



Understanding heart failure guidelines

Patient empowerment and self-care

What is this guide, and who is it for?

The Heart Failure Policy Network has developed this guide as a lay summary of key principles in the European Society of Cardiology (ESC) guidelines, England's National Institute for Health and Care Excellence (NICE) guidelines and position statements by the Heart Failure Association of the ESC. The guide seeks to raise awareness of key elements of best practice in the care and management of heart failure (HF). It will be of interest to non-specialist audiences such as people with HF, patient advocates, non-cardiology healthcare professionals, clinical advocates of best practice and health system reform, organisational leaders, and political or public officials.

Guidelines are documents with suggestions or recommendations for care that derive from scientific evidence to aid patients and healthcare professionals in their decision-making – they are not prescriptive documents. Care must be tailored to each person's needs through careful collaboration between the person with HF, their family/carers and the HF care team.

This document neither replicates nor supersedes established clinical guidelines for the purpose of formal professional training or accreditation, patient therapeutic education or clinical decision-making. Clinicians, patients and service managers should consult European and national guidance as appropriate.



Patient empowerment and self-care

People with heart failure (HF) have an essential role in improving their own health outcomes because HF must be managed on a daily basis – away from hospitals, doctors and nurses.¹ This type of care is referred to as self-care: behaviours and activities that each person with HF can engage in to manage their own condition.² Other terms may be used, such as self-management and patient activation.



Heart failure facts

People with HF who are empowered and adequately supported in self-care are at a lower risk of hospital readmission and depression.²

What does self-care look like?

People with HF and their families/carers should be encouraged to learn how to monitor HF symptoms, prevent HF from worsening and contact the HF care team for help if/when needed. Self-care behaviours include:

- daily weighing to monitor fluid retention
- monitoring blood pressure and heart rate
- eating a healthy diet, including plenty of fruit and vegetables and limiting salt intake
- adhering to the medication plan
- exercising regularly
- quitting smoking
- limiting alcohol consumption
- seeking mental health support to maintain emotional and psychological wellbeing
- seeking social welfare support and financial help, if required.^{1,3,4}





How is self-care best supported?

Maintaining self-care behaviours can be difficult, and the HF care team should help people with HF develop their own strategies to remain motivated and engaged with their care.² HF nurses are especially well-placed to provide self-care education,⁵ and expert patients – people who are particularly skilled and knowledgeable in managing their HF – may also help empower others to self-care.

Self-care education should be:

- initiated early and continued as an integral part of HF management
- delivered by a multidisciplinary team to the person with HF and their family/carers
- tailored to each person and their needs, considering potential barriers and additional health conditions that may hinder self-care.¹³

What do the guidelines say?

The guidelines outline how people with HF and their families/carers can manage HF in everyday life, and how the HF care team can support them in doing so.

Self-monitoring of HF symptoms



Heart failure facts

Self-monitoring of HF symptoms reduces mortality in people with HF.⁶

HF symptoms can vary considerably between individuals, and may include extreme fatigue, breathlessness, reduced exercise capacity and fluid retention, which may present as rapid weight gain or swelling (often in the lower limbs and abdomen).³ Monitoring symptoms is crucial because changes in HF symptoms may indicate decompensation or disease progression.¹³

The HF care team should teach people with HF how to spot significant changes in their symptoms and respond adequately.¹³ For example, they may teach people with HF to adjust their medication for fluid retention (diuretics) in response to symptom changes.¹³⁷

Best practice from key European guidelines

When discussing HF symptoms, people with HF and their care team can use descriptors, such as symptom intensity (how strong were the symptoms?), duration (how long did they last for?) and pattern (did they appear at specific times?).¹

People with HF should be encouraged to weigh themselves daily for signs of fluid retention. In the event of rapid weight gain, they should follow recommendations from their care team – this may include adjusting the dosage of diuretics and/or contacting the care team for help.¹

All people with HF should know when and how to contact their care team.³

Diet and fluid management



Heart failure facts

Limiting fluid and salt intake according to medical recommendation improves symptoms in people with HF.⁸

Excessive salt and fluid intake can cause fluid retention and contribute to worsening HF symptoms.^{1,3} The HF care team should provide dietary advice tailored to the needs and nutritional status of each person with HF.

Best practice from key European guidelines

People with HF should be encouraged to avoid excessive salt and fluid intake.^{1,3} All sources of fluids should be considered, including alcohol, certain fruits and vegetables, and drinks used to take medication. Recommendations for the ideal volume of fluids may need to be adjusted with hot weather or vomiting/diarrhoea.

Alcohol intake should be limited to one unit per day in women and two units per day in men (one unit equals 76ml of wine, 250ml of beer or 25ml of spirit), while people with previous complications from excessive alcohol consumption should abstain.³

The HF care team may provide dietary information through brochures, HF cookbooks, healthy cooking websites or healthy eating activities, such as low-sodium cooking classes.¹ They may refer people with HF to a dietitian if needed.





Adherence to the medication plan



Heart failure facts

Adhering to the medication plan increases treatment effectiveness and helps prevent HF deterioration.³

Treatment adherence refers to taking medication in line with the plan agreed with the HF care team.⁹ Simply making recommendations to people with HF about the medicines they should take is not enough to ensure adherence. Many factors may lead to people not taking their medicines, including lack of information about the treatment, denial about their diagnosis, distress at side effects, depression/anxiety or memory issues.^{3,9} The HF care team should discuss beliefs about HF and medicines, and teach relevant skills to support treatment adherence.^{1,3}

Best practice from key European guidelines

The HF care team should provide written and oral information about the medication plan, making each person with HF aware of the purpose, benefits and potential side effects of the medicines they are prescribed.³

In addition, the HF care team should identify potential barriers to adherence and tailor support based on what is relevant for each person.^{1,9} For example, identifying and treating depression, offering pill boxes to people with memory issues or teaching people to read medication labels may address barriers and help ensure adherence.

Exercise



Heart failure facts

Exercise is an important aspect of HF care because it helps maintain heart function.¹

Exercising is a challenge for people with HF, who may lack the energy and enthusiasm for it. However, exercise is a vital aspect of self-care. The recommended level of exercise varies per person^{3,7} – it should take into consideration the physical and psychological constraints of HF.

For people with HF and a body mass index greater than 35kg/m², the HF care team may consider and tailor weight-loss methods to manage symptoms and improve exercise capacity.³

Best practice from key European guidelines

People with stable HF are advised to exercise for 20 minutes at least three times per week, achieving mild to moderate breathlessness.¹ Daily activities such as walking and housework are also recommended.¹⁰

The HF care team should offer tailored exercise advice, recognising physical or functional limitations such as frailty and other health conditions.³ Exercise plans should be created around settings that are easy for people with HF to access, including their home or an HF clinic.^{1,3,10}

Information about preventing or delaying HF through exercise is included in [Understanding heart failure guidelines: Prevention](#).

Smoking cessation



Heart failure facts

Smoking cessation may help reduce morbidity and mortality in people with HF.¹

Smoking is a significant risk factor for many cardiovascular conditions, including HF.³ Smoking cessation is, therefore, important in preventing or delaying the onset and deterioration of HF.

Best practice from key European guidelines

People with HF should refrain from smoking and avoid passive smoking where possible. Healthcare professionals can support people with HF to stop smoking by offering smoking cessation services and psychological support.^{1,3}

Information about preventing or delaying HF through smoking cessation is included in [Understanding heart failure guidelines: Prevention](#).





References

1. Lainscak M, Blue L, Clark AL, *et al.* 2011. Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 13(2): 115-26
2. The Heart Failure Policy Network. 2018. *Pressure point 4: Patient empowerment and self-care*. London: The Heart Failure Policy Network
3. Ponikowski P, Voors AA, Anker SD, *et al.* 2016. 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. *Eur J Heart Fail* 18(8): 891-975
4. The British Heart Foundation. Healthy eating. Available from: <https://www.bhf.org.uk/information-support/support/healthy-living/healthy-eating> [Accessed 22/08/19]
5. McDonagh TA, Blue L, Clark AL, *et al.* 2011. European Society of Cardiology Heart Failure Association standards for delivering heart failure care. *Eur J Heart Fail* 13(3): 235-41
6. Goldberg LR, Piette JD, Walsh MN, *et al.* 2003. Randomized trial of a daily electronic home monitoring system in patients with advanced heart failure: the Weight Monitoring in Heart Failure (WHARF) trial. *Am Heart J* 146(4): 705-12
7. National Institute for Health and Care Excellence. 2018. *Chronic heart failure in adults: diagnosis and management*. London: NICE
8. Philipson H, Ekman I, Forslund HB, *et al.* 2013. Salt and fluid restriction is effective in patients with chronic heart failure. *Eur J Heart Fail* 15(11): 1304-10
9. Nunes V, Neilson J, O'flynn N, *et al.* 2009. *Medicines adherence: Involving patients in decisions about prescribed medicines and supporting adherence*. London: NICE
10. Piepoli MF, Conraads V, Corra U, *et al.* 2011. Exercise training in heart failure: from theory to practice. A consensus document of the Heart Failure Association and the European Association for Cardiovascular Prevention and Rehabilitation. *Eur J Heart Fail* 13(4): 347-57



Acknowledgements

Considerable thanks and acknowledgement are due to all members of the Project Advisory Group for their continued input throughout this project:

- Dr Josep Comín-Colet (Bellvitge University Hospital, Spain)
- Professor Salvatore Di Somma (University La Sapienza Rome, Sant'Andrea Hospital and Associazione Italiana Scompensati Cardiaci, Italy)
- Professor José Ramón González-Juanatey (University Hospital Santiago de Compostela, Spain)
- Ms Penilla Gunther (FOKUS Patient and former Member of Parliament, Sweden)
- Mr Neil Johnson (Croí, West of Ireland Cardiac Foundation, Ireland)
- Mr Steven Macari (Association Vie Et Cœur (AVEC), France)
- Ms Sandra Mulrennan (St Bartholomew's Hospital Heart Failure Service, Barts Health NHS London, United Kingdom)
- Ms Patricia Vlasman (Let the Beat Go On, the Netherlands).

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 and its care. All Network content is non-promotional and non-commercial. The Secretariat is provided by The Health Policy Partnership Ltd, an independent health policy consultancy based in London.

