

# Integration of a palliative approach into heart failure care: a European Society of Cardiology Heart Failure Association position paper

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The Heart Failure Association of the European Society of Cardiology has published a previous position paper and various guidelines over the past decade recognizing the value of palliative care for those affected by this burdensome condition. Integrating palliative care into evidence-based heart failure management remains challenging for many professionals, as it includes the identification of palliative care needs, symptom control, adjustment of drug and device therapy, advance care planning, family and informal caregiver support, and trying to ensure a 'good death'. This new position paper aims to provide day-to-day practical clinical guidance on these topics, supporting the coordinated provision of palliation strategies as goals of care fluctuate along the heart failure disease trajectory. The specific components of palliative care for symptom alleviation, spiritual and psychosocial support, and the appropriate modification of guideline-directed treatment protocols, including drug deprescription and device deactivation, are described for the chronic, crisis and terminal phases of heart failure.

**Keywords** Heart failure • Palliative care • Clinical guidance

## Introduction

Over the last 30 years, the 5-year survival rate for patients with heart failure (HF) has improved by approximately 30% across all healthcare settings, predominantly related to advances in treatment

for HF patients with a reduced ejection fraction (HFrEF).<sup>1</sup> At present, there are no particularly effective treatment modalities for those exhibiting HF with a preserved ejection fraction (HFpEF), care being directed towards management of their symptoms and comorbid/antecedent conditions. Better survivorship is manifest

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in more elderly patients living longer with chronic HF,<sup>2</sup> a condition with a fluctuating and unpredictable disease trajectory associated with a severe symptom burden and poor quality of life.

Clinical guidelines and consensus papers advise the concurrent provision of palliative and supportive care alongside life-prolonging therapies in HF management.<sup>3–5</sup> Palliative care as defined by the World Health Organization, is an approach that improves the quality of life of patients and families through the prevention and relief of suffering,<sup>6</sup> focusing on expert assessment and management of symptoms, evaluation and support of informal caregivers, and the interdisciplinary coordination of continuing care.

Since the first position statement on palliative care by the Heart Failure Association (HFA) of the European Society of Cardiology (ESC) in 2009,<sup>4</sup> palliative care in HF has been addressed in numerous conferences and workshops, the subject area supported by a growing body of research.<sup>7</sup> Nevertheless, according to the HFA atlas, only 10 out of 42 European countries have designated palliative care units for patients with advanced HF, with the European Association of Palliative Care describing 8 countries as providing fully integrated palliative and cardiology services.<sup>8,9</sup> Whilst many professionals recognize the importance of palliative care as part of everyday HF management, not all patients receive this support. Potential barriers include the intrinsic uncertainty of the HF trajectory, a lack of organizational resources, staff training and available time, and healthcare professionals (HCPs) perceiving palliative care as being of low priority.<sup>10–12</sup> In addition, there may be psychosocial, ethical and legal issues, sometimes involving patient and informal caregiver expectations, or related to deprescribing, anticipatory prescribing, deactivation of implanted devices, and the enactment of advanced directives and resuscitation policies.<sup>13,14</sup> Acknowledging the worldwide diversity in legislation, cultural norms, professional education, role perception and resource availability, this paper offers day-to-day guidance for HCPs managing patients with HF. Furthermore, informed by insightful contributions from ESC Patient Forum representatives, it prioritizes features relevant to patients as service users. The overall aim of this document is to synthesize the available evidence and provide clinical guidance on integrating palliative and HF care. We highlight gaps in knowledge, and signpost areas for future research.

## When and how to address palliative needs

Many patients with HF would derive benefit from the early integration of a palliative approach within the care provided by all members of the HF multidisciplinary team (MDT), recognizing this supportive intervention complements optimal guideline-directed therapies (Figure 1). However, often the attention of HCPs is drawn to prognostic indicators rather than undertaking a comprehensive assessment of patients' needs.<sup>15,16</sup> Patient-reported outcome measures (PROMs) are useful in collating multidimensional symptoms, a number of tools being used internationally within clinical practice and HF research.<sup>17,18</sup> However, such evaluation tends to be directed at those with chronic HF, and there is a relative paucity of

validated instruments applicable to patients admitted with acute HF or cardiogenic shock for whom treatment outcomes remain particularly uncertain.<sup>19</sup> Cultural and religious beliefs should also be characterized and considered within this support matrix to better ensure responsive healthcare practice is coherent with each patient's unique sociocultural worldview.<sup>20–22</sup>

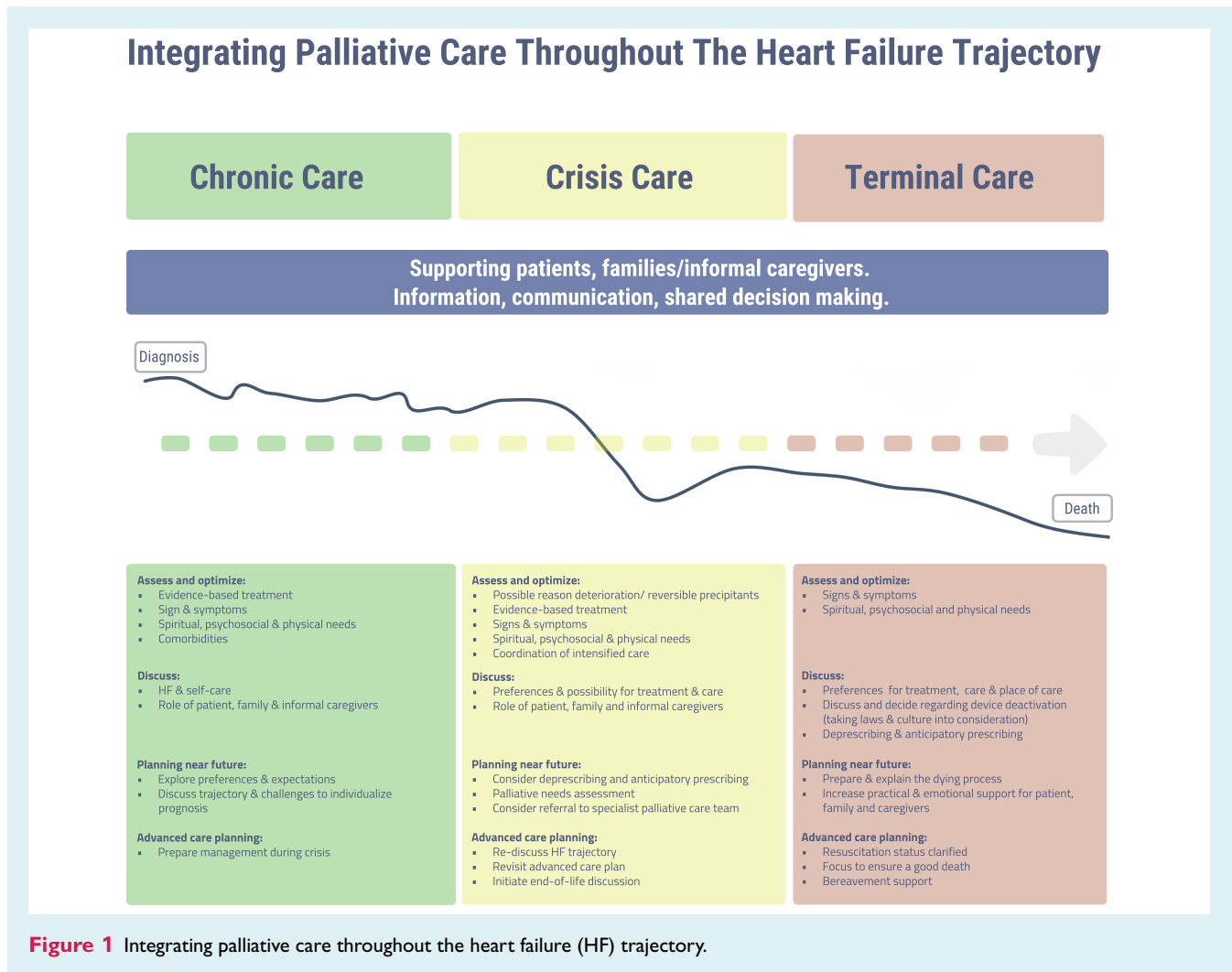
## How to identify the need for a palliative approach?

Tools for patient-reported symptoms (online supplementary Table S1<sup>23–36</sup>) may assist in identifying the need for a palliative approach. In addition, persistent severe impairment of quality of life, escalating symptoms and mood disturbance, may be regarded as indicators for assessment by a palliative care specialist.<sup>30,37</sup> The 'I need help' acronym<sup>38</sup> includes key features helpful in identifying those who may be worthy of palliative care, in accordance with American and ESC guideline criteria and consensus statements.<sup>39,40</sup>

Several prognostic risk calculators are available and have been critically reviewed,<sup>16,41,42</sup> although prognostication on an individual basis remains challenging. Clinical markers useful as prognostic indicators include the presence of right ventricular systolic and diastolic dysfunction,<sup>43,44</sup> persistent elevation of natriuretic peptide and cardiac troponin levels,<sup>45,46</sup> and elevated pulmonary capillary wedge and right atrial pressures.<sup>47</sup> Worthwhile prognostic information, easily accessible in everyday practice, includes advanced age, progressive worsening of renal function, intolerance of disease-modifying agents,<sup>42,48,49</sup> the presence of chronic obstructive pulmonary disease or diabetes, persisting hypotension, a markedly reduced ejection fraction, symptomatic classification as New York Heart Association (NYHA) III–IV,<sup>42,48</sup> anaemia and/or iron deficiency,<sup>48,49</sup> and an anorexia–cachexia syndrome.<sup>42,50</sup>

## What are the roles of families and informal caregivers?

Families and informal caregivers are crucial partners in the HF care team, their support influencing patients' self-care and mental well-being, as well as prognosis, their involvement often changing and intensifying during clinical crises and the terminal phase<sup>51</sup> (Figure 1). At the time of diagnosis, informal caregivers and family members may have to deal with emotional distress and a disruption of 'normal' life as they help the patient cope with loss of independence, social isolation, increasingly burdensome symptoms, and an awareness that death might be imminent.<sup>52</sup> They may often feel 'hopeless or powerless', with hospitalization events and post-discharge transitions from hospital to home particularly stressful periods.<sup>53</sup> In advanced disease, caregivers are often called upon to navigate the healthcare system, contribute to decisions regarding complex treatment options and deal with complicated pharmacological treatment regimens and devices. The HF Caregiver Questionnaire (HF-CQ) is a validated instrument, which may be used to assess caregiver burden and prompt appropriate support.<sup>54</sup>



## What is advance care planning?

Advance care planning (ACP) is synonymous with anticipatory care planning and advance directives. These may include a living will, which in some jurisdictions is a legally binding document.<sup>55</sup> Irrespective of age, nearly half of all patients with HF have some degree of cognitive impairment,<sup>56</sup> emphasizing the need for early ACP and palliative care discussions. In addition, as the prevalence of dementia correlates with increased age,<sup>57</sup> there is a widespread recognition of the need for dementia-specific palliative care strategies.<sup>58</sup>

For many patients, the issues addressed within ACP tend to be limited to treatment choices if capacity is lost when close to death, often focused on cardiopulmonary resuscitation policies, the use of mechanical ventilation or artificial hydration/nutrition,<sup>59</sup> or when a decision is required on the deactivation of an implantable cardioverter-defibrillator (ICD). Consideration for therapy withdrawal needs to take into account the patient's physiological status, overall quality of life, cultural and spiritual beliefs, current or previously declared treatment preferences, setting these elements within the local legal jurisdiction. Potential benefits of ACP include

reduced readmission rates, increased involvement in palliative care services, and through shared decision making with the patient and family, an increased probability of fulfilling their preferences for the place of care and death.<sup>60–62</sup>

This paper takes a neutral stance and does not offer guidance on assisted suicide or euthanasia. However, it should be noted that both assisted suicide and/or active euthanasia are legal in some European countries.

## How to effectively manage distressing symptoms

Over recent years the mode of death for HF patients has changed, fewer succumbing to sudden death.<sup>63,64</sup> However, more than half still die from a cardiovascular cause.<sup>65</sup> Many of these patients have interlinking comorbidities, therefore their final few months of life may be characterized by distressing, debilitating and refractory symptoms, arising from both cardiac and non-cardiac conditions, including cancer (Table 1).<sup>24,66–92</sup> Patients are also subject to the practical, psychological and social consequences

**Table 1** Assessment and management of prevalent symptoms

Symptoms and burden	Comorbidities to consider	Clinical assessment (include tools)	Clinical management
<b>Breathlessness</b> Up to 90% of patients with advanced HF	Anaemia COPD CTEPH ILD	IPOS, Borg or Likert scales. Quality of life scores. BDI-TDI VAS NRS	<i>Non-pharmacology:</i> Sitting upright, hand-held fans, relaxation techniques, breathing exercises <i>Pharmacology:</i> Optimal HF medical therapy. Consider benzodiazepines for anxiety and opiates (morphine). Little benefit of supplementary oxygen in advanced HF alone <sup>66,67</sup>
<b>Fluid retention</b> Affects >50% of hospice patients with HF	CKD Pulmonary hypertension Cardiorenal syndrome	Physical exam including weight Quality of life scores Implantable or non-invasive intrathoracic impedance measurement or pulmonary pressure measurement devices, e.g. OPTIVOL/ CardioMEMS Portable lung ultrasound (V scan)	<i>Non-pharmacology:</i> Support stockings/leg elevation. Long-term in-dwelling drains, e.g. PleurX™ for chronic pleural effusions and ascites <i>Pharmacology:</i> Diuretic therapy – intravenous or subcutaneous within home or hospice. Tolvaptan for severe congestion and hyponatraemia. Calcium-sensitizing inodilator, levosimendan could be considered intermittently in the ambulatory setting <sup>68–72</sup>
<b>Thirst</b> 20–46% of the HF population	CKD Fluid restriction Diuretic Anxiety Diabetes	VAS NRS Thirst Distress Scale	<i>Non-pharmacology:</i> Free fluids, artificial saliva, sucking ice chips, peppermint or buttermilk candies, chewing gum <i>Pharmacology:</i> Optimal HF and hypoglycaemic medical therapy <sup>73,74</sup>
<b>Xerostomia</b>	Cancer DM Oral infection	Saxon test NRS VAS	<i>Non-pharmacology:</i> Frequent oral hygiene, candies and suck ice cubes <i>Pharmacology:</i> Artificial saliva as gel, topical spray, rinse, dissolving tablets <sup>24,75</sup>
<b>Pain</b> 90% of patients with NYHA class IV symptoms	Musculoskeletal Cardiac	VAS McGill Pain Questionnaire (SF-MPQ) Brief Pain Inventory (BPI)	<i>Non-pharmacology:</i> Acupuncture, physical therapy, mindfulness-based stress reduction, exercise and music <i>Pharmacology:</i> Neuropathic pain can be treated with non-opioid medications (anticonvulsants, antidepressants) and opioids. Tramadol, oxycodone, hydromorphone, and fentanyl provided orally, intravenous and transdermal <sup>76–78</sup>
<b>Sexual dysfunction</b>	DM Medications for anxiety and depression Hypertension	SHIM IIEF QEQ Brief Sexual Function Index for Women	<i>Non-pharmacology:</i> Exercise, smoking cessation <i>Pharmacology:</i> Medication replacement if needed, e.g. change of beta-blocker, use of PDE-5 inhibitors (sildenafil, tadalafil, vardenafil). Caution with combining with nitrates. Women—advise topical vaginal oestrogen preparation <sup>79–81</sup>
<b>Nausea and vomiting</b> Prevalent at all stages of HF	Cancer DM Organ failure Hyponatraemia	ESAS <sup>24</sup> VAS	<i>Non-pharmacology:</i> Removal/replacement of offending medications. Try individual dietary changes, avoid triggering smells, alternative or complementary medicine <i>Pharmacology:</i> Metoclopramide (caution as may prolong QT), promethazine, prochlorperazine, ondansetron, benzodiazepines (caution as sedative)
<b>Constipation</b>	Cancer DM Depression Advanced age Dementia	Bowel Function Index	<i>Non-pharmacology:</i> Physical activity, dietary changes <i>Pharmacology:</i> Laxative, stool softeners, methylaltrexone (when opioids are used), osmotic agents <sup>82</sup>
<b>Fatigue</b>	Iron deficient Anaemia Dysthyroidism Renal failure COPD Malnutrition Cancer	6-min walking test ESAS Borg scale Dutch Fatigue Scale (DUFs) Dutch Exertion Fatigue Scale (DEFS) Fatigue Severity Scale VAS	<i>Non-pharmacology:</i> Exercise, dietary modifications/supplementations <i>Pharmacology:</i> Adjust drug dosage (diuretics, beta-blockers), address comorbidities (iron supplementation) <sup>83,84</sup>
<b>Depression/anxiety</b> More than 50% of patients 40–70% in hospitalized HF patients with NYHA III–IV symptoms	Poor spiritual well-being	PHQ-9 HADS Quick Inventory of Depressive Symptomatology 7-item Questionnaire on Generalized Anxiety Disorder (GAD-7) PHQ-2	<i>Non-pharmacology:</i> Open communication, cardiac rehabilitation, exercise and psychological therapies, e.g. CBT <i>Pharmacology:</i> SSRIs safe and relatively well tolerated in HF but limited evidence of efficacy <sup>85–92</sup>

BDI-TDI, Baseline Dyspnoea Index-Transitional Dyspnoea Index; CBT, cognitive-behavioural therapy; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; CTEPH, chronic thromboembolic pulmonary hypertension; DM, diabetes mellitus; ESAS, Edmonton Symptom Assessment Scale; HADS, Hospital Anxiety and Depression Scale; HF, heart failure; IIEF, International Index of Erectile Function; ILD, interstitial lung disease; IPOS, Integrated Palliative Care Outcome Scale; NRS, Numerical Rating Scale; NYHA, New York Heart Association; PDE, phosphodiesterase; PHQ, Patient Health Questionnaire; QEQ, Quality of Erection Questionnaire; SHIM, Sexual Health Inventory for Men; SSRI, selective serotonin reuptake inhibitor; VAS, visual analogue scale.

of living with a chronic progressive disease, or the side effects of medications.<sup>63,85,93</sup> Symptoms can cluster, and whilst they can be mitigated to some extent, toward the end of life, they can seem overwhelming. For patients hospitalized due to decompensated HF symptoms, inotropic therapy may be considered<sup>3</sup> with levosimendan proposed as appropriate for patients on beta-blocker therapy.<sup>68</sup> For the HF cohort, robust evidence for many symptom control interventions are lacking, but this should not deter from pursuing on a trial basis.

Early intervention is required to maintain optimal physical functioning and psychological well-being as many patients with HF have reduced exercise tolerance and fatigue, which can detrimentally impact prognosis and quality of life.<sup>94,95</sup> To achieve optimum clinical benefit from exercise, patients' hydration status, electrolytes and dietary intake including supplements should be actively managed. Exercise-based cardiac rehabilitation is recommended for patients with relatively stable chronic HF (NYHA I–III).<sup>96,97</sup> During a clinical crisis phase (Figure 1), patients' tolerance of physical activity becomes extremely limited. Furthermore, for patients in the terminal phase of life, it is advised that physical therapy be restricted to maintaining a sense of balance, with passive limb exercises to prevent contractions. Involvement of a physiotherapist may be beneficial. (online supplementary Table S2 outlines HF phases and corresponding exercise prescription<sup>96–98</sup>).

## Frailty, cachexia and sarcopenia

Frailty, cachexia and sarcopenia are associated with the advanced stages of HF. Frailty, exhibited in a poor physiological reserve and increased vulnerability, is considered to be prevalent in about 45% of HF patients. However, the proportion affected is uncertain as no assessment tool has been specifically validated for the HF population.<sup>99,100</sup> Cachexia and/or sarcopenia may be evident in 5–15% of patients with either HFrEF or HFpEF.<sup>101</sup> Recognition varies within clinical practice, the first indicator often being a >5% involuntary non-oedematous weight loss over a period of 3–12 months. If diagnosed early, frailty, cachexia and sarcopenia may be attenuated through exercise and dietary interventions provided alongside optimal guideline-directed HF therapy.<sup>99,102,103</sup>

## Communication with patients, families, and informal caregivers

As demonstrated in Figure 1, the turbulent nature of the HF trajectory requires HCPs to revisit earlier decisions on therapy with their patients, recalibrating goals of care to ensure treatment policies remain appropriate to the phase of the condition. If the disease progresses inexorably, previously expected outcomes may have become unrealistic and now represent false hopes.<sup>104</sup> Sensitive conversations demand protected space and good communication skills to avoid increasing patients' and family members' anxiety, undermining care plans and adversely impacting patient outcomes.<sup>105</sup> To ensure continuity and prevent misunderstanding, discussions and decisions should be fully documented, regularly reviewed, and routinely communicated to all involved in the

patient's care. Although there is no standard formula for good communication, the following steps may be helpful (Table 2).

Despite a relatively light literature base, useful insights into effective approaches to end of life communication have been collated and reviewed.<sup>106,107</sup> Professionals appear to benefit from formal communication skills training, particularly focusing on breaking bad news. Question prompt lists (QPL) are tools that can generate useful discussion during consultations and are readily accessible and easily adopted into routine practice. An example of a QPL designed for HF patients has been pilot tested.<sup>108</sup> Basic considerations when advising patients and informal caregivers are provided (online supplementary Table S3).

## Managing treatment expectations

Many patients with advanced HF maintain a sense of optimism, valuing quality but hoping through the provision of evidence-based drug, device or surgical options, that their lives will also be prolonged.<sup>1,5,109</sup> Beliefs and hope for a positive outcome vary across international borders and cultures,<sup>110</sup> and can be attributed to past experiences, unrealistic expectations of treatment benefits, and the availability of advanced technology and local expertise.<sup>111</sup> Some patients may demonstrate a 'protective denial' of their poor prognosis, indicating they are not psychologically attuned to acknowledge the progressive nature of their disease or discuss end of life care.<sup>112</sup> The continued pursuit of disease-modifying therapy should be balanced and integrated with a palliative approach.<sup>113,114</sup> Due to the ambiguous disease trajectory, professionals may feel justifiably uncertain about an individual's prognosis, and uncomfortable initiating difficult conversations early in the course of the disease.<sup>115–117</sup> However, deferment runs the risk of information exchange being 'too little and too late'.<sup>118</sup>

## Bereavement care

Bereavement is a universal experience, defined as the 'situation of having recently lost a significant person through death'. Bereaved individuals may experience a range of debilitating physical and psychological responses,<sup>119</sup> and these should be addressed by an assigned member of the MDT. For some, having experienced the significant suffering of a relative or friend, death may be viewed as a release. For others, bereavement is deep and protracted, and is characterized as complicated grief,<sup>120</sup> perhaps not unexpected in those exposed to the sudden cardiac death of a loved one. Involvement of specialist palliative care may significantly support affected individuals.

## How to provide palliative care

All professionals within the HF MDT are equipped, to some extent, in identifying clinical decline, initiating appropriate discussions, alleviating burdensome symptoms, negotiating supportive resources within the healthcare system, and providing some elements of palliative care.<sup>66,121,122</sup> While the current empirical evidence base for the delivery of palliative care by HF professionals is limited, this



**Table 2** Communication strategies

Initiating discussion: This includes establishing a rapport and supportive relationship with the patient and family, as the healthcare professional explores their general thoughts about preferences and expectations for treatment and care.

Example:

*'While I cannot cure your heart failure there are still many things that I can do for you. I want you to be able to speak openly with me, so I can best help you. No matter what happens, I can be here for you — you are not alone'*

Clarifying prognosis: Be direct, yet caring, be truthful, but sustain hope, use simple everyday language.

Example:

*'Most people with heart failure at your stage of the disease, continue to live well, but I cannot predict exactly for how long you will live. I certainly hope that you will do better than average, but you may do worse'*

Identifying goals: Facilitate open discussion about desired treatment and care and targets to be achieved however small.

Example:

*'I want to make sure we are always doing the things that might help you, and that we never do anything that either do not help you, or you would not want. So, I need to know what things are most important to you, given your illness. What things do you still wish to do?'*

Developing a treatment plan: This includes providing guidance to promote understanding of treatment and care options, making recommendations regarding their appropriateness, clarifying resuscitation orders and possible deactivation of devices, initiating further support, when indicated, and discussing how to act in case of a medical emergency.

Example:

*'We have talked about your illness and your poor prognosis. You have told me about how you want to spend your final months. I also need to know your thoughts about the use of cardiopulmonary resuscitation'*

**Table 3** Possible triggers for the involvement of specialist palliative care for those with heart failure

Refractory or complex symptoms

When there is spiritual or existential distress

Recurrent HF admissions

Increasingly frequent appropriate ICD shocks

When considering ICD deactivation or non-replacement

Before LVAD implantation or transplant referral

When initiating palliative inotropic therapy

Declining functional status due to progressive HF or a comorbidity

If patients and/or informal carers/surrogates disagree on goals of care

If there is a request for assisted suicide

HF, heart failure; ICD, implantable cardioverter-defibrillator; LVAD, left ventricular assist device.

approach has also been proposed as a sustainable model, supported by evidence that upskilling of specialist HF nurses reduces referral rates to specialist palliative care services.<sup>123,124</sup> However, patients close to the end of life, may require specialist palliative care involvement. Table 3 provides some possible prompts when this should be considered.

Current models have a 'shared care' or collaborative approach, concentrating on the relief of physical, psychological, social and/or existential burdens, and improving quality of life and spiritual well-being.<sup>23,30,114</sup> These are centred on MDT involvement with input from allied professionals, depending on individual patients' needs. The process of integrating palliative care into HF management will be determined by national healthcare structures and local service configuration.<sup>30,125,126</sup> To date, no dominant paradigm of HF palliative care has emerged, but several service models have been developed showing positive outcomes in dealing with the needs of hospital inpatients with incident acute or

decompensated chronic HF,<sup>34,127,128</sup> those transitioning to care in the community post discharge,<sup>129,130</sup> and home-based services directed at community-dwelling people living with chronic HF.<sup>23</sup> The responsibilities of the team members within such MDTs should be defined, and it may be helpful to nominate a HCP to act as interlocutor between the patient/informal caregiver and service provider. For patients treated in independent hospices, it is important to ensure the availability of HF medication, and unrestricted access to the means and expertise of deactivating devices such as ICDs.<sup>131,132</sup>

## How to deal with devices

The possible withdrawal of cardiovascular implantable electronic devices, either as standalone ICDs or those combined with cardiac resynchronization therapy (CRT-D), should be sensitively broached within a valid informed consent process pre-implantation,<sup>133,134</sup> with further and more detailed discussions at regular intervals. However, patients, family members and HCPs often avoid this uncomfortable discourse, with the discussion dependent on patient and professional factors, such as triggered by the experience of a shock.<sup>117,135</sup> Many reports document that ICD activity is often maintained in patients imminently dying<sup>136</sup> despite guidelines having been formulated to facilitate ethically appropriate ICD deactivation.<sup>137</sup> It is important that local protocols are in place to ensure the timely availability of equipment and adequately trained staff to facilitate both emergency suspension of defibrillator function by means of a magnet, and definitive deactivation by reprogramming, across all patient care settings, inclusive of community-based palliative care and primary care services. For CRT-D patients, only the shock function should be suspended, as interruption of CRT may increase symptom burden, a risk also inherent in the rarely indicated withdrawal of a permanent pacemaker implanted for bradycardia. Even after death, device

deactivation is still necessary to prevent a shock risk to pathology or mortuary staff, and both ICDs and pacemakers require to be explanted prior to cremation.<sup>138</sup>

In recent years, mechanical circulatory support (MCS) has emerged, notably in the form of left ventricular assist devices (LVADs), implanted as a bridge to decision making or recovery, a bridge to transplantation, or as destination therapy (DT-LVAD).<sup>139</sup> Some patients are offered 'preparedness planning' prior to implantation of MCS, with exploration of their short- and long-term preferences for care,<sup>140</sup> synergizing the complementary skill sets of primary care, cardiology and specialist palliative professionals.<sup>141,142</sup> For DT-LVAD patients, the most common modes of death are multi-organ failure, stroke, or progressive HF,<sup>143</sup> the terminal phase often occurring in a hospital intensive care unit. In the face of major complications, planned discontinuation of LVAD therapy might be indicated, death usually occurring within an hour of withdrawal.<sup>144</sup> Brush *et al.*<sup>145</sup> have drawn up a flow-chart illustrating one approach to end of life care for patients with DT-LVADs, and a number of decision aids and informational tools may assist patients and families facing such dilemmas.<sup>146,147</sup>

Palliative care support should also be offered to those individuals who are deemed to be device ineligible or choose to forgo primary device implantation or replacement. Similar support is also applicable to those turned down for transcatheter aortic valve implantation,<sup>148</sup> or MitraClip™ (Abbott Cardiovascular Systems, Abbott Park, IL, USA) for severe functional mitral regurgitation, the benefits of which are currently uncertain in the general HF population.<sup>149–151</sup>

## How to ensure a good death

Whilst much of the 'good death' template has been founded on the cancer model, transferability to HF care is worthwhile, particularly within an elderly care setting.<sup>152</sup> General principles of what characterizes a 'good death' have been developed (online supplementary Table S4).<sup>153–155</sup> First and foremost is the need to recognize that the patient has reached their final days of life.<sup>156,157</sup> An important and difficult aspect to discuss is the care setting in which patients wish to receive terminal care and ultimately die.<sup>158</sup> It is well recognized that hospice care is underused by patients with HF, mainly accommodating people with cancer.<sup>9,12,63</sup> Achievement of the preferred place of death is accepted as a quality indicator of good end of life care, which can be facilitated through involvement of palliative care.<sup>159,160</sup> Most people prefer to die in their comfort zone at home, where they have a sense of control, familiarity, and are in the presence of family. Yet for some older adults, such home deaths are more difficult to achieve, requiring adaptations to facilitate a 'hospital at home' arrangement. Care at home can often entail reduced input from specialist services, with increased reliance on primary care physicians and community-based nurses. In cases of poor pain control or the need for an enhanced level of care beyond the capabilities of informal caregivers and primary care team, patients might opt to die in an institution.<sup>159,160</sup> However, many hospital deaths may be inappropriate and avoidable,

**Table 4 Medications used for anticipatory prescribing**

Situation	Prescribe
Shortness of breath	Opioids (morphine, oxycodone)
Pain	Paracetamol, opioids (morphine, oxycodone)
Nausea/vomiting	Metoclopramide, ondansetron
Congestion and oedema	Furosemide, bumetanide, torasemide, metolazone
Anxiety	Benzodiazepines (lorazepam, clonazepam)
Preparing for palliative sedation	Midazolam
Sore wounds level 1–2	Dressings and preparations

All medications should include oral/intravenous/subcutaneous routes of administration where possible.

often preceded by multiple admissions featuring aggressive treatment protocols, disrupting care continuity, impacting the quality of remaining life, and ultimately a good death.<sup>158</sup>

People close to the end of life should still expect to receive good care, this presumption founded on trust, confidence and hope, all of which may be tempered by their past and current subjective experiences of interacting with HCPs or the local healthcare system.<sup>161</sup> Moreover, the reality and process of 'dying' is intensely personal, requiring time for people to deal with any unfinished business with family or friends, and finally reach a stage of acceptance.<sup>162</sup>

## Anticipatory prescribing and deprescribing

Maintaining patient and family autonomy, preparing them for unpredictable situations and providing the necessary means for self-care are essential elements for successful care at home. One approach to promote this lies in 'anticipatory prescribing', namely writing prescriptions for medications that might be needed as a matter of urgency in the near/intermediate future. Having such medications (Table 4) readily accessible at home with detailed instructions for their use, can empower patients and caregivers in self-management until professional supervision is available. If the patient is at home, responsibility for such prescriptions may be with primary care physicians, HF specialist nurses or community-based nurse managers, in accordance with local governance arrangements. For patients in a hospital or hospice setting, the cardiologist or palliative care physician may undertake this responsibility. It is important that decisions are synchronized through the MDT process, offering access to a breadth of clinical expertise. For example, the sensation of dyspnoea is often clustered with anxiety. Opiates can be used for breathlessness, and benzodiazepines may be considered as an anxiolytic. However, even the short-term use of benzodiazepines can cause somnolence and increase the risk of falls, particularly in the elderly.

Medication deprescribing is a proactive, patient-centred approach, founded on a seamless revision of good prescribing principles, taking into consideration the context of patients changing goals of care, values, preferences and perceived life expectancy.<sup>163</sup> Most scientific literature on drug discontinuation stems from the field of cancer and geriatric palliative care.<sup>164</sup> There are a variety of reasons to deprescribe in the setting of inexorable HF progression: where treatment burden outweighs benefit, the risk of adverse drug reactions increases with polypharmacy, declining pharmacologic and metabolic efficacy, and poor patient adherence.

Professionals may be reticent or experience resistance to the withdrawal of established and sometimes long prescribed drug therapies. Some prescriptions worthy of possible withdrawal include medications no longer conferring symptomatic benefit such as statins or antiplatelet therapies. Optimizing diuretic therapy and down-titrating beta-blockers may be considered in the face of worsening congestion. Similarly, symptomatic hypotension may require down-titration of both beta-blockers and renin–angiotensin–aldosterone system inhibitors.

During the deprescription process, professionals need to motivate change by engaging with and supporting patients and families. A potentially useful electronic resource on medication deprescribing is available, and may provide confidence and reassurance.<sup>165</sup>

## Who takes cares of the healthcare professional?

Healthcare professionals regularly handling life and death situations are particularly exposed to both clinical and ethical dilemmas which undermine their resilience, putting them at risk of moral distress and burnout. Emotional exhaustion, depersonalization and detachment can lead to declining empathy, with a lack of compassion hampering clinician–patient relationships and the quality of care delivery.<sup>166,167</sup> Whilst these issues are more common in intensive care unit staff, HCPs involved with HF patients are not immune to such responses. Debriefing, mindfulness, and reflective practice can support the spirit and stamina of HF professionals.<sup>168,169</sup> Additional options include the availability of safe spaces within MDTs, Schwartz rounds, and team meetings dedicated to mutual support.

## Conclusions

### Future recommendations and developing the evidence base

A palliative care approach should be introduced early in the care for patients with HF, focused on optimizing symptom control, and responsive to dynamic changes in goals of care, during different phases of the disease trajectory. Concrete proposals and advice include:

1. **Consider palliative care throughout the HF trajectory.** We recommend that all patients with HF should be considered for palliative care, regardless of stage of their illness. Patients in the advanced stages and those considered for MCS or heart

transplantation should receive a palliative care consultation before such interventions as a matter of protocol. ACP should be considered for all patients with advanced HF (as outlined in *Figure 1*).

2. **Addressing needs and preferences for treatment.** For patients with HF, their families or informal caregivers, their supportive needs and preferences for treatment should be systematically taken into account, especially in the terminal phase. Tools and programmes that support patients and families engaging in such discussion and decision-making, including their views on palliative and end of life care, should be developed and implemented.
3. **Optimal symptom control as the focus of care.** Better assessment of palliative care needs supported by evidence-based validated PROMs is advised. Healthcare providers need to appreciate the importance of palliative care, and this should be highlighted and incorporated more definitively in the specialist HFA training curricula for both cardiologists and nurses.
4. **Specialist palliative care and a palliative care approach by all professionals.** Both should be considered within HF management, the latter predominately addressing symptom alleviation, ensuring treatment modalities are aligned with preferences for care, offering psychosocial support, and fostering care coordination. With regard to integration of a specialist palliative care MDT model, this requires a degree of operational flexibility to accommodate local variation in healthcare structures, available resources, and the spectrum of professional competences. We recommend that HF palliative care be the subject of further primary research, alongside future surveys, registries, and quality assurance initiatives on a pan-European basis.
5. **Preferences for treatment and care of patients, their families and caregivers.** These need to be taken into account and addressed more systematically throughout all stages of HF, but especially in the terminal phase. Tools and programmes that assist patients and families undertaking difficult discussions, and supporting shared decision-making on treatment options should be developed and implemented.

## Supplementary Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Table S1.** Tools to identify the need for a palliative approach.

**Table S2.** Heart failure phases and exercise prescription.

**Table S3.** Basic considerations for patient and informal caregiver teaching.

**Table S4.** Checklist outlining principles for a 'good death'.

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