your caregiver or family to take notes. This way you will not feel confused and you will remember what to do.

## Coping with difficult situations

### Managing your mood

Being diagnosed with heart failure can cause you to feel many different emotions, such as anxiety, low mood, anger or fear. It can help to discuss your thoughts and feelings with family and friends. You might consider joining a heart failure support group, where you can talk with people going through the same things as you. Exercise (within your limits), cognitive behavioural therapy (a talking therapy) and antidepressant medications may also help improve your mood.



## Managing heart failure progression

As your condition progresses, you may require additional treatment and other interventions to manage your symptoms. You may experience increased breathlessness and fatigue and reduced tolerance to physical activity. Early intervention with exercise-based cardiac rehabilitation can help maintain exercise tolerance. Frailty, unintentional weight loss and muscle wasting may be prevented by exercise and changes to your diet if diagnosed early.

## Palliative and end-of-life care

Palliative care is a person-centred, holistic approach that deals with your overall quality of life rather than just your heart failure, and will usually involve your whole treatment team. Palliative care includes ways to support you psychologically, socially, physically and spiritually. Palliative care may be suggested if your quality of life is persistently impaired, or your symptoms become rapidly worse.

Palliative care may include end-of-life care. Your treatment team may discuss the best way to care for you during the end-of-life period to make you as comfortable as possible. These options may include the deactivation of your ICD or other devices if you have them. Breathlessness, bodily swelling and fatigue are very common in the advanced stages of heart failure. Your palliative care team may suggest extra steps you can take and prescribe treatments to minimize these symptoms. It is important that you talk honestly with your family about your prognosis so that they have time to prepare, and you have time to discuss your wishes. Some patients with heart failure can develop problems with remembering and making decisions; therefore, it is best to have these conversations with your family as soon as possible.

# I'm in control of my heart failure

## My goal card

Goal	Data set	Data achieved

## My medical history

<input type="text"/>		<input type="text"/>
Name		Age
<input type="text"/>		
Date of heart failure diagnosis		
<input type="text"/>		
Doctor		
<input type="text"/>		
Other medical diagnoses		
<input type="text"/>		
Other medications		
<input type="text"/>		
Allergies		
<input type="text"/>		
Family history of disease		



## My hospitalization card

Date of hospitalization

Department/unit

Reason for hospitalization

Length of stay

Operation/treatments

Other notes

## My medical appointment card

Date of visit

Healthcare team member

Reason for visit

Healthcare provider's notes

Other notes

## My medication

Medication	Dose	How and when to take

## My physical activity card

Date	Type and duration of activity	Notes (e.g. exacerbation of symptoms)

## My test/examination results

Date of test/examination	Location of test/examination	Type of test/examination	Result of test/examination

## *My hospital discharge checklist*

Name

Cause of heart failure

Hospital/department

Date of admission

Date of discharge

Primary care physician

Heart failure nurse

Follow-up visits(s) (date/location)

## My hospital discharge checklist

I confirm that the following issues were discussed with me

	YES	NO	If NO, give reason
What is heart failure?			
How common is heart failure?			
What causes heart failure?			
Symptoms of heart failure			
Factors that can make heart failure worse			
How is heart failure diagnosed?			
Medications for treating heart failure			
Recommendations, uses, dosage and side effects of medications			
Non-pharmacological methods for treating heart failure			
Surgical procedures for treating heart failure			
Food and drink, and weight			
Exercise			
Sexual activity			
Travel and leisure activities			
Sleep optimization			
Mental health (psychological problems, special situations)			
Vaccination and preventing infections			
Smoking and stimulants			
The importance of self-monitoring symptoms (measuring and recording heart rate, blood pressure, weight, appetite, mood)			
The use of Alert Zones (green, amber, red) to help respond appropriately to worrying heart failure symptoms			

# My daily measurements

Week starting

	MON	TUE	WED	THU	FRI	SAT	SUN
Heart rate (bpm)							
Blood pressure (mmHg)							
Weight (kg)							
Appetite (poor/normal/increased)							
Mood (very good, good, OK, poor, very poor)							
Heart failure Alert Zone (green/amber/red)							
Other notes							

## Glossary

**Angiotensin converting enzyme inhibitor (ACEI)** – a type of medicine used to treat heart failure that helps to ‘open up’ your blood vessels to increase blood flow and lower blood pressure.

**Angiotensin receptor blocker (ARB)** – a type of medicine used to treat heart failure that helps to ‘open up’ your blood vessels to increase blood flow and lower blood pressure.

**Beta-blocker** – a type of medicine used to treat heart failure that slows down your heartbeat.

**Cardiac resynchronization therapy (CRT)** – when a pacemaker is implanted in the chest to help keep the heart pumping with a steady rhythm.

**Cognitive behavioural therapy** – a type of talking-based psychological therapy.

**Compensated heart failure** – a category of heart failure where your body ‘compensates’ for working less well so your symptoms may be mild and easy to manage.

**Coronary artery bypass grafting (CABG)** – a type of surgery on the blood vessels of the heart that helps to keep blood flowing to the heart.

**Decompensated heart failure** – A category of heart failure where your heart is not able to keep up with the demands of your body and you may experience symptoms.

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**Echocardiogram ('echo')** – a type of ultrasound scan that tests for heart failure by producing an image of the heart and checking how well it is beating.

**Ejection fraction** – the amount of blood pumped out of your heart with each heartbeat, expressed as a percentage.

**Electrocardiogram (ECG)** – a type of test for heart failure that checks the electrical activity of the heart.

**Heart failure with mid-range ejection fraction (HFmrEF)** – a type of heart failure that is in between HFpEF and HFrEF.

**Heart failure with preserved ejection fraction (HFpEF)** – a type of heart failure in which your heart can't fill with blood properly between heartbeats. Sometimes called 'diastolic heart failure'.

**Heart failure with reduced ejection fraction (HFrEF)** – a type of heart failure in which your heart can't contract strongly enough to pump blood around your body when it beats. Sometimes called 'systolic heart failure'.

**Hyperkalaemia** – a higher-than-normal level of potassium in the blood

**Implantable cardioverter defibrillator (ICD)** – a type of defibrillator that is implanted in the chest and helps to maintain a regular heartbeat.

**Left ventricular ejection fraction (LVEF)** – the proportion of blood that flows into the left side of your heart that is pumped out with each heartbeat.

**Mineralocorticoid receptor antagonist (MRA)** – a type of medicine used to treat heart failure that reduces blood pressure by causing your body to pass more fluid as urine.

**Multidisciplinary care** – a type of healthcare in which patients are supported by a team of healthcare professionals who are specialists in different aspects of care.

**Natriuretic peptide test** – a blood test that checks your levels of natriuretic peptides. You may be tested for NT-proBNP (Nterminal pro-B-type natriuretic peptide) or BNP (B-type natriuretic peptide).

**Palpitations** – a feeling that your heart has skipped or added a beat.

**Percutaneous coronary intervention (PCI)** – surgery to open up the blood vessels of the heart using a small device called a stent. Sometimes called an angioplasty.

**Risk factors** – things that increase your chance of developing a disease. They may be other medical conditions or things related to your lifestyle, job or diet.

**Sleep apnoea** – a condition in which your breathing temporarily stops during sleep.



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