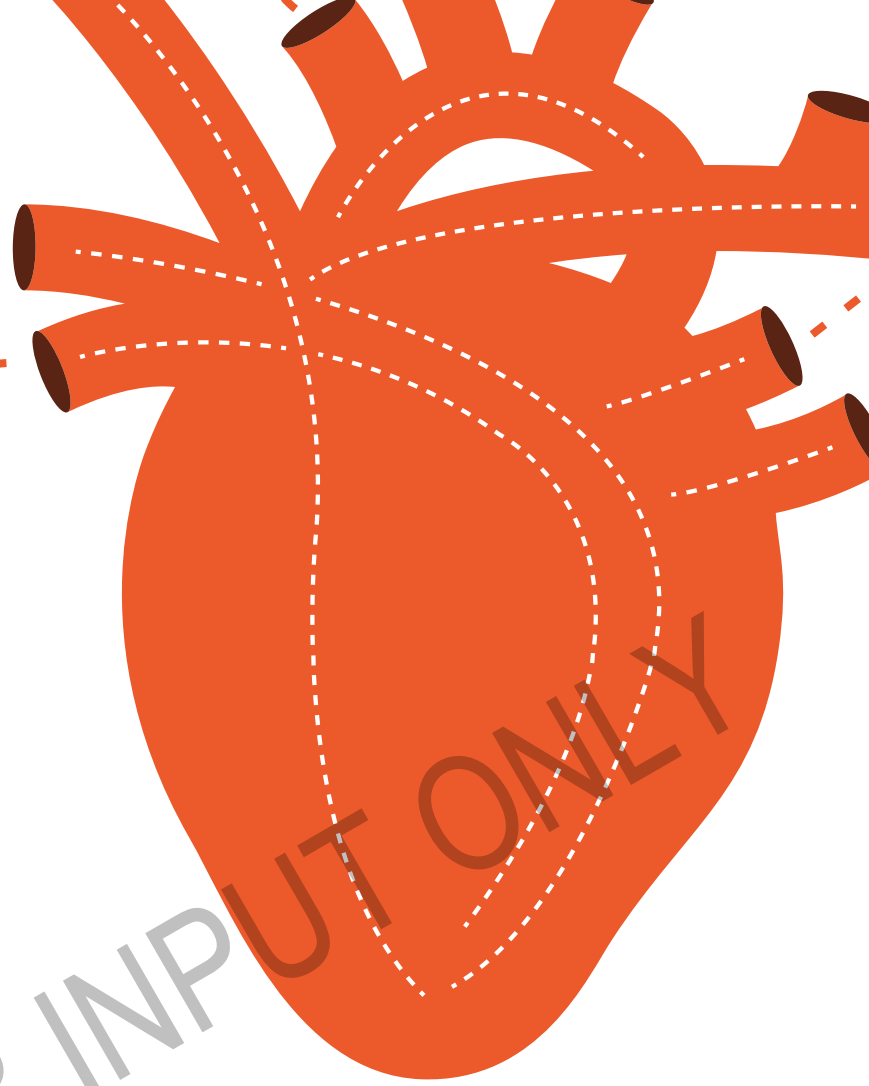


Quality
Standards



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*

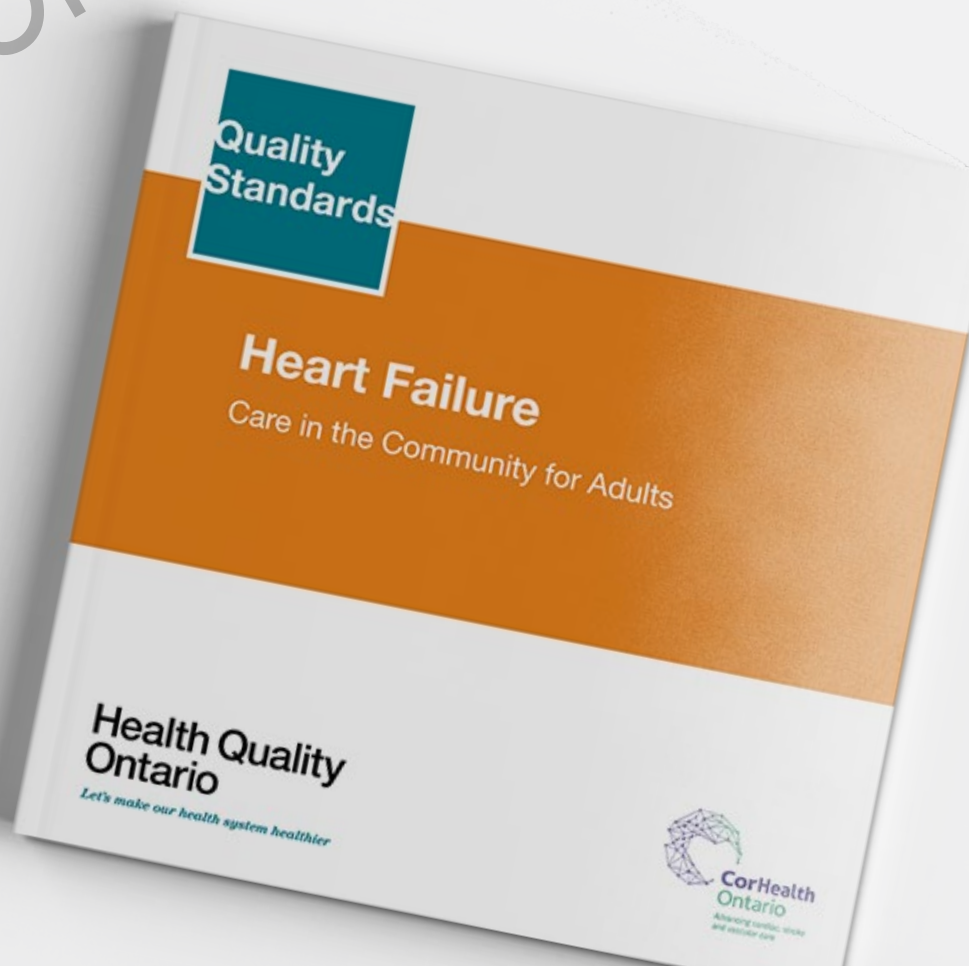
As the provincial advisor on the quality of health care, Health Quality Ontario is committed to helping health care providers and organizations improve the quality of health care for patients.

To help address the gaps and unnecessary variations in care for specific conditions—heart failure and others—we produce Quality Standards.

A Quality Standard is a document for health care providers that outlines **what quality care looks like for a given condition** and is based on the **best evidence and input from clinicians, patients and caregivers**.

We've used the information from [Health Quality Ontario's](#) quality standard for heart failure, which was developed in partnership with [CorHealth Ontario](#), to create this conversation guide for patients. It is not meant to be a complete guide to heart failure, but rather a tool to enable you to have informed discussions with your health care providers to help ensure you receive the best quality care.

[Download Health Quality Ontario's quality standard for heart failure to read more.](#)



WHAT IS THIS GUIDE?

This conversation guide is designed to help you play an active role in getting the best possible care. We know that in Ontario, not every adult with heart failure receives the same level of care—evidence shows there are wide variations and gaps in care that need attention.

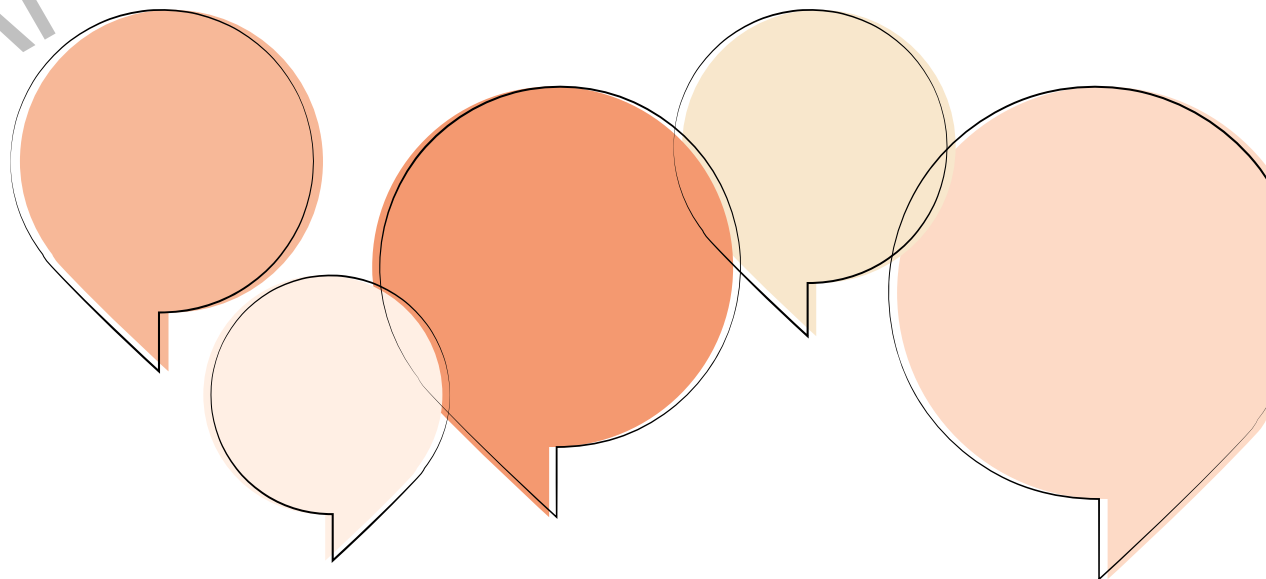
This guide aims to shine a light on the conversations or subjects that may be missed between patients and health care providers as people are treated for heart failure.



Inside this guide you will find:

- Starting points for important conversations
- Thoughtful questions you may want to ask your health care providers as you work together to make a plan for your care.

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WHAT IS HEART FAILURE?

Heart failure occurs when your heart isn't pumping as well as it should be. This can cause fluid to build up in your lungs and in other places, like your ankles. Congestion in the lungs and lack of oxygen may cause you to feel more tired than usual and short of breath. This condition is also known as congestive heart failure.

Heart failure is a serious condition with no cure. Receiving a diagnosis can feel jarring and living with heart failure can be hard on you and your family and caregivers, physically and emotionally.

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

START TALKING

Living with heart failure is a big deal. 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**—be it 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

There are many topics to cover here (and you may have more you'd like to add)—they may not all be addressed at once or in a single visit, but can be revised and referred to over time. It's OK to ask lots of questions and also to get second opinions.



Write it down

Feel free to write down your notes (either in a printed copy or right into this electronic version) and use this guide many times over as you review your treatment plan with your health care providers. We recommend you do this every six months.



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:

Why is it important for you to be well?

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”

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 TO HER WIDOWED MOTHER FOR 23 YEARS

Start talking: Your goals (continued)

Continued from the previous page

Are there any milestones or goals you have in mind? This could include taking an evening walk around the block, or attending a social event.



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Start talking: Your treatment

As you and your health care providers discuss treatment, you should clearly understand how medication or other interventions will help.



Here are some key questions you may want to ask:

What symptoms will be typical for me at this stage?

What medication should I take? What does it do?*

**Health care providers say this is one of the most important things for patients to know*

How do I take my medications?

Does my heart failure medication interact with other meds I am taking?

Start talking: Your treatment (continued)

Continued from the previous page

.....
What other types of treatments—pacemakers, other devices or surgery—should I consider?



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



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Start talking: Your well-being

Slowly and over time, you will learn how to effectively manage your heart failure. Your health care providers should act as your coach, offering counselling, education and training so that you and your family can feel confident and capable of managing your condition.



Here are some of the things you should 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 moderating alcohol:*

**Health care providers say these are priority topics to discuss with them*

Start talking: Your well-being (continued)

Continued from the previous page

.....
Stress management:



.....
Mood and anxiety:



.....
Sexual function:



.....
Socioeconomic concerns (ie: income, cost of medicine and healthy food):



.....
Designated decision-makers (to make your health-care decisions if you are not able to):



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Start talking: Symptoms



Heart failure is a condition with good days and bad days. When you are well, it's important to discuss the best ways forward with your health care providers.

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

.....

What symptom changes should I be concerned about?

.....

What do worsening symptoms look like for me? What's an emergency?

.....

Who do I call if my symptoms get worse?

Did you know?

If you experience any significant changes to your physical, emotional or psychological well-being, it's important your health care provider review your care plan with you.

These changes may include:

- Getting more short of breath
- Getting tired more easily
- More ankle and leg swelling
- Mood changes
- You need more help at home

Start talking: Hospitalization



If you end up in hospital, asking some key questions can help smooth your transition home again.

You may ask:

.....
What kinds of tests did I have in hospital? What was their purpose?
What are the results? May I have a copy?

.....
Do any of my medications need adjusting?

.....
What changes should be made to my care plan?

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

.....
Should I see a specialist once I leave the hospital? And how soon?

.....
What other kind of follow-up care do I need?

Start talking: Palliative care

Heart failure is incurable, it will get worse and it is often unpredictable. Because of this, it's best to talk to your health care providers and your family about the goals of your care sooner rather than later after diagnosis.



A palliative approach to care is about focusing on yours and your family's full range of needs— physical, social, spiritual—at all stages of your illness. It's more about feeling in control and actively involved in your care, and less about a service that's provided when treatment stops working.

”

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 throughout—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)

As you begin to consider what palliative care means to you, you may want to talk about it with your health care providers and/or family or caregivers.

.....
What palliative care supports are available in my area?

.....
Are all of my health care providers communicating with one another about my palliative care needs?

.....
Who is my designated decision-maker, for when I can't make health care decisions on my own?

.....
Have I discussed with them my wishes, values and beliefs around the kind of health and personal care I would like to have in the future?

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A NOTE TO CAREGIVERS

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

But we also recognize the unique concerns for caregivers as they support someone with a chronic illness. This condition is changeable—at first the patient may be very involved in their care, but as their illness progresses, 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 CARE

You may take this condition day by day, but planning ahead is also key:

Are you familiar with your patient's health care providers? Do you know what worsening symptoms look like and what to do/who to call in an emergency?

Have you spoken to the patient about palliative care?

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

.....
How are you feeling?



.....
What are your goals and needs?



.....
Support/peer groups are important—which ones are accessible to you?



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WHAT'S NEXT?

Remember, everybody is different.

The care plan you land on with your health care providers and the support you require 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 with them should any questions or concerns come up.

Need more information?

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

For more reading on heart failure, read the quality standard at: hqontario.ca/qualitystandards



FOR YOUR REFERENCE: THE QUALITY STANDARD IN BRIEF

The quality standard for heart failure is a document for health care providers that outlines what quality care looks like for this condition. It is based on the best evidence and input from health care clinicians, patients and their caregivers.

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

Diagnosing Heart Failure:

People suspected to have heart failure undergo an initial evaluation that includes, at minimum, a medical history, a physical examination, blood work, 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 still suspected after these tests, an echocardiogram is then performed.

What this means for you:

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

Comprehensive Care Plan

People with heart failure and their families have a comprehensive care plan they develop in collaboration with their care providers. 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 family.

What this means for you

Your health care providers should work with you to make a care plan that addresses all of your needs. They should review this care plan with you at least every 6 months. If you choose, your family can also help you make your care plan.

Empowering and Supporting People With Self-Management Skills

Health care providers should collaborate with people with heart failure and their families 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

Your health care providers should make sure that for the first 6 months after diagnosis, each of your appointments includes coaching to help you learn to manage your heart failure effectively at home. If family is involved in your care, they should also be given this information and coaching.

Continued from the previous page

Physical Activity and Exercise:

People with heart failure are informed of the benefits of physical activity. They are offered advice on types of exercises to consider, based on their abilities and activity goals.

What this means for you:

Your health care providers should explain the benefits of exercise to you. They should also work with you to create an exercise program that matches your abilities and goals. Depending on your plan, this could be anything from adding regular walking to your daily routine, to a structured exercise program. If your health care providers are not sure which exercises are best for you, they may refer you to someone else with the appropriate expertise.

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”:

- An angiotensin-converting enzyme (ACE) inhibitor or an angiotensin II receptor blocker (ARB) if they cannot tolerate an ACE inhibitor
- A beta blocker
- A mineralocorticoid receptor antagonist (MRA)

People with HFrEF have their medications adjusted to target doses as tolerated. If their heart failure symptoms persist and their ejection fraction remains less than or equal to 40%, they have their ACE inhibitor or ARB replaced by an angiotensin receptor neprilysin inhibitor.

People with HFrEF may require additional medications and are prescribed these as needed.

What this means for you

When you and your health care providers work on your care plan, your health care providers should explain the different types of medications 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 pills (called “triple therapy”). You may need other medications as well. Your health care providers should explain how to use your medications, including how and when to take them.

Continued from the previous page

Worsening Symptoms of Heart Failure

People with known heart failure who report worsening symptoms are assessed by a care provider and have their medications adjusted (if needed) within 24 hours.

What this means for you

If you are feeling more tired or more short of breath, are having trouble sleeping, or your weight has gone up in the last few days, you should contact your health care providers. Someone 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 24 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 health care providers should talk with you about different ways to manage your heart failure at home to prevent this from happening again.

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

Often people with heart failure have other illnesses that also need to be treated. Your family doctor, nurse practitioner, cardiologist, or heart specialist can help you manage your heart failure alongside other conditions, or they may connect you with other health care providers who can help you with your care needs.

Transition From Hospital to Community

People who are hospitalized for heart failure receive a follow-up appointment for reassessment of 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

After you are discharged from the hospital after being admitted for heart failure, you should have an appointment with a member of your regular health care team within 7 days of returning home.

Continued from the previous page

Specialized Multidisciplinary Care

People who have been hospitalized for heart failure are offered a referral to specialized multidisciplinary care for heart failure.

What this means for you

If you have been in the hospital for your heart failure, or if your health care provider is worried that you may need extra attention for your heart failure management, they should offer you the chance to work with a team of health 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.

Palliative Care and Heart Failure

People with heart failure and their families are offered palliative care support to meet their physical, psychosocial, and spiritual needs.

What this means for you

If you have heart failure, you should be offered the palliative care supports you need.

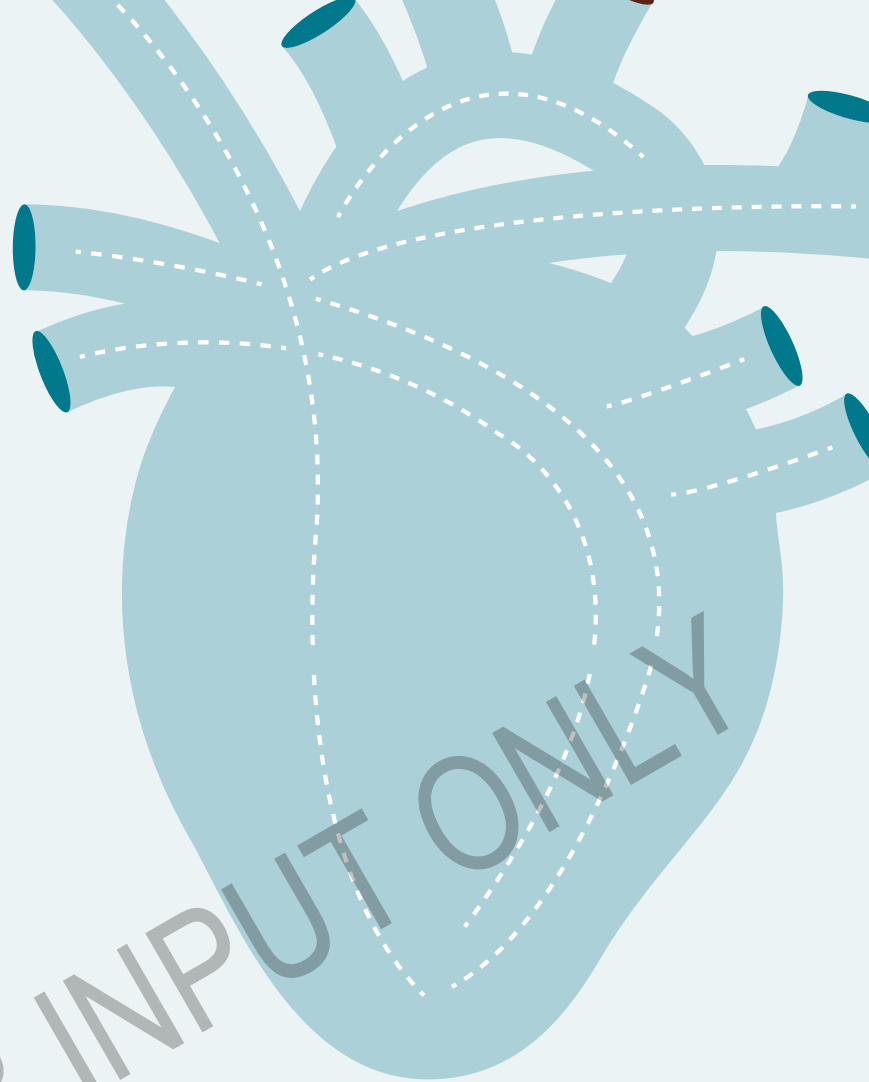
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APPENDIX: ADDITIONAL RESOURCES

There are many great sources for information about heart failure. Here are some that might be helpful:

- Heart and Stroke Foundation:
heartandstroke.ca/heart/conditions/heart-failure
- Toronto Rehab: healthuniversity.ca/en/cardiacollege
- HeartLife Foundation (a patient-led heart failure organization): heartlife.ca
- Speak up Ontario (advance care planning): speakupontario.ca

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**FOR MORE INFORMATION,
PLEASE VISIT:**

Health Quality Ontario: hqontario.ca

CorHealth Ontario: corhealthontario.ca

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