



Tips for caregivers



Looking after a friend or family member with a long-term condition is tough.

We know that living with heart failure can be frightening, restrictive and distressing for both patients and their carers, and that caring for a person with this condition often has a considerable effect on the psychological and physical health of caregivers¹.

Caregivers often make considerable sacrifices to look after family members or friends with a long-term condition, such as heart failure, and their job, hobbies, freedom and health can all suffer.

The good news is that there is help available, and it is possible to relieve some of the burden of caring for a person with these types of conditions. Please read on to find out more.



The value of knowledge

Having a good knowledge and understanding of your friend or family member's heart condition is a huge advantage for carers. A lot of the distress and anxiety suffered by carers comes from not understanding what is happening to their loved-one, and not knowing what to expect.

Here are some useful tips to help you understand patients with heart failure better:

Patients with heart failure often experience good days, following by bad days, followed by more good days.

This often confuses carers, who are distressed to see their family member or friend apparently getting better, only to see them relapse. However, carers who have a good knowledge of the condition are prepared for this, and that makes them better able to handle the emotions involved.

Knowing how patients experience their condition, and the challenges and demands that face them, helps carers to see why those patients are often irritable or distressed.

While some patients will take out their unhappiness on the people closest to them; the experience feels less personal and less distressing for both parties if the carer knows and understands why it is happening.

Knowing more about heart failure may help you to see things from the patient's perspective, and help you to better prepare for the challenges involved.

Understanding heart failure can also help you to be a more effective carer. But how do you, a busy carer, find out more about such a specialist subject?



Sources of information

One source of information is your family member's or friend's healthcare team. Although going to appointments with them may be difficult or time-consuming, it can be vital. You can use this time to ask the doctors to tell you more about your family member's situation, and to fully understand their treatment. This can be extremely important, because many people with heart failure may have problems with their memory that can cause them to forget to take medicines. If you know what needs to be done, you can step in when needed.

Another great source of information are any booklets given to your family member or friend by their healthcare team. This can give you a great overview of heart failure, and you can read it in your own time.

Finally, your family member's healthcare team will be able to tell you about national and local organisations that can give you both information and support. There is evidence that having somebody to talk to, especially somebody who is in the same position, can make caregivers feel better^{2,3}.



Tips for looking after yourself

- Remember that while the focus may often seem to be on the person who is ill, the health and happiness of carers is important too. If you do not take good care of yourself, you may burn out and be unable to care for your family member or friend.
- Ask your local authority or council, local healthcare organisation and/or your family member's or friend's healthcare team, about counselling services available to you.
- Make sure you have somebody to talk to or support group, and hobbies, friendships, activities, interests outside the home that will help you to rest and relax.
- Rest is important for patients, but it is also crucial for carers. Make sure you get sufficient rest and sleep.
- Ask for help when you need it — friends and family members can be sources of support and practical assistance.





Understanding your family member's or friend's condition can help you take care of them more efficiently. Please also ask them to share with you the information that we have provided in this program, this information is likely to improve your understanding of heart failure.

If you happen to have an urgent medical concern, please call your doctor, go to your local emergency room, or call your local Emergency Contact number. Remember, your doctor is your primary source for information on your condition and treatment. Be sure to speak with them if you have any questions or concerns.

References

1. Pattenden JF, Roberts H, Lewin RJP. Living with heart failure; patient and carer perspectives. *Eur J Cardiovasc Nurs* 2007 Dec; 6 (4): 273-9.
2. Imes CC et al. Descriptive study of partners' experiences of living with severe heart failure. *Heart Lung* 2011; 40 (3): 208-16.
3. Martensson J, Dracup K, Fridlund B. Decisive situations influencing spouses' support of patients with heart failure: a phenomenographic analysis. *Can J Cardiovasc Nurs* 2010; 20 (3): 9-17.