



Integrating Palliative Care and Heart Failure:

# Realist Synthesis

(PalliatHeart Synthesis)



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# Context

**H**EART failure is a debilitating life-limiting condition where the heart cannot pump blood sufficiently around the body to meet its needs. It mainly affects older people (average age 73 years), but can affect all age groups.

Despite advances in treatment, people living with heart failure can experience frequent and distressing symptoms, such as pain, shortness of breath, swelling from a build-up of fluid, and excessive tiredness.

Heart failure is now referred to as a modern-day epidemic, and is projected to impact 64 million people worldwide by 2050. In the United Kingdom, it is estimated that heart failure accounts for a total of one million inpatient bed days (2% of all NHS inpatient bed days), 5% of all emergency medical admissions to hospital, and healthcare costs of around £2 billion per annum.

Palliative care includes holistic support (care of the whole person, including physical, psychological, social and spiritual needs), care planning, symptom management, rehabilitation and family support. Research evidence shows that integrating palliative care into heart failure management helps improve the wellbeing of people who have heart failure and their families and carers.

Integrated palliative care and heart failure also reduces the burden on the healthcare system as it lessens the need for hospital use through improved symptom management.

Despite over two decades of research, policy and clinical guidelines advocating for the integration of palliative care into heart failure management, integration remains difficult to achieve in routine practice. The Health and Care Act 2022 establishes a legal duty to commission palliative care services that meet the needs of the local population in every part of England. This includes people with heart failure and other chronic life-limiting conditions. However, given there is no standard to guide integration of palliative care and heart failure services applicable across all nations of the United Kingdom, this report is timely.

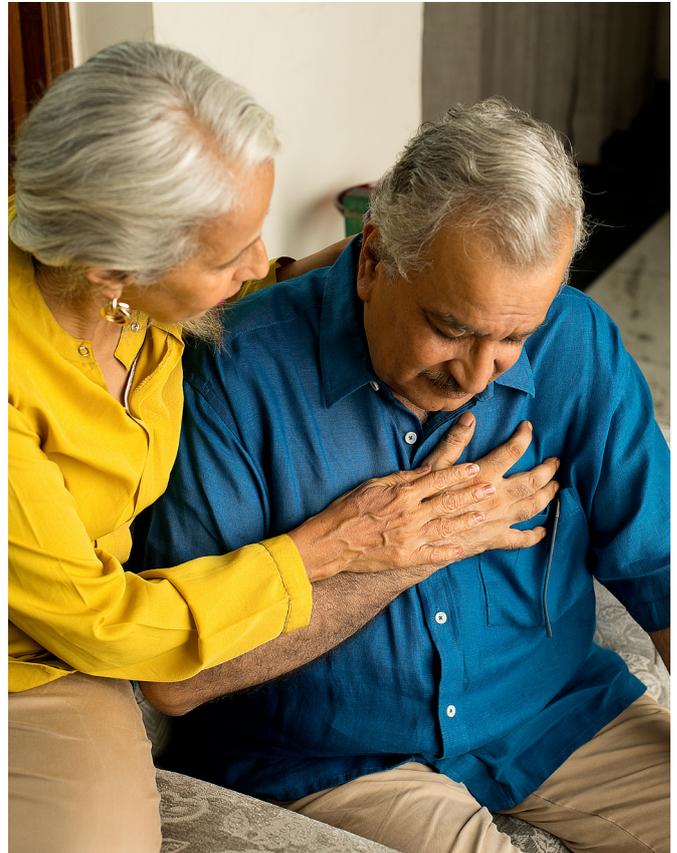
# Findings and implications

## 1. Misunderstanding palliative care as being only for cancer or end-of-life care hinders its earlier integration into heart failure management.

Even though heart failure is more common than the four most diagnosed cancers combined, only 7% of people with advanced heart failure are placed on the palliative care register in the UK, compared to 48% of those with advanced cancer. Furthermore, patients with heart failure are entered on the palliative care register much later than those with cancer. This may be explained in part by clinicians' reluctance to discuss poor prognosis because of heart failure's unpredictable course or to engage in palliative conversations for fear of removing hope or being seen to give up.

Health and social care professionals and patients, their families and carers may also believe that palliative care is for patients with cancer or for care at end-of-life only. Although palliative care as an approach had its origins in cancer care, a model is required to recognise and respond to the needs of people with heart failure and other non-cancer conditions.

**More education around what palliative care is and how it can support heart failure management is needed for health and social care professionals, patients and the public in order to overcome misunderstandings that act as a barrier to its integration.**



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**“Dad would have benefitted from palliative care support certainly in his last year and this would have prevented unnecessary hospital admissions.” – Carer**



## 2. Palliative care education must include palliative care for heart failure and other chronic life-limiting illnesses.

Two opportunities to change culture and misunderstandings are palliative care education for all health and social care professionals from a range of professional disciplines, embedded throughout undergraduate, postgraduate and continuing professional development; and a public health approach to educate patients and the public.

Educational strategies include experiential learning. This could help health and social care professionals learn from each other and optimise their communication skills and confidence to initiate, discuss and decide on future expectations/goals of care and treatment options with patients who have heart failure and their families and carers. These conversations should be based on patient needs, not on stage of illness.

**A review of education for health and social care professionals is needed to make sure that palliative care for patients with chronic life-limiting conditions such as heart failure is adequately covered. A public health approach is needed to help dispel myths and misunderstanding around palliative care.**

## 3. Collaborative working across specialities is crucial.

The findings highlighted the importance of shared decision-making between multidisciplinary teams (MDTs), including primary care, heart failure specialists, palliative care specialists, geriatricians, nurses, social workers, chaplains, pharmacists, allied health professionals, and patients and their families and carers.

MDT working is more likely to be successful when there is a champion across specialities and a key worker overseeing the coordination of meetings.

MDT working improves continuity of care and patient outcomes, and facilitates joint learning and understanding of each other's roles and responsibilities.

**Establishing and future proofing MDT meetings for professionals involved in palliative care and heart failure should be prioritised. Well-functioning MDTs enhance trusting relationships and collaborative working, and create opportunities to learn from each other.**

#### 4. We must win hearts and minds.

Champions are important across all levels – from patients and their families and carers to health and social care professionals and senior decision-makers in the health and social care system. They highlight the importance of palliative care, and therefore influence and engage those responsible for integrating palliative care and heart failure management.

Champions can do this by showing examples of good practice and improved patient, carer and healthcare system outcomes.

**Policy, practice and service user champions should be identified and supported to advocate for the integration of palliative care and heart failure. Every opportunity should be taken to share the benefits of integrated care.**

#### 5. Time and resources must be assessed and addressed.

Additional key challenges to integrating palliative care and heart failure management include the increasing time pressure on palliative care and heart failure health and social care professionals and

lack of confidence to initiate palliative care conversations with patients.

Insufficient palliative care services also presents challenges for the onward referral for patients with more complex needs and challenges to integrated MDT working.

**In services that are sufficiently reconfigured to provide integrated palliative care and heart failure management, heart failure health and social care professionals are more likely to have time to assess and address their patients' palliative care needs.**

#### 6. Guidelines for integrating palliative care and heart failure must be visible and accessible.

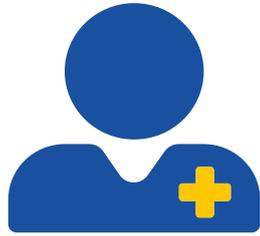
Findings highlight the need for clear guidelines outlining responsibilities and timeframes so that staff have clarity over expectations and roles. As a result, patients with heart failure are more likely to have their palliative care needs assessed at the right time, by the right people.

**Existing guidelines need to be visible and in an accessible format for health and social care professionals, so they become embedded in routine clinical practice.**

**“Palliative care needs redefining as a quality of life issue, and needs to be applied much earlier in the heart failure timeline.” – Patient**

# Recommendations

## 1. Palliative care education for health and social care staff must support integrated care across chronic life-limiting illnesses, including heart failure.



Departments of health, along with higher education institutions for staff who work in MDTs (medicine, nursing, physiotherapy, social work, etc.) should ensure that palliative care education is on the curriculum and aligned with regulatory bodies' (e.g. Nursing & Midwifery Council) education quality standards.

Core components of palliative care should be embedded in undergraduate through to post-registration education and training, and include care for those with cancer and non-cancer life-limiting conditions. It should focus on: needs-based care (rather than prognosis-based care); effective communication skills; and joint multidisciplinary, experiential learning.

Failure to do so will mean palliative care and heart failure staff will not see the need to integrate palliative care into the care for those with heart failure. This could result in continued high symptom burden and overutilisation of unnecessary medications and hospitalisations.

## 2. Campaign for increased public awareness.



Governments, alongside palliative care and heart failure charities, should support and implement public-awareness-raising activities around what palliative care is (holistic care delivered alongside active heart failure management based on patient need) and what it is not (only for patients with cancer and/or end-of-life care), and how to access it.

Failure to do so will not address public misunderstandings and will make it more challenging for health and social care professionals to initiate palliative care conversations with people living with life-limiting chronic conditions and their families and carers.

# £14,109.36

An integrated palliative care and heart failure service in Wales found an estimated average saving of at least £14,109.36 per referral. Overall, it estimated that the integrated service saved approximately £2.4 million over five years.<sup>1</sup>

<sup>1</sup>Atkinson, C., Hughes, S., Richards, L., Sim, V. M., Phillips, J., John, I. J., & Yousef, Z. (2022). [Palliation of heart failure: value-based supportive care](#). *BMJ Supportive & Palliative Care*.

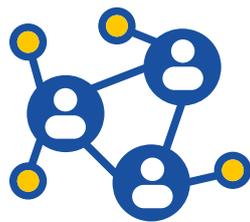
### 3. Champion the value and benefits of integrating palliative care into heart failure management.



Health and social care professionals working within integrated palliative care and heart failure services should identify a credible champion to advocate for integration and share examples of integrated palliative care and heart failure management, e.g. through clinical visits and placements.

Patient, public and government-level champions are also required to ensure adequate commissioning of services and meet patient demand for integration of palliative care into heart failure management. Failure to do so will result in a postcode lottery and inequity of care.

### 4. Integrate palliative care and heart failure teams.



Integrated palliative care and heart failure champions should develop forums, co-speciality steering groups and/or networks to support and proactively share experiences to foster health and social care professionals' acceptance and support for integration.

This will also improve collaborative working and communication between the two specialities.

Failure to develop multidisciplinary integrated palliative care and heart failure service delivery will result in a lack of understanding of each other's roles, lack of communication, ongoing fragmentation of services and sub-optimal patient care.

### 5. Increase the use of integrated palliative care and heart failure guidelines in routine heart failure management.



Palliative care and heart failure clinical service leads should ensure that integrated palliative care and heart failure national guidelines are visible and accessible for all health and social care professionals in their service.

Departments of health, along with higher education institutes, should ensure these guidelines are part of the palliative care core curriculum for all health and social care professionals. Failure to do so will mean that, when it comes to integrating palliative care into heart failure management, health and social care professionals remain unsure of who should be doing what and when, and how to do it. This in turn leads to ongoing fragmentation of services and inconsistency in service provision.

## Co-leads

**Dr Tracey McConnell**, Marie Curie Senior Research Fellow, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK; Marie Curie, Northern Ireland, UK

**Prof Joanne Reid**, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

## Co-authors

**Dr Carolyn Blair**, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

**John Burden**, British Heart Foundation Patient and Public Involvement Network member, UK

**Linda Cooper**, Patient and Public Involvement Member, UK

**Claire Duddy**, Nuffield Department of Primary Care Health Sciences, University of Oxford, | Oxford, UK

**Dr Loreena Hill**, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

**Dr Clare Howie**, School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

**Bob Jones**, British Heart Foundation Patient and Public Involvement Network member, UK

**Bob Ruane**, British Heart Foundation Patient and Public Involvement Network member, UK

**Prof (Associate) Geoff Wong**, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK

## More information

[www.palliatheartsynthesis.co.uk](http://www.palliatheartsynthesis.co.uk)



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## Correspondence

### Dr Tracey McConnell

Marie Curie Senior Research Fellow,  
School of Nursing and Midwifery  
Queen's University Belfast,  
97 Lisburn Road, Belfast, BT9 7BL, UK

[t.mcconnell@qub.ac.uk](mailto:t.mcconnell@qub.ac.uk)

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