



**The Heart
Failure Policy
Network**

Pressure point 5: Advance care planning



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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 Advance care planning is the process of enabling the person living with a chronic disease to understand their future care options and define treatment goals and preferences.¹ It considers the use of palliative care to support living with advanced disease. It is not intended to hasten or postpone death, but rather to understand and address the person's needs, wishes and preferences to ensure they are comfortable throughout the course of the disease.^{1,2}

2 Worsening symptoms and comorbidities of later disease stages call for continual reassessment and re-communication of care objectives, making advance care planning vital.³⁻⁷ Patients should be engaged in palliative care discussions, for example to indicate their preferences for life-sustaining treatments (such as resuscitation).⁸

3 Advance care planning should start early – care in later disease stages should not be left to a reactive approach in response to urgent needs.^{6,9-12} Advance care planning ensures people living with HF are able to make plans and fully communicate their wishes and preferences, and gives them and their family members more time to cope.¹³

4 Leading models of advance care planning and palliative care can reduce hospitalisations and symptom burden while improving patient self-efficacy, satisfaction and quality of life.^{3,14-17} Such models are cost-effective, reducing costs, for example, from hospitalisations.^{1,2,17}

5 Coverage of advance care planning is poor in HF, and most people receive palliative interventions only when they reach the last stage of the disease, if at all.^{6,18} People with HF are less likely to access palliative care specialists or hospice care than cancer patients.^{9,19} Despite proof of benefit to patients and systems, wider progress is undermined by a relatively weak research base compared with other conditions.^{1,15,17,20}

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

 **See section 4:**
What is good practice?

 **See section 3:**
Evidence of effectiveness

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

2. What is the issue?

The needs of people living with HF change significantly in later stages of the disease

With advancing disease, people living with HF usually experience worsening symptoms, such as dyspnoea, pain and depression.³ Cognitive impairment, including memory difficulties, is also common.⁴ This limits their ability to interact with other people, to self-care and to be independent, reducing their quality of life. This decline can take several years.³

Changing needs call for a change in objectives of care

People living with HF should have the opportunity to indicate their future preferences for life-sustaining treatments at later disease stages, based on comprehensive information about the potential outcomes of different options.⁸ Usual care is often insufficient to address all patients' needs with advanced HF, so it is important to support people to engage with palliative interventions to manage symptoms. This includes management of comorbidities and other competing care needs.³



What are advance care planning and palliative care?

Advance care planning is the process of enabling the person with a chronic disease to understand and define palliative treatment goals at late disease stages.¹ It aims to align care with the individual's wishes.

Palliative care focuses on symptom management (prevention and relief of suffering, such as pain), emotional and family support, and management of physical, psychosocial or spiritual problems.^{2 11 21} Many HF associations argue for a more modern, person-centred care model where symptoms and quality of life, rather than expected survival, trigger a referral to palliative care, thus allowing earlier access.²²

²³ Palliative care is considered in advance care planning discussions; neither is intended to hasten or postpone death.²

Advance care planning varies across countries and care providers

There is no single model of advance care planning in HF. The understanding of some professional roles in palliative care, such as psychologists, is inconsistent across Europe.²⁴ In addition, the main point of contact in the palliative care team and the main carer may be different people depending on the country.⁹

3. Evidence of effectiveness

Research has shown the benefits of palliative care and advance care planning in HF:

- Leading models of palliative care can reduce hospitalisations and days spent in hospital; hospital readmissions have been estimated to be reduced by 42%.¹⁶
- Palliative care improves quality of life and patient satisfaction with care, and better alleviates symptoms such as dyspnoea, nausea, sleep quality, depression and anxiety compared with normal care.^{3 14-17}
- Palliative care increases self-efficacy of those living with late-stage HF.¹⁵
- Palliative interventions enable death at home rather than in hospital,^{15 16} which is aligned with the wishes of the majority of people living with HF.⁶
- Palliative interventions provided at home and by a multidisciplinary team following a person-centred approach show the greatest improvements, reducing symptom burden at the end of life without adding to family members' grief.^{16 25}
- Person-centred home-based palliative models have been shown to be cost-effective: they improve quality of life while reducing costs.¹⁷

Research has shown the benefits of advance care planning in HF and other diseases:

- Advance care planning in HF can alleviate anxiety, increase hospice use and decrease invasive and life-prolonging treatments at the end of life.³ It is an effective model for ensuring palliative interventions are not neglected.¹
- Advance care planning in other diseases improves patient satisfaction and quality of life, use of palliative care and quality of patient–clinician communication, and reduces hospitalisations.^{1 2}

4. What is good practice?

Palliative care is an important consideration at all stages of disease

European guidelines and leading models of care call for the incorporation of palliative specialists and elements of advance care planning from early disease stages – even at point of diagnosis – with intensification as required, rather than a reactive approach in response to urgent need.⁶ ⁹⁻¹² Early conversations about different stages of the disease and possible care strategies ensure people living with HF can plan the future when they are able to fully communicate their wishes and preferences, and they and their family have more time to cope.¹³ Discussions might include, for instance, resuscitation measures upon cardiac arrest. For example, people with an implantable device should be made aware of the shocks they may receive from the device at end-of-life so they can decide the best time for deactivation.²⁶

People living with HF should communicate their wishes early and often

Each person has a different balance of individual needs, personal wishes, and emotional and spiritual preferences across changing symptoms, to which the multidisciplinary team must align.⁷ The person's preferences may also change over time with disease progression and changes in prognosis, calling for continual communication and reassessment.⁵⁻⁷

Trust, clear processes and shared decision-making are fundamental

High-quality advance care planning requires clear roles, responsibilities and processes. It is important to clarify these to the person living with HF, their family and carers, including the identity of the main point of contact in the professional team.⁹

See PP:
Presentation
and diagnosis

See section 5:
Involving a
multidisciplinary
team

The whole care team must be ready to play their part

In advanced HF, palliative care specialists may be required to take over coordination of care.¹³ However, all members of the HF team have a role in aligning care with the wishes of the individual and in providing palliative care.⁷ All healthcare professionals should be able to tailor the conversation to the person's health literacy, communication style and ability, and personal values.¹ Structured models of advance care planning with the involvement of palliative specialists can help all members of the HF team improve their knowledge about palliative care and their communication skills – particularly important in the scope of difficult conversations.⁶

Advance care planning requires integrated structures and specialist settings

Palliative interventions are typically understood to be best provided at home or in a residential facility, such as a hospice.⁶ Healthcare providers must coordinate responsibilities and enable data-sharing across different organisations and settings, such as between residential hospices and local healthcare providers. People living with HF value efficient information-sharing, for example via electronic health records, as this allows all members in the care team to be aware of their situation and care strategy.²⁷

Palliative care should also support the family

Palliative interventions should promote the family's understanding of the disease and of their loved one's condition.⁷ They should consider the family's goals and help them deal with the emotional burden of HF.

5. Involving a multidisciplinary team



High-quality support for palliative care should be provided by a multidisciplinary team, including professionals with different and complementary skills.¹³

 Role	Patient	Patient advocacy groups	Psychologists	Palliative care specialists (physician/nurse)	Nurses	Primary care physicians and cardiologists	Pharmacists
 Responsibilities	<p>The wishes and preferences of each person may change with disease progression, highlighting the need for continual communication with the care team. The discussions should lead to regular (re)alignment of care and care objectives to the goals of the person living with HF.^{5,6} They should feel supported and comfortable expressing their wishes and participating in decisions about treatment and overall care.⁷</p>	<p>Patient advocacy groups have a role in raising awareness of the importance of advance care planning and palliative interventions in HF. For example, Hospice UK, an association that supports the development of hospice care in the UK, not only raises awareness of palliative interventions in HF but also suggests ways to engage with hospice care via publications showcasing creative solutions used in hospice settings.¹⁹</p>	<p>Conversations about disease progression and end of life can be challenging; psychologists can support those living with HF to discuss and communicate their care preferences to their family and the wider healthcare team.²⁸ Psychologists can support both the person living with HF and their family¹⁰ when end of life is anticipated.</p>	<p>Palliative care specialists have an important role assisting with difficult decision-making and symptom management in advanced HF, even if patients are still receiving disease-modifying therapies.⁷ They should have a central role in care of end-stage HF.¹³ By including palliative care specialists in the care team early on, all members of the team, including the person living with HF, may be more receptive to advance care planning.⁶</p>	<p>Nurses can provide palliative care themselves and can take a case manager role in palliative care programmes. They can be a source of trust and comfort, acting as a link between all levels of care and the individual, and ensuring their wishes are followed.¹³</p>	<p>In early stages of HF, clinical responsibility for advance care planning should fall on GPs or cardiologists. They should be empowered to provide palliative care to people living with HF, calling on the support of palliative care specialists in more complex cases.¹³</p>	<p>Pharmacists can communicate with patients and carers to improve the pharmaceutical care of people living with HF throughout the continuum of care, including in advance care planning. They can visit patients at home or in residential care homes to do so. They should assess the appropriateness of medication orders, ensure provision of medication, counsel and educate the hospice team, and ensure patients and carers understand and follow the directions provided.²⁹</p>

Involving a multidisciplinary team (cont.)

 Role	Dietitians	Carers and family	Physiotherapist
 Responsibilities	Dietitians should assess the patient's nutritional status. ³⁰ They can counsel the patient, their family and carers on diet to support the loss of appetite and the cardiac cachexia (a metabolic disorder that leads to progressive weight loss) that may accompany end-stage HF. ²⁶	Carers and family members can help make care plans and support the person living with HF by talking to them about what may happen in the future. Carers can also help those they care for develop documents explaining their medical wishes. ³¹	Physiotherapists can conduct physical assessments and support the rehabilitation needs of people living with HF. ³² This may include support to manage breathlessness and mobility issues. Physiotherapists can help people be as independent as possible for as long as possible.

6. What is really happening, and why?

People living with HF have limited access to palliative and hospice care

Despite reported benefits of palliative interventions, physicians rarely discuss prognosis, death and palliative care with people living with HF.^{8,33} For example, a Dutch study in the outpatient setting found that advance care was discussed with only 3.9% of patients with chronic HF.⁸ People living with HF are less likely to access palliative care specialists or hospice care than cancer patients,^{9,19} despite having a comparable overall burden.¹⁶ In fact, in the UK fewer than 10% of people living with HF have been registered in the palliative care registry, compared with almost half of all cancer patients.¹⁸

 See section 3: Evidence of effectiveness

Advance care planning and palliative care are often started too late, or are incomplete

People living with HF are often referred to palliative interventions only when they reach the last stage of the disease,⁶ which limits the potential benefits of palliative care. A UK study of HF patients registered in the palliative care registry showed that almost one-third were entered within a week of their death.¹⁸ Quality of patient-physician communication at end of life is poor;⁸ even when discussions take place, they may lack aspects such as grief and bereavement care, treatment in the last hours of life and continual goal adjustment.³³

Palliative care specialists are not consistently included in HF care

Despite growing interest, high-quality advance care planning is not yet the norm in the treatment of HF.³³ Across Europe, palliative care professionals are still not consistently part of HF care networks and are frequently not recognised as a member of the care team by people living with HF.⁹ There are conflicting views of who should be responsible for providing advance care planning and palliative care, which could be prevented by involving palliative specialists from an early stage.³

Clinicians frequently delay referral and inclusion of palliative care specialists

Poor uptake of advance care planning may be related to low awareness among clinicians of the benefits of palliative specialists and the difficulty faced by care leads in anticipating the terminal phase of HF.^{6 15 34} Clinicians sometimes hesitate to provide advance care planning before the patient reaches end of life, for various reasons: feeling uncomfortable discussing the issues; fearing the patient and their family are not ready to discuss end of life; fearing taking away hope; or for lack of time.^{3 19 35} Clinicians need to develop the skills and knowledge to have these conversations – only then can they help people living with HF overcome their own fears.¹⁹

What prevents advance care planning and palliative care in HF?

Among the reasons behind poor advance care planning in HF are:

- limited capacity and availability of trained personnel³⁵
- lack of standard definitions of advance care planning and palliative care³³
- the need for improved communication among healthcare professionals to better share information, identify the need for specialist input and improve referral
- the need for improved communication between the care team and the person living with HF, their family and carers,⁶ acknowledging their emotional reactions, cultural and religious beliefs, and potential cognitive difficulties
- the need for sustainable palliative models with adequate reimbursement structures in earlier stages of the disease.^{7 13}

Palliative care research has been overlooked in HF

Research and models on advance care planning and palliative care have mostly focused on cancer.^{1 15 17 20} Cost-effectiveness studies of advanced home care for people living with HF are lacking,¹⁷ contributing to limited awareness among clinicians of the benefits of palliative care in people living with non-malignant diseases. Published research and internationally recognised models have also been heavily focused on English-speaking countries.

Carers' needs have not been fully considered

HF places a heavy burden on those caring for people living with the disease. This role has many challenges and requires a long-term commitment of both time and energy.³⁶ However, the needs of HF carers have not yet been clearly identified in research.

Three main areas of support have been discussed: psychosocial, support with daily living, and assistance navigating the healthcare system.³⁷ Some countries provide some level of support to carers, for example Germany via the Long-Term Care Insurance model that offers temporary leave and financial support to carers,^{38 39} and the UK with health assessments and financial benefits.^{40 41}

7. Case studies and reproducible tools

This section presents case studies of innovative and best practice in advance care planning and palliative care alongside tools to support advance care planning.

Case studies



Palliative care model, University Health Network, Canada

The University Health Network in Toronto, Canada developed a multidisciplinary palliative care model.⁶ The model has four key areas:

- advance care planning
- shared decision-making
- routine measurement of symptoms and quality of life
- specialist palliative care at HF end of life.

The model ensures a person-centred journey at the end of life.



Caring Together Programme, Glasgow, UK

The British Heart Foundation, Marie Curie Cancer Care and NHS Greater Glasgow and Clyde established the Caring Together Programme in 2010 to improve both access to and quality of palliative care for advanced HF patients.¹⁹ Services are provided by a cardiologist and an HF palliative nurse. They are based on needs rather than a specific diagnosis or prognosis, and they aim to develop a plan for future care, including place of care or death and resuscitation status.



Brent and Harrow Advanced Heart Failure Improvement Programme, Harrow, UK

St Luke's Hospice in Harrow, UK developed a programme with local NHS trusts to improve advanced HF care. The programme developed a tool to help community HF nurses identify patients who could benefit from palliative care.¹⁹ These cases are discussed in a monthly meeting at the hospital before a final decision about care is made. The programme has increased the adoption of palliative care terminology, access to advance care planning and specialist palliative care services, death outside of hospital, and job satisfaction of community HF nurses.¹⁹



Palliative advanced home care and heart failure care, Skellefteå Hospital, Sweden

Palliative advanced home care and heart failure care (PREFER) is a palliative care model developed in Sweden, in the Skellefteå Hospital catchment area.¹⁵ It involves a comprehensive team of healthcare professionals who collaborate for provision of patient-centred care. The model has been shown to improve health-related quality of life, nausea, total symptom burden, self-efficacy and HF functional class.¹⁵



Palliative services, St Christopher's Hospice, UK

In 2011, St Christopher's Hospice in London refined its palliative services with a particular focus on HF management and supportive palliative care.¹⁹ One central aspect of the intervention is the rehabilitative palliative care service that supports individuals to achieve personal goals. Patients and carers value the personal and flexible service, which helps them according to their needs and not within a set review schedule.

Tools to support advance care planning



Trigger tool, UK

St Luke's Hospice in Harrow, UK developed a trigger tool to help community HF nurses identify the transition to final stages of HF. The trigger tool is a list of criteria assessing the patient's condition. If a patient meets at least two of the criteria, the case should be brought to a multidisciplinary team discussion.¹⁹ The tool has been used in the Brent and Harrow Advanced Heart Failure Improvement Programme.



Ask-Tell-Ask, international

Ask-Tell-Ask is a communication technique useful to discuss advance care planning with patients (and their families, if patients so wish). When using the technique, clinicians should start by asking what the person living with HF (and family) knows about the disease and treatment options, and how much they want to know.⁷ Clinicians should then answer questions and clarify misconceptions. Finally, they should ask the person to repeat back the information to assess their understanding.



NURSE mnemonic, international

It is important for clinicians to respond with empathy when people living with HF – or their families – react emotionally to medical or care information. One mnemonic that clinicians can use for this is NURSE, which stands for Naming the emotion expressed in the conversation, demonstrating Understanding of the emotion, Respecting the emotion, Supporting the people displaying the emotion, and Exploring the emotion in the context of the discussion.⁷

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