



**The Heart
Failure Policy
Network**

Pressure point 4: Patient empowerment and self-care



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About the Heart Failure Policy Network

The Heart Failure Policy Network is an independent, multidisciplinary group of healthcare professionals, patient advocacy groups, policymakers and other stakeholders from across Europe whose goal is to raise awareness of the unmet needs surrounding heart failure (HF) and its care. All members donate their time for free. All Network content is non-promotional and non-commercial.

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1. Top five things you need to know


1 Heart failure (HF) is a long-term condition with a considerable burden of symptoms.¹ Most people living with HF can and should develop self-care skills and adopt self-care behaviours to manage their condition. These include dietary restrictions, monitoring of vital signs, rehabilitative exercise, adhering to the medication plan and notifying healthcare professionals of changing symptoms.^{2,3}


2 Adjusting to life with HF is challenging; it requires continual and personalised support, both clinical and psychosocial.⁴ Self-care education and support is therefore widely recognised as a key component of multidisciplinary care,⁵ and should start as soon as possible after diagnosis, ideally in hospital.^{2,6}


3 Patient empowerment and self-care models are effective and practical. People with HF who are empowered to self-care are at lower risk of hospital readmission⁶⁻⁹ and depression.¹⁰⁻¹² Effective self-care models have been demonstrated in many settings.^{2,12,13}


4 It is important to involve a multidisciplinary team in the delivery of self-care education.^{2,6} The person with HF themselves, their carers, family members and healthcare professionals are all vital partners in maintaining that person's health.^{14,15} Two roles deserve particular focus: HF specialist nurses¹⁶ and patient advocacy groups.^{6,17}

5 Access to high-quality and personalised self-care education and support is inconsistent, hindering self-care behaviours and impacting clinical outcomes.¹⁸⁻²¹ People living with HF commonly report low understanding of HF, its symptoms and risks, and a lack of suitable information.^{13,22}

 **See section 2:**
What is the issue?

 **See section 3:**
Evidence of effectiveness

 **See section 5:**
Involving a multidisciplinary team

 **See section 6:**
What is really happening, and why?

2. What is the issue?

People living with HF have an essential role in improving their own health outcomes

While it is important to respect that some people living with HF do not wish to have a formal role in their care,¹³ many people do.^{23 24} Supporting people who live with HF to self-care is both ethical good practice and a pragmatic approach to realising each person's full potential within the care team.

What is self-care in HF?

There are three widely recognised components of self-care in HF:²⁵

- Maintenance: sustaining physical and emotional stability
- Monitoring: keeping regular watch on signs and symptoms, and recognising when to alert clinical supervisors
- Management: adapting treatment to day-to-day changes in signs and symptoms

People are often best motivated by their own lives and hopes for the future

The effective adoption of routine self-care is linked to individual personal motivations, life circumstances and levels of social support.¹⁰ People living with HF can develop their own behavioural and psychological coping strategies to remain engaged and motivated.⁶ This is critical, as making the lifestyle changes required to maintain health, and monitor and manage the signs and symptoms of HF, is often challenging,^{2 6 26} especially over the long term.

Most people living with HF will benefit from psychological support

Psychological health and self-confidence is vital in adapting to life with HF. Many people living with HF report lacking confidence and knowledge in performing self-care and the need for psychological support to remain motivated and engaged.^{6 26} Depression is unfortunately common in HF, affecting some 20–40% of people living with chronic HF.²⁷

3. Evidence of effectiveness

Research has shown the benefits of self-care models:

- People living with HF who participate in self-care programmes have better self-care behaviours than those who do not, and are more likely to adopt lifestyle changes that help maintain health and manage symptoms, for example showing greater adherence to treatment.^{8 14 15}
- Education on self-care during hospitalisation can improve clinical outcomes.^{25 28}
- People who are involved in their own HF care and adhere to their care plan are at lower risk of hospital readmission.⁶⁻⁹
- In outpatient settings, effective self-care improves clinical outcomes and quality of life, such as reducing depression.¹⁰⁻¹²
- Engaging people in their own HF care can reduce healthcare spending per patient.⁷
- Good adherence to prescribed medications is associated with lower death rates from all causes.⁶

4. What is good practice?

People living with HF should be given clear information about their condition

People living with HF should, at a minimum, be given information about HF in general (including an explanation of what it is), the individual prognosis and the purpose and benefits of behavioural changes. Self-care conversations should clarify expectations of treatments ahead and support active participation in key decisions. A fundamental and immediate task for all those living with HF is to engage with their medication plan and dietary recommendations.

Self-care recommendations should be personalised and adaptable to levels of engagement

Care and support must be aligned to the individual's needs, circumstances, values and wishes wherever possible. This includes providing each person with personalised self-care recommendations,⁸ which should consider comorbidities, motivations, cognitive ability, confidence in self-care and willingness to receive information.^{13 29} Healthcare professionals should routinely assess engagement with self-care and respond constructively to different levels of ability, confidence and motivation of people living with HF.^{9 30} Structured tools assessing self-care behaviour can be used to measure effectiveness of interventions and inform healthcare professionals of the need for additional support for effective self-care.³¹

Self-care support should be flexible and reinforced over time

Receiving self-care and management recommendations in combination with a diagnosis (or difficult news, such as significant disease progression) may be overwhelming.¹³ Thus, recommendations should be provided at regular and appropriate time intervals and delivered in the context of a relationship of trust and continuous care.¹³

There is a need to develop confidence of people living with HF and their carers

Quality educational interventions can help develop the confidence of both patients and carers, which influences adherence to care and self-care.^{6 32 33} People living with HF often draw motivational and psychological resilience from support offered by their social network, including patient advocacy groups.¹⁰ Patients often place high trust in peer contacts (other people living with HF), highlighting the importance of training and involving patient representatives in care.

Effective self-care education has been demonstrated in many settings

Effectiveness of self-care education and support has been shown in hospital wards, primary care, HF outpatient clinics and at home.^{2 12 13} For hospitalised patients, it should start in the ward or clinic.^{2 6} Outside of the acute setting, self-care support may be delivered via phone calls, clinic appointments or home visits. Research suggests people feel more relaxed at home and may be more receptive in this environment.^{16 34}

Key components of self-care education and support

Self-care recommendations in European guidelines include:

- reducing salt and fluid intake
- limiting alcohol consumption
- smoking cessation, including referral to a specialist for advice when needed
- regular monitoring of weight and the signs or symptoms of disease
- regular and guided exercise, ideally within a cardiac rehabilitation programme
- cognitive exercises
- education about medicines, including diuretic dosing adjustments when needed
- the need to contact a healthcare professional should signs and symptoms change.^{2 3}

Other relevant topics include implanted devices, surgical interventions, sleeping and breathing, and immunisation.²

Both oral and written information is important, and should be accessible in lay language.¹³ Healthcare professionals should consider barriers to communication and be honest about the uncertainty associated with disease trajectory.^{2 13}

See section 7:
Case studies and reproducible tools



See PP:
Advance care planning

See section 5:
Involving a multidisciplinary team


See PP:
Discharge planning and early follow-up

5. Involving a multidisciplinary team

It is important to involve a multidisciplinary team in the delivery of self-care education and support.^{2 6}

 Role	Patient	Patient advocacy groups	Primary care physician	Primary care and HF specialist nurses	Pharmacists	Psychologists
 Responsibilities	<p>The goal of HF self-care education is to involve the person living with HF in their own care, making them a unique partner to other members of the care team. They can play a vital role in everyday monitoring and management by adopting lifestyle behaviours and habits that can maintain or improve health.^{13 35}</p>	<p>Patient advocacy groups can provide information and coordinate discussion groups,³⁶ for example via online platforms where people can learn about HF and self-care from their peers.⁶ These groups can also support families to adapt to the diagnosis of a loved one and play a more effective supporting role.³⁶</p>	<p>GPs are usually the first point of contact for HF patients experiencing new, recurring or worsening symptoms.³⁴ They can educate the person with HF on lifestyle and dietary behaviours important to manage their condition.</p>	<p>Nurses are widely regarded as having a crucial role in HF self-care conversations and in the optimisation of medical therapy in outpatient care settings.³⁷ HF specialist nurses can be a key link between primary and secondary care. They are well placed to develop long-term relationships with those living with HF, to understand their motivations and work with them to make self-care behaviours part of their daily routine.¹⁶ Nurses can tailor the education sessions to each person. They can provide care in the primary care facility, by visiting the person in their own home, or via telephone.³⁴</p>	<p>Pharmacists can help prevent medication issues, side effects and interactions between different medicines, by educating the person living with HF about their pharmacological regimen.³⁸ They can also identify and help overcome issues that may lead to medication non-adherence.^{8 39}</p>	<p>Psychologists can help motivate people living with HF and support them in overcoming the challenges that come with HF. Depression and low mood are common, which may have an impact on motivation and success of care strategies.⁴⁰</p>

Involving a multidisciplinary team (cont.)

 Role	Dietitians	Physiotherapists	Carers and family
 Responsibilities	Dietitians have an important role in helping people living with HF maintain an adequate diet, including restricting sodium and fluid intake and managing the higher risks of vitamin and micronutrient deficiencies caused by HF medication. ⁴¹ They can provide practical and safe advice, and should make the entire care team aware of the optimal diet for each individual. ²	Physiotherapists should be involved in HF care to tailor physical exercise to the person's needs and engage them in the exercise programme to maximise health outcomes. ^{2 6} Evidence suggests that engagement with exercise is more important than how the exercise is performed, ⁴² suggesting that psychological support and motivation to follow the programme is fundamental.	Carers and family members have a vital role in ensuring adherence to self-care strategies and good outcomes. ^{6 10} They can provide practical help and motivation, and should be able to recognise and act on deteriorating symptoms. ⁶ Although more commonly mentioned for frail people and those with cognitive impairment, ² carers are important for all people living with HF. Ultimately, carers help the individual put self-care behaviours into practice. ⁴³

6. What is really happening, and why?

Self-care education varies significantly in quality, availability and uptake

Despite proven benefits, access to high-quality and personalised self-care education and support is inconsistent, limiting the person's knowledge and ability to self-care.¹⁹⁻²¹ This is recognised in European consensus documents and has been demonstrated in different countries, for example Italy^{44 45} and France,⁴⁶ where implementation of multidisciplinary self-care education programmes is very challenging.

Self-care education varies by healthcare provider

Clinical settings that are not HF-specific frequently omit self-care conversations.⁴⁷ People living with HF being treated in these settings have to be proactive and seek information themselves to learn how to manage their HF.¹³ For example, GPs have great potential to offer self-care education and support but, in reality, many experience time pressures and low awareness of specialist guidelines.⁴⁷

Few clinicians are trained and confident in providing high-quality self-care education

There are few opportunities for nurses to qualify as HF specialists,^{48 49} which limits their ability both to empower those living with HF to self-care, and to educate carers in providing support. For GPs, limited HF-specific knowledge and lack of confidence discussing prognosis and treatment decisions are common factors obstructing communication with patients.⁴⁷

Organisation of care may challenge self-care support

Existing pressures on the traditional system may explain many current failings. For example, the limited time healthcare professionals have for each patient in traditional settings may mean self-care support is neglected.^{13 50 519}

 See PP: Clinical management

 See section 7: Case studies and reproducible tools

7. Case studies and reproducible tools

This section presents case studies of innovative and best practice in self-care, alongside tools to evaluate provision of self-care education and support or assess self-care behaviours.

Case studies



Belgian Working Group on Heart Failure website, Belgium

The website of the Belgian Working Group on Heart Failure provides practical information for the general public, healthcare professionals and people living with HF.⁵² Healthcare professionals can find an HF library on the website and can order a DVD featuring additional information and self-care recommendations. People living with HF can find information on HF, including self-care recommendations. They can also find charts for control of their weight, blood pressure, pulse and medication.



Programme ITERA, Spain

The programme ITERA was developed to support the creation of HF clinics in Spain by providing logistical support and professional training.⁵³ The programme made a number of tools available to support people in living well with HF:⁵⁴

- a guide explaining what HF is, including symptoms and causes, possible treatment and general recommendations⁵⁵
- a chart for control of medication⁵⁶
- a guide with detailed dietary recommendations⁵⁷
- a guide of recommended exercises⁵⁸
- a chart to record weight measurements and aiming to help the person identify when escalation to a healthcare professional is needed.⁵⁹

ITERA has since developed into the programme PRISMA, also focused on promoting integrated HF management programmes.⁶⁰



Mobile support, Italian Association of Heart Failure Patients, Italy

The Italian Association of Heart Failure Patients (Associazione Italiana Scompensati Cardiaci) has developed a mobile programme to provide support to people living with HF and to raise awareness of HF across the country.^{61 62} The association distributes educational material in the meetings and provides specialist visits on the spot.

Tools for assessing self-care education and practice



My Marvellous Symptom Checker and Big Pocket Guide to Heart Failure, Pumping Marvellous, UK

The UK HF advocacy charity Pumping Marvellous developed the tool My Marvellous Symptom Checker to help people living with HF understand their symptoms.⁶³ It uses a traffic-light scale to support identification of what action should be taken based on how the person is feeling.⁶⁴ Pumping Marvellous also developed a pocket guide to support people to live well with HF.⁶⁵ The guide covers topics from diagnosis to self-care.



Heart Failure Matters website, Europe

The Heart Failure Association of the European Society of Cardiology developed an educational website, Heart Failure Matters, to support HF care.⁶⁶ It offers advice on lifestyle habits and behaviours that can support people living with HF,⁶⁷ along with information for families and carers. The website has five tools to support HF self-care: a diary to record events and symptoms;⁶⁸ a chart to monitor HF signs every day;⁶⁹ a list of warning signs to help identify when the situation should be escalated;⁷⁰ a document to record appointments;⁷¹ and a chart to list medications.⁷² The website is available in ten languages.⁶⁶



European Heart Failure Self-care Behaviour scale, Europe

The European Heart Failure Self-care Behaviour scale (EHFScB) is a tool to assess people's ability to self-care.³⁷ It has been used to group people living with HF according to their self-care behaviours, allowing for better tailoring of education interventions to improve patient activation (or engagement) and self-care effectiveness.²⁰ In 2009, the EHFScB was revised into a nine-item scale, and it is available in several languages.⁷³



My Heart Failure Passport, Optimize Heart Failure Care, international

'My Heart Failure Passport' is a tool developed for the Optimize Heart Failure Care programme with worldwide focus.⁷⁴ The tool was designed to help people living with HF play an active role in the monitoring and management of their condition, by recording the medication they are taking and adhering to lifestyle behaviours that can lead to better outcomes.



MyHF app, Optimize Heart Failure Care, international

MyHF is a smartphone app developed under the scope of the Optimize Heart Failure Care programme.⁷⁴ It is dedicated to self-care education and follow-up. MyHF allows people living with HF to build up a complete picture of HF, and it may be useful for follow-up appointments with healthcare professionals.



Patient Activation Measure, international

The Patient Activation Measure is a tool for healthcare professionals to assess self-care engagement.⁷⁵ Although not specific for HF, it has been used in HF studies to measure self-care behaviours and understand the impact of interventions on self-care, or of self-care on outcomes or risks.^{9 30} In 2005 the scale was reduced from 22 to 13 items.⁷⁶



Self-Care of Heart Failure Index, international

The Self-Care of Heart Failure Index helps professionals assess self-care behaviour. It comprises three subscales measuring self-care maintenance, management and confidence.^{31 77} It has been used to measure self-care engagement, determine its association with clinical outcomes,¹⁴ and identify opportunities for improvement in self-care education and support.⁴⁵

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Notes



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