



A patient support program by



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Please note: This booklet should not replace and/or substitute the interactions with and advice you and your loved one gets from your doctor/s, and if you have any concerns about their condition, you should discuss these with your doctor/s at the earliest opportunity.

You are reading this booklet most probably as your loved one has been diagnosed with heart failure. If you are the one who has the primary responsibility of taking care of your loved one this booklet will be helpful. It has been developed as an easy reference guide to enable you to understand the condition and how you can help your loved one to self-manage it.

A caregiver's guide

Most people don't hesitate when they are called upon to help a loved one who is ill. But being a full-time caregiver may be an unfamiliar role for you. It is important to consider the long-term implications of this commitment, because so many people with heart failure will progress to an end stage of their disease and will need assistance to survive.

Being a carer for someone who has a heart condition can be very demanding - both physically and emotionally. Some carers will juggle their job at work with home and family life as well as looking after their partner or relative. Caring for someone with heart failure means understanding the condition and its impact on life, but should

not mean that you are defined by the condition. Hence, a set of principles that helps you to take care of yourself, as well as him or her.

Try to always remember the following and talk these through with your loved one.

- Remember you are doing a great job, take pride in that.
- Try and have time for yourself, ensure that you still undertake hobbies or events that you most enjoy.
- Take care of yourself - it is important to remember this is not being selfish but sensible, you need to be well in order to be able to help your loved one be well.
- Don't be afraid to ask for support - everyone has their limits, recognise yours and call on those who can support you.
- It is perfectly normal to have a range of difficult emotions, feeling angry or down, having good days and bad days; on those days, do not feel guilty.
- It is important that your commitment to your loved one is recognised and that family and friends also understand the significance of your role, so talk about your role and any difficulties that you may be having.

Understanding Heart Failure

The heart is a strong, muscular pump helping deliver oxygen-and nutrient-rich blood to the body's cells. When the cells are nourished properly, the body can function normally. With heart failure, the heart doesn't pump properly and is often enlarged as it works harder to pump blood. Heart failure symptoms usually develop over time as heart becomes weaker and less able to pump the blood that the body needs.¹

The vast majority of the time heart failure is due to the heart muscle being damaged because of poor blood supply to heart. This can happen when there has been a heart attack, or a history of high blood pressure, which has affected the heart.^{2,3} Various other causes could be related to the heart (genetics, virus infection, valve damage, etc.) or due to lifestyle factors (obesity, smoking, alcohol, recreational drugs, etc.).^{3,4}

There's no question that this heart condition is serious. But the good news is that there is a lot of understanding about the condition, a number of effective treatments available and in development, and several things you and your loved one can do to play an active role in the management of their heart condition.



Heart failure symptoms can sometimes get rapidly worse. This is called an acute episode or acute heart failure. This may be due to a temporary event and not last for long, but acute heart failure will require some form of intervention from health care professionals.³

Important to understand the severity of Heart Failure

The severity of the disease, as explained by the doctor and what your own circumstances are, will determine how much of an impact the heart condition of your loved one has on your day-to-day life. One of your most important role is to help your loved one to stay positive and have a can-do attitude – this can really help them to play an active role in their own condition. Research shows that those who can adapt to their illness and take control of it have a better quality of life.^{5,6}

Although it will probably change aspects of your own life, it does not need to take over your life completely. Whether your caring involves emotional support, taking on extra chores or caring for someone 24 hours a day, you need to have a life of your own and to take care of your own physical and mental wellbeing too. This includes taking regular breaks and time out for yourself. It has been seen that focusing on yourself and giving yourself some time away from ‘caregiving’ makes you a better caregiver

Helping with daily activities

The person you are caring for may have considerable physical limitations and must rely on others for help with relatively simple but important tasks. Some of the ways in which you can help are listed below.⁷



Driving: A person with heart failure may no longer be able to drive because of irregular heart rhythms, fainting spells, or other complications of heart failure. But he or she will need to go to frequent doctor appointments and will need someone else to drive to these appointments and to other destinations too.



Drugs: Most people with heart failure require multiple medicines to control their symptoms. Many of these drugs must be taken several times each day. Help your loved one by organizing the drugs, perhaps using a pillbox with one compartment for each day of the week or marking a calendar to help keep track of when to take medicines.



Monitoring symptoms: If your loved one cannot keep track of his or her own weight, you may need to help. Even small changes in weight can signal a dangerous buildup of fluid. You should encourage your loved one to weigh himself or herself at the same time every day and to call the doctor if there is a sudden increase in weight. Call the doctor if other symptoms of heart failure get worse.





Encourage your loved one to keep an eye on:³



Sudden weight increase
(1.8-2 kg in 2 to 3 days)



Swelling on lower legs,
abdomen or feet



Difficulty in breathing or
increased coughing



Increase in fatigue affecting
day-to-day activities



Dizziness causing them
to stumble or fall



Medication side effects
or if they feel it's not
having the desired effect



Temperature: Symptoms of heart failure often get worse during hot, humid days. Try and remain indoors and in a cool environment



Giving emotional support: Your loved one will have good and bad days, both physically and emotionally. Although you will always try to be as supportive as possible, you too will have good and bad days, and sometimes you may find it gets too much.

You can help provide the emotional support that your loved one needs by⁷



Offering encouragement: Adopting the lifestyle changes that doctors recommend for heart disease can be difficult for your loved one. Encourage him or her to start slowly and gradually build up to an overall goal.



Offering help encourage your loved one to remain active: Even though your loved one may have physical limitations, he or she should still try to stay as active as possible. Moderate exercise and doing simple tasks around the house can be safe. This can help your loved one feel better both physically and mentally. If you are concerned about what activities are safe, talk with the doctor.



Asking if you can participate in doctor visits : You can offer support by sitting in on doctor visits and taking notes. This can help your loved one remember important instructions. He or she may also feel less alone during recovery.

Taking care of yourself

Being a caregiver can be mentally and physically challenging. There are steps you can take to help make the situation more manageable for yourself. Remember that you will be an effective and loving caregiver only if you are in good physical and mental shape.⁷

Additionally, your loved one's heart failure may impact areas of your life for which you may need to consider seeking some help and guidance, whether that is related to:

- Finances
- Work
- Intimacy of your relationship

Tip: Try and support your loved one wherever possible to be self-reliant in managing their illness





Talk to your loved one

A significant part of caring for someone with a heart problem is helping them to get on with their life and have as much independence as possible, within the limits of the symptoms they experience. That's why it's good to talk regularly about the help you are giving, and to find out what is important to them to be able to do. It may be they would like to try to do a little more for themselves and don't need some of the help you have been giving, or that there are particular tasks – like taking a shower or getting dressed in the morning – that with your help would become less daunting.

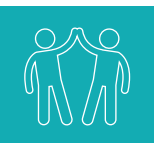
During these talks, you may also find that the person you care for opens up about how they feel about being diagnosed with heart failure (angry, confused, fearful, relieved they are alive, frustrated) which can also help you make decisions together about the support you give. For example, if the person you care for feels depressed or frustrated and these feelings don't go away, it might be a good idea to encourage them to speak to their family doctor.



Enlist help when you need it: If possible, don't take all the responsibilities on yourself. You may be able to involve other family members or a visiting nurse. If required, try to hire a food delivery or housekeeping service to help with the shopping and cleaning.

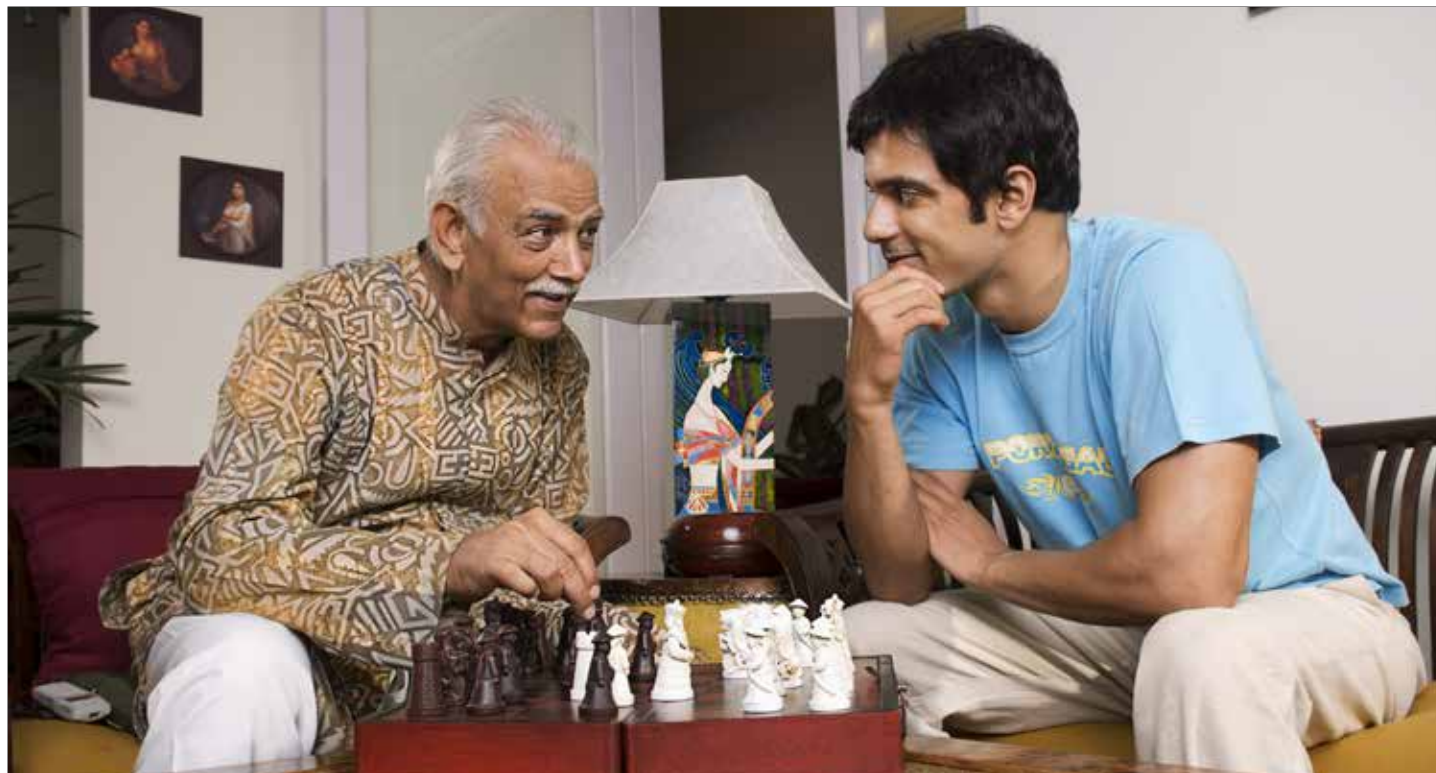


Take time for yourself: Being a caregiver can be stressful and time-consuming. To avoid "burnout" and to continue to provide care and support, it is important to save some time for activities that you enjoy.



Seek emotional support when you need it: Being a caregiver to a loved one whose health is deteriorating can be emotionally difficult. If you are having trouble coping with your feelings, seek advice and counseling from family members, trained mental health professionals, or spiritual advisors.





Talking to the person you care for about what is important to you is also essential. It can help them understand why you are, for example, overprotective (you don't like to see them struggle) or why you sometimes try to persuade them to do more (you want them to be as independent as possible) or get a bit irritated with them (it's may be because you are worried about how you are doing as their caregiver). It can also help to ensure that the person you are caring for understands that whilst you want to support and help them, you also need time to look after yourself too.

Remember, your loved one may not see the need for support in the same way that you do. They are receiving support from you – the caregiver. You need to make sure that there is someone to look after you as well, and that there are enough people on the team to make sure you do not feel isolated and overburdened.

In the beginning, it's difficult to find a balance between doing too much or not enough. You want to encourage independence but also be realistic.

Important to note: Caring for a loved one with heart failure will probably change certain aspects of your own life, but it does not need to take over your life completely.

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