

Living with heart failure

A guide for families and carers



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An electronic version of this document is available at www.health.qld.gov.au/clinical-practice/referrals/statewide-specialist-services/heart-failure-services

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Introduction

Anyone can become a carer at any time. Carers are not always paid workers but may also be family or friends caring for someone with a disability or illness.

While there is general advice available about caring for people with disability and illness, the Heart Health Consumer Advisory Group within Queensland Health – after much discussion, research, and consultation – decided that a carer's guide specific to caring for someone with heart failure was warranted.

Heart failure is a complex clinical syndrome, which can have significant impact on the patient, both emotionally and with regards to a reduction in physical functionality. Because of the way the illness progresses, the heart failure patient may find themselves regularly having to adjust to changes to their health and mood.

This booklet is aimed at supporting those caring for someone with heart failure by helping them to understand a little more about living with the condition, with some important tips on how to keep the carer healthy as well.

Heart Health Consumer Advisory Group
Queensland Health

For you, the carer

It is important that those caring for someone with heart failure understand the condition and its impact on the life of the person living with heart failure. But equally important is the fact that caring for someone with heart failure may sometimes be a very challenging, worrying, and tiring responsibility, and that you, the carer, need looking after too.

Carers Queensland suggests a few tips to help you, as a carer, stay healthy.

Manage stress by:

- scheduling 'me time',
- staying organised,
- joining a support group,
- reminding yourself what a great job you are doing,
- asking for support when needed.

Look after your physical health by:

- eating regularly and following a balanced diet,
- being active and exercising each day.

Look after your relationships by:

- letting those close to you know that you are now caring for someone with heart failure and that your needs will change,
- organising regular catch-ups with friends and family.

There are many more ways that a carer may look after themselves. The most important thing to remember is that you are living with heart failure too.

Where to go for help

Commonwealth Respite and Carelink Centre

Ph: 1800 052 222 (business hours)

Ph: 1800 059 059 (emergency respite outside standard business hours)

National Carer Counselling

Program for carer support groups & community care options

Ph: 1800 242 636

Relationships Australia

Ph: 1300 364 277

Carers Queensland for more information and support in your area
carersqld.com.au

Carer Gateway is a government site dedicated to the needs of carers
carergateway.gov.au

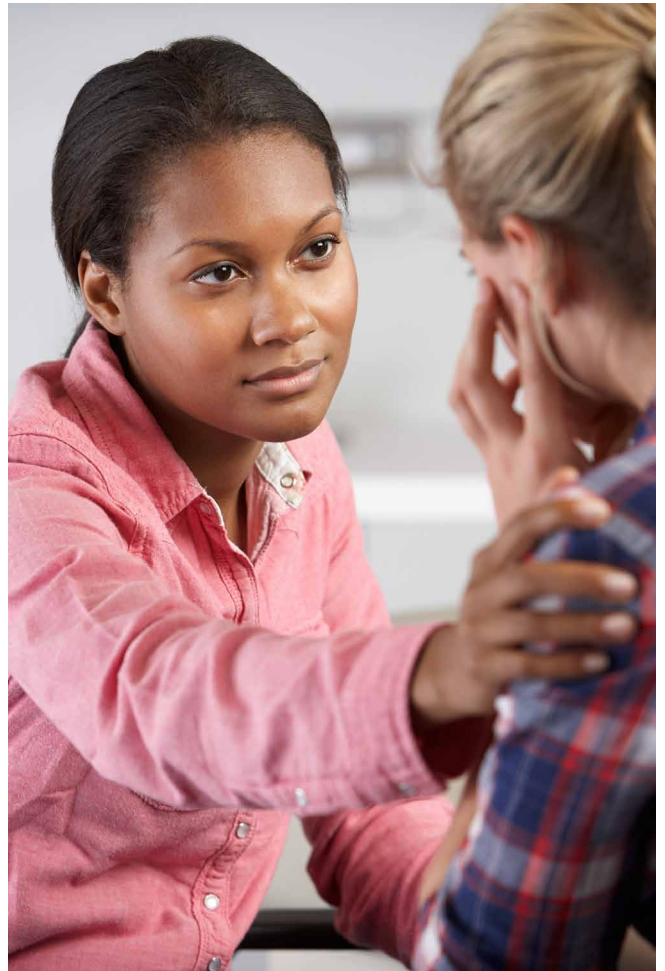
Understanding heart failure

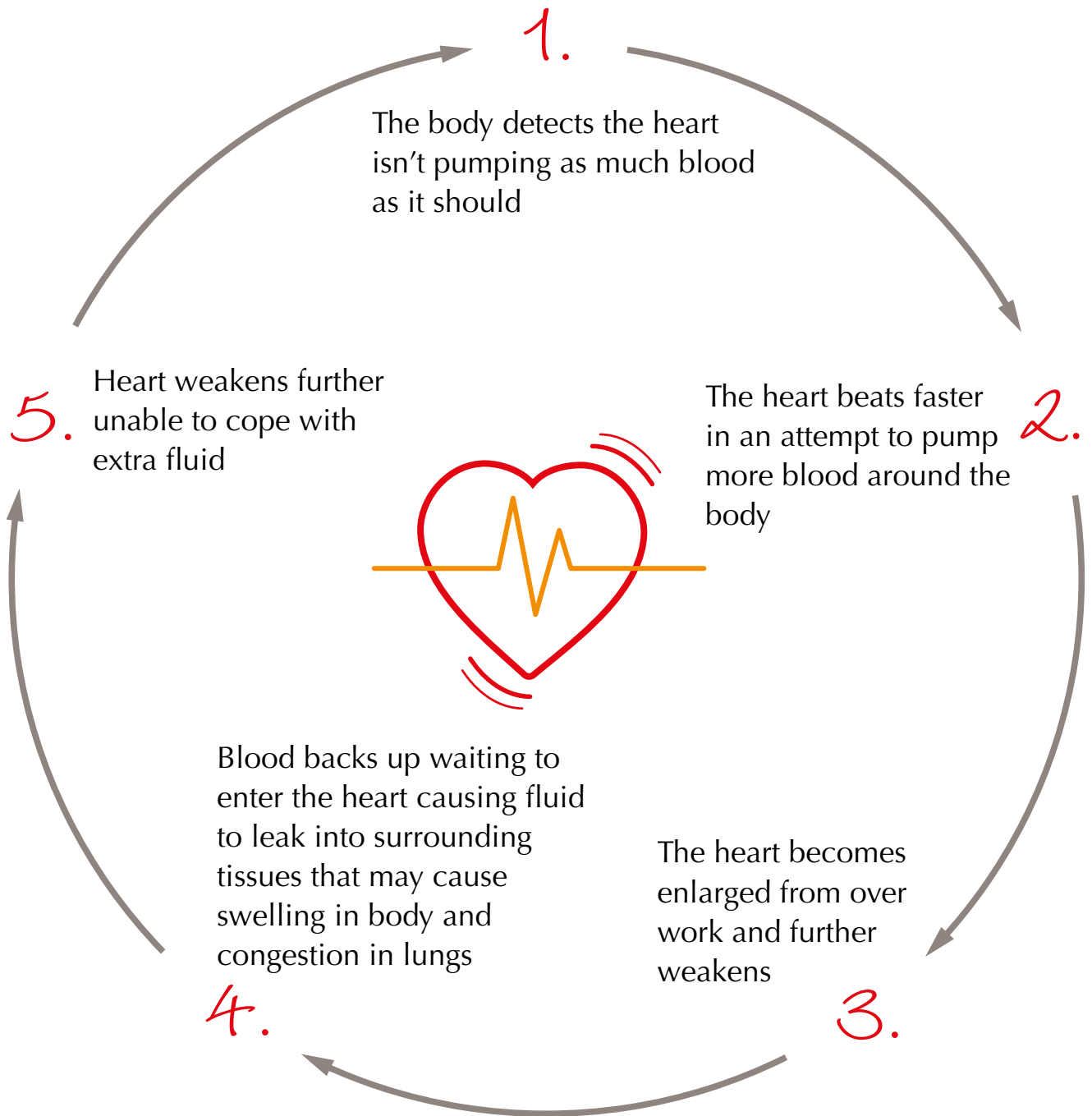
Heart failure affects the heart's ability to fill or pump blood to the body. Failure means that the heart's pumping action is struggling to meet the needs of the body.

The most common causes of heart failure are heart attack from blocked arteries (myocardial infarction) and high blood pressure (hypertension). However, there are many other reasons including: abnormal heart beat (arrhythmias including atrial fibrillation), heart valve problems, heart muscle disease, genetic abnormalities, diabetes, viral infections, alcohol and drug misuse, chemotherapy (cardiotoxicity), radiation, iron overload (haemochromatosis).

Once the heart pump is damaged, not enough blood is pumped through the body, causing fatigue. The following diagram shows the response of the body to the failing pump.

The body's natural response is to fix the problem, for example, by the heart beating faster to pump more blood around the body. However, over the long-term, adaptations by the body further weaken the heart muscle making the condition worse.









Symptoms of heart failure

The most common symptom of heart failure is breathlessness (dyspnoea) which can occur when resting or active. Other common symptoms may include lack of energy, heart palpitations, dizziness, fainting (syncope), poor appetite (anorexia), night time cough, and abdominal bloating (ascites).

Using the New York Heart Association (NYHA) functional class

The NYHA functional class can help patients with heart failure rate symptoms to communicate their energy levels. The functional class can help you, the carer, understand how the needs of the person for whom you are caring can change from day to day.

As a carer it is easy to fall into a habit of taking over and doing everything. However, it is better to encourage independence when possible, as patients who can take control and adapt to changing symptoms often have a better quality of life.

NYHA Class	Symptoms	
I		No limitation of physical activity. Ordinary activity does not cause undue breathlessness, fatigue, or palpitations
II		Slight limitations of physical activity. Comfortable at rest, but ordinary activity results in undue breathlessness, fatigue, or palpitations
III		Marked limitation of physical activity. Comfortable at rest but less than ordinary activity results in undue breathlessness, fatigue, or palpitations
IV		Unable to carry out any physical activity without discomfort. Symptoms at rest can be present. If any physical activity is undertaken, discomfort is increased

Symptoms to keep an eye on

There are a few symptoms that need to be monitored regularly in people with heart failure. As a carer, you can help by encouraging the person you are caring for to keep an eye on their own symptoms and to take action as needed.

Keep an eye on:	Encourage the person you are caring for to:	Seek help:
Fluid build-up and/or swelling	<ul style="list-style-type: none">• Weigh every morning and monitor changes up or down• Stick to recommended daily fluid intake• Raise swollen feet or legs• Control thirst by using sugarless gum, sucking on ice, avoiding salty or sweet food	<ul style="list-style-type: none">• If weight increases quickly by 2kg or more over 2 days or swelling significantly increases (feeling bloated or clothing or shoes are tight)• If weight rapidly decreases this may be due to dehydration
Changes in breathing	<ul style="list-style-type: none">• Avoid stairs and hills• Sit upright and use extra pillows to sleep	<ul style="list-style-type: none">• If breathing becomes more difficult, (for example preferring to sleep in a lounge chair), or worsening cough
Tiredness	<ul style="list-style-type: none">• Have rests before becoming too tired• Break tasks into manageable pieces	<ul style="list-style-type: none">• If fatigue worsens significantly and regular activities become difficult to complete
Light headedness	<ul style="list-style-type: none">• Move slowly in stages when changing position such as getting out of bed and or standing up	<ul style="list-style-type: none">• If the light headedness is causing the person you are caring for to experience falls or lose their balance

Tests and monitoring

Below are brief descriptions of some common medical checks that guide the management of heart failure. These checks are to help the person you are caring for manage their heart failure in the best way possible.

Blood test to check if:

- the kidneys and liver are working well and processing medications,
- the blood is carrying enough oxygen from the lungs to the body,
- the thyroid is functioning correctly.

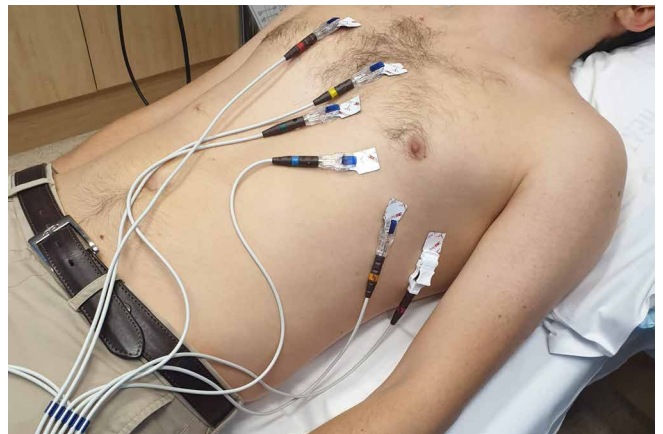
Chest x-ray is used to detect fluid build-up (congestion) on the lungs.

Coronary angiogram is where a thin, hollow tube called a catheter is inserted into a large blood vessel that leads to the heart. A dye injected through the catheter shows up on x-rays and helps the doctor to find narrowing or blockages of blood vessels that supply the heart.

Echocardiogram (Echo) is an ultrasound of the heart that looks at the size, structure, and heart movement. The ejection fraction (EF) is the percentage of blood in the heart that is pumped into the body during contraction (normal is between 50% and 70%). This procedure is important to determine the diagnosis and the type of heart failure.



Electrocardiogram (ECG) is where several leads are connected to electrodes that have been stuck onto the body and a machine records the rhythm and speed of the heartbeat.

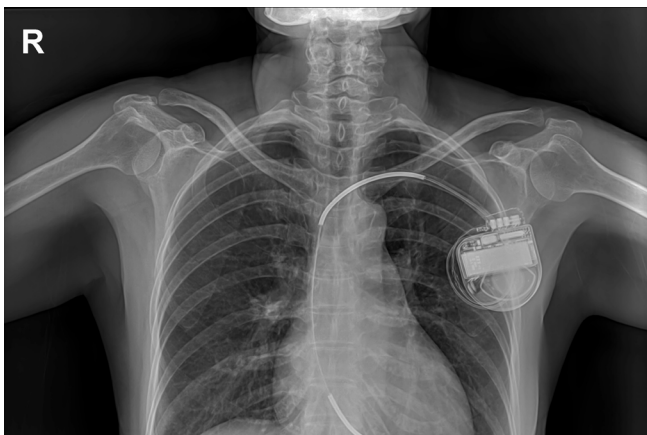


Magnetic resonance imaging (MRI) is used to get a much more detailed picture of the heart than can be obtained by an echocardiogram.

Cardiac devices

Under certain circumstances, the doctor might recommend a cardiac device. Below is a brief description of some of the implantable cardiac devices used in heart failure patients:

Pacemakers monitor heart rate and send small electrical impulses to the heart chamber to keep the heart beat regular. This device may be used if the heart beat is too slow and is not helped by medication. A pacemaker is small and is implanted just below the collarbone. It contains a computer, a battery, and some electrodes.



Cardiac resynchronisation therapy (CRT) device helps coordinate the contraction of the chambers of the heart so it pumps blood to the body more effectively. The device also acts as a pacemaker. The CRT device is implanted just below the collarbone.

Implantable cardioverter defibrillator (ICD) may be used in heart failure patients who have an irregular heart rhythm. Upon detecting a slight irregularity in the heart rhythm, the device delivers small electrical impulses to the heart. If this doesn't correct the rhythm, the device delivers a small electrical shock to the heart. If this still fails to correct the rhythm, the device sends a bigger electrical shock to the heart muscle from the inside of the heart. This bigger electrical shock is called defibrillation.

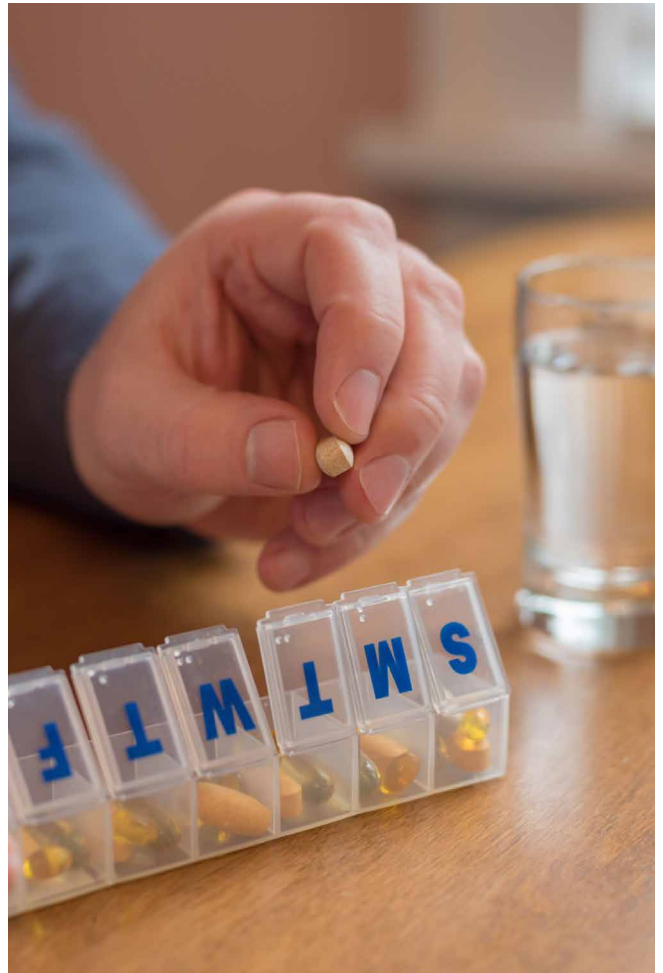
Left ventricular assist device (LVAD) may be used when a heart failure patient is waiting for a heart transplant, or when a transplant may not be possible. This device assists the heart in pumping blood around the body. The device does not replace the heart, or the function of the heart, but simply assists the heart.

Medications

There can be many medications prescribed to manage heart failure. Remember, patients can have heart failure for very different reasons, so the medications for the person you are caring for may differ from that of another heart failure patient. Some medications cause mild side effects and can take some getting used to.

You can help by encouraging the person you are caring for to:

- persevere and follow the doctor's instructions,
- seek advice from the doctor, pharmacist, or nurse if the side effects are significant, rather than suddenly stopping a medication,
- understand the purpose of each medication,
- use memory aids, such as setting a regular alarm, or using a dosette box or Webster Pack from a pharmacy,
- fill prescriptions before the medication runs out,
- not use 'Dr Google' (the Internet) for advice on medications,
- not take 'natural' medications without first consulting the doctor,
- carry an updated medication list at all times (e.g. in your wallet, purse or on your phone).



Some of the more common heart failure medications are explained briefly in the table below.

Class of drug	Common examples	What they do	Possible side effects
Angiotensin-converting enzyme inhibitor (ACEI)*	Perindopril Ramipril Lisinopril	Relax blood vessels to reduce the workload of the heart	<ul style="list-style-type: none"> • Dizziness • Cough • Headache
Angiotensin receptor blocker (ARB)*	Valsartan Irbesartan Candesartan	Relax blood vessels to reduce workload of the heart	<ul style="list-style-type: none"> • Dizziness • Headache
Beta blocker	Bisoprolol Metoprolol XL Carvedilol Nebivolol	Reduce heart rate to reduce workload of the heart	<ul style="list-style-type: none"> • Tiredness • Dizziness
Mineralocorticoid receptor antagonist (MRA)*	Spironolactone Eplerenone	Prevent heart enlargement	<ul style="list-style-type: none"> • Enlargement of male breast(s)
Angiotensin receptor-neprilysin inhibitor (ARNI)*	Sacubitril-Valsartan	Relax blood vessels & increase salt & fluid elimination to reduce workload of the heart	<ul style="list-style-type: none"> • Dizziness
Sinus node inhibitors	Ivabradine	Reduce heart rate	<ul style="list-style-type: none"> • Visual disturbances
Digitalis	Digoxin	Help to regulate heart beat and allow the heart to pump more efficiently	<ul style="list-style-type: none"> • Nausea • Headache
Diuretics*	Furosemide (Frusemide)	Help the body get rid of excess fluid to ease congestion	<ul style="list-style-type: none"> • Increased urine output • Dehydration
Anticoagulant	Warfarin NOACs	Inhibit the formation of blood clots	<ul style="list-style-type: none"> • Bruising • Minor bleeding
Nitrates	Glyceryl trinitrate	Cause the blood vessels to relax to reduce workload of the heart	<ul style="list-style-type: none"> • Headache • Flushing • Dizziness

* It is recommended that kidney function and potassium levels be checked for people taking ACEIs, ARBs, MRAs, ARNIs or Diuretics.

Special circumstances



Caffeine intake – caffeine intake is considered relatively safe in heart failure, but it must be remembered that caffeine consumption needs to be included in the daily fluid restriction, so limiting intake to 1–2 cups of coffee a day is recommended.



Contraception – while the oral contraceptive pill has been associated with increased blood pressure and development of blood clots, the use of a low dose oral contraceptive is possible in heart failure. Other options may include barrier contraception, intrauterine devices, partner vasectomy, and tubal ligation. As with pregnancy, consult the doctor before taking action.



Driving – if the person you are caring for has a Queensland Drivers Licence, the heart failure diagnosis must be reported to the Department of Transport (in Queensland, Australia). This is because medical conditions such as heart failure may interfere with the ability to drive safely. The GP is able to assess the person you are caring for to determine their fitness to drive and if declared fit to drive, issue them with a medical certificate. This assessment must be lodged with the Department of Transport and it may be that the Drivers Licence then becomes a conditional licence with an “M” placed in the conditions section of the licence.

This medical certificate must always be carried with the Drivers Licence. A conditional licence usually needs to be reviewed annually.



Flying – air travel should not be undertaken if heart failure symptoms are poorly controlled. Those with stable symptoms and no recent changes to medications may consider air travel. Contact the airline before travelling if home oxygen is being used.

Short air travel (under 3 hours) is considered low risk. During a long-haul flight there is risk of fluid build-up, dehydration, and deep vein thrombosis (DVT). These risks can be managed by moving legs and feet for 3–4 minutes per hour while seated and moving around the cabin occasionally. Patients should wear travel socks, fitted by a community pharmacist or medical equipment supplier, both during the flight and for several hours after arrival at the destination. When travelling overseas patients should take a letter from their doctor itemising the list of medications and other equipment required for travel.



Pregnancy – a heart failure diagnosis is likely to impact upon plans to become pregnant.

Pregnancy can worsen heart failure and increase the risk of death for mother and foetus. The person you are caring for should consult their doctor before attempting to become pregnant.



Sex – both men and women with heart failure report problems with sexual function and interest. In men, erectile dysfunction can be worsened by medications.

In addition, sexual activity requires mild to moderate exertion (exertion comparable to climbing three flights of stairs, doing general housework or gardening). Sexual activity is considered safe in heart failure patients with mild or no symptoms (NYHA class I and II) but should be deferred in heart failure patients with more severe symptoms, until symptoms are controlled.

If you, the carer, are involved in an intimate relationship with the person you are caring for, it is important that you understand these issues. They carry the potential to create significant problems within an intimate relationship, but an understanding and caring attitude, along with some creative flexibility and lots of conversation, can help to head off any problems.



Vaccination – heart failure patients are at increased risk of respiratory infections which can

place stress on the heart. It is recommended that all heart failure patients are vaccinated against influenza (the “flu”) every year, and pneumococcal disease periodically. In many cases, these vaccinations will be provided free of charge to heart failure patients.



Weather – the person you are caring for is less able to regulate their own body temperature because of the altered processes of the body caused by heart failure. Some medications can also interfere with the ability to regulate body temperature. This appears to be particularly so during exercise.

You can help by encouraging the person you are caring for to wear appropriate clothing to avoid getting too hot or cold. During hot weather, the person you are caring for can drink a little more to avoid dehydration and should avoid exercise except in an air-conditioned environment.

Money matters

Many chronic conditions like heart failure can affect you financially due to the cost of treatments and loss of work. There are many schemes that could financially help you or the person for whom you care. The Human Services website (humanservices.gov.au) provides up-to-date information on the benefits listed below.

Aged Care Assessment Team (ACAT) is available for patients over 65 years of age (over 55 years if Aboriginal or Torres Strait Islander) to identify eligibility and approvals for packages of care to assist the person to remain in his/her own home or for respite or permanent care in a residential facility.

Carer Allowance is a fortnightly supplement if you give additional daily care to someone who has a disability, serious illness, or is frail aged. There is an annual income test, but no assets test. Carer Allowance is not taxable and is in addition to your wages, Carer Payment, or any other income support payment.

Carer Payment provides financial help to people who are unable to work in substantial paid employment. This must be because they provide full time daily care for either someone with severe disability or medical condition, or who is frail aged.

Carer Supplement is an annual lump sum payment. It helps with the costs of caring for a person with disability or a medical condition. You'll get Carer Supplement if you're receiving Carer Payment or Carer Allowance.

Safety Nets are available for medicines and doctor visits through the Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Schedule (MBS). It is important that the person you are caring for registers for a PBS Safety Net card and the Medicare Safety Net in order to access benefits once a certain threshold is reached. For more information pbs.gov.au/info/healthpro/explanatory-notes/section1/Section_1_5 Explanatory Notes.

National Disability Insurance Scheme (NDIS) is for people under 65 years who usually need support because of a permanent disability. For more information ndis.gov.au. The National Disability Insurance Scheme (NDIS) can still be accessed even if the person is getting a Disability Support Pension (DSP).

Total and Permanent Disability or Income Protection may be available to the person you care for if they have extra insurances or those attached to their superannuation. You may also both be eligible to access your superannuation early on grounds of financial hardship.

Your emotional health

It's common for carers to experience a range of feelings about their role and responsibilities. Caring for someone can be rewarding and satisfying. However, at times you may experience more challenging emotions. Many of the feelings you experience may also be experienced by the person for whom you care, such as worrying a lot, feeling anger and frustration, or guilt. Many people also feel lonely and isolated.

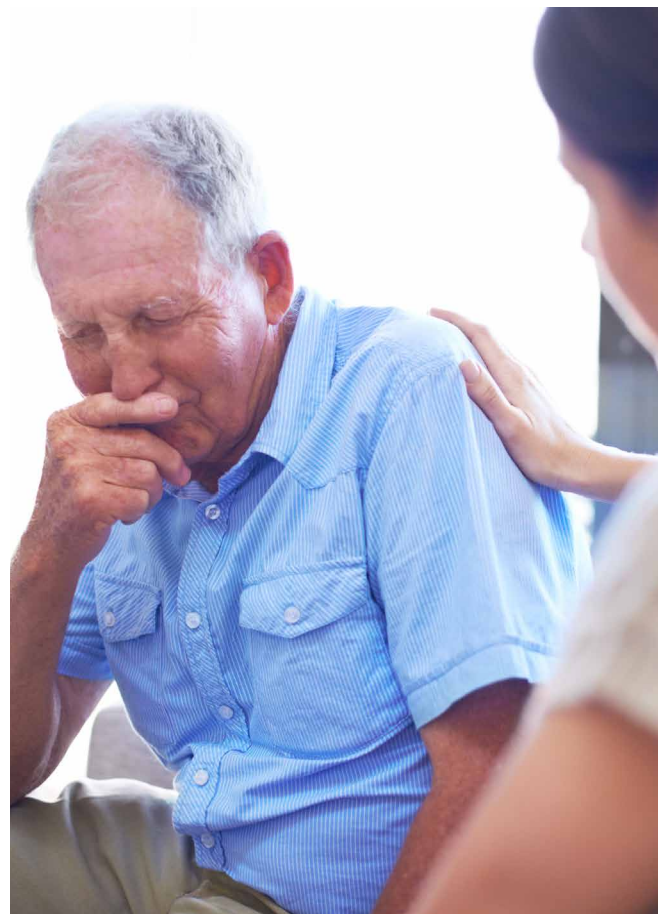
At times you, or the person you look after, may feel down or sad. Clinical depression is where these feelings do not go away. Some symptoms of depression include:

- feeling sad or empty,
- losing interest and pleasure in activities you used to enjoy,
- feeling tired all the time and/or having trouble concentrating,
- having problems sleeping,
- feeling that life isn't worth living.

Talk to your doctor if you or the person whom you care for is depressed. There are various options available for treating depression in heart failure, so do not despair. Avoiding carer burnout is important for your well being and ability to continue your support role effectively. Keeping yourself healthy and asking others for help is important.

Other tips to help you cope include accepting limits to your care (e.g. providing personal care) and getting help for these tasks. Taking some time for yourself most days, such as meditation, a short walk, reading, or a social contact is very important.

Dealing with uncertainty of heart failure can be stressful for both you and the person with the condition. You both may find it easier to cope with uncertainty if you focus on things you can currently control.



Relationships

Heart failure can impact the ability to function in any of the roles the person you are caring for normally plays, including that of spouse/partner, parent, friend, or child. This has the potential for placing a lot of strain on relationships.

This inability, for the person you are caring for, to participate in all the activities that they once did can create significant feelings of loss and grief and sadness in both the person you are caring for and yourself. It isn't difficult to see how this can happen, especially if the person you are caring for is limited in their ability to drive, to travel, to engage in physical activity, or to engage in a sexual relationship.

Sometimes household responsibilities (such as paying bills, grocery shopping, housework, gardening) may need to be redistributed. Undertaking more responsibilities can place a greater burden on you, as the carer, and it can also change the dynamics of your relationship.

Added to all the matters above, the unpredictable progression of heart failure can add stress to an already changed relationship.

The important thing for you to remember, as the carer, is that starting a conversation about anything that is concerning you, can help to head off any issues before they can be allowed to grow so big that they impact on your relationship in any detrimental way.

The best advice is to talk, talk, talk!



References

- Atherton J, Sindone A, De Pasquale C, et al. 2018. National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand: Guidelines for the Prevention, Detection, and Management of Heart Failure in Australia 2018. *Heart, Lung and Circulation*, 27(10), 1123–1208.
- Atherton J, Audhem R, and Connell C. 2019. Heart failure guidelines: A concise summary for the GP. *Medicine Today*, 20(6), 14–24. Retrieved from <https://www.heartfoundation.org.au>
- Carers Queensland. 2018. *Staying Healthy – Fact Sheet*. Retrieved from <https://carersqld.com.au/staying-healthy-fact-sheet/>
- Carers Queensland – Making life better. 2019. Retrieved from <https://carersqld.com.au/>
- Dornelas E, and Sears S. 2018. Living with heart despite recurrent challenges: Psychological care for adults with advanced cardiac disease. *American Psychologist*, 73(8), 1007–1018.
- Heart Failure Matters. Retrieved from https://www.heartfailurematters.org/en_GB
- Medical fitness to drive. 2019. Retrieved from <https://www.qld.gov.au/transport/licensing/update/medical/fitness>
- National Heart Foundation of Australia. Living well with heart failure. Melbourne: National Heart Foundation of Australia, 2018
- Novartis. *A Quick Guide to Caring for Someone with Heart Failure* [eBook]. Retrieved from <https://www.novartis.com/sites/www.novartis.com/files/nvs-hf-carer-booklet.pdf>
- Patient Education. 2019. Retrieved from <https://www.heartonline.org.au/articles/patient-education/education-topics-for-heart-failure-education>

