

### Heart information

# Living well with chronic heart failure









## This booklet has been developed to:

- help you, your family and your caregivers better understand chronic heart failure and its treatment
- offer guidance to help you manage this condition and improve the quality of your life
- help guide your discussions with the health professionals involved in your care
- answer some of the questions commonly asked by people with chronic heart failure.

You may find it useful to keep this booklet and refer back to it from time to time.

Keep a copy of your action plan on the fridge or somewhere else handy so that you will know when to call your doctor or nurse, and when to seek emergency help.

#### Introduction

Chronic heart failure is a life-threatening condition that affects around 300,000 Australians and kills more than 2,500 each year. Like other chronic diseases (such as diabetes and asthma), chronic heart failure is a condition that will be with you for life, and it presents daily challenges. While it can be very serious and difficult to manage, the good news is that you can control the symptoms of heart failure, avoid unnecessary hospital visits and live a long, healthy life by taking charge of your condition and working in partnership with your healthcare team.

This booklet is based on guidelines developed by the National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand in 2006 (available at www.heartfoundation.org.au). These guidelines provide health professionals with key treatment recommendations for people with heart failure. These include:

- using echocardiography to assess the health of your heart
- prescribing medicines including ACE inhibitors and beta-blockers
- avoiding medicines that can make heart failure worse
- referring you to a heart failure management program, where possible
- ensuring you understand the lifestyle changes necessary to help you control your symptoms.

While these recommendations are based on the best available scientific evidence, it is important to note that your treatment will be tailored to make sure it is right for you. If you have any questions, make sure you discuss them with your healthcare team. See page 22 for some questions you may like to ask them.

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## What is chronic heart failure?

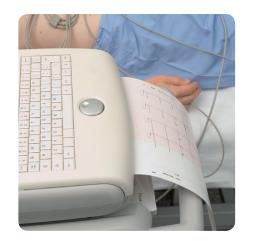
Chronic heart failure is an ongoing condition in which the heart muscle is weakened and can't pump as well as it normally does. The main pumping chambers of the heart (the ventricles) become larger and/or thicker and either can't contract (squeeze) or can't relax as well as they should. The most common causes of chronic heart failure include coronary heart disease, previous heart attack, high blood pressure and cardiomyopathy—a disease of the heart muscle that causes the heart to enlarge and become weaker.

Chronic heart failure is sometimes described as a 'weak' or 'tired' heart. See page 18 for an explanation of some medical terms used to describe chronic heart failure.

## How is chronic heart failure diagnosed?

Your doctor may suspect chronic heart failure because of the symptoms you describe (see pages 6–7 for more information), and he or she may recommend a number of tests to check the health of your heart and confirm the diagnosis. These tests may include:

- an echocardiogram, which uses ultrasound to show both the structure of your heart and how well it is working
- an electrocardiogram (ECG), in which electrical leads are placed on your chest, arms and legs to detect the small electrical impulses travelling through the heart muscle
- a coronary angiogram, in which (under a local anaesthetic) a thin tube (catheter) is inserted into an artery in your arm or groin and guided into the heart.
   Dye is then injected through the catheter into the arteries leading to the heart and X-rays are taken, giving detailed information about the condition of these arteries.
- a chest X-ray.



Electrocardiogram (ECG)

## How is chronic heart failure treated?

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

Remember that your treatment will be tailored to suit you, taking into account things such as the severity of your chronic heart failure and any other health problems you may have.

You will probably find that your symptoms tend to 'flare up' every now and then, and your heart may continue to weaken over time, even with treatment. As your condition changes, so will your treatment, and the people involved in your care (see 'A team approach').

Understanding your condition and working with your healthcare team to manage it will help you to remain out of hospital and live life to its fullest potential.

## Symptoms of chronic heart failure

Many symptoms can be associated with chronic heart failure. You may not experience all the symptoms listed on the next page, and those you do notice may range from mild to severe.

If you experience any new symptoms, if any existing symptoms get worse, or if you are worried, speak to your doctor or heart failure nurse. It is important to know when to immediately call your doctor or call Triple Zero (000) for an ambulance. See the action plan on the back cover.

The following table lists common symptoms of chronic heart failure and recommendations for managing them.

#### A team approach

Evidence shows that a team approach to the management of chronic heart failure is best.
Your team may include a cardiologist, GP, nurse, dietitian, physiotherapist, pharmacist, occupational therapist, social worker, psychologist, palliative care specialist and/or other healthcare professionals. You and your family or carer are also vital members of this team.



#### Table: Symptoms of chronic heart failure

Computers and usual sausa	Decompositions
Symptom and usual cause  New or worsening shortness of breath	Recommendations  Taking your medicines as prescribed and
<ul> <li>(particularly during physical activity or waking you up at night)</li> <li>&gt; Usual cause A weakened heart results in excess fluid building up in the lungs.</li> </ul>	following the lifestyle advice outlined in this booklet can help.
	You may find using extra pillows, so that you are sleeping in a semi-upright position, helps.  If you have worsening shortness of breath with your normal activities, call your doctor or heart failure nurse as soon as possible.
Weight gain  Vusual cause  Fluid build up may cause weight gain.  1 litre of fluid = 1 kilogram.  You will lose weight as you lose fluid.	If your weight increases by more than 2 kg over 2 days, further restrict your fluid intake and contact your doctor or heart failure nurse immediately. It is also important to avoid salty food—see page 10 for more information.
<ul> <li>Swelling of the ankles or belly (you may notice that your shoes and/or belt are tighter than usual)</li> <li>Usual cause Fluid leaking out of the blood vessels into the tissues of the body causes swelling. This is called oedema.</li> </ul>	Weigh yourself every day to keep track of your fluid balance (see page 9).  When you are sitting down, put your feet up on a stool to help return fluid to your heart.
Tiredness  • Usual cause  You may tire easily if there is less blood going to the major organs and muscles of the body.	Plan your day, and don't forget to rest when you need to. Avoid strenuous work, or ask for help.
Dizziness  • Usual cause  Lowered blood pressure and a temporary reduction in the amount of blood going to the brain may cause dizziness. Some medicines may also cause dizziness, especially when you start taking them, or when the dose is increased.	Stand up slowly when you have been sitting or lying down. If dizziness continues, call your doctor or heart failure nurse. If you feel faint or very dizzy, seek help as soon as possible.
<ul> <li>Heart palpitations</li> <li>Usual cause Palpitations may be due to: <ul> <li>an increased awareness of your normal heart rhythm</li> <li>feeling your heart beat faster than usual</li> <li>an abnormal heart rhythm.</li> </ul> </li> </ul>	If you are feeling dizzy, stop and rest until you feel better. If symptoms persist, contact your doctor or heart failure nurse immediately. If symptoms are associated with chest pain or discomfort, emergency action may be required—see next page.

#### **Recommendations** Symptom and usual cause Chest pain or discomfort in parts of the If you experience any of these symptoms, immediately stop what you are doing and rest. upper body (Including tightness, fullness, pressure, If you have been prescribed medicine such as a squeezing, heaviness or pain in your chest, tablet or oral spray to treat bouts of chest pain neck, jaw, throat, shoulders, arm, back) or discomfort, you should take this as directed. Usual cause If you are with someone, tell them what you People with chronic heart failure often have are experiencing. other forms of heart disease that may restrict If the chest pain is not completely relieved the flow of blood to the heart muscle, causing within 10 minutes of onset by rest and temporary chest pain, tightness or discomfort medicine, or if it is severe or gets worse in parts of the upper body (known as angina). quickly, this is an emergency. Call Triple Zero (000)\* and ask for an ambulance. Don't hang up. Wait for advice from the operator. See your action plan for more information. \*If calling 000 does not work on your mobile phone, try 112. Cough Contact your doctor or heart failure nurse if your cough persists. Usual cause A build up of fluid in the lungs, particularly at night, can cause coughing. A dry, irritating cough can be a side effect of commonly used medicines called ACE inhibitors. Sleep disturbance You may find using extra pillows, so that you are sleeping in a semi-upright position, helps. Usual cause Shortness of breath may keep you awake at Taking your diuretic earlier in the day (rather night (see previous page). A condition called than near bedtime) can also improve your sleep. sleep apnoea, in which breathing temporarily stops while you are sleeping, can also be a problem. You may find that you need to go to the toilet more often during the night because of your diuretic medicine (fluid tablets). You may wish to eat smaller meals more often. Loss of appetite Usual cause If you are losing too much weight, a special diet This may be due to a number of causes, or the use of supplements can help. including a build up of fluid in the digestive organs, which gives you a 'full' feeling. Constipation Increasing your intake of fibre (by eating more high-fibre foods, such as fresh fruit and Usual cause vegetables, or taking a fibre supplement) and Immobility, frailty, fluid restriction and

increasing your mobility can help.

meals can contribute.

dehydration, and eating smaller, low-fibre

#### At a glance

The three main things you can do to help minimise the symptoms of chronic heart failure and stay healthy are:

- 1. Monitor and control your fluid balance (establish a daily routine) pages 8–9.
- 2. Make some long-term lifestyle changes pages 11–12.
- 3. Take your medicines as prescribed pages 13–15.

#### **Tips**

- Know how much fluid your favourite glass, cup or mug holds, and keep a record of how many you drink until you get used to monitoring your fluid intake.
- Fill a jug with your 'allowance' each morning, and drink from this throughout the day.
   Remember to pour out the equivalent amount of water when you have other fluids (juice, milk etc).
- In hot weather your doctor may advise you to drink more.
- On hot days, try sucking on some ice blocks to keep cool without drinking too much fluid.

## How to manage your symptoms

#### Monitor and control your fluid balance

You will need to establish a daily routine of weighing yourself. This has nothing to do with whether or not you are carrying a few extra kilos (although for some, long-term weight loss will also be important). Weighing yourself accurately every day will help you to know whether fluid is building up in your body. The extra fluid can cause symptoms such as shortness of breath and swelling, and put extra strain on the heart. If you put on more than 2 kilograms in two days, further restrict your intake of fluids and contact your doctor or heart failure nurse immediately.

There are three ways you can help to control your fluid balance:

- control your fluid intake
- restrict salt intake
- take diuretic medicines as prescribed by your doctor to help you pass more fluid through urine.

#### Control your fluid intake

Your doctor may recommend that you restrict your fluid intake. Typically, this might mean consuming only 1 to 1.5 litres per day, although you will need to decide with your doctor what amount is right for you. The amount of fluid you need in hot weather may be more than usual. Remember that 'fluid' includes:

- water
- juice and other drinks
- soups
- ice cream
- fruit with a high water content (such as watermelon)
- tea and coffee.

See page 11 for further information on alcohol and drinks containing caffeine.

#### Weigh yourself every day

Try to weigh yourself at the same time each morning. This way it will become part of your daily routine. When you wake up each morning:

#### Step 1

Go to the toilet.

#### Step 2

Weigh yourself before breakfast (wearing the same type of clothing and at the same time each day).

#### Step 3

Write down your weight in a notebook or diary.

#### Step 4

Contact your doctor or heart failure nurse if you have gained more than 2 kilograms in the last 2 days.

#### Feeling sad or worried?

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

However, if you feel sad, 'down', or miserable most of the time, or if these feelings make it harder for you to go about your daily activities, you may be affected by depression. Many people with chronic heart failure experience depression at some time, affecting their work, relationships

or wellbeing. If you suspect you have depression, talk to your doctor sooner rather than later because there are effective treatments. See page 21 for groups and resources that may help. If you often feel anxious, and particularly if your anxiety makes symptoms such as shortness of breath worse, stress management or relaxation techniques may help.







#### **Tips**

- Choose products with a sodium content of 120 mg/100 g, or as near to it as possible. Look for the 'Qty per 100 g' column in the nutrition panel (on food packaging) to find this information.
- Remember that foods labelled 'low fat' can still be high in salt as well as sugar.

#### Salt restriction

The salt in your food will affect your body's fluid balance, as it causes the body to retain fluid. Look for the sodium content of the foods you buy—this reflects the amount of salt they contain. It is recommended that you do not add salt during cooking or at the table. To reduce your salt intake:

#### Choose:

- plenty of fresh vegetables and fruit
- foods normally processed without salt and foods labelled 'no added salt' or 'low salt'\*
- 'low salt' breads and cereals
- water or plain mineral water, low or reduced fat milk or 'added calcium' soy beverages.

#### Avoid everyday foods that are high in salt, such as:

- ham, bacon, luncheon meats, sausages and hot dogs
- tomato sauce, mayonnaise, commercial sauces and salad dressings
- canned soups, packet seasoning and stock cubes (other than those that are labelled 'no added salt' or 'low salt')
- fish canned in brine
- high salt take-away foods like pizza, pies, pasta and hamburgers
- potato chips/crisps and salted nuts
- foods preserved in brine
- Asian foods, soy sauce, pickles, olives and dips.

#### Avoid using salt\*\* in cooking or at the table:

- To flavour food use freshly ground pepper, fresh or dried herbs, vinegar, lemon juice, fresh mustard (made from powdered mustard), fresh garlic or garlic powder, onion, chives, spring onion and horseradish.
- Buy commercial 'no added salt' sauces or try making your own salad dressing, sauces, pickles and chutneys without adding salt.

 $<sup>^{</sup>st}$  'low salt' means no more than 120 milligrams of sodium per 100 grams

<sup>\*\*</sup> includes sea salt, rock salt, cooking salt, salt flakes, pink salt, chicken salt, onion salt, celery salt, garlic salt, MSG, beef and chicken stock cubes, stock powder, soup cubes, gravy powder and soy sauce

### Other lifestyle issues

#### Be smoke-free

Smoking reduces the amount of oxygen in your blood, and damages the walls of your arteries. Stopping smoking can reduce your risk of further heart disease. For information and support talk to your doctor or call the Quitline on 13 7848 (13 QUIT).

#### Enjoy healthy eating

As well as limiting salt intake (see page 10), it is important to enjoy a variety of foods from the different food groups. For more information on healthy eating, call the Heart Foundation on 1300 36 27 87.

#### Address your alcohol intake

Alcohol can damage your heart, and you should discuss your alcohol intake with your doctor. It is very important that you do not drink more than one to two standard drinks of alcohol per day\*. If your chronic heart failure has been caused by alcohol, you should not drink it at all.

#### Limit caffeinated drinks

Too much caffeine can cause problems if you tend to get abnormal heart rhythms, and it can raise your heart rate and blood pressure. Try to have no more than one or two cups of coffee, tea or cola per day, and remember that these will count towards your daily fluid intake. See page 8.

#### Achieve and maintain a healthy body weight

While you will be monitoring day-to-day changes in your weight to keep track of your fluid balance, you may also be advised to lose some excess body fat if you are overweight. Losing body fat will lower the workload of your heart. Some people with chronic heart failure have the problem of losing too much weight, which can make symptoms of weakness and tiredness worse. In either case, ask your doctor or dietitian for help.

You may be able to attend a specialised program that will help you manage your condition and avoid future hospital stays. These programs usually involve input from a number of health professionals, such as nurses, dietitians and exercise specialists. The Heart Foundation strongly recommends that you participate in one of these programs if you can. A national directory of community or hospital-based programs is available from the Heart Foundation. Call us on 1300 36 27 87.



Chronic heart failure programs

<sup>\*</sup> a standard drink contains 10 grams of alcohol, such as a can of mid-strength beer, a small glass of wine or a nip of spirits)

#### "I find it hard to complete daily activities, so how do I do exercise as well?"

Planning your daily activities to allow for rest periods will help you complete your tasks and enable you to include some physical activity as well. Increased physical activity levels will make daily activities easier in the long run, by strengthening your muscles, increasing your endurance and helping to ward off or improve mild depression. Remember, however, that getting enough sleep and resting when you are unwell are also important. See your action plan for details of when to contact your doctor or heart failure nurse.

Specialised group exercise programs can provide professional support, monitoring of your activity level and personalised advice. Call the Heart Foundation on 1300 36 27 87 for details of community-based programs in your area.

#### Be physically active

Regular light- to moderate-intensity physical activity, such as walking, cycling on an exercise bike and lifting light weights, is important. Try to be active every day. Do what you can without getting short of breath or overtired; you should be able to talk easily while doing physical activity. Avoid:

- strenuous activities (unless approved by your doctor)
- exercising in extremes of temperature; for example, in very warm or very cold swimming pools, as it may cause rapid changes in blood flow that can put extra strain on your heart.

Talk to your doctor about the type and level of activity that is suitable for you.

#### Manage diabetes

If you have diabetes, it is important that you keep your blood glucose level in the normal (non-diabetic) range. Regular diabetes reviews with your doctor can help you achieve this.

#### Vaccination

People with chronic heart failure are at increased risk of developing life-threatening complications from influenza ('the flu') and are at high risk of pneumococcal infection. Talk to your doctor about annual influenza and regular pneumococcal vaccinations.

#### Ambulance cover

Most people with chronic heart failure will need to go to hospital at some point (and often several times) over the course of their lives. Make sure you have ambulance cover, so that you don't have to worry about the cost of ambulance transportation if you need it in an emergency.

#### Advance care directives

Many people with chronic heart failure feel reassured by not only making a will for financial matters but by preparing an 'advance care directive', which tells your family and doctors what your wishes are for your healthcare in the event that you are unable to do this. It is best to do this when you are well and in control, rather than during a period of crisis.

#### **Medicines**

There are many medicines for chronic heart failure that can improve symptoms and help you stay out of hospital and live longer. You may be prescribed a number of medicines to achieve these goals, and for other medical conditions you may have (such as coronary heart disease or diabetes). The following pages describe the most common and important medicines used to treat chronic heart failure. They will help you to get the most out of your medicines and manage any side effects.

#### Common heart failure medicines

Ask your doctor, heart failure nurse or pharmacist to help you fill in the names of your medicines next to each heading. Note that not all of these medicines may be appropriate for you, and it may be useful to discuss with your doctor the reasons why.

#### 

#### Aldosterone receptor blockers

My medicine: \_\_\_\_\_

These can help you live longer, especially if you have severe heart failure.

#### **Glycosides**

irregular heart rhythm.

My medicine: \_\_\_\_\_\_

These help the heart to pump more efficiently and help regulate an

Anti-arrhythmics My medicine: \_\_\_\_\_

These help to control the heart's rhythm.

Other My medicine/s: \_\_\_\_\_



### Medicines you should not take

It is important to know that there are some medicines you should not take when you have chronic heart failure, as they can be dangerous in combination with your other medicines. These include some prescription medicines as well as common over-the-counter medicines such as pain relievers and anti-inflammatory arthritis treatments. Be sure to check with your doctor or pharmacist before taking any new prescription, over-the-counter or complementary, natural or 'traditional' therapies.

#### Remember

- Never stop taking your medicines without talking to your doctor first—even if you start to feel better.
- Make sure you have enough of your medicines at all times.
- If you're having trouble remembering to take your medicines, talk to your doctor or pharmacist. They can suggest simple ways to help you remember. Having your medicines dispensed in special 'Webster packs' or putting them into dosette boxes can make it easier to remember to take all of your medicines at the right time.

#### Remember

Although they are uncommon reactions to chronic heart failure medicines, you should call your doctor immediately if you notice:

- dizziness severe enough to make you feel that you will fall
- swelling of the mouth, tongue or face.

#### Tips for using medicines wisely

Keep a list of your medicines handy and include:

- their names each of your medicines will have a 'generic' name (the name of the actual drug) and a brand name
- the correct dose and when you should take them
- how they work
- possible side effects, and which side effects you should report to your doctor immediately.

Your pharmacist can help you with this information.

If you feel your medicines are not working or are causing you problems, or you have any questions, talk to your doctor or heart failure nurse. Your pharmacist can also tell you more about your medicines, and you can ask him or her for a Consumer Medicine Information leaflet for each of them. You may wish to call the Medicines Line on 1300 633 424.

#### Side effects

Unfortunately, all medicines can cause unwanted side effects. In many cases these are mild and/or temporary, and the benefit of the medicine far outweighs the risk or the inconvenience of mild side effects. However, your doctor will work with you to minimise side effects while making sure you have the best possible treatment.

You may not experience any side effects from your medicines, or they may only occur when you first start taking a medicine or when the dose is increased. The table on the next page describes some common side effects of chronic heart failure medicines, and some tips for managing them.

#### Common side effects of chronic heart failure medicines

If you are experiencing any new symptoms or side effects it is important that you contact your doctor. Regular blood tests may be required to ensure your medicines are working as they should, and/or to monitor and minimise side effects.

	Tips to manage side effects
Dizziness (especially when standing up quickly)	This side effect can occur with ACE inhibitors and beta-blockers, especially when they are first introduced. It is important to sit or lie down when you get dizzy, and get up slowly in the morning or any time you have been sitting or lying down. If dizziness continues, talk to your doctor, heart failure nurse or pharmacist about taking these medicines in the evening, rather than earlier in the day.
Needing to go to the toilet at inconvenient times	This is often an effect of diuretics or fluid tablets. Avoid taking these tablets too close to bed time if you find you are waking in the night to go to the toilet. You may find it helpful to avoid taking your tablets just before going out. It is useful to take the time to plan ahead for your activities.
Dry, persistent cough	Remember that this side effect may occur with ACE inhibitors. It is often temporary, occurring when you first start taking an ACE inhibitor, or when the dose is increased. Monitoring how often and when your cough occurs can help your doctor minimise this side effect.
Irregular heartbeat	Many people with chronic heart failure have an irregular heartbeat. However, sometimes this can be caused by certain medicines. If you notice that your heartbeat is irregular or slower than usual, talk to your doctor or heart failure nurse. It may be necessary to have blood tests to check your blood potassium levels.
Worsening shortness of breath	Call your doctor immediately if you have worsening shortness of breath with your normal activity.  Occassionally this can mean that your medicines (e.g. beta-blockers) need to be adjusted.
Loss of appetite, nausea or vomiting, visual disturbances	Digoxin can cause these side effects if its level in the blood becomes too high. If you are taking this medicine and you experience any of these side effects, call your doctor as soon as possible.

### Symptom or side effect?

Sometimes it can be difficult to tell whether new 'symptoms' are related to your chronic heart failure or the medicines you are taking. This is one of the reasons why it is important to report any new or worsening problems to your doctor or heart failure nurse. It is also useful to monitor your symptoms (such as shortness of breath) over time, and note the things that either make you feel better or worse.

# Other possible side effects occurring with chronic heart failure medicines:

- headache
- wheezing
- tiredness/weakness
- excessive fluid loss
- skin rash
- attacks of gout
- sensitivity to the sun.

## Other treatments for chronic heart failure

#### Implantable devices

For some people with chronic heart failure, devices may be implanted in the chest wall and attached to the heart to help it work more effectively.

In some cases, a pacemaker may be recommended to help maintain your heart rhythm if it is too slow, particularly if you are often feeling dizzy and/or fainting. Pacemakers are designed to make the heart beat at a certain regular rate. Some pacemakers attach to only one of the heart's pumping chambers (the left ventricle). Newer pacemakers used in some people with chronic heart failure 'pace' both ventricles at the same time. This is called 'biventricular pacing' or 'cardiac resynchronisation therapy' (CRT).

In other instances, a device known as an implantable cardiac defibrillator (ICD) may be recommended, particularly if you have had, or are at high risk of developing, dangerous abnormal heart rhythms that can lead to cardiac arrest. Among other things, an ICD can identify a life-threatening heart rhythm and deliver an electrical shock to return the heart rhythm to normal. More information on these devices can be found in our information sheets *Artificial pacemakers* and *Implantable cardiac defibrillators* available at www.heartfoundation.org.au.



Implantable cardiac defibrillator (ICD)

#### Heart transplant

If your heart failure becomes severe, a heart transplant may be required. However, only a small percentage of the people who have chronic heart failure need heart transplants. For more information, refer to our information sheet *Heart transplants and organ donation*, available at www.heartfoundation.org.au.

#### Palliative care

When you are told you have a serious medical condition, it is normal to experience feelings of sadness and loss, and to also consider the possibility of dying. This is a normal and expected reaction. It is important that you feel comfortable about discussing your thoughts and wishes with your family, doctors and other health professionals. Although it is necessary to understand how serious your heart condition is, it is also important to remain positive in your outlook and remember that many people live happily for many years with chronic heart failure. Sometimes this can be difficult—particularly if you experience a setback—but remember that as heart failure progresses, there is a broad range of health professionals available to support you and help you make decisions about your care. If your symptoms become difficult to manage, despite the treatments outlined in this booklet, a palliative care specialist may join your healthcare team to discuss your treatment options. These specialists are experts in managing symptoms (such as severe shortness of breath) and helping you make decisions regarding your wishes for treatment.

Palliative Care Australia can provide further information. See page 21 for details.

#### Terminology

Different medical terms are often used to describe chronic heart failure and related conditions. Some of the terms you may hear include:

Congestive cardiac failure: another term for chronic heart failure.

Cardiomyopathy: a disease of the heart muscle that causes the heart to enlarge and weaken, often leading to chronic heart failure.

Biventricular failure (or dysfunction): this is when both of the heart's main pumping chambers (the ventricles) are weakened.

Left ventricular failure (or dysfunction): this is when only one of the heart's main pumping chambers (the left ventricle) is weakened.

Systolic heart failure (or dysfunction): this is when the heart is unable to contract (squeeze) normally, and therefore can't pump blood as efficiently as it should.

Diastolic heart failure (or dysfunction): this is when the heart is unable to relax and refill properly, meaning that less blood is pumped to the body with every heartbeat.

Preserved function or preserved systolic function heart failure: see 'diastolic heart failure'

## Commonly asked questions

#### Will I ever be cured of chronic heart failure?

In most cases chronic heart failure is a condition that cannot be cured completely but working with your healthcare team, making some lifestyle changes and taking your medicines as prescribed can relieve your symptoms, reduce the risk of hospitalisation and help you live longer.

## Why do I get short of breath when I lie down, as well as when I am being active?

This is usually due to a build up of fluid in the lungs which occurs because the heart is unable to remove this fluid as efficiently as it used to. See page 6 for more information.

### What happens if I miss a dose of my medicine?

Do not take a double dose of the medicine. Depending on when you realise that you have missed a dose, it is often best to just wait and take the next regular dose. If in doubt about what to do, contact your doctor or pharmacist for advice.

#### Is heart failure the same as heart attack?

No. A heart attack occurs when there is a sudden, complete blockage of a blood vessel that supplies part of the heart muscle. Heart attack is a medical emergency because there is a high risk of dangerous changes to the heart rhythm and, if the blockage is not cleared, the heart can be permanently damaged.

## Will chronic heart failure affect my ability to work?

This depends on how physically demanding your job is—talk to your healthcare team. It is particularly important to discuss your return to work with your healthcare team if you have been hospitalised because of your chronic heart failure.

## Can I travel on an aeroplane or on a long trip?

Talk to your doctor before your trip. Usually travelling is not a problem, but remember:

- Your medicines may need to be adjusted.
- If travelling to hot or humid climates, your fluid balance may need to be closely monitored.
- Do not miss taking any of your medicines. It may help to ask a travelling companion to remind you when to take your medicines.
- On long flights, remember to stretch your legs and ankles and wear support stockings to avoid excessive swelling and to reduce the risk of blood clots forming in your legs.
- A lot of pre-prepared and restaurant food is high in salt and it may be more difficult to avoid these while you are travelling.
- Avoid travel to high altitude destinations, as there is less oxygen in the air and this can worsen shortness of breath.

#### Can I drive my car?

Talk to your healthcare team about driving if you have been particularly unwell and/or in hospital for an extended period of time. The Road Traffic Authority in your state may also be able to provide some helpful information about when you can and when you shouldn't drive.

#### Can I still have sex?

Yes. If you can walk up two flights of steps without symptoms, then having sex is likely to be safe. If you become short of breath or have any chest pain, you may need to stop and rest, or find a position that will not put as much strain on the heart. Talk to your doctor about any problems or concerns you may have.

#### Remember

If you need more information, or have any other questions, talk to a member of your healthcare team.

#### Tip

Be clear and confident when discussing your health problems with your healthcare team, and consider asking a family member or friend to come with you to appointments for support if feel you need it.

# Communicating effectively with your healthcare team

It is important to develop good working relationships with the members of your healthcare team, as this will help to ensure that you receive the best possible care.

Make the most of the time you have with the health professionals involved in your care by being well-organised for all your appointments. It is helpful to:

- Write a list of any concerns and questions that you have (see page 22 for some suggestions).
- Take the time to ensure you have an accurate list of medicines that you are taking (including vitamins and other non-prescription medicines).
- Keep a diary noting your symptoms and take this with you when you go to your appointments.

When talking to the members of your healthcare team, remember to:

- Tell them how you feel about your treatment and your hopes for the future.
- Ask for further explanation if you don't understand what you have been told or if you still have questions.
   Don't feel worried that you are asking 'silly' questions, or too many questions.
- Let them know how much information you want.
- Advise them if you have any particular religious or cultural beliefs that may affect your treatment.
- Be sure that you are aware of treatment goals and potential side effects.

#### Contacts and resources

### The Heart Foundation's heart health information service and website

Trained heart health staff at the Heart Foundation's telephone information service can provide more information on chronic heart failure and support groups as well as other heart health topics. Send an email to health@heartfoundation.org.au or call 1300 36 27 87 (local call cost) during business hours. Also visit www.heartfoundation.org.au.

#### Support groups

There are several support groups for people with chronic heart failure, including Heart Support Australia and the Cardiomyopathy Association of Australia. Call 1300 36 27 87 for details of the group nearest to you.

#### International resources

- Heart Failure Society of America: www.abouthf.org
- The American Heart Association: www.americanheart.com
- DIPEx–Personal experience of health and illness: www.dipex.org/heartfailure

#### Information about medicines

The National Prescribing Service: www.nps.org.au or the Medicines Line: 1300 633 424

#### Other information

- Quitline: 13 7848
- beyondblue: the National Depression Initiative www.beyondblue.org.au
- Diabetes Australia: www.diabetesaustralia.com.au
- Palliative Care Australia: www.pallcare.org.au
- Commonwealth Carelink Centres: Freecall 1800 052 222 or visit www9.health.gov.au/ccsd/index.cfm

### Other local contacts

Use the space below to fill in contact details of relevant individuals, groups or services in your area, e.g. hospitals, exercise programs, disability support groups and services, interpreter services.

#### My healthcare team

Name:
Title:
nue.
Phone:
Name:
Title:
Title.
Phone:
Name:
Title:
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Phone:
Name:
Title:
Phone:
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### Key questions for your doctor

The following questions are based on the key recommendations of current chronic heart failure guidelines for health professionals. Knowing the answers to these questions will help you manage your condition.

What tests will I need to evaluate my heart health and how often should I have them?  • echocardiography  • blood tests  • other	
• chest X-ray	
What medicines should I be taking (and what doses), and what are the possible side effects? You may like to note down the brand names of your medicines.  • an ACE inhibitor • a diuretic • a beta-blocker • other	
Are there any medicines I should avoid?	
How do I regulate my fluid balance?	
What lifestyle changes should I make to help control symptoms and better manage my condition?	
When should I see my doctor, and when should I go to hospital?	
Which health professionals will be involved with my care?	
Is there a chronic heart failure management program I can attend?	
Will I need a pacemaker or other implantable device?	
What vaccinations should I have?	

## Development of this booklet

This booklet is based on a review of a previous Heart Foundation publication and on recommendations contained in recent guidelines for the diagnosis and management of chronic heart failure.

It has been developed by a working group comprising various health professional and public health groups as well as consumers.

The booklet has been tested with both consumers and health professionals prior to publication, and amended according to the feedback received.

Members of the Heart Failure Consumer Resource Working Group (in alphabetical order):

Roshmeen Azam National Prescribing Service

Meredith Cameron National Institute of Clinical Studies,

National Health and Medical Research Council

Robyn Clark University of South Australia

**Eleanor Clune** National Heart Foundation of Australia **Patricia Davidson** Curtin University of Technology, Sydney

Andrea Driscoll Austin Health, Melbourne

Nancy Huang National Heart Foundation of Australia

James McVeigh Prince of Wales Hospital, Sydney

Vilma Paguio National Heart Foundation of Australia

**Graeme Percival** Consumer

Sue Phillips National Institute of Clinical Studies,

National Health and Medical Research Council

Sepehr Shakib Royal Adelaide Hospital

**Agnes Vitry** University of South Australia

Jill Waddell National Heart Foundation of Australia

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### Chronic heart failure action plan

**Note:** It is important that you develop an individualised action plan with your healthcare team that takes into account the severity of your heart failure, any other health problems you may also have, and your healthcare preferences.

#### Every day:

- Weigh yourself and keep track of your weight.
- Restrict your fluid intake and salt intake as recommended by your doctor.
- Take your medicines as prescribed.
- Be physically active.
- Remember to call for medical assistance when the need arises (see below).

Call your doctor or heart failure nurse as soon as possible if:

- you gain or lose more than 2 kilograms over 2 days
- you have worsening shortness of breath with your normal activities
- your heart is beating very quickly
- you are very dizzy, or you pass out (faint)
- your angina is getting worse
- there is increased swelling in your ankles, legs or abdomen
- you are coughing a lot especially at night
- you are generally feeling more tired or sad than usual.

## When you have angina:

\*If calling 000 does not work on your mobile phone, try 112.

- Immediately stop and rest.
- If rest alone does not bring rapid or effective relief, take a dose of your angina medicine
- If the angina is not relieved within 5 minutes, take another dose of your angina medicine
- If the angina is not completely relieved within 10 minutes of onset by rest and medicine OR is severe OR gets worse quickly, this is an emergency. Get help fast.
   Call Triple Zero (000)\* and ask for an ambulance.
   Don't hang up. Wait for advice from the operator.

#### Call Triple Zero (000)\* and ask for an ambulance if:

You suddenly have severe shortness of breath, or you are experiencing new 'blackouts' \*If calling 000 does not work on your mobile phone, try 112.

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