



# Understanding heart failure guidelines

## Advance care planning

### 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.

# Advance care planning

**Advance care planning and palliative care are essential elements of the heart failure (HF) care journey.**<sup>1,2</sup> Advance care planning is the process of enabling a person with a chronic disease to understand their future care options and define tailored treatment goals/preferences.<sup>3</sup> It considers the use of palliative care, which focuses on symptom management and the prevention or relief of suffering.<sup>2,4</sup>

Advance care planning and palliative care focus on maintaining quality of life and wellbeing in the face of life-threatening disease, without hastening or postponing death.<sup>4</sup> They should be collaborative processes involving the person with HF, their family/carers and the HF care team.<sup>3</sup>



## Heart failure facts

Advance care planning and palliative care for HF reduce hospitalisations, symptom burden and healthcare costs, and improve patient satisfaction and quality of life.<sup>5-7</sup>

## What does high-quality advance care planning look like?

Advance care planning in HF should include discussions about:

- stopping treatment that does not benefit symptom management or quality of life
- resuscitation preferences
- deactivating cardiac devices
- preferred places for care and death, such as at home or in a hospice.<sup>1</sup>

## What does high-quality palliative care look like?

Palliative care in HF should:

- include physical, psychological and spiritual care for people with HF and their families/carers
- focus on maintaining quality of life and reducing symptom burden
- be available to all people with HF who need comprehensive treatment, not just those with advanced HF
- involve all health and social care professionals, as well as support settings involved in HF care.<sup>1,2</sup>

More information about treatment approaches in HF care is included in [Understanding heart failure guidelines: Clinical management](#).





## What do the guidelines say?

The guidelines offer information about introducing advance care planning and palliative care in HF management.<sup>1,2</sup>

### Introduction of palliative care



#### Heart failure facts

Palliative care is not just for people with advanced or end-stage HF.<sup>2</sup>

People with HF are often referred to palliative care services late in their care journey; however, palliative care is a key component of high-quality care for all people with HF.<sup>2</sup> The early introduction of palliative care can help people with HF and their families/carers manage symptoms and discomfort.

#### Best practice from key European guidelines

Several clinical signs may suggest a need for palliative care:

- Repeated episodes of HF deterioration despite treatment (decompensation)
- A life-threatening irregular heartbeat (malignant arrhythmia)
- Frequent or continuous intravenous therapy
- Chronically poor quality of life
- Persistent HF symptoms at rest, with increased discomfort during physical activity
- Loss of fat, muscle and bone (cardiac cachexia).<sup>2</sup>

The decision to start palliative care should be made by the person with HF together with their family/carers, cardiologist, nurse and primary care physician.<sup>1</sup>

## Consideration of wishes and preferences



### Heart failure facts

Physicians often do not discuss prognosis, palliative care and end of life with people with HF,<sup>8</sup> limiting the opportunity to include the person's wishes and preferences in HF care.

People's wishes, preferences and needs regarding their care, including palliative care, can change over time.<sup>1,2</sup> It is important to discuss them frequently and incorporate them into the HF care programme.

### Best practice from key European guidelines

Advance care planning should start early and be revisited on a regular basis so people with HF and their families/carers can communicate their changing needs, wishes and preferences fully.<sup>1,2</sup> Important topics include resuscitation, treatment goals and access to psychosocial and bereavement support services. Goals for palliative care should be documented and communicated to all relevant health and social care professionals.<sup>1,2</sup>

Cognitive impairment, confusion and/or additional health conditions may make palliative care discussions more difficult.<sup>2</sup> Advice from palliative care specialists, hospital ethicists and patient advocates may be helpful.

## Management of physical symptoms



### Heart failure facts

People with advanced HF may experience symptoms that affect their quality of life, such as breathlessness, fatigue, limited mobility and pain.<sup>9</sup>

Managing physical symptoms helps prevent or relieve suffering – an important component of palliative care.<sup>2</sup>





## Best practice from key European guidelines

People receiving palliative care for HF should continue to take their HF medicines to maintain optimal symptom relief.<sup>2</sup> Morphine can reduce pain and breathlessness in people with end-stage HF, although dosage guidelines are lacking.<sup>1,2</sup>

Many people with advanced HF also have other health conditions, and palliative care strategies should address both cardiovascular and non-cardiovascular symptoms.<sup>2</sup>

*More information about HF and other health conditions is included in [Understanding heart failure guidelines: Comorbidities](#).*

## Psychological and spiritual support



### Heart failure facts

Depression affects 32% of people with advanced HF – and it is linked to a higher symptom burden.<sup>10</sup>

People living with HF usually experience worsening symptoms with advancing disease, which may result in increased anxiety and depression.<sup>11</sup> HF may also raise spiritual questions and concerns, such as those related to a person's sense of self. Psychological and spiritual care should support people with HF and their families/ carers with these challenges, helping them maintain or improve quality of life and emotional wellbeing.<sup>2</sup>

## Best practice from key European guidelines

People with HF can be referred to psychologists for psychological support.<sup>2</sup> Medication may also be recommended to help manage anxiety and depression. The HF care team should provide a safe environment for people with HF to discuss spiritual concerns comfortably, without their beliefs being questioned. Spiritual advisers, chaplains or pastoral counsellors may support the HF care team in providing spiritual care.<sup>2</sup>

*More information about HF and depression is included in [Understanding heart failure guidelines: Comorbidities](#).*

## Review of cardiac devices



### Heart failure facts

The deactivation of cardiac devices is rarely discussed in clinical appointments and is frequently overlooked during advance care planning for HF.<sup>12</sup>

The HF care team should discuss the deactivation of cardiac devices with the person with HF and their family/carers before they are faced with the issue.<sup>2</sup>

### Best practice from key European guidelines

Repeated device firing (shocks) can cause significant distress and discomfort, and this typically occurs in people with advanced HF.<sup>2</sup> It is important to discuss the possibility of deactivating devices such as implantable cardioverter-defibrillators (ICDs) and defibrillators with cardiac resynchronisation therapy (CRT-D) with the person with HF and their family/carers.

People with severe HF may receive a ventricular assist device (VAD) – an implantable device that functions as a mechanical pump to send blood to the rest of the body – either while awaiting heart transplantation or as long-term treatment.<sup>1,2</sup> Deactivating a VAD, for example when a person experiences device-related complications, poses an ethical dilemma as there may be no other strategies available to prolong life. The HF care team may consult palliative care specialists when considering device deactivation.<sup>2</sup>





## References

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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 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.