

Living with Advanced Heart Failure

Coping with Symptoms and Uncertainty



Who is the booklet for?

This booklet is for people, families, friends and caregivers of people living with advanced heart failure.

It is designed to:

- Help you understand more about heart failure and how it affects you and your family member or care recipient.
- Describe ways for caregivers to help their family member/care recipient.
- Suggest how to work with the health care team.
- Provide suggestions and resources to help you cope in your role as caregiver.

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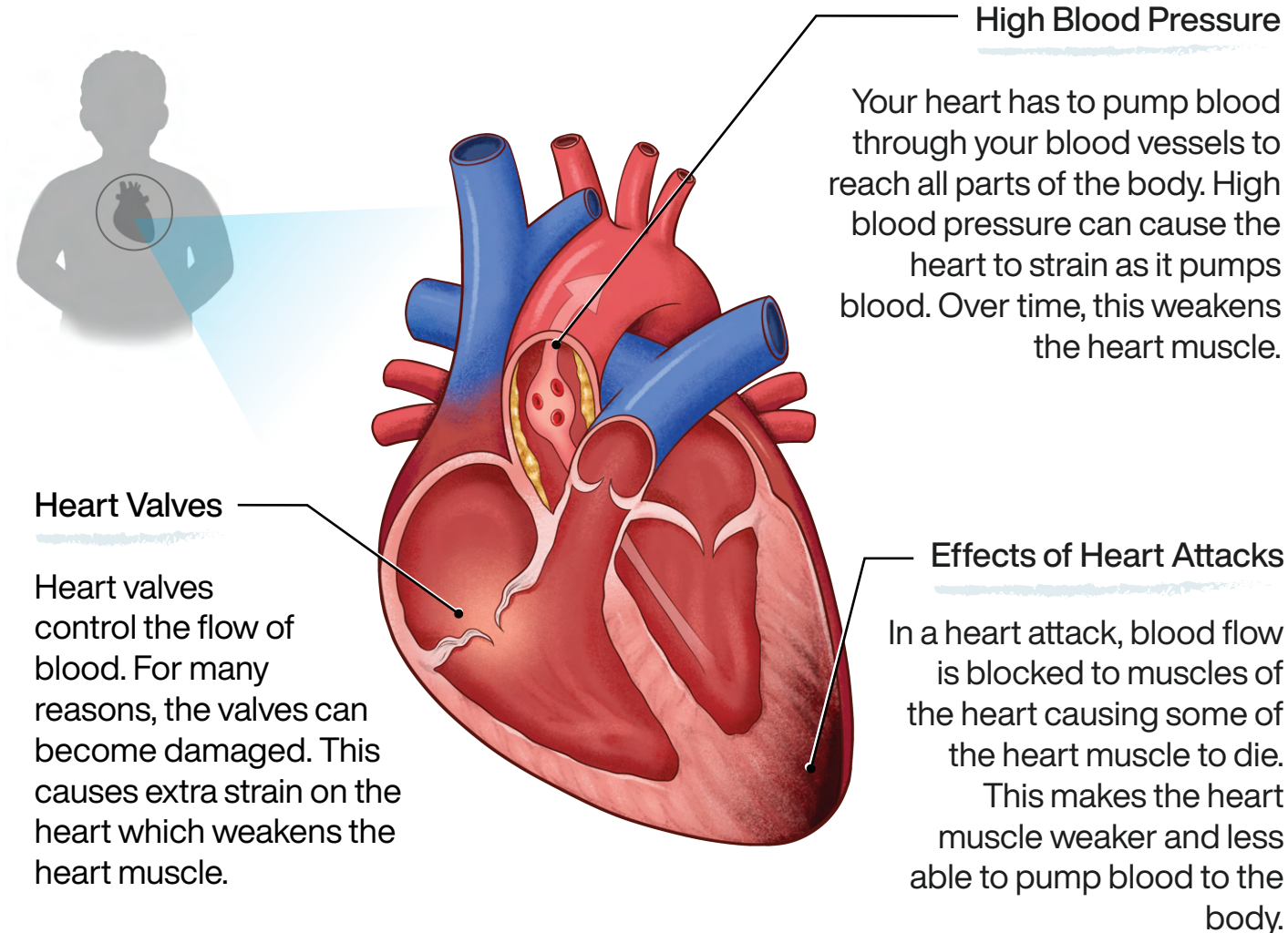
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What is advanced heart failure?

What is heart failure?

Heart failure is any condition where the heart cannot pump enough blood to meet the body's needs.

Common reasons for a weakened heart are:



Many other conditions can cause heart failure. Please talk to your health care team for more information.



Remember: You and your family member are not alone. Nearly 750,000 Canadians are living with heart failure and 50,000 people are diagnosed each year. About 10 percent of these patients have advanced heart failure.

[Click here to learn more on The Heart Hub](#)

How will advanced heart failure affect me, my family member, or care recipient?

Families and caregivers find it helpful to be informed about what to expect for the future. This allows them to start to prepare and to find the support they need to help the person with advanced heart failure in the future.

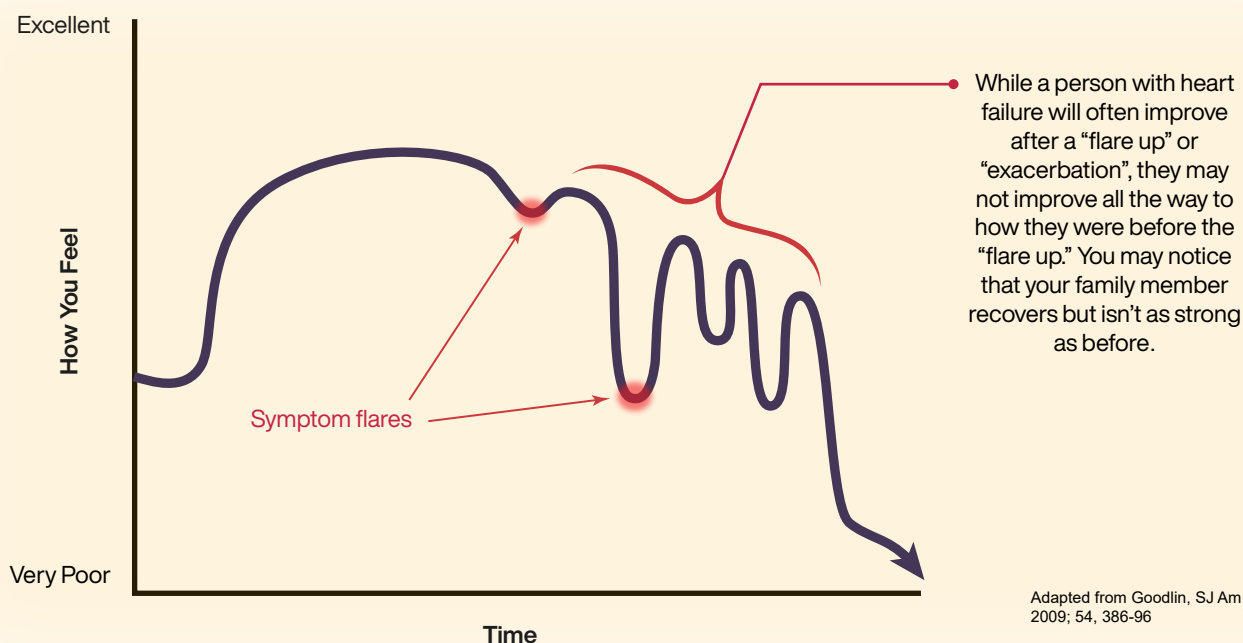
While it is impossible to predict specifically what will happen, we do know the general pattern of what to expect with advanced heart failure. Knowing what to expect in the future helps people prepare and be able to support their family member.

The symptoms of heart failure can be quite variable and unpredictable. Symptoms may get worse and better. Sometimes, a person's symptoms worsen over several days. They might feel more tired, more short of breath, and/or have more swelling. Sometimes medications can be adjusted at home. Other times, a person will come to a hospital or clinic for assessment.

We call these flare-ups "heart failure exacerbations" or "decompensated heart failure".

Over time, you may also notice more frequent "flare-ups". And you may notice that you or your family member is not recovering back to how they were before the "flare up". This pattern is shown in the picture below:

"Flare-Ups"



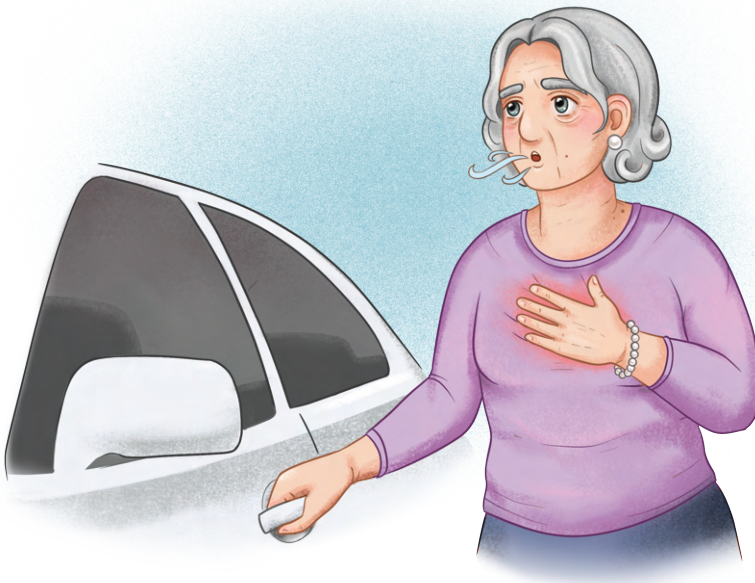
Although everyone is different and there are good medications and treatments to improve symptoms and increase longevity, people with advanced heart failure often have a shortened life expectancy. This is because there are no treatments that cure advanced heart failure.

Symptoms of advanced heart failure

Advanced heart failure can cause many symptoms. In this section, you will learn about common symptoms. Please discuss these symptoms with your healthcare team.

Breathlessness

Breathlessness is the feeling of not being able to catch your breath. It is also called “shortness of breath”. It is a common feeling, and can occur during activity, while resting, or even while sitting or lying down. Sometimes it gets worse when a person lies down flat.



Why it happens:

The heart needs to pump blood from the lungs to the body.

Fluid backs up into the lungs, making it difficult to breathe.

Breathlessness can be a frightening sensation. Feelings of panic can make the breathlessness worse, leading to a vicious cycle.

What can help:



Increasing “water pills” (diuretics) that help eliminate extra fluid through urine



Oxygen



Breathing exercises can help decrease the feeling of breathlessness and panic



Managing fluid intake



Other medications, such as opioids*, that help reduce the feeling of breathlessness.

[Click here to learn more on The Heart Hub](#)

***Speak with your doctor before adjusting your medications.**

• Fatigue

Fatigue is weakness or feeling tired more easily.



Why it happens:

In heart failure, the heart cannot pump enough blood to the organs and muscles of the body.

When the muscles and organs of the body don't get enough blood, a person tires more easily and feels fatigued (tired and weaker).

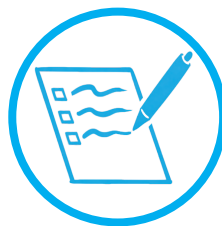
What can help:

Learn how to conserve your energy to build up your strength for daily activities and other things you enjoy. Practice the 4 Ps to conserve your energy: Prioritize, Plan, Pace, and Position.



Prioritize:

Decide what's most important and focus on that first



Plan:

Plan ahead to avoid extra trips and alternate between heavy and light tasks



Pace:

Maintain a slow and steady pace, resting before you feel tired. Listen to your body and know your limits



Position:

Sit when you can. Avoid bending and reaching too much as they can cause fatigue and shortness of breath

Learn more about conserving your energy [here](#)

Click here to learn more on [The Heart Hub](#)

Swelling

Swelling means that a person's feet, ankles, legs or abdomen will have more water in them and become swollen. They may feel heavy and painful. This may be at its worst at end of day or after sitting a long time.

Why it happens:

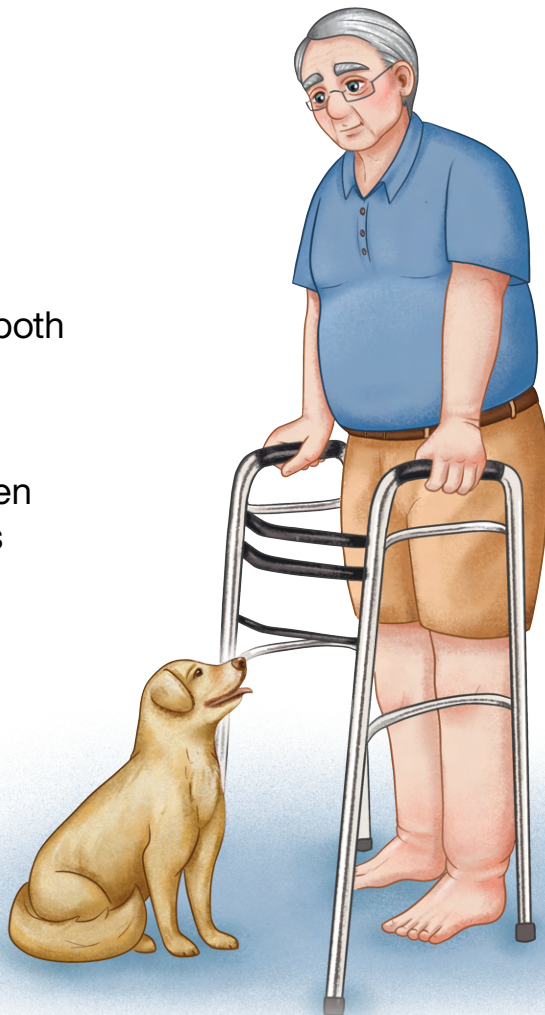
The heart is weakened and cannot pump blood effectively around the body.

Since the blood can't go forward from the heart, fluid backs up behind the heart into both the lungs and the body.

Without enough blood going to the body, organs such as the kidneys can suffer. When the kidneys aren't working well, a person is less able to make urine and get rid of extra fluid.

Fluid pools in lower areas due to gravity.

This can cause weight gain, mobility problems, and fatigue.



What can help:



Managing (decreasing) fluid and salt intake. Follow any instructions from your healthcare team



Increasing "water pills" (diuretics) to try and help your kidneys get rid of extra fluid



Elevating the legs

Click [here](#) to learn more about managing fluids.

Pain

Pain can happen in the chest or be experienced as general body aches and weakness. Chest pain can feel like tightness, cramping, or aching. There can also be general body ache and weakness.



Why it happens:

There are many reasons why people have pain. They may have chest pain from heart disease or pain from other common symptoms such as arthritis. There can also be general body aches and weakness.

What can help:



Acetaminophen*



Coping strategies like distraction, attention focusing, and imagery



If pain is more severe, low dose opioids**

***DO NOT TAKE** anti-inflammatory medications, such as ibuprofen (Advil), naproxen (Aleve), or acetylsalicylic acid (Aspirin) for pain or fever.

Low-dose aspirin for cardiovascular protection is okay if prescribed.

****Please speak with your doctor before adjusting your medications.**

[Click here to learn more on The Heart Hub](#)

• Nausea and changes in appetite

You, your family member, or care recipient may experience feelings of nausea or a decrease in appetite. They may not feel hungry, eat less than they used to or feel full after eating just a small amount of food.

Why it happens:

The heart is not pumping as well as it used to, causing fluid to build up in and around the stomach and intestines.

This will make a person feel bloated and less hungry.

There is less blood flow to the digestive system as well, making it harder to digest food.

Lastly, some medications can cause nausea.



What can help:



Focus on eating things they enjoy. Eat small amounts more frequently



Do not force yourself or your care recipient to eat



Sometimes a prescription medication called metoclopramide can relieve this symptom

[Click here to learn more on The Heart Hub](#)

• Confusion

Confusion means that it becomes harder to think clearly or remember things.



Why it happens:

Heart failure means less blood is being pumped to the brain.

Toxins can stay in the body longer because the kidneys can no longer get rid of them.

Both these things can lead to confusion.

What can help:



Provide a calm, quiet environment that is well-lit during the day



Ensure any hearing or visual aids are easily accessible



Talk to your family member to keep their mind active (for example, remembering the past)



Keep visitors to a minimum to prevent overstimulation



Install a night light in bathrooms or hallways

Try to have regular sleeping patterns



Encourage activity if you or your care recipient is physically able

[Click here to learn more on The Heart Hub](#)

● Anxiety/Depression

The persistent feeling of being worried or sad.

Why it happens:

Changes in a person's body such as weakness, fatigue, and other effects of heart failure can cause feelings of sadness or worry.

These feelings are common and important to talk about.



What can help:



Talk about how you are feeling, or encourage your family member/care recipient to share their feelings



Some people may benefit from medications to help with symptoms of depression and anxiety



Talk about your concerns or questions with your health care provider

Click here to learn more on
The Heart Hub

Coping Strategies

Additional Supports

Palliative Care

Palliative care teams are dedicated to improving the quality of life of people living with heart failure. They do this through careful attention to your symptoms, psychological and social support, education, and discussions to help people prepare for the future.

Palliative care can be added to existing care — in other words, palliative care support is available in conjunction with cardiology care. Palliative and supportive care is not only for help at end of life – but all along the illness journey, adding an additional layer of support to people living with heart failure.



Palliative care is available in all care settings including many heart function clinics and hospitals. In addition, palliative care supports are available when people living with heart failure wish to focus care more in the home environment.

Do not hesitate to talk to your cardiologist if you think you might benefit from adding palliative care. As well, your cardiology team might recommend palliative and supportive care when they see a need.

Interprofessional Teams

There are many other health care providers who may be able to support the needs of the person living with heart failure. Social workers assist with practical needs such as government support, caregiver benefits, and other programs that lend support. Physical and occupational therapists can help with mobility and safety in the home. Homecare supports provide personal care in the home such as bathing or respite. Ask your cardiology team if you feel you or your care recipient would benefit from an assessment.

■ Monitor Symptoms

Your cardiology team will teach you what symptoms to monitor. Make sure you are clear about what to watch for, such as increased weight, swelling, or breathing trouble. They will also tell you who to call when symptoms are getting worse.

Consider keeping a log book of important symptoms and information like daily weights, swelling, and breathing. It also helps the team to treat these symptoms and help your family member/care recipient live comfortably! At the end of this booklet, there are sample charts that might help you to keep track.

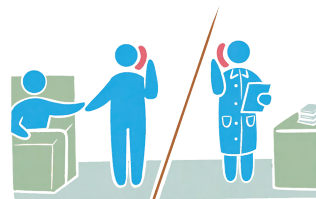
Keep track of the medications you or your recipient is taking and why. Your cardiology or palliative/supportive care team can help you understand these medications. There is a page at the end of this booklet to write them down.

When symptoms are changing:

Understand who to call if symptoms get worse. Discuss this with your healthcare team in advance. For example:

Primary care clinician (family doctor, nurse practitioner, etc.)

Your contact: _____



Heart failure clinic

Your contact: _____



Health care team member who monitors a person's symptoms remotely at home using a scale and blood pressure cuff or monitor.

Your contact: _____



Medical practitioners who visit at home

Your contact: _____



■ Cope with uncertainty

You can ask your health care team any questions you have. It can help to discuss with your friends and family in advance and write down your questions. Some families have difficulty asking questions about their family member's condition and what changes to expect over time. You can use the questions below to help ask about these topics:



1. How can I expect my/their health to change over time?
2. Are there other supports we should have (e.g., home nursing, palliative care)?
3. How long can I expect to live/expect them to live?
4. What kind of treatments might I/they need?
5. What is the best we can hope for? What is the worst we might face?
6. How will this illness and its treatment affect me/how will it affect our family?
7. Who do we call when we need help?

It is important to remember that the answers to these questions may change over time, and you can feel free to ask the same questions at future appointments.

Click here to learn more on
The Heart Hub

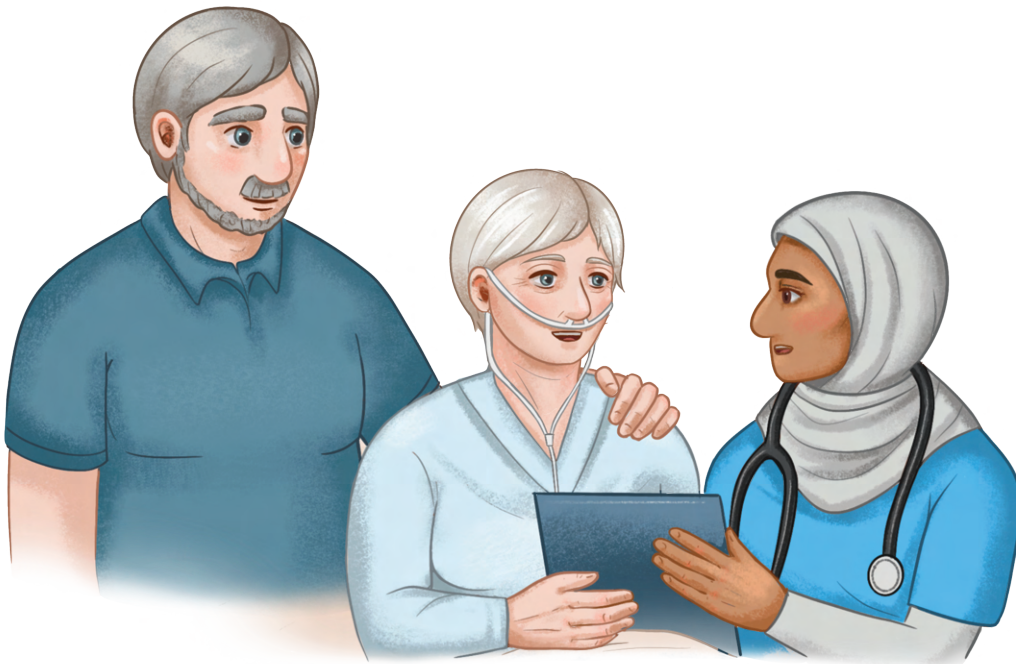
■ Prepare for the future

Advanced Care Planning

Advanced Care Planning is a process of learning about health, learning about what to expect in the future, and then thinking about and sharing what is important. Advanced care planning helps you and your family or caregiver be prepared for the future by understanding:

- The role of a substitute decision maker
- Information about an illness and what to expect in the future and
- What is important to a person.

This prepares a person and their substitute decision-maker for the future.



These are normal, healthy conversations that can happen over time. They are not one-time conversations. Although there is a lot of uncertainty with advanced heart failure, being prepared as much as possible is a good way to manage the uncertainty.

Here are resources that will help you understand more and work through how to prepare yourself and your family member for the future.

See more about Advanced Care Planning [here](#).

■ Self-care

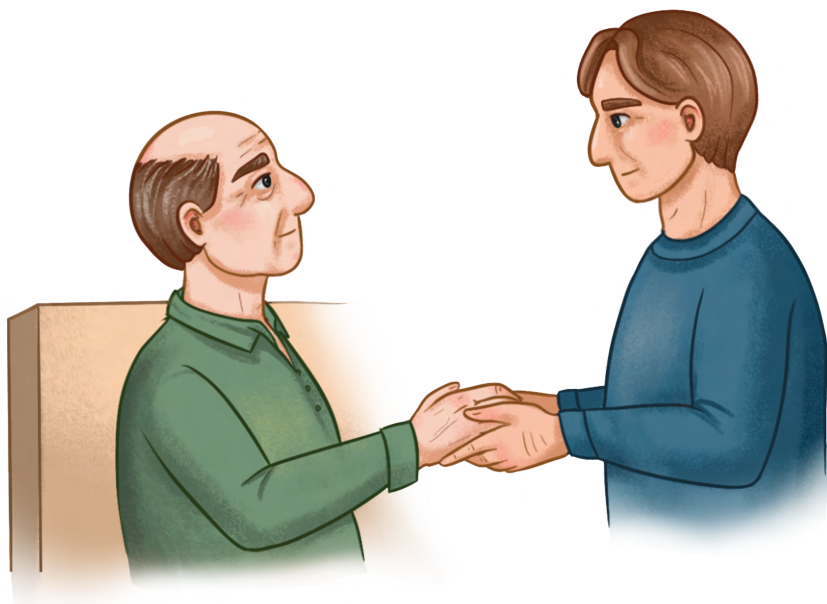
What might you feel emotionally?

Is it normal for moods to change? Yes! For both the person living with heart failure and the caregivers. Stress and emotional changes are expected when living with heart failure. It is important to recognize these changes and to talk about them with health care professionals and loved ones.

You may feel:

- Loneliness
- Emotional or Physical Stress
- Worry
- Sadness
- Anger
- Frustration

Why might you feel this?



Caregiver

- Caring for a family member or care recipient is difficult
- It is common to not know how to cope with these emotions
- You may feel isolated

Recipient and Caregiver

- Dealing with sickness is stressful
- There are many emotions involved as a person becomes more ill
- It is hard to balance illness with managing other obligations and activities

What can you do?

- Talk about it! Mood and mental health are just as important as the physical symptoms of heart failure. No change is too small to talk about with your health care provider, counselor, spiritual advisor, or anyone else you like
- Early management is best!
- Identify what makes you stressed and how you respond
- Maintain friendships and social contacts



What techniques can you use?

Try relaxation techniques like:



Deep
Breathing



Guided
Imagery



Exercise



Listening to
Music



The Mayo Clinic's website has more information on relaxation techniques.

To visit the Mayo Clinic website, click [here](#).

Self-care continued

- Contact your friends and other personal supports
- Take a moment to practice your relaxation technique
- Keep a log of your stressors and how you handle them. What works? What doesn't?
- Seek ongoing help from all members of your health-care team
- Practice daily relaxation techniques
- Continue to eat well, exercise, and maintain social contacts



Helpful Tools: Symptom Tracking Chart

Date	Weight	Breathing	Swelling	Fatigue	Appetite	Other

Track appointments and medication changes

Date	Doctor	Updates	Medication

Notes

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Partners and Acknowledgements

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Learn more at:

ourhearthub.ca