

Canadian Heart Failure Patient & Caregiver Charter



What Is Heart Failure?

Heart Failure (HF) is a condition where the heart cannot pump enough blood through the body to meet its needs. The heart is unable to fill with enough blood, or its pumping action isn't strong enough, or both.

HF is common, and on the rise in Canada. As more people are surviving heart attacks and other acute heart diseases, more people are going on to develop HF.

Symptoms Of Heart Failure

MOST COMMON SYMPTOMS:

- Shortness of breath
- Swelling of legs or belly
- Low energy level

OTHER SYMPTOMS INCLUDE:

- Nausea
- Vomiting
- Weight loss
- Lack of appetite
- Persistent cough
- Symptoms are often vague - some people think they have the flu. Others don't experience any symptoms at all.

Causes

LEADING CAUSES: DISEASES THAT DAMAGE THE HEART MUSCLE, SUCH AS:

- Coronary artery disease (eg, heart attack, angina, etc.)
- High blood pressure
- Diabetes

SOME PEOPLE DEVELOP HF FOR OTHER REASONS, SUCH AS:

- Viral disease
- Genetic factors
- Congenital anomalies
- For some people, the cause of their HF is unknown.



Diagnosis & Management

HF is a common and serious condition that requires medical care. Living with HF is a journey that has its ups and downs. Early diagnosis and treatment are important! **By treating HF at its early stages, people can live longer, fuller, and more active lives.**

Recommended treatments vary depending on the type and severity of the HF.

TREATMENTS INCLUDE:

- Medications
- Lifestyle changes (eg, modifying exercise and diet; quitting alcohol and smoking)
- Some people will need medical device therapy and/or a transplant

The Bottom Line

Although we don't yet have a cure for HF, medical therapies and lifestyle changes can help people living with HF to manage their condition well.

For more information, visit HeartLife Foundation www.heartlife.ca.

What Is A Patient/Caregiver Charter?

A Patient/Caregiver Charter outlines a **set of rights and responsibilities** to support the creation and implementation of a national standard of care for Canadians living with HF and their caregivers.

Access to care, medical therapies, and support services varies widely from one region to the next. The overall goal of this Charter is to support establishment of **high quality care** that is provided consistently across the country. It provides a guide:

FOR PATIENTS AND CAREGIVERS:

- To know what to expect throughout their care continuum.
- To be empowered to ask the questions that matter to them.
- To understand their individual responsibilities for their own health.

FOR HEALTHCARE PROVIDERS:

- To understand the lived experience, recognize opportunities within their system of care, and identify solutions that will fit their local setting.

FOR POLICYMAKERS AND PRIVATE PAYERS:

- To guide the identification of opportunities within their jurisdictions and support development of solutions.

Aim

Improve overall quality of life for Canadians with Heart Failure (HF) throughout the care continuum:

- **Establish a core set of patient/carer rights** to create and advocate for a national standard of care for HF in order to improve quality of life and reduce HF-related mortality and hospitalizations.
- **Establish a core set of patient/carer responsibilities** to empower individuals with HF in managing their health and living a better quality of life.
- **Call upon policymakers**, health care providers and private payers to recognize HF as a serious, lethal, chronic disease and unite in the campaign for greater awareness of this illness.
- **Support effective collaboration** between patients/caregivers, health care providers, policymakers, and payers.
- Establish the important role of patients/caregivers in **future research** decisions and treatment guidelines.



Who Is This Charter Intended For?

- Patients
- Caregivers, including family members and loved ones
- Health care providers
- Policymakers
- Private payers

Why Does Canada Need a Patient/Caregiver Charter for Heart Failure?

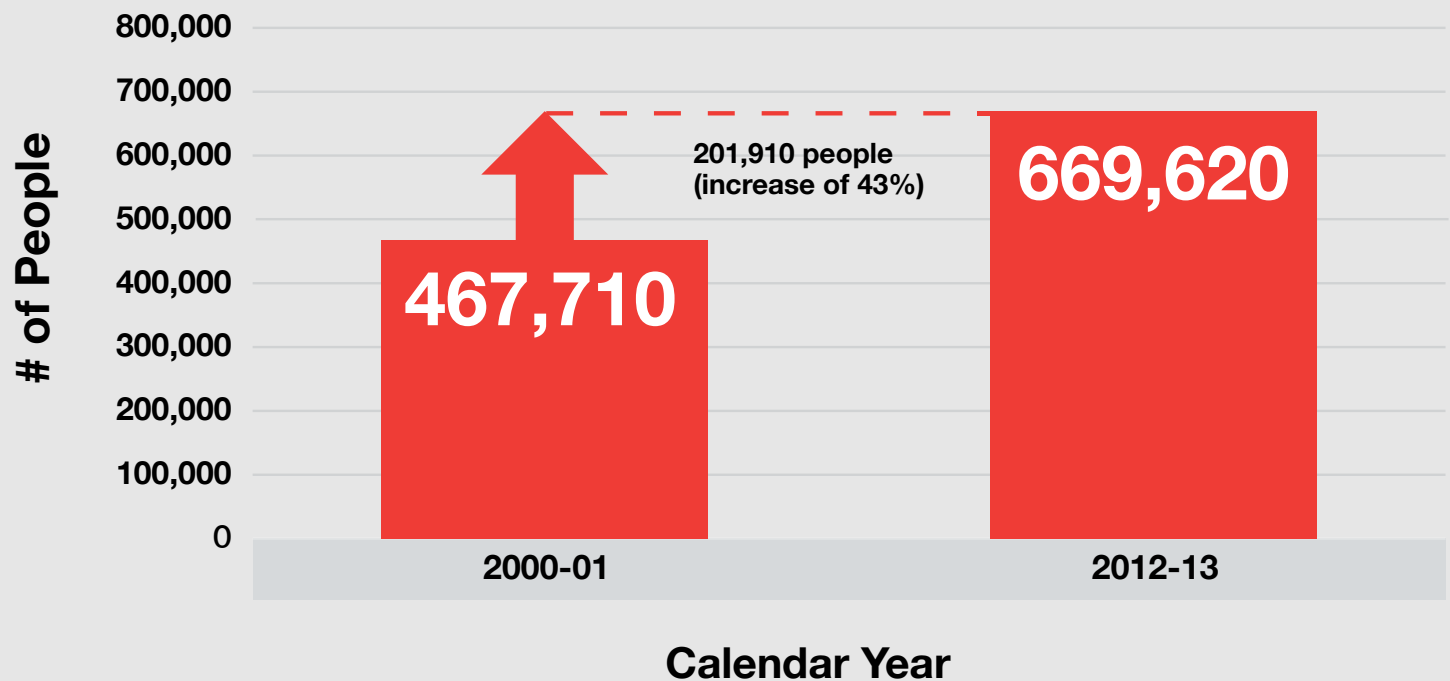
The Burden of HF is Profound - on **Patients**, **Caregivers** and our **Society**.

INCIDENCE

Each year, 92,900 Canadian adults are newly diagnosed with HF.⁵

PREVALENCE

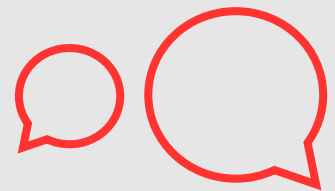
669,600 Canadians are living with HF. That's 3.6% of the population – and an increase of 43% over 13 years.⁵



Burden on patients and caregivers

Patients and their caregivers suffer from greatly reduced functional capacity and quality of life - a burden similar to having advanced cancer or AIDS.^{2,6}

HF is a leading cause of hospitalization. Canadians hospitalized with HF have readmission rates >20% at 30 days and mortality rates of 30% at 1 year.³



“Adapting to a new normal was difficult at my age. We had to change our lifestyle completely and we didn’t know anyone with heart failure. Who else could we talk to?”

JONATHAN, PATIENT, AGE 66

“It is difficult to try and tell all of the details of my story and how for most of my adult life I have suffered. How, at 28, heart failure literally squeezed the life out of my body. How I struggled to breathe with what felt like a vice around my chest.”

MARION, PATIENT, AGE 44

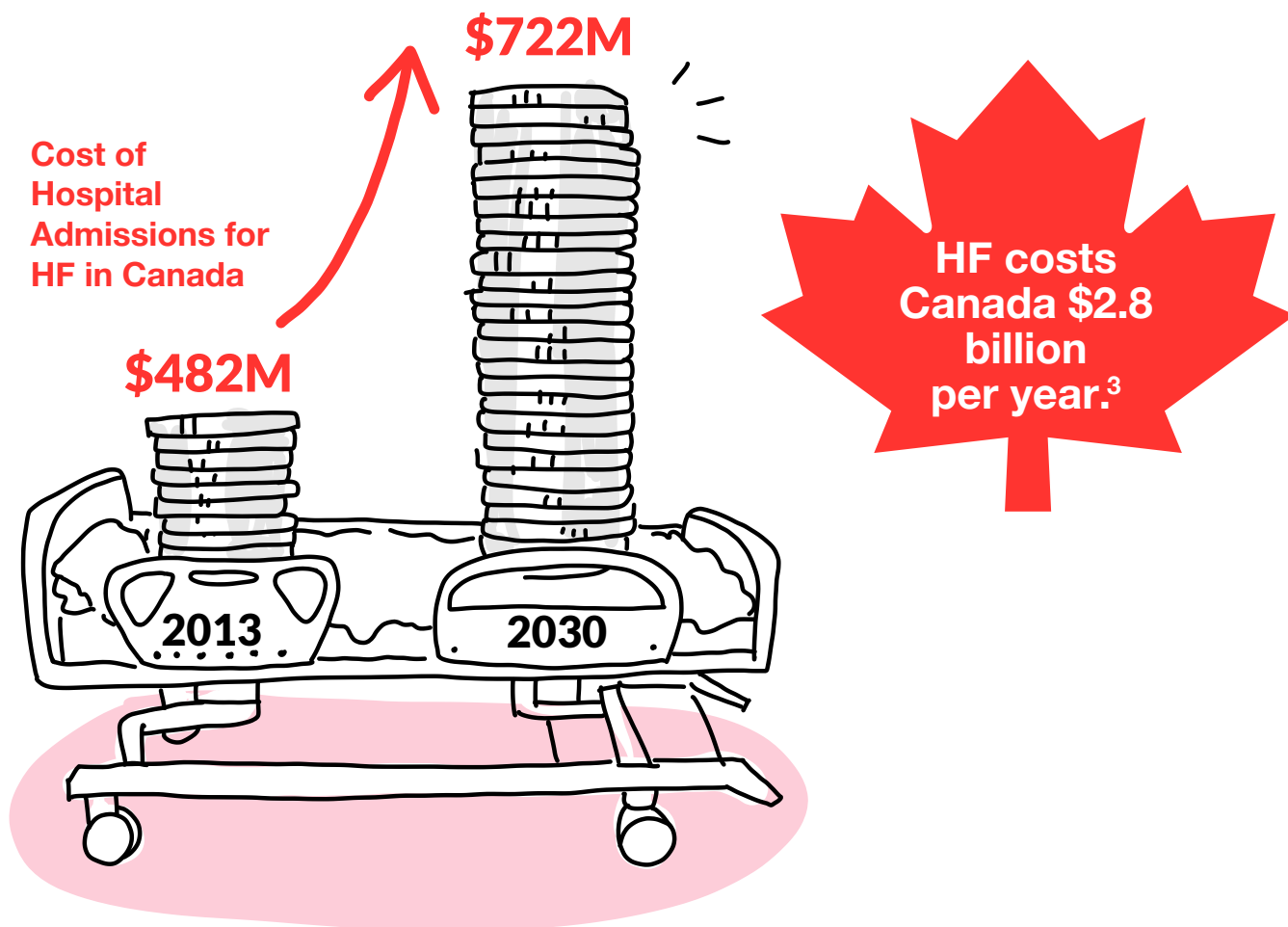
“Our lives were essentially flipped upside down. It was difficult to hear that our son’s heart was failing and there was nothing we could do about it. Little did we know, the most difficult times were ahead. Heart failure was to become a family disease.”

SOPHIA, CAREGIVER, 62

“After all the testing was complete, my doctor told me that my ejection fraction was up and I was no longer in active heart failure. I should be glad of that and not want to fix what isn’t broken. I said, “But it is broken, I feel horrible and not myself.”

ISAAC, PATIENT, AGE 52

Burden on society



The healthcare available to HF patients varies widely across Canada. A Charter serves as a **tool for stakeholders in HF** – government, healthcare providers, private insurance companies, patients & caregivers - to cross-check and identify local gaps to resolve.

It helps us to work collaboratively toward a common **goal of improving the lives of Canadians** living with HF, which in turn benefits patients, caregivers, and society as a whole.

¹ Tran DT, Ohinmaa A, Thanh NX, et al. The current and future financial burden of hospital admissions for heart failure in Canada: a cost analysis. CMAJ Open 2016 Jul 21;4(3):E365-70.

² Virani SA, Bains M, Code J, et al. The Need for Heart Failure Advocacy in Canada. Can J Cardiol. 2017 Nov;33(11):1450-4.

³ 2016 Report on the Health of Canadians: The Burden of Heart Failure. Heart and Stroke Foundation; 2016. Available: <https://www.heartandstroke.ca/-/media/pdf-files/canada/2017-heart-month/heartandstroke-reportonhealth-2016.ashx?la=en> (accessed 2020 Apr. 18).

⁴ Heart Disease in Canada: Highlights from the Canadian Chronic Disease Surveillance System. Public Health Agency of Canada; 2017. Available: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/heart-disease-canada-fact-sheet.html> (accessed 2020 Apr. 18).

⁵ Report from the Canadian Chronic Disease Surveillance System: Heart Disease in Canada, 2018. Public Health Agency of Canada; 2018. Available at: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/report-heart-disease-Canada-2018.html> (accessed 2020 Apr. 18).

⁶ Alpert CM, Smith MA, Hummel SL, Hummel K. Symptom burden in heart failure: assessment, impact on outcomes, and management. Heart Fail Rev. 2017 Jan;22(1):25-39.

Patient Rights

As a Canadian living with Heart Failure, I have the following rights:

01 Receipt of an accurate and timely diagnosis of HF.



02 Availability of services and resources to support my mental health throughout my care continuum.



03 Access to educational tools and resources, including an advance care plan, to empower me to effectively self-manage my health.



04 Empathy and compassion from health care providers.



05 Access to multidisciplinary care team throughout my journey that includes a Heart Failure specialist, a nurse, a pharmacist, mental health support, a dietitian, a cardiac rehab specialist, and my general practitioner.



06 Timely access to the best standards of care and medical therapies that are currently available.



07 Opportunity to provide input into decisions regarding future research into HF.



01

Receipt of an accurate and timely diagnosis of HF.

An **accurate and timely diagnosis** is essential to initiate treatment that will relieve my symptoms, improve my quality of life, reduce hospitalizations, and prolong my survival.

This requires:

- ➔ National initiatives to increase awareness of HF signs and symptoms among health care providers who are most likely to be my first point of contact, particularly primary care and emergency physicians.
- ➔ Timely referral to a physician who has the expertise needed to evaluate me and conduct the appropriate investigations in accordance with current evidence-based guidelines.

02

Availability of services and resources to support my mental health throughout my care continuum.

Mental health issues, including but not limited to depression, anxiety, and mental stress, are common in HF patients and our caregivers; these disorders have a deeply negative impact on our overall well-being. Addressing this challenge requires:

- ➔ Standardizing the psychosocial evaluation of both me and my caregivers.
- ➔ Establishment of local and/or virtual support groups for both me and my caregivers.
- ➔ Access to publicly funded in-person and virtual mental health support systems throughout my care journey

03

Access to educational tools and resources, including an advance care plan, to empower me to effectively self-manage my health.

Throughout my journey as a HF patient, my family/caregivers and I will have many questions about my disease and how we can optimize our wellbeing. To support us, we need educational materials and resources that answer our questions, are available at any time, and address a variety of topics, including:

- Understanding HF and where to access more information about the disease.
- Medications, cardiac rehab, and other recommended therapies: benefits, risks, and potential side effects.
- Surgical procedures: benefits, risks, post-surgery expectations.
- Signs/symptoms of when to seek medical care.
- When and how to access my HF care team.
- Life after HF diagnosis: transitioning from hospital to home, diet, sleeping issues, cognitive challenges, impact on family/caregivers, exercise and other activities, etc.
- ➔ Community resources are available to us (in-person and/or remotely), such as multidisciplinary information sessions about HF and psychosocial support sessions.
- ➔ A care plan upon discharge that is signed off by the members of my multidisciplinary care team. This plan is reviewed and updated regularly throughout my ongoing care.

04

Empathy and compassion from health care providers.

- ➔ Recognition amongst health providers that my designated caregivers have the right to access and interact with them on my behalf.
- ➔ Standard patient-driven training for health professionals about the burden of HF on patients/caregivers and how to support us.
- ➔ Openness among health providers to respectfully discuss any questions I have about alternative therapies.

05

Access to multidisciplinary care team throughout my journey that includes a Heart Failure specialist, a nurse, a pharmacist, mental health support, a dietician, a cardiac rehab specialist, and my general practitioner.

- An integrated system of care that enables my HF care team to collaborate with other services and health practitioners that I may need, including other physician specialties, community/homecare resources, palliative care, etc.
- A case manager (patient navigator) who coordinates my care and serves as a single point of contact for me.
- My team functions through a patient-centred 'hub and spoke' model, with me and my caregivers at the centre of the hub.
- The use of virtual health systems will support my team in ensuring monitoring visits are effective and occur as scheduled, especially if I live in a rural and/or indigenous community.

06

Timely access to the best standards of care and medical therapies that are currently available.

- Access to healthcare professionals who have the expertise needed for my health condition within timelines outlined in current, evidence-based standards of care.
- Cardiac rehab services that are available locally; or with my travel expenses covered, if necessary; or virtually, if that is an option for me.
- Use of virtual services to ensure I have timely access to qualified healthcare professionals, no matter where I live.
- Access to medications and device therapies that are appropriate for me in accordance with current, evidence-based standards of care.
- Public funding of medications and device therapies that will aid in my care.
- Timely access upon request to copies of my personal health records.

07

Opportunity to provide input into decisions regarding future research into HF.

- Establishment of a federally funded research track that is solely patient driven.
- Establishing mandatory requirements for approval of research funding applications:
 - Patients and caregivers are involved in developing the protocol.
 - Quality of life indicators are included, whenever possible.



Patient Responsibilities

As a Canadian living with HF, I am ultimately responsible for taking care of my own health. I am supported by my healthcare team, who do their best to guide and assist me and my loved ones.

As a patient or family/carer, I am responsible for:

MAINTAINING HEALTHY BEHAVIOURS.

- I am solely responsible for the choices I make.
- My choices have an impact on my health, either positive or negative.
- I will do my best to make the right choices to improve my health (eg, follow nutritional guidelines, exercise regularly, take my medications as prescribed, reduce alcohol intake, quit smoking and all other illicit substances).

SELF-MONITORING MY HF SYMPTOMS.

- My active participation in monitoring my symptoms is essential to my well-being.
- I will monitor and record my symptoms on a schedule that I will agree upon with my doctor.
- I will be alert to any changes in my symptoms that I should bring to my doctor's attention.

SEEKING MEDICAL HELP WHEN I NEED IT.

- I will evaluate any changes I observe in self-monitoring my HF symptoms and determine what action I need to take. If I decide I need medical help, I will do so without delay because I understand that my health may suffer if I do not get the help I need quickly.
- Afterwards, I will review my decision and determine whether I made the best choice. This reflection will help me to make the best decisions possible in the future.

TAKING MY MEDICATIONS AS MY TEAM PRESCRIBED.

- I will take my medications as my team has prescribed so that I will feel as well as possible.
- My team and I will work together to determine the best treatment plan for me. I know that some medications may have unpleasant side effects, but that the benefits to me are greater than these downsides. If I experience side effects that are especially difficult for me, I will not stop or decrease my medications without first discussing my situation with my team. We will determine together if changes to my treatment plan are best for me.
- I will advise my team of all natural or alternative therapies I am choosing to take beyond those that are prescribed.

FOLLOWING THE ADVICE OF MY HEALTHCARE PROVIDERS.

- My doctor and other members of my healthcare team provide me with their best advice to support my well-being. It is my responsibility to follow their advice, attend appointments, and get recommended diagnostic and lab tests.

ASKING QUESTIONS WHEN I DON'T UNDERSTAND.

- Because I am responsible for my own health, I need to understand my treatment plan and other information I receive from my healthcare team. If I have any questions, I will ask them.



Who Developed This Charter?

This Charter was built upon the findings from the **HeartLife Foundation** between 2019 and 2020. HeartLife worked with patients and family carers from across the country in order to gain insight into the challenges facing Canadians directly affected by Heart Failure.



About HeartLife Foundation

HeartLife Foundation is Canada's first – and only – national patient-led Heart Failure organization. We are a Federal Charity aimed at raising public awareness of Heart Failure, engaging patients, families, and caregivers to provide education and support, facilitate access to the latest research, innovations, and treatments, and advocate better care for all.

Mission

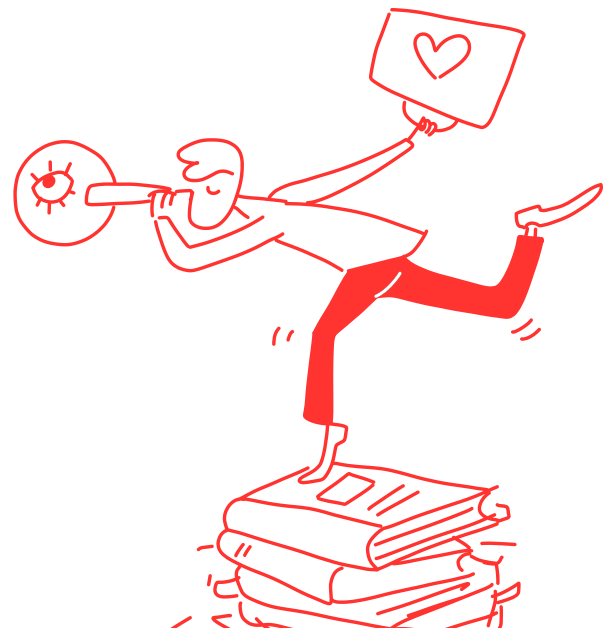
HeartLife Foundation is a patient-driven charity whose mission is to transform the quality of life for people living with Heart Failure by engaging, educating, and empowering a global community to create lasting solutions and build healthier lives.

Vision

To create a better everyday life for people living with Heart Failure. It's about life, not failure.

Jillianne Code, Ph.D
Co-Founder

Marc Bains
Co-Founder



Ways to get involved



DONATE

Help people live a heart life.



Visit us at www.heartlife.ca

Drop us a line via info@heartlife.ca

Follow us on [Instagram](#)

Join our [facebook community](#)