



# Heart Failure Patient & Caregiver Charter



An International collaboration  
of heart failure patient  
organisations and patients

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# What is Heart Failure?

Heart Failure (HF) is a condition where the heart cannot pump enough blood through the body to meet its nutrients needs. This happens because the heart is unable to fill with enough blood, or its pumping action isn't strong enough, or both. This causes fluid to build up in the body, mainly in the feet, ankles and legs.

HF is common, and on the rise across the world. As more people are surviving heart attacks and experiencing heart issues that lead to HF, more people will develop the condition.

# SYMPTOMS OF HEART FAILURE

HF can affect different people in different ways. Symptoms can come on suddenly and be initially severe (acute HF) or they can appear over time and gradually worsen (chronic HF). If someone has HF, they may have one, or a combination, of the following symptoms.

## Most common symptoms and signs:

- Shortness of breath - in particular, new onset - during minimal physical exercise or when lying down
- Irregular heartbeat or palpitations
- Swelling of legs, feet or stomach
- Coughing/wheezing
- Weight gain over a short period of time (>2kg over 2 days)
- Extreme tiredness, low energy, or no energy
- Loss of appetite

## Other symptoms and signs include:

- Dizziness, nausea, vomiting
- Cognitive problems such as difficulty concentrating or problems with memory
- More frequent urination, especially at night

# CAUSES

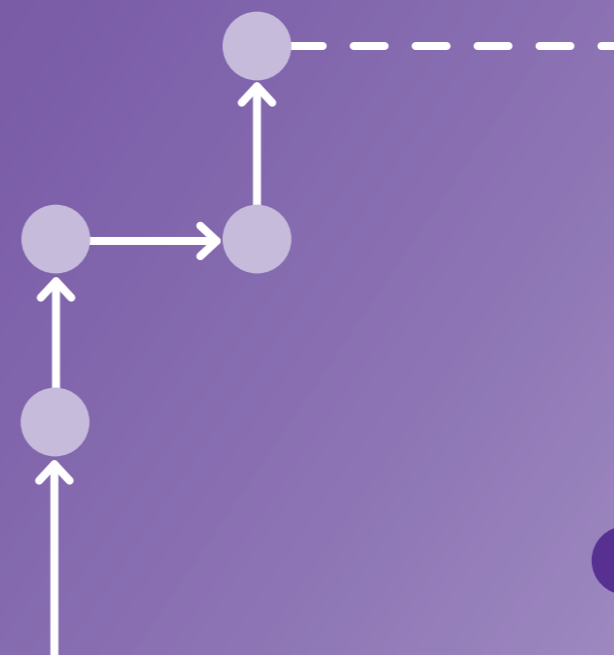
Other heart conditions are the main causes that can lead to HF and patients with HF normally have one or more of the conditions listed below. Having more than one of these factors increases the risk of developing HF.

## Damage to the heart muscle caused by:

- Coronary artery disease
- High blood pressure
- Heart Valve Disease
- Irregular heart rhythm
- Heart Muscle Disease
- Myocardial infarction (Heart attack)
- Diabetes

## Some people develop HF for reasons such as:

- Viral disease
- Chronic lung disease
- Smoking or alcohol / drug abuse
- Obesity
- Sleep Apnea
- Severe Anemia
- Congenital heart anomalies (heart problems you are born with)
- Consequences of certain medical treatments e.g., Chemotherapy or Radiotherapy
- For some people, the cause of their HF is unknown



# DIAGNOSIS AND 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 in its early stages, people can live longer, fuller and more active lives.

## Multiple tests are used to establish a definitive HF diagnosis, including:

- Clinical history
- Physical examination
- Blood tests to assess natriuretic peptides (BNPs - hormones produced by the heart)
- Chest X-ray
- Electrocardiogram (ECG - a test that checks the heart's rhythm and electrical activity)
- Echocardiogram (Echo - a scan that provides a detailed overview of the heart)



Recommended treatments vary depending on the type of the HF, its severity and comorbidities. Three types of HF based on the heart's left ventricular ejection fraction (LVEF) are:

- **HF with reduced ejection fraction (HFrEF)** - the left ventricle is unable to contract effectively so less or equal of 40% of the blood in the heart is pumped to the rest of the body.
- **HF with mildly reduced ejection fraction (HFmrEF)** - the left ventricle contracts with reduced effectiveness and between 41% and 49% of the blood in the heart is pumped to the rest of the body.
- **HF with preserved ejection fraction (HFpEF)** - the left ventricle contracts effectively and more or equal of 50% of the blood in the heart is pumped to the rest of the body, but holds a small volume of blood - so even if all the blood in the heart is sent to the rest of the body, it is not enough to meet the body's needs.

## Treatments include:

- Medications
- Lifestyle changes (such as modifying exercise and diet, quitting alcohol and smoking)
- Some people may need medical device therapy and/or a heart transplant

## The Bottom Line

Although there is currently no cure for HF yet, medical therapies and lifestyle changes can help people living with HF to manage their condition well and lead productive and fulfilled lives. For more information, visit the websites listed at the end of this Charter.





# What is the Patient/Caregiver Charter?

The Patient/Caregiver Charter outlines a set of expectations and responsibilities to support the creation and implementation of an internationally accepted standard of care for individuals living with HF and their caregivers.

The overall goal of this Charter is to support the development of optimal high-quality care and to promote its adoption internationally across all healthcare systems.

## IT CALLS ON...

### Patients and caregivers:

- To know what to expect throughout their care pathway.
- To be empowered, to ask the questions that matter to them.
- To understand their individual rights and responsibilities regarding their own health.

### Healthcare providers:

- To understand the lived experience and identify opportunities and solutions in their local setting, that would have a beneficial impact for patients.

### Policymakers and other stakeholders:

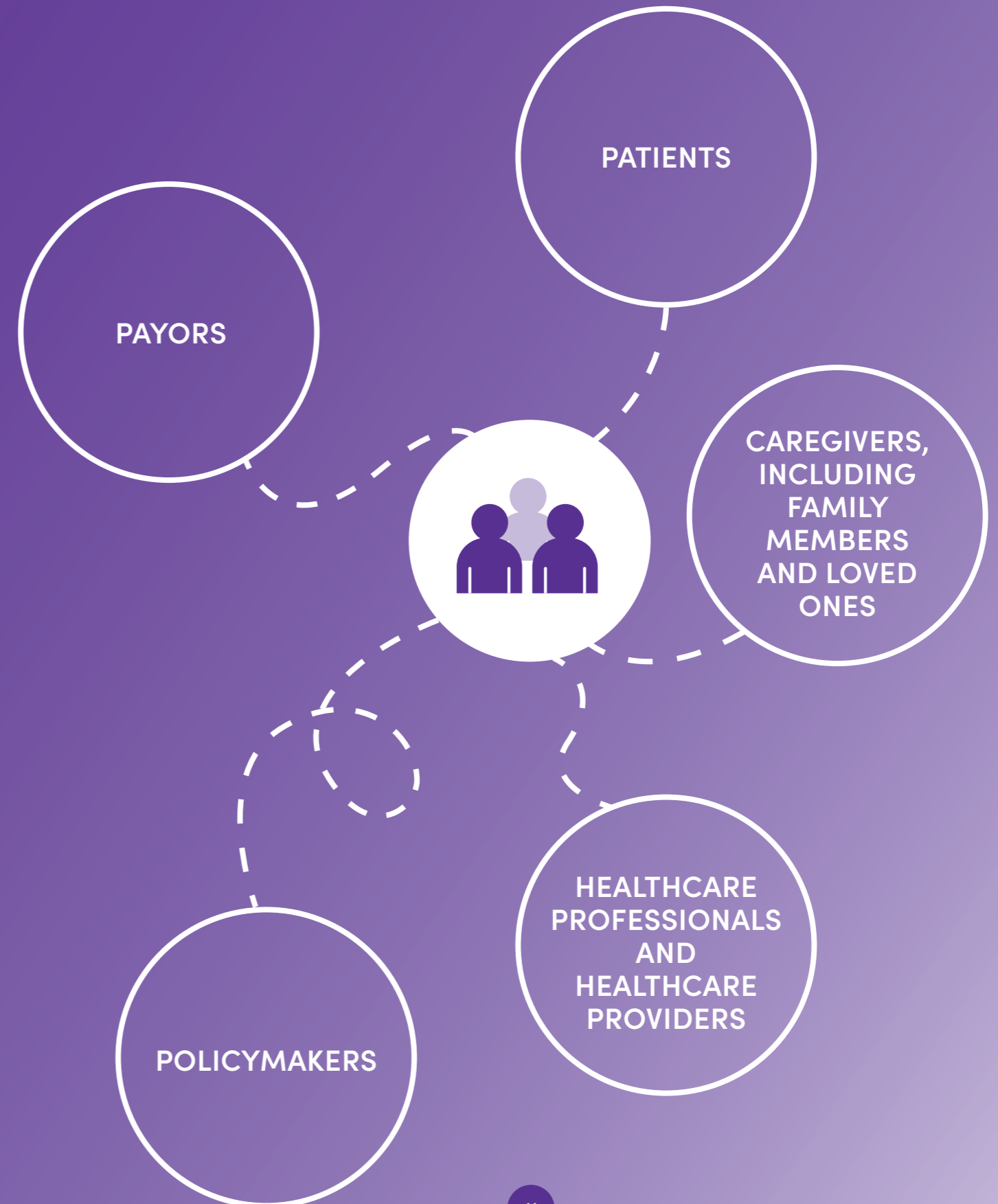
- To guide their knowledge and opportunities to create change and deliver improvements in HF care with patient involvement.

# AIM OF THIS CHARTER

- **Improve the overall quality of life** for individuals with HF throughout the care pathway.
- **Establish a core set of patient/caregiver expectations** that would be incorporated into an internationally accepted standard of care for HF, which would optimise patients' quality of life and reduce HF-related mortality and hospitalisations.
- **Establish a core set of patient/caregiver responsibilities** to empower individuals with HF to manage their health and enjoy a better quality of life.
- **Call upon policymakers**, healthcare providers and payors to recognise HF as a serious, chronic condition which requires a united effort from awareness through to treatment and care.
- **Foster effective collaboration** between all stakeholders - patients/caregivers, healthcare professionals, healthcare providers, policymakers and payors.
- Ensure that the important role of patients and caregivers is recognised in **future research** activities, the **development** of treatment guidelines and overall cardiovascular disease health policy.



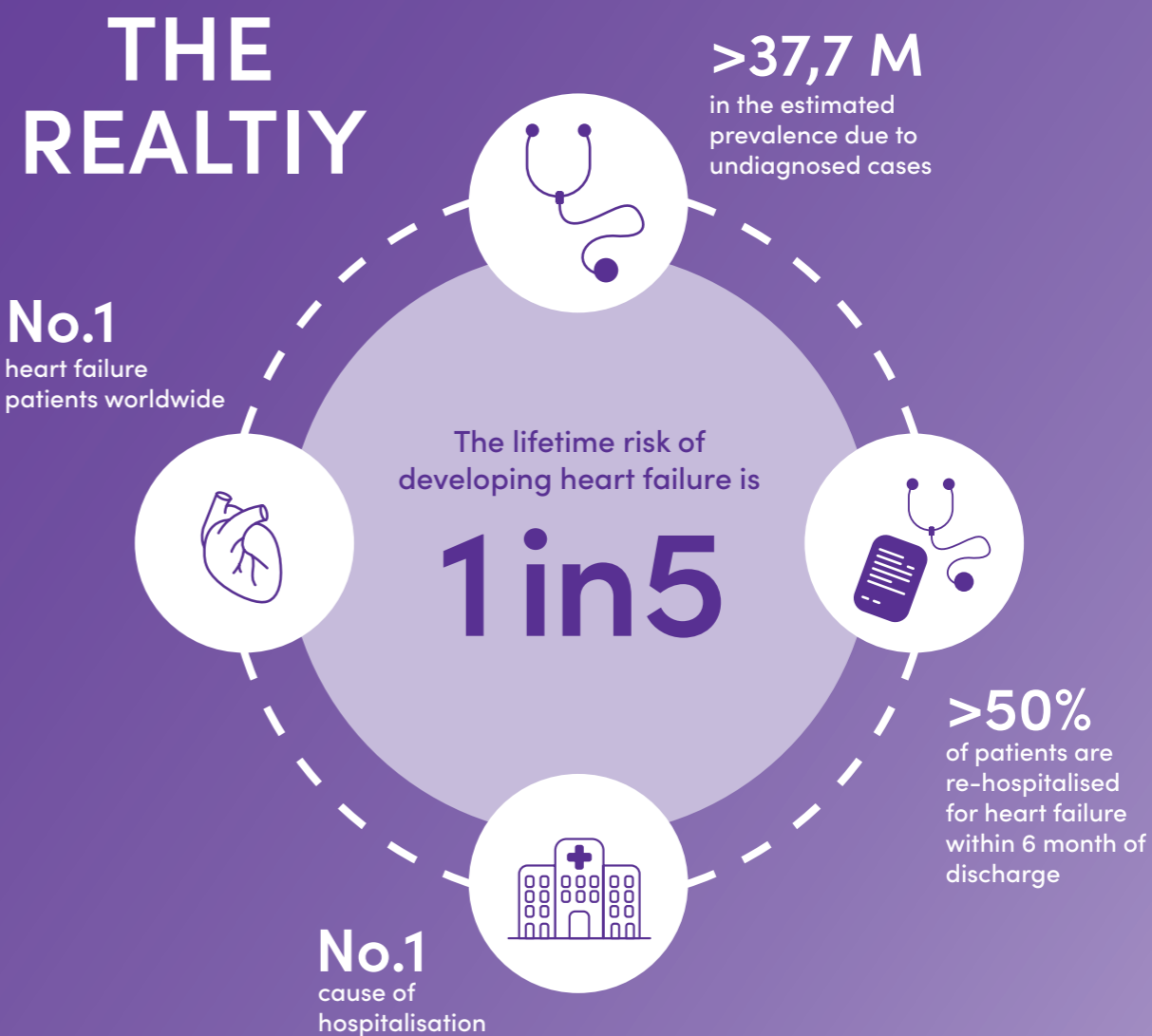
# WHO IS THIS CHARTER INTENDED FOR?





# Why do we need a Patient & Caregiver Charter for HF?

The burden of HF is profound on patients, caregivers and our society.



The healthcare available to HF patients varies widely across the world. This Charter serves as a tool for stakeholders in HF such as government, healthcare providers, insurance companies, patients and caregivers to identify and resolve local issues and take opportunities to implement change. It unites us to work collaboratively towards a common goal of improving the lives of individuals living with HF, which in return benefits patients, caregivers, and society as a whole<sup>1</sup>.

# 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<sup>2,3</sup>. HF is a leading cause of hospitalisation. More than half of all HF patients are re-hospitalised within six months of discharge.

# GENDER DIFFERENCES IN HEART FAILURE:

The overall incidence of HF is similar for both women and men, although pronounced gender differences are seen in HF such as:

- Takotsubo syndrome occurs almost exclusively in women and is often triggered by emotional or physical stress. More than 90% of reported cases occur in postmenopausal women who are aged 58–75 years<sup>4,5</sup>.
- Women with hypertension triples the risk of developing HF<sup>6</sup>. Excess risk of HF associated with diabetes is greater in women than in men and obesity is a stronger risk factor for HF in women<sup>7</sup>.

# PATIENT TESTIMONIALS

HF patient, 80, Italy

"I felt limited at work because I had to give up travel. I felt useless, a burden for myself and for others, a fragile person and completely different from what I used to be. After a heart attack, you live by the day, if not by the hour."

HF patient, 60, Netherlands

"Having now lived with Heart Failure for nearly five years, it is obvious that this has had a tremendous effect on my life as well as my family. For the first few years I had to rely heavily on the help from my son and close friends. It remains an on-going learning process. My personal and professional life has changed drastically. Learning to 'go with the flow' has become my new mantra."

HF caregiver, 66, Australia

"The first adjustment I had to make as his wife was to convince him this was not going to change his life dramatically. We had always worked through health issues together as a team and I assured him we would get through this. We started to resume all the activities we used to do but at a slightly different pace. He soon realised that a full and productive lifestyle was achievable."

"Hearing the diagnose of Heart Failure just right before my 30<sup>th</sup> birthday, back then I thought that my life was over. I have always been very independent during my heart health journey as my focus was to feel better, be knowledgeable about my illness, do everything in my power to control it and still enjoy life as much as possible."

- HF patient, 35, Lithuania





# Patient Expectations

As an individual living with Heart Failure, I have the following expectations:

- 1** To receive a timely and accurate diagnosis of HF.
- 2** To have timely access to the best standards of care and medical therapies currently available.
- 3** To have access to an integrated multidisciplinary care team and to be included in shared decision-making throughout my care journey.
- 4** To have access to educational tools and resources, including a care plan which empowers me to self-manage my health effectively.
- 5** To have access to services and resources necessary to support my mental healthcare from diagnosis onwards.
- 6** To experience empathy and compassion from my healthcare providers.
- 7** To have the opportunity to contribute and participate as an equal stakeholder in future HF research.

## To receive a timely and accurate diagnosis of HF

1

Receiving a **timely and accurate diagnosis** is essential to initiate treatment that will relieve my symptoms, reduce hospitalisations, improve my quality of life and extend longevity.

- National initiatives to increase the awareness of HF signs and symptoms among the healthcare 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 necessary expertise to medically assess me and conduct the appropriate diagnostics in accordance with current evidence-based guidelines to provide a timely and accurate diagnosis of HF.

## To have timely access to the best standards of care and medical therapies currently available

2

- Access to healthcare professionals who have the expertise needed for my health condition within timelines outlined in current, evidence-based standards of care.
- Access to a local cardiac rehabilitation service. Virtual access can be an option.
- Access to ongoing support from qualified HF healthcare professionals, including tele-medicine if necessary, 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 and recommendations.

3

## To have access to an integrated multidisciplinary care team and to be included in shared decision making throughout my care journey

- Access to an integrated system of care that enables my HF care team to collaborate with each other as well as with health practitioners and services that I may need such as other physician specialities, community/home care resources, palliative care, etc.
- Access to a case manager/patient navigator or designated healthcare professional who coordinates my care and can serve as a single point of contact for me.
- Access to a HF care team that functions through a patient-centred 'hub and spoke' model, with me and my caregivers at the centre of the hub.
- Access to a digital health system which supports my HF care team coordinate and schedule my monitoring visits and check-ups, especially if I live in a rural and/or indigenous community.

4

## To have access to educational tools and resources, including a care plan which empowers me to self-manage my health effectively

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

- Understanding HF and where to access more information about the condition.
- Medications, cardiac rehab and other recommended therapies: benefits, risks and potential side effects.



## > Expectations 4

- Surgical procedures – benefits, risks, expectations and post-surgery limitations/challenges and care management.
- 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.
- 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.

## 6 To experience empathy and compassion from my healthcare providers

- Recognition by healthcare providers that my designated caregivers have the right to access and interact with them on my behalf.
- Ensure that healthcare professionals working in the field of HF have the necessary training and skills to understand the burden of HF on patients/caregivers and how best to support us.
- Openness among healthcare professionals to respectfully discuss any questions I have about alternative or complementary therapies.

## To have access to services and resources necessary to support my mental healthcare from diagnosis onwards

### 5

Mental health issues, including but not limited to depression, anxiety and mental stress are common in HF patients and our caregivers; these conditions have a deeply negative impact on our overall well-being and quality of life.

- A standardised psychosocial evaluation of both me and my family/caregivers.
- Access to a local and/or virtual support groups for both me and my family/caregivers.
- Access to in-person and virtual mental health supports as an integrated part of my healthcare journey.

## 7 To have the opportunity to contribute and participate as an equal stakeholder in future HF research

- Ensure that PPI (Public and Patient Involvement) is a prerequisite for all government funded HF research.
- Ensure that as part of PPI, patients and caregivers are involved in developing the research protocol and ensuring that quality of life indicators are always included where possible.



# Patient Responsibilities

As an individual living with HF, I am ultimately responsible for taking care of my own health, supported by my family/caregivers and healthcare team, who do their best to guide and assist me

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

## 1 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 (e.g., follow nutritional guidelines, exercise regularly, take my medications as prescribed, reduce alcohol intake, quit smoking and all other illicit substances).

## 2 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 in agreement with my doctor.
- I will be alert to any changes in my symptoms that I should bring to my doctor's attention.

## 3 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.



## 4 Taking my medication as my team prescribed

- I will take my medication as my team has prescribed so that I 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.

## 5 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.

## 6 Asking questions when I don't understand

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

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# Who Developed This Charter?

This Charter has its origins in the HeartLife Foundation Canadian HF Patient Charter ([www.heartlife.ca](http://www.heartlife.ca)) and has been adapted by the Global Heart Hub, in partnership with patients and family carers globally.

## ABOUT THE GLOBAL HEART HUB

The Global Heart Hub is an international alliance of heart patient organisations established to provide a voice for those living with, or affected by, cardiovascular disease.

Our vision is to create a united, informed and empowered community of patient organisations and advocates. Our mission is to create a global cardiovascular disease community that supports and educates patients, caregivers and healthcare providers to ensure the best possible outcomes for those living with cardiovascular disease.

Join the Global Heart Hub  
All cardiovascular disease patient groups, organisations and advocates across the world are welcome to be part of the Global Heart Hub. Affiliation is free and is open to the heart patient community.

Learn more at [www.globalhearthub.org](http://www.globalhearthub.org) or contact us at [info@globalhearthub.org](mailto:info@globalhearthub.org).

This Charter is endorsed by Global Heart Hub Affiliates, including:





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