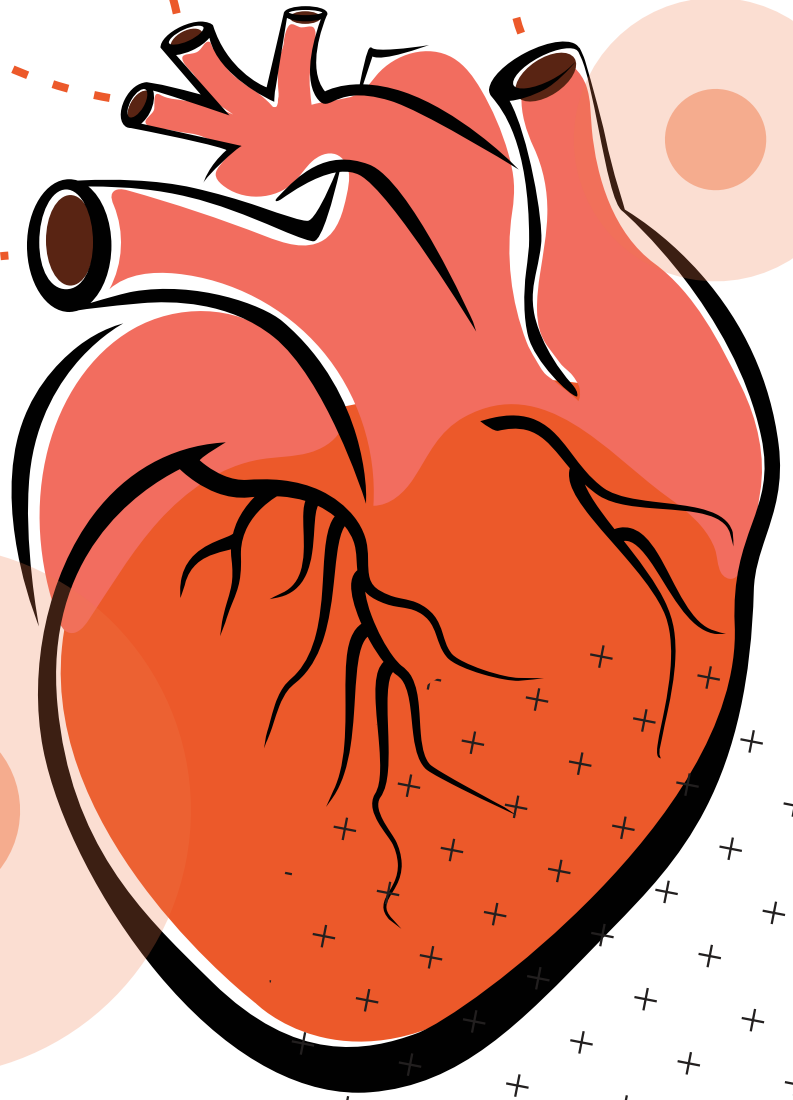


Quality  
Standards



# Heart Failure

a conversation guide to help people with  
heart failure receive high-quality care

Health Quality  
Ontario

*Let's make our health system healthier*



**CorHealth  
Ontario**

*Advancing cardiac, stroke  
and vascular care*

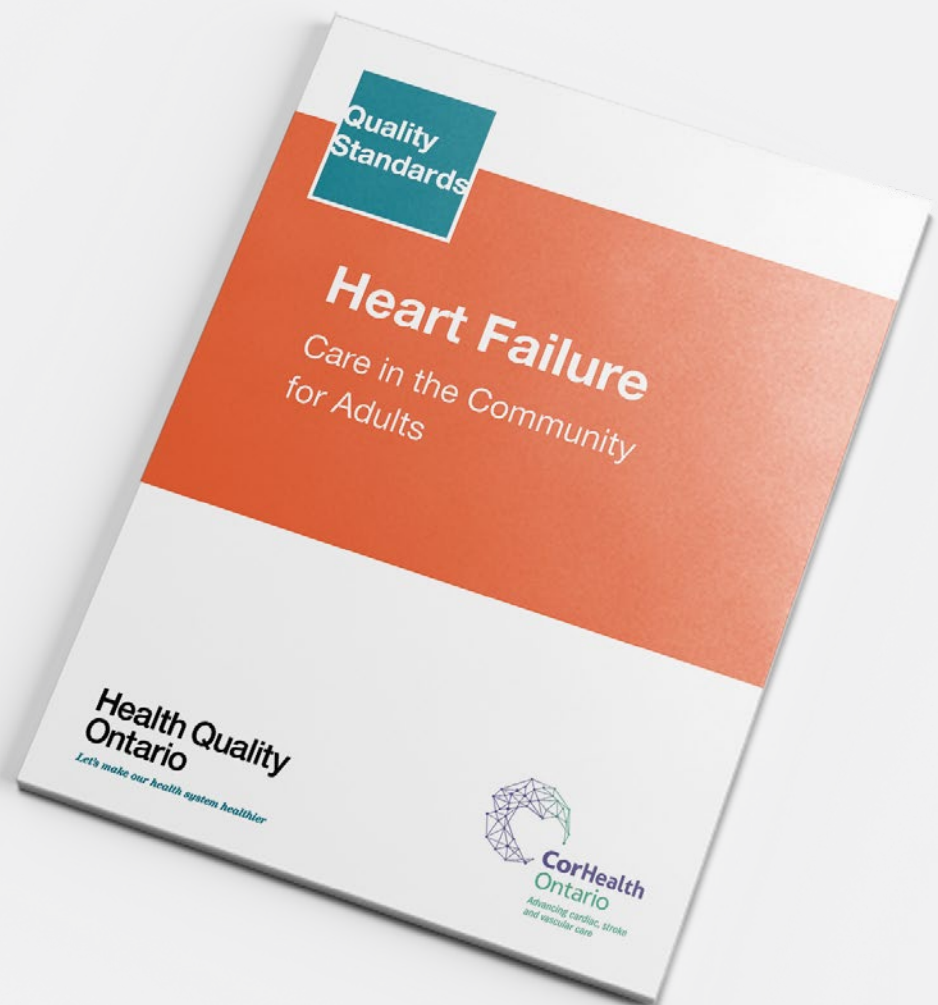
Health Quality Ontario is committed to helping patients, health care providers, and organizations improve the quality of health care in Ontario.

We know that not everyone across the province receives the right care, every time.

So, to help address gaps in care, we produce quality standards, which outline **what quality care looks like** for specific conditions, such as heart failure.

Quality standards are **based on current best evidence and input from patients, caregivers, and health care providers.**

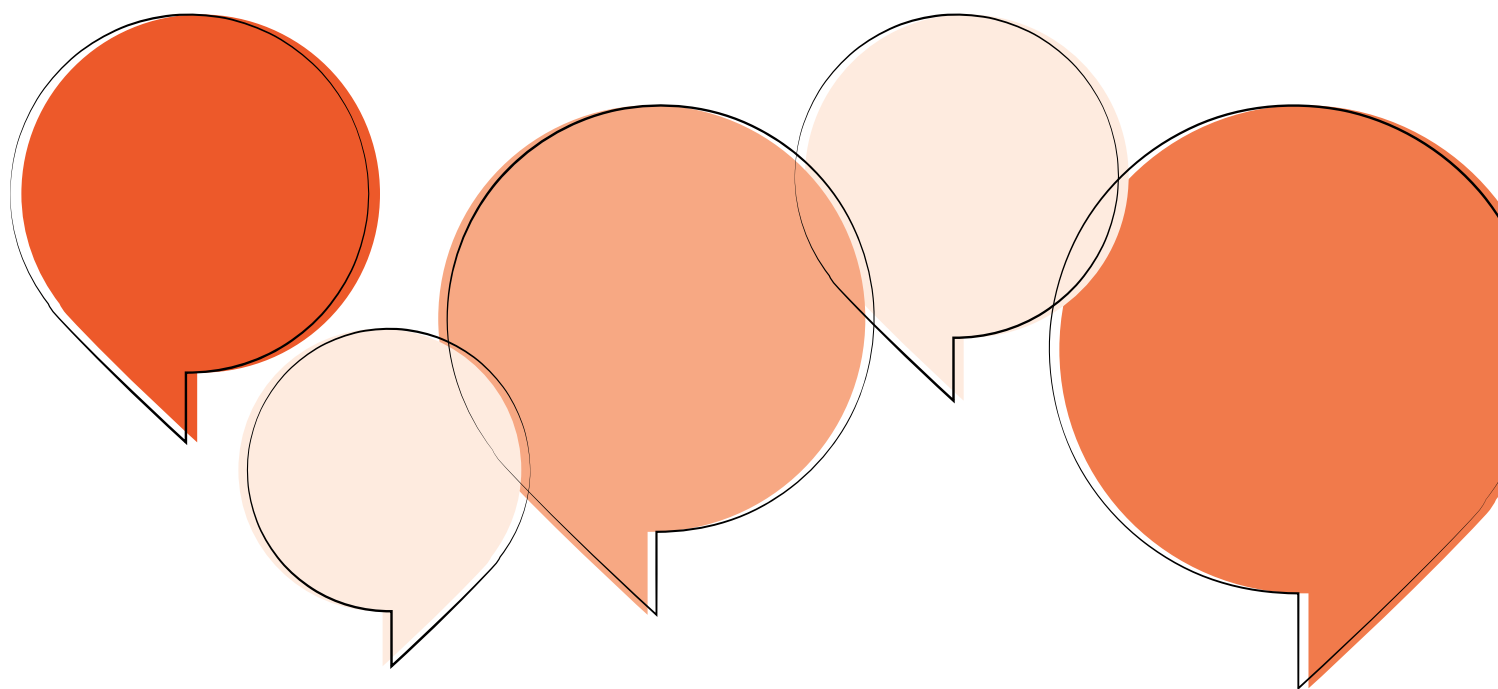
**Download Health Quality Ontario's *Heart Failure: Care in the Community for Adults* quality standard, developed in partnership with CorHealth Ontario, to read more.**



# The following pages contain questions to help you and your health care providers work together on a care plan for your heart failure.

This patient guide is based on information from Health Quality Ontario's quality standard *Heart Failure: Care in the Community for Adults*. This quality standard focuses on care provided to people with heart failure outside of the hospital. It is not meant to be a complete guide to heart failure but a tool to help you talk with your health care providers about the topics that matter to you.

Our goal: to empower you to ask for and receive the best-quality care.



# What is heart failure?

Heart failure occurs when your heart isn't pumping as well as it should be. This means you may feel tired or short of breath because your heart can't deliver enough oxygen and nutrients to your body. Heart failure can also cause fluid to build up in your lungs and in other places, like your ankles. Heart failure is sometimes called congestive heart failure.

Heart failure is a serious condition with no cure. Learning you have heart failure can feel scary, and living with heart failure can be hard on you and your family and caregivers, both physically and emotionally.

But you and your family don't have to manage it alone. There are things you can do to help feel in control of your condition and improve your quality of life—this guide is designed to help support you along the way.



## Learn more

There's a lot of information out there about heart failure, but it can be challenging to know what's reliable. The patients, caregivers, and clinicians we spoke with to put this guide together told us these are resources they find useful:

- [Heart and Stroke Foundation](#)
- [Toronto Rehab](#)
- [HeartLife Foundation](#) (a patient-led heart failure organization)
- [Speak Up Ontario](#) (advance care planning)
- [The Health Line](#) (home and community care services)

Though these resources may not always say the same thing as what's in the quality standard for heart failure, we hope you find them useful.

# Start talking

Living with heart failure can be hard. You'll have days where you feel supported and in control, and others that may seem lonely and overwhelming. Talking through the details of your treatment and your concerns can help ease some of that pressure.

You may have many discussions with a range of health care providers. **Use the topics outlined here to guide your conversations with them**—your family doctor, a nurse practitioner, a cardiologist, or another clinician—as you work together to create the best care plan for you:

- Your goals
- Your treatment
- Your well-being
- Symptoms
- Hospitalization
- Palliative care
- Help for caregivers

There are many topics to cover here—you may have more you'd like to add, and you may decide that some are particularly important to you. They may not all be addressed in a single visit or by a single provider, but you can adjust them and refer to them over time. **It's OK to ask lots of questions and to get advice from a range of health care providers.**



## Write it down

It may help you to take notes as your symptoms develop and change. Having written details on hand when you talk with your care providers will help you give a more complete description of your experience.

Consider making your notes right in this electronic file, or in a printed copy, and use this guide each time you visit and review your care plan with your health care providers.



## Start talking: **Your goals**

As best you can, share information about your priorities and goals with your health care providers. The more they know, the better they can help build the right care plan to help you live the best life you can.

### Some things you might want to consider:

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What is important to you? For example, are there any specific goals you have in mind?  
This could include taking a walk around the block or attending a social event.



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What do you hope for in the future? For example, what would feeling better allow you to do differently?



*I don't recall my mother being asked what was important to her, or what she wanted to see as part of her care plan. Maybe it's being able to walk the dog around the neighbourhood—just incorporating those things that are really meaningful and valuable.*

**CAREGIVER FOR 23 YEARS**



## Start talking: **Your treatment**

As you and your health care providers talk about your options, you should clearly understand how medication and other treatments will help.

### Here are questions you may want to ask:

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What symptoms will be typical for me at this stage?



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What medications should I take? What do they do?



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How do I take my medications? For example, do I take my medication with food? Are there any foods, other medications, supplements, or vitamins that I should avoid taking while I'm taking my heart failure medications?





## Start talking: **Your treatment (continued)**

*Continued from the previous page*

Are there any types of activity I should not do while I'm on my heart failure medications?



What other types of treatments (like surgery or an implantable cardiac defibrillator [ICD]) should we consider?



Will I need to see a heart failure specialist?



How does my heart failure treatment affect my other health conditions?







## Start talking: **Your well-being**

Over time, you can learn how to manage your heart failure to help you feel better. Your health care providers should act as your coaches, offering counselling, education, and training so that you and your family can feel confident in your ability to manage your condition.

**Here are some of the things you might want to discuss with your health care providers. Some of these may not apply to you—and that's OK!—and there may be others you'd like to add.**

- 
- Daily weight checks and weight changes
  - Diet guidelines
  - Physical activity and exercise
  - Stopping smoking and reducing how much alcohol you drink
  - Stress management
  - Mood and anxiety
  - Sexual function
  - Financial concerns (for example, having less income, dealing with the cost of medications and healthy food, and how to get the most from your available resources)
  - Having a substitute decision-maker (a person you choose to make health care decisions for you if you are not able to)





## Start talking: **Symptoms**

Heart failure is a condition with good days and bad days.

### For tracking day-to-day symptoms, you may ask:

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What makes my symptoms better? What makes them worse?



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How will I know if my symptoms are getting worse?



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What should I do and who should I call if my symptoms get worse?





## Start talking: **Symptoms (continued)**

*Continued from the previous page*

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What kind of symptoms mean an emergency?



### Did you know?

**If you experience any big changes to your physical health or to your emotions or mood, it's important to let your health care provider know.** Changes in how you're feeling may mean that your care plan needs to be adjusted.

These changes may include:

- Feeling more short of breath
- Getting tired more easily
- More ankle and leg swelling
- Mood changes (for example, crying more than usual, feeling irritable, not wanting to socialize, having trouble concentrating)
- Not being able to complete tasks that you can normally do
- Needing more help at home



## Start talking: **Hospitalization**

If you have been treated for your heart failure in the hospital or emergency department, you might be nervous about going home. Talking with your primary care providers (for example, your family doctor or nurse practitioner) or your community health care team once you leave the hospital can help you feel more comfortable.

### Questions you may want to ask before leaving the hospital:

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What kinds of tests did I have in the hospital? Why did I have them?



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What were my test results? May I have a copy of them?



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Do any changes need to be made to my medications or my care plan?





## Start talking: **Hospitalization (continued)**

*Continued from the previous page*

.....  
How will my other health care providers know what happened to me and what changes we'll be making?



.....  
Should I see a specialist? If I should, how soon?



.....  
What other kinds of follow-up care might I need?



.....  
How can my family or caregivers support me once I'm back home?





## Start talking: **Palliative care**

Heart failure is incurable and unpredictable, so it is often difficult to know when and by how much your symptoms will get worse. Because of this, it's important to talk with your health care providers and your family about your goals as soon as you can, keeping in mind that as your symptoms change, your goals may change, too.

A palliative approach to care is about focusing on all of your needs and your caregivers' needs—physical, social, spiritual, and practical—at all stages of your condition.

Palliative care is not just for when treatment stops working or when you are very sick. It is about making sure you feel as well as possible all the time.



*We need to take the fear out of the word: [people think] that 'palliative' somehow equals imminent death—and it really doesn't.*

*There needs to be some education around what a palliative approach to care actually means—it's very different from end-of-life care. It's about quality of life from the moment of diagnosis—a holistic team approach to care.*

**CAREGIVER WHO ADVOCATED FOR HER MOTHER TO HAVE BETTER PALLIATIVE CARE IN A NURSING HOME**



## Start talking: **Palliative care (continued)**

*Continued from the previous page*

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**As you begin to consider what palliative care means to you, you may want to talk about the following topics with your health care providers and your family or caregivers:**



- Finding palliative care supports that are available where you live
- Ensuring all of your health care providers are talking with one another about your needs
- Choosing a substitute decision-maker if you can't make health care decisions on your own
- Thinking about your wishes, values, and beliefs for the kind of health care you would like to have in the future and talking about it with your substitute decision-maker
- Choosing what kinds of resuscitative effort you'd like if your heart stops beating or if you stop breathing

# A note to caregivers

If you're helping to care for someone with heart failure, this whole guide is for you, too—you need this information as much as they do.

We also recognize the unique concerns you might have as a caregiver as you support someone with a chronic condition. If you're caring for someone with heart failure, their needs will change over time—at first, they may be very involved in their own care; but as their condition gets worse, they may rely more on you.



*What I felt was alone. My husband had major surgery out of our community, and we are still waiting for follow-up with a specialist. It's been many months. Feeling alone is very hard on the caregiver physically and emotionally.*

## CAREGIVER WHO TRAVELS WITH HER HUSBAND FOR HIS CARE

**Planning ahead is important. Here are some things to think about for the future:**

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Do you know all of the health care providers who look after the person you are caring for?



Do you know what worsening symptoms look like?





*Continued from the previous page*

**Planning ahead is important. Here are some things to think about for the future:**

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Do you know what to do and who to call in an emergency?



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Have you spoken with the person you are caring for about their goals of care and their end-of-life wishes?



**Because your well-being is just as important, you might consider:**

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How are you feeling?



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Do you have your own primary care provider (a family doctor or nurse practitioner)?



*Continued from the previous page*

Are you looking after your own health needs?



What are your goals and needs?



Support from other people is important. This support could be from family, friends, or a support group, for example. What types of support are available to you?



# What's next?

## Remember, everybody is different.

The care plan you decide on with your health care providers and the support you need will be unique to you.

## This conversation guide is meant only as a starting point.

You may have other topics you want to cover with your health care providers. It's important to speak to them about any other questions or concerns.

## Need more information?

If you have any questions or feedback about this guide, please contact us at [qualitystandards@hqontario.ca](mailto:qualitystandards@hqontario.ca) or 1-866-623-6868.

For more reading on heart failure, read the quality standard at: [hqontario.ca/qualitystandards](http://hqontario.ca/qualitystandards)



# For your reference: The quality standard in brief

The *Heart Failure: Care in the Community for Adults* quality standard is a document for health care providers that outlines what quality care looks when caring for people with heart failure outside of the hospital. It is based on the best evidence and input from health care providers, patients, and their caregivers.

Below is a summary of the quality standard. **For further reading, download the full version [online](#).**

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## Diagnosing Heart Failure

People suspected to have heart failure undergo an initial evaluation that includes, at minimum, a medical history, a physical examination, initial laboratory investigations, an electrocardiogram, and a chest x-ray. If appropriate, natriuretic peptide levels are tested to help formulate a diagnosis. If heart failure is confirmed or suspected after these tests, an echocardiogram is then performed.

## What this means for you

If you or your care provider think that you have heart failure, your care provider should ask you how much exercise you can do, how you are sleeping at night, and what medications you are currently taking. Your care provider should also do a physical examination, take blood samples, and order tests that give them images of your heart.

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## Individualized, Person-Centred, Comprehensive Care Plan

People with heart failure and their caregivers collaborate with their care providers to develop an individualized, person-centred, comprehensive care plan. The care plan is reviewed at least every 6 months, and sooner if there is a significant change. It is made readily available to all members of the person's care team, including the person and their caregiver(s).

## What this means for you

Your care provider should work with you to make a care plan that fits your values, wishes, and goals. Your care team should use this plan to provide care that meets your needs. They should check in with you regularly to see if your goals for care have changed. If you choose, your caregiver(s) can also help you make your care plan.

*Continued from the previous page*

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**Empowering and Supporting People With Heart Failure to Develop Self-Management Skills**

People with heart failure and their caregiver(s) collaborate with their care providers to create a tailored self-management program with the goal of enhancing their skills and confidence so that they can be actively involved in their own care.

**What this means for you**

At each of your appointments for the first 6 months after diagnosis, you should be offered coaching and support to help you learn about managing your heart failure effectively. If you choose to include your caregiver(s), they can also be offered this information and coaching.

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**Physical Activity and Exercise**

People with heart failure are informed of the benefits of daily physical activity and offered a personalized, exercise-based cardiac rehabilitation program.

**What this means for you**

Your care provider should explain to you the benefits of physical activity and exercise. They should offer you a personalized cardiac rehabilitation program in a setting and format that is easiest for you to do. This includes creating a program that matches your abilities and goals. If your care provider is not sure which exercises are best for you, they may refer you to another care provider with the appropriate expertise.

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**Triple Therapy for People With Heart Failure Who Have a Reduced Ejection Fraction**

People with heart failure who have a reduced ejection fraction (HFrEF) and New York Heart Association (NYHA) class II to IV symptoms are offered pharmacological management with “triple therapy.” They may require additional medications and are prescribed these as needed.

**What this means for you**

When you and your care provider work on your care plan, your care provider should explain the different types of medication you will need and how they will help you. If you have heart failure with reduced ejection fraction, you should be offered medication that includes at least three different types of medication; this is called “triple therapy.” You may need other medications as well. Your care provider should explain how to use your medications, including how and when to take them.

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### **Worsening Symptoms of Heart Failure**

People with heart failure who report gradual, progressive, worsening symptoms are assessed by a care provider and have their medications adjusted (if needed) within 48 hours.

### **What this means for you**

If you are feeling more tired, more short of breath, are having trouble sleeping, or your weight has gone up in the last few days, you should contact your care provider. A health care provider should assess you. You may need your medications changed to keep you from feeling worse, and if so, this should be done for you within 48 hours. It is better to make these changes when you first start feeling worse rather than waiting too long and needing to go to the hospital. Once you are feeling better, your care provider should talk with you about different ways to manage your heart failure at home to prevent this from happening again.

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### **Management of Non-cardiac Comorbidities**

People with heart failure are treated for non-cardiac comorbidities that are likely to affect their heart failure management.

### **What this means for you**

People with heart failure sometimes have other illnesses that also need to be treated. If you have other illnesses, the care providers helping you manage your heart failure may also be able to treat these, or they may refer you to another care provider or providers.

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### **Specialized Multidisciplinary Care**

People with newly diagnosed heart failure, those who have recently been hospitalized or treated in the emergency department for heart failure, and those with advanced heart failure (NYHA III–IV) are offered a referral to specialized multidisciplinary care for heart failure.

### **What this means for you**

If your care provider thinks you may need extra attention to manage your heart failure, they should offer you the chance to work with a team of care providers who specialize in heart failure. This team should work closely with you to manage your care, improve your quality of life, and help prevent future hospitalizations related to your heart failure.

*Continued from the previous page*

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**Transition From Hospital to Community**

People hospitalized or treated in the emergency department for heart failure receive a follow-up appointment to reassess volume status and medication reconciliation with a member of their community health care team within 7 days of leaving the hospital.

**What this means for you**

You should have an appointment with a member of your community health care team within 7 days of returning home after a hospital visit for heart failure.

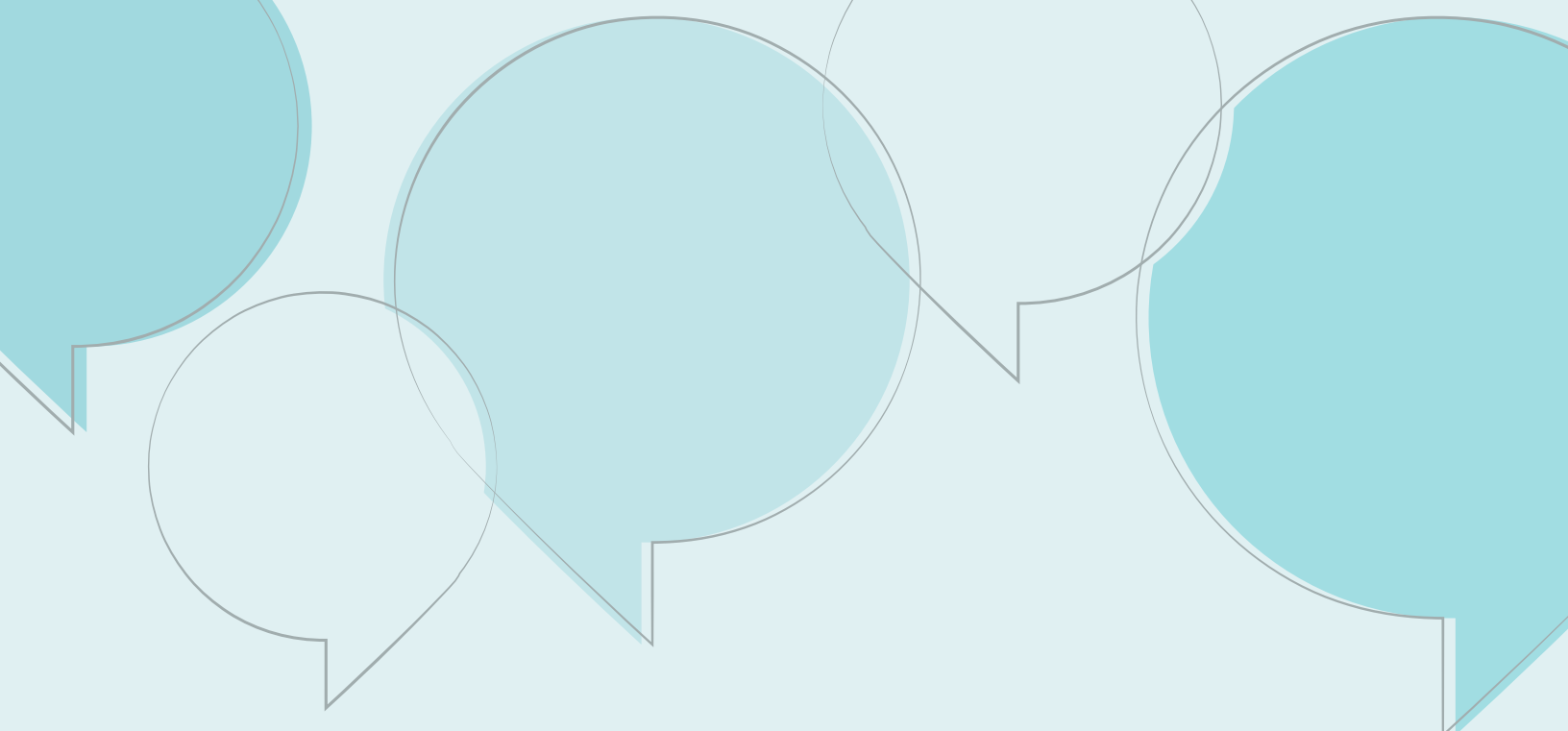
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**Palliative Care and Heart Failure**

People with heart failure and their families have their palliative care needs identified early and are offered support to address their needs.

**What this means for you**

If you have heart failure, your care team should assess your palliative care needs. This includes your physical, mental, emotional, cultural, and spiritual well-being. You should be offered supports to address your needs.



For more information, please visit  
Health Quality Ontario: [hqontario.ca](http://hqontario.ca)  
CorHealth Ontario: [corhealthontario.ca](http://corhealthontario.ca)

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