

Supportive Cardiology: Living with Advanced Heart Failure

A GUIDE FOR PATIENTS AND FAMILIES



**NORTH
YORK
GENERAL**

*Making a World
of Difference*

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Contact information

SUPPORTIVE CARDIOLOGY CLINIC

North York General Hospital
4001 Leslie Street (6N – Room 605)
Toronto, ON M2K 1E1
T 416.756.6000 ext. 4522
F 416.756.6702

HEART FUNCTION CLINIC

North York General Hospital
4001 Leslie Street (6N – Room 601)
Toronto, ON M2K 1E1
T 416.756.6978
F 416.756.6702

Advanced heart failure care at North York General Hospital

The Supportive Cardiology Program at North York General Hospital offers specialized cardiac care for people living with advanced heart failure. This is a comprehensive service that acts as an added layer of support to you and your family. The focus is on improving quality of life. An interdisciplinary team will work collaboratively with your cardiologists, family doctor, and community providers. The program is designed to reduce hospital admissions and emergency room visits by connecting you with community resources to help manage heart failure at home. Assistance with advanced care planning, counselling and support to achieve your goals is also provided.

Speak to your cardiologist and/or family doctor if you feel supportive cardiology is right for you. We are here to help support you and your family.

“I can’t imagine navigating the system without the help of the team; their support is invaluable.”

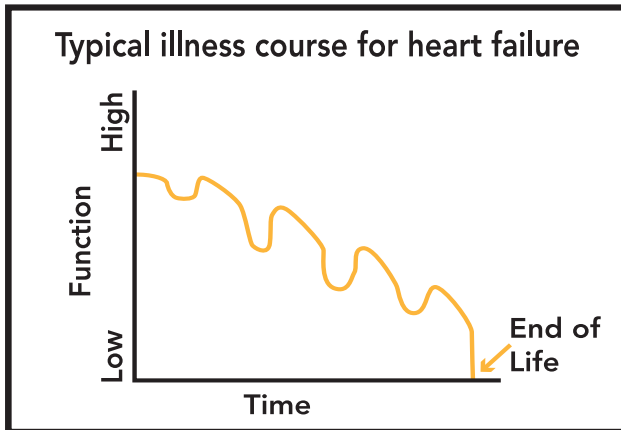
Brenda Albuquerque-Boutilier, daughter of a clinic patient

What is heart failure?

Heart failure is the leading cause of hospital admissions for adults 65 years and older. Approximately 500,000 Canadians are living with heart failure and 50,000 Canadians are newly diagnosed each year¹. Heart failure is a chronic, life-limiting illness that can affect your quality of life. In heart failure, the chambers of the heart stretch, and the muscle pumping action weakens. Over time your body will not be able to compensate for a weak heart and you can experience symptoms such as shortness of breath, pain and feeling tired.

At this point, your cardiology team may recommend adding supportive cardiology to your care plan. The supportive cardiology team members are experts in managing challenging symptoms of heart failure and strive to improve your quality of life through specialist level symptom management.

Supportive cardiology care is offered at the same time as your cardiac care.



1. Adapted from Heart and Stroke Foundation of Canada. www.heartandstroke.com.

Recurrent hospitalizations for treatment of symptoms is common as heart failure advances into later stages of illness.

Causes of heart failure

There are various causes that may contribute to heart failure. Some of these conditions may be present without you knowing it. Having more than one of these factors can greatly increase your risk of developing heart failure.

CONDITIONS THAT CONTRIBUTE TO HEART FAILURE

- Coronary artery disease
- Past heart attack
- High blood pressure
- Abnormal heart valves (e.g. aortic stenosis)
- Diabetes
- Heart muscle disease or inflammation
- Heart defects at birth
- Lung disease
- Sleep apnea
- Cardiomyopathy
- Atrial fibrillation

Symptoms of heart failure

SYMPTOM	WHY IT HAPPENS	TREATMENT YOUR TEAM MAY SUGGEST:
<p>Shortness of breath (also called dyspnea) is breathlessness during activity, rest, or sleep.</p>	<p>Shortness of breath occurs when blood backs up in the pulmonary veins (the veins that return blood from the lungs to the heart) because the heart cannot keep up with the supply. This may also cause fluid to enter the lungs.</p>	<ul style="list-style-type: none"> ■ Increasing diuretics ■ Oxygen ■ Opioids and/or anti-anxiety medications ■ Deep breathing exercises ■ Managing fluid and salt intake
<p>Swelling (also called edema) is the build-up of excess fluids in tissue. You may notice swelling in your feet, ankles, legs or abdomen.</p>	<p>Swelling occurs when blood flowing out of the heart slows and blood returning to the heart through the veins backs up, causing fluid to build up in the tissues.</p>	<ul style="list-style-type: none"> ■ Increasing diuretics ■ Elevating legs ■ Managing fluid and salt intake
<p>Fatigue is often associated with feeling tired and having difficulty with your everyday activities like showering, climbing stairs and walking.</p>	<p>Fatigue occurs when the heart cannot pump enough blood to meet the needs of your body.</p>	<ul style="list-style-type: none"> ■ Energy conservation techniques ■ Getting a good night's sleep
<p>Lack of appetite is feeling full or not hungry. It is very normal as heart failure worsens.</p>	<p>Lack of appetite occurs when your digestive system receives less blood flow.</p>	<ul style="list-style-type: none"> ■ Focus on eating things you enjoy ■ Do not force yourself to eat
<p>Palpitations are the feeling of your heart racing/throbbing or beating faster than usual.</p>	<p>Palpitations, which are common in heart failure, can occur on their own or can be related to anxiety or worry.</p>	<ul style="list-style-type: none"> ■ Adjustment of cardiac medications ■ Anti-anxiety medications
<p>Anxiety/depression is the persistent feeling of being worried or sad.</p>	<p>Anxiety or depression can occur when you experience changes in your body that cause you to feel worried, sad or hopeless.</p>	<ul style="list-style-type: none"> ■ Talk about your feelings with your family and care team – our team is here to help you
<p>Difficulty sleeping</p>	<p>Difficulty sleeping can be caused by shortness of breath and/or anxiety and worry.</p>	<ul style="list-style-type: none"> ■ Talk to our team ■ We may recommend a sleeping pill

Treatment of heart failure

Treating heart failure symptoms often requires several different medications. It is important to talk to your health care team about your medications and ensure that you and your family understand how they should be taken and their potential side effects. The following chart provides an overview of some of the most common medications you may be prescribed.

MEDICATION	USE
Diuretics (also known as water pills) <ul style="list-style-type: none"> ■ furosemide (Lasix) ■ hydro-chlorothiazide ■ spironolactone (Aldactone) ■ metolazone (Zaroxolyn) ■ eplerenone (Inspira) ■ bumetanide (Burinex) 	<ul style="list-style-type: none"> ■ Help reduce breathlessness by decreasing the build-up of fluid in the lungs and abdomen ■ Help reduce discomfort from the build-up of fluid in the legs, ankles and feet
Opioids <ul style="list-style-type: none"> ■ morphine (Statex) ■ hydromorphone (Dilaudid) 	<ul style="list-style-type: none"> ■ Help relieve the sensation of breathlessness ■ Treat pain
Laxatives <ul style="list-style-type: none"> ■ senna (Senokot) ■ peg3350 (Lax-a-day) ■ docusate sodium (Colace) 	<ul style="list-style-type: none"> ■ Help prevent and treat constipation
Benzodiazepines <ul style="list-style-type: none"> ■ lorazepam (Ativan) ■ clonazepam (Rivotril) 	<ul style="list-style-type: none"> ■ Help relieve the sensation of breathlessness ■ Treat anxiety
Cardiac Glycosides <ul style="list-style-type: none"> ■ digoxin (Lanoxin) 	<ul style="list-style-type: none"> ■ Increase the strength of the pumping action of your heart
Beta Blockers <ul style="list-style-type: none"> ■ metoprolol (Lopressor) ■ atenolol (Tenormin) ■ bisoprolol (Monacor) ■ carvedilol (Coreg) 	<ul style="list-style-type: none"> ■ Help lower blood pressure ■ Slow down heart rate
Ace Inhibitors <ul style="list-style-type: none"> ■ ramipril (Altace) ■ perindopril (Coversyl) 	<ul style="list-style-type: none"> ■ Used to lower blood pressure ■ Improve blood flow to the heart
Vasodilators (also known as nitrates) <ul style="list-style-type: none"> ■ isosorbide dinitrate (Isordil) ■ hydralazine (Apresoline) 	<ul style="list-style-type: none"> ■ Relax blood vessels and increase blood supply to the heart

Supportive Cardiology at North York General Hospital

North York General Hospital (NYGH) supports a large number of patients with heart failure both through inpatient and outpatient programs. Some heart failure patients are treated in NYGH's Heart Function Clinic. Supportive Cardiology consists of an interdisciplinary care team, which includes; **specialized physicians**, a **clinical nurse specialist**, and a **pharmacist**. The Supportive Cardiology team will work with your existing care team, which may include your cardiology team, family doctor and Heart Function Clinic team.

Supportive Cardiology care is provided at the clinic and over the phone. The team may connect you and your family with community resources to reduce Emergency Department visits and hospital admissions related to symptoms of heart failure.

SUPPORTIVE CARDIOLOGY CLINIC

Who are our patients?

- Patients diagnosed with advanced heart failure with bothersome symptoms (e.g. shortness of breath) despite being on cardiac medications.
- Patients with more than 1 hospital admission in the past 6 months for heart failure.
- Patients with 2 or more visits to an emergency department for heart failure.

Our health care team

- Your specialized team includes the following dedicated healthcare professionals:
 - Physician
 - Clinical Nurse Specialist
 - Pharmacist

Our services

- We are an added layer of support to your care.
- We have expert knowledge in treating symptoms common to heart failure such as pain, shortness of breath, swelling, palpitations, fatigue, anxiety, and depression.
- We work with your cardiology team and family doctor who will continue to provide you with primary care.
- We assist with advanced care planning and ask you questions to ensure your care plan matches your goals.
- We make referrals to community resources and other supportive outreach programs to help you manage at home.

SUPPORTIVE CARDIOLOGY CLINIC

What can you expect?

- A dedicated care team will support you and your family throughout your illness.
- We will conduct a thorough assessment and may ask questions such as:
 - How do your symptoms affect daily life for you?
 - What are your goals and hopes?
 - How is your family coping at home?
- We offer both inpatient services and outpatient follow-up in our clinic.
- We do not replace your Heart Function Clinic team or family doctor.
- We work with your existing health care team to control your symptoms and maximize your quality of life.
- We will help you and your loved ones navigate community resources and maximize your supports at home.

What are the benefits?

Patients referred to similar Supportive Cardiology teams have reported:

- Increased satisfaction with care received
- Improved confidence with managing symptoms at home
- Increased quality of life
- Greater emotional and spiritual support
- Decreased need to visit the emergency department and require hospitalization
- Increased access to community resources and supports

Frequently Asked Questions to our team

- How can you help me better manage my breathing/pain or other symptoms at home?
- What other supports are there for me at home?
- What is the difference between supportive care and hospice care?
- Should I continue to see my cardiologist?
- What is advanced care planning?

Advanced care planning

Advanced care planning involves anticipating future scenarios and ensuring your wishes and preferences are known ahead of time. This ensures that your care providers are able to respect your wishes. Most Canadians believe it is important to have the opportunity to have their voice heard regarding future personal care. Someone you trust can be given the authority to act on your wishes if there comes a time when you are unable to make decisions regarding personal care. This person is called a Substitute Decision Maker (SDM). You can select someone to be your SDM by choosing a Power of Attorney for Personal Care. The Supportive Cardiology team will speak to you and your loved ones in more detail about your wishes and provide more resources to ensure that your wishes are known to your entire care team.

ASK US about End of Life Planning & Care

TALK TO US ABOUT YOUR END OF LIFE CARE PLANS AND DECISIONS

1. Your doctor may suggest that you consider your end of life care wishes.

2. Talk to your family about your wishes, beliefs and values around your end of life care preferences. Designate your Substitute Decision Maker (SDM).

3. Revisit your end of life preferences based on your prognosis and stage of life.

Ontario's Doctors are making health care better.

OMA
ONTARIO MEDICAL ASSOCIATION

www.OntariosDoctors.com/EOLPC

Image taken from the Ontario Medical Association.
https://www.oma.org/Resources/Documents/EOLC_InfographicDiscuss.pdf

Is palliative care or hospice right for me?

Palliative care is a medical speciality that helps patients and families with a serious illness by treating pain and other symptoms with the goal to prevent and ease suffering. You can receive palliative care **at the same time** you receive heart failure treatment. You do not have to be at end-of-life to receive palliative care. Palliative care is typically offered when your symptoms continue to occur despite medications and interventions your cardiologist is using to manage your illness. At NYGH, the Supportive Cardiology team provides similar care to our palliative care team.

Hospice care in Canada refers to palliative care in a home-like setting. This can occur in a residential hospice or a palliative care unit. The goal is to manage symptoms and keep you as comfortable as possible, focusing on your physical, psychological, social and spiritual needs. Typically, patients must be in the last 3 months of life to be considered for referral to hospice.

If you have any questions about whether you qualify to receive palliative care, please ask a member of our team for more information.

Community supports

Whether you are seen during your hospital stay or in the Heart Function Clinic, the Supportive Cardiology team will assist in connecting you with community resources that can help improve your quality of life at home. The Central Community Care Access Centre (CCAC) team can coordinate in-home and community-based care. You may have a CCAC case manager assigned to you. CCAC assesses patients to determine eligibility and need for all services and equipment.

COMMUNITY SUPPORTS

CCAC services

- Your CCAC case manager may arrange for some or all of the following:
- A **Registered Nurse** and/or a **Nurse Practitioner** to help manage your symptoms at home and discuss care planning that matches your goals
 - A **Personal Support Worker (PSW)** to help with personal care (toileting, bathing, etc.)
 - A **Health Links Care Coordinator** to arrange a conference to discuss your care plan with all of your care providers
 - An **Occupational Therapist** to complete a home safety assessment (for home equipment such as grab bars in the shower, raised toilet seats, commodes, etc.)
 - A **Physical Therapist** to help you gain strength and prevent deconditioning

CCAC works closely with your family doctor and other community outreach (at-home) programs, which are discussed later in this booklet. Your case manager will work with you to determine if these programs are right for you.

Patients and families are also able to privately hire care from a nurse or personal support worker. Please ask a member of your health care team if you would like more information on this.

Home equipment

Some patients require additional equipment at home. The Supportive Cardiology team can provide information about what may be helpful for you and your loved ones and how to access these supports.

HOME EQUIPMENT

Personal aids	Personal aids may include equipment in the home such as a shower bar or chair, raised toilet seat or bedside commode to assist in daily care.
Hospital bed	For people who find it difficult to transfer in and out of bed, we may suggest having CCAC assess the need for a hospital bed to be delivered to your home. The bed can assist with your comfort and mobility as it allows for easy adjustments of the head and feet.
Medical emergency alert services	There are medical alert systems to allow for greater independence living at home. In case of an emergency or a fall, you can simply press a button to notify a trained response associate that you need help (e.g. Life Line, Alarm Force).
Home oxygen	Some people require oxygen at home to help them breathe. The Supportive Cardiology team will assess whether oxygen is right for you. Home oxygen should be used in combination with prescribed medications to help you to breathe comfortably.

Prescriptions

During your visit with the Supportive Cardiology team, you may be prescribed medications to help manage your symptoms. These medications are to be taken **in addition** to medications prescribed by your cardiologist and family doctor.

MEDICATION MANAGEMENT

Prescriptions

- You and/or your loved one may be provided with prescriptions for medications to assist with the management of your symptoms related to heart failure.
- These prescriptions will be in addition to your regular cardiac medications prescribed by your cardiologist and family doctor.
- **You should not stop taking any medications prescribed by your cardiology team unless instructed to do so.**
- Once you are home, if you have any questions about your medications, please call the Supportive Cardiology Clinic for support at 416-756-6000 ext. 4522.

How to refill your prescriptions

- If you are prescribed medications by the Supportive Cardiology physician and need a refill:
- Call your pharmacy and have them fax a request refill form to 416-756-6702.
 - Your prescription will be written by a physician and faxed to your pharmacy within 2 business days.
 - Prescriptions can only be refilled during business hours, Monday to Friday between 8 a.m. and 4 p.m., excluding holidays.

Do not adjust your medication without consulting with a physician.

If you have any concerns regarding your medications, please call the Supportive Cardiology Clinic at 416-756-6000 ext. 4522.

Outreach (at-home) programs

There are various programs in the Greater Toronto Area that can help you manage advanced heart failure in the comfort of your own home. If your family doctor does not provide home visits and if you and your loved ones feel that care at home would better meet your needs, our team can help connect you with one of these programs. Outreach or home programs are suitable for those who would like to exclusively focus on comfort, prefer not to come back to the hospital for appointments, and are accepting of palliative care or hospice care. Our team can help determine if you qualify for one of these programs.

OUTREACH PROGRAMS

Hospice Palliative Care Team

- Offers 24/7 access to clinical nurse consultants available to your care team.
- These nurses will assist with pain and symptom management and reduce your need to visit the emergency department.
- The nurse works collaboratively with your general practitioner, the Heart Function Clinic team and the cardiology team to address your needs.
- The nurse will assist in connecting you to hospice palliative care resources in your community.

Central CCAC Nurse Practitioners

- Offers 24/7 access to nurse practitioners available in person, by phone, or by email.
- These clinicians will assist with pain and symptom management and reduce your need to visit the emergency department.
- The nurse works collaboratively with your general practitioner, the Heart Function Clinic team and the cardiology team to address your needs.
- The nurse will assist in connecting you to hospice palliative care resources in your community.

Important phone numbers

CALL	WHO	WHEN
911	Emergency	If you are having a medical emergency
	CCAC Coordinator	For any issues related to home care or increasing support - if you are unsure who to call
	Home visiting Doctor/Nurse ***Call first for any non-urgent issues***	<p>If you have symptoms that you are concerned about:</p> <ul style="list-style-type: none"> ■ Increasing shortness of breath ■ Difficulty breathing when lying down ■ Increasing pain or discomfort ■ Increasing leg swelling <p>If you have questions regarding your cardiac medications</p>
416.756.6978	NYGH Heart Function Clinic	If you would like to speak with your cardiology team
416.756.6000 Ext. 4522	NYGH Supportive Cardiology Clinic	<p>If you have any non-emergency symptoms that you are concerned about:</p> <ul style="list-style-type: none"> ■ Increasing shortness of breath ■ Increasing pain or discomfort ■ Increasing leg swelling <p>If you have questions regarding whether you qualify for home services. If you would like to talk about quality of life or changes in goals of care</p>

Information in this guide has been referenced from the following sources:

1. American Heart Association (heart.org)
2. Canadian Cardiovascular Society (ccs.ca)
3. Centre to Advance Palliative Care (capc.org)
4. Ontario Medical Association (oma.org)

Notes

nygh.on.ca/supportivecardiology
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