hearts4heart

Global Heart Hub

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 nutritional 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 lungs, feet, ankles and legs.

HF is common, and on the rise across the world. As more people are surviving heart attacks, live longer 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 anaemia
- 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 – an ultrasound scan that provides a detailed overview of the heart function)

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 or cannot fill properly – 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, reducing salt and fluid intake)
- Some people may need medical device therapy, heart valve surgery, coronary artery bypass grafting/stenting 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 payers 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 payers.
- 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?

PATIENTS

PAYERS

CAREGIVERS, INCLUDING FAMILY MEMBERS AND LOVED ONES

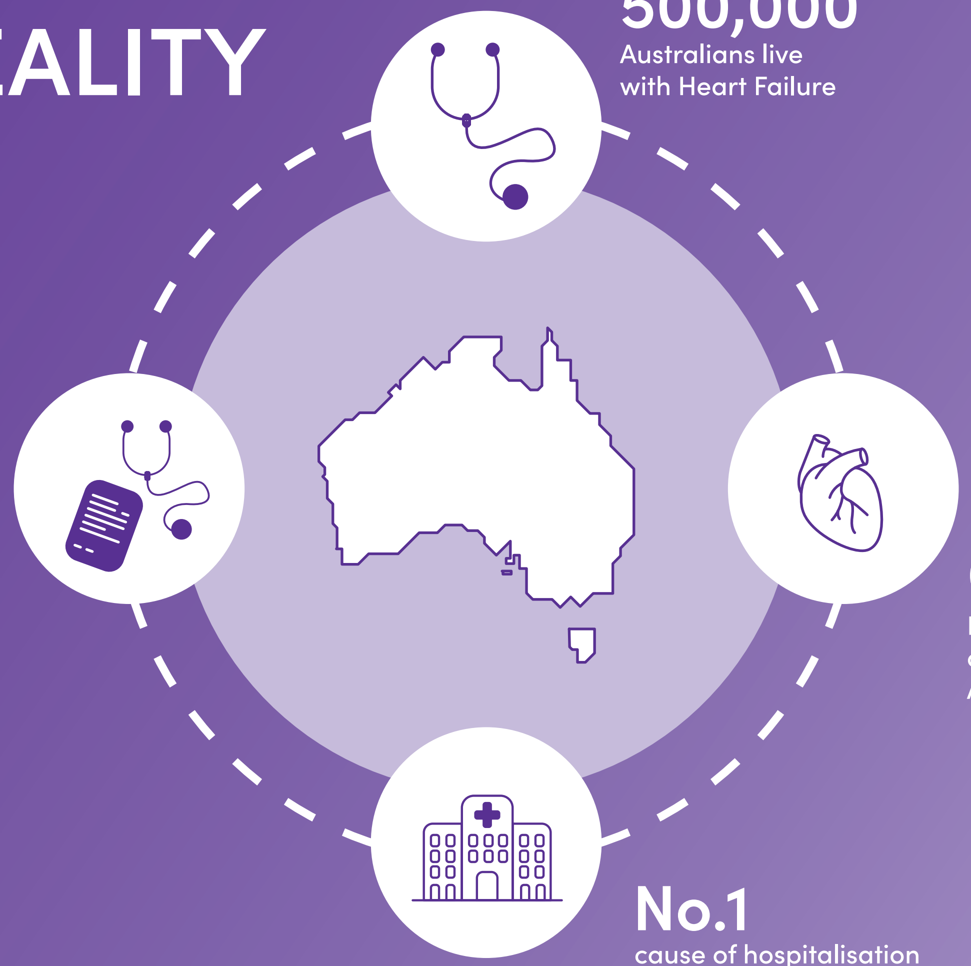
HEALTHCARE PROFESSIONALS, HEALTHCARE PROVIDERS AND RESEARCHERS

POLICYMAKERS

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

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

THE REALITY



500,000
Australians live with Heart Failure

61,000
HF-related deaths occur each year in Australia

No.1
cause of hospitalisation in Australians aged 65+

1.1 M
days spent in hospital annually due to HF

The healthcare available to HF patients varies widely across the world. This Charter serves as a tool for stakeholders in HF such as patients, caregivers, healthcare providers, government and insurance companies, 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[1].

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[2,3]. HF is a leading cause of hospitalisation. More than half of all HF patients are re-hospitalised within six months of discharge.

Even if heart failure cannot be 'cured', the symptoms, risk of hospitalisation and risk of dying can be 'controlled' with appropriate management.

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:

- Women with hypertension triples the risk of developing HF[6]. 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[4].
- At age below 65 more men have heart failure with reduced ejection fraction and over this age more women have heart failure with preserved ejection fraction.

PATIENT TESTIMONIALS

HF patient, 62, Australia

The diagnosis of heart failure was not the end, it was the beginning of new life choices, more exercise, better diet, treatment with medications and the implantation of a cardioverter/defibrillator - the latest version of a pacemaker, have given me renewed confidence and a new base for taking on the best that life has to offer... My heart function is steadily being restored - I am grateful to be part of the cohort that regains function due to good treatment and rehabilitation

HF patient, 69, Australia

Heart failure happened in an instant and changed the way my family and I approach the simple things in life. I realised very quickly the need to adjust to a new way of thinking and and a new way of working with my family. I have made sure I continue to exercise on a daily basis, eat correctly and maintain an active family life also. After a few months I realised it wasn't the end of the world for me, exercise and diet have always been the mainstay of my health. I now enjoy a very active lifestyle with grandchildren and extended family. There is always hope and there's always a future.

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.

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 health care 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.
8. To enquire if more can be done, such as further opinions from other health professionals specialising in heart failure if the care is not felt to be achieving optimal outcomes.

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.

- Embedding 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.
- Symptoms may be non-specific and if HF is not considered, then the diagnosis may be delayed or missed.

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.
- If there is doubt, for healthcare professionals to consult with other experts to optimise care.

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.
- For ongoing communication between healthcare providers which includes the patient and caregivers and allows them to be involved in decision making.

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.

- 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.
- To have access to other supports to allow patients to live as independently as possible and to reduce the burden on carers.

5

To have access to services and resources necessary to support my mental health care from diagnosis onwards

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.

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.

7

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

- Ensure that 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.
- To have access to centres which participate in research into newer treatments to allow the opportunity for treatments which have the possibility of improving the patient's outcomes and help others in the future.

8

To enquire if more can be done, such as further opinions from other health professionals specialising in heart failure if the care is not felt to be achieving optimal outcomes

- It is the right of all patients and their carers to seek help from other healthcare professionals if they feel that more could be done to improve their health status.

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.

References

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Who Developed This Charter?

This Charter has its origins in the Heartlife Foundation Canadian HF Patient Charter (www.heartlife.ca) and has been adapted by the Global Heart Hub and hearts4heart in partnership with patients and family carers globally.

ABOUT HEARTS4HEART

Supported by Australian and New Zealand cardiologists, hearts4heart is a health promotion charity and peak body that supports, educates and advocates for people living with heart disease.

hearts4heart brings together patients and healthcare professionals with the shared goal to reduce the burden to heart patients. hearts4heart provides targeted educational programs, resources and services to improve the diagnosis, treatment and quality of life for people affected by heart disease. We achieve this through support, information, education, awareness/screening events and advocacy.

Learn more at www.hearts4heart.org.au or contact us at info@hearts4heart.org.au.

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.

Learn more at www.globalhearthub.org or contact us at info@globalhearthub.org.

This Charter is endorsed by

AUSTRALIAN & NEW ZEALAND SOCIETY OF CARDIAC & THORACIC SURGEONS

ACvA
Australian Cardiovascular Alliance

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