



# Palliative Care for Heart Failure Patients: Practical Tips for Home Based Programs

Parag Bharadwaj, MD, AAHPM Anjali Chandra, MD  
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## Palliative Care for Heart Failure Patients: The Need

In the United States more than 5 million people suffer from heart failure (HF). About half of the people who develop HF die within 5 years of diagnosis.<sup>1</sup> In addition, the disease comes with a high symptom burden. These patients would benefit from active palliative care intervention to ensure comfort and optimization of treatment plan and goals.<sup>2</sup>

## Definition of Heart Failure

HF is a pathophysiologic condition in which the efficiency of the myocardium is reduced through damage and overloading, resulting in decreased cardiac output (CO) and circulatory failure. HF is characterized by recurrent decompensation and persistent symptoms.

## Relevant Pathophysiology

Heart failure can be described as the inability of the heart to pump adequate blood to meet the requirements of the metabolizing tissues. HF can be categorized into different types, such as systolic vs diastolic HF, amongst other distinctions.

Systolic heart failure represents impaired contractile function of the heart with a reduction of ejection fraction (EF). In contrast, diastolic heart failure is represented by a preserved EF; however, ventricle filling is impaired during the relaxation phase.<sup>3</sup> The normal EF is usually considered between 55 and 60% and an EF of less than 40% might indicate systolic heart failure.

## Clinical Features

Predominantly identified symptoms include:

- Shortness of breath manifested as exertional dyspnea
- Orthopnea
- Paroxysmal Nocturnal Dyspnea
- Acute Pulmonary Edema
- Pain around the chest and other parts of the body – this symptom is underdiagnosed and underreported but significantly impairs quality of life in HF patients.<sup>4,5</sup>

Other common signs and symptoms include fatigue, weakness, weight gain, nausea and bloating, sexual dysfunction, insomnia, lack of concentration, cognitive decline, memory loss and, in late stages, muscle wasting and cachexia.

## Disease Management

HF treatment comprises both non-pharmacological and pharmacological interventions, as well as invasive strategies. Depending on disease severity, HF patients benefit from exercise, diet, particularly sodium restriction and fluid restriction, and nutrition.

### Pharmacologic Therapies

- Diuretics
- Vasodilators
- Inotropic drugs including beta adrenergic receptor blockers, angiotensin-converting enzyme inhibitors (ACE inhibitors), and angiotensin II receptor blockers (ARBs) among other drugs.
- Supplemental oxygen might be needed.<sup>6</sup>

### Invasive Therapies

- Electrophysiologic intervention devices such as cardiac resynchronization therapy (CRT), pacemakers, and implantable cardioverter-defibrillators (ICDs).
- Introduction of the ventricular assist device (VAD) as bridge to transplant and destination therapy has brought about a drastic change in the management, outcomes and longevity of patients with advanced HF.
- Coronary artery bypass grafting (CABG) and percutaneous coronary intervention (PCI) are revascularization procedures considered in selected patients with HF.
- Other invasive interventions include valvular surgery - valve replacement or repair, and ventricular restoration.<sup>7,8,9</sup>

Patients with severe HF refractory to pharmacologic therapy and invasive strategies are considered for heart transplantation.

## Palliative Care In Heart Failure Patients At Home

Patients with heart failure have a unique disease trajectory and needs. While heart failure is a chronic progressive disease, it is not as predictable when compared to conditions such as dementia and cancer. There are certain signs and symptoms that indicate the progression of

the disease or the need to make changes to medication regimens for better control of symptoms and to prevent acute crises, such as fluid overload.

Meeting the patient's needs at home lessens patient and caregiver burden and helps prevent avoidable admissions to the hospital. The delivery of this type of care requires intense planning and care coordination between all involved medical specialties as well as family/caregivers/ psychosocial supports.

## Clinical

The initial visit should involve all palliative care team members. Areas of focus on initial and sub-sequent visits at home may include:

### 1. Physical Indicators

#### ■ Vital signs

- Oxygen saturation
- Pain - often underdiagnosed and underreported in heart failure patients. Can be as common as dyspnea.

#### ■ Physical exam

- Observe for labored breathing
- Fluid overload and/or progression of disease
- Jugular venous distension, crackles on auscultation of lungs and pedal edema

#### ■ Weight and fluid input/output

- Monitor for weight gain - fluid overload. Input should be less than output. Account for 600-900 ml/day of water loss.

#### ■ Functional status: use one tool consistently.

- Suggest use of Palliative Performance Scale (PPS)
- Monitor for change- fluid overload, progression of disease.

#### ■ Screening for symptoms: use one tool consistently.

- Suggest use of Edmonton Symptom Assessment Scale (ESAS)
- Symptoms are often missed if a screening tool is not used.

#### ■ Medication reconciliation – review how each medication is dispensed.

- Assess ability of patient/family to manage medications; ensure a clear understanding of importance and purpose of each medication and that there is an adequate supply to optimize compliance.

#### ■ Hardware check, e.g. pacemakers, ICDs

- Relevance of the devices in relation to goals needs to be revisited on a regular basis.

#### ■ Intravenous inotrope infusions

- Inotropic therapy might enable patients to stay at home and often requires a higher level of maintenance. Often programs allow this therapy to be administered at a fixed dose that is not titrated.

#### ■ VADs and post-transplant patients

- The involvement of an inter-disciplinary team experienced in the management of patients with chronic heart failure is paramount. Protocols, including one for turning off the device at home, should be put in place in advance.

**■ Review records to get a baseline on the various clinical parameters**

- Essential to know baseline to be able to identify significant changes.

Any changes in the above will require a more thorough assessment by making changes in the home regimen or by escalating care to the next level, such as setting up an appointment with the cardiologist or a transfer to the hospital. All changes should be implemented in collaboration with the heart failure service.

**2. Additional needs assessment****■ Emotional/financial support screening**

- Request social worker follow up, if needed, in addition to routine social worker visits.

**■ Spiritual needs screening**

- Request chaplain visit, if needed, in addition to routine chaplain visits.

**■ Caregiver screening**

- All community resources need to be well known to the team to be able to connect them with the patient and caregivers. Ensure social worker and chaplain support to caregiver(s). Monitor for burn out.

**3. Patient goals**

**■ Care plan and patient goals should be reviewed frequently with the patient and caregiver to ensure the appropriate care is being delivered.** Change in status of the patient requires an in depth conversation to ensure clear understanding of the disease process and the expected trajectory and outcomes.

**■ Every patient should have an advance directive completed, preferably a POLST (Physician Orders for Life Sustaining Treatment).** Any changes in goals should be promptly reflected in the documents. *These documents should be readily available to the patient, caregiver and paramedics (if called). Many programs have placed them on the refrigerator.*

Depending on the patient's clinical status, options and goals should be readdressed on a regular basis. Informing the patient and the caregiver of options, including hospice, is necessary.

**4. Review and education**

**■ Any changes in the treatment plan should be shared with the patient and caregiver in writing and reviewed with them during the visit.** Include specific instructions regarding a preventive plan, detailing which medical service to call when changes occur or in an emergency. *A good practice is to ask the patient/caregiver to repeat back the changes.*

**■ Before leaving the patient's residence, patients and/or caregivers should be instructed to call the palliative care service with any questions or concerns.** Ensure they have the number and review the backup plan for times when the palliative care service is not available. *Ideally, a call to the primary physician/cardiologist should be made from the patient's home during every visit and the plan of care should be reviewed.*



## Operational

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### Scope of practice

- Role of each member of the team
- There needs to be a clear understanding that optimization of care to the patient requires that the team function as one unit with team members being able to rely on each other.
- Routine Interdisciplinary Team (IDT) meetings are essential.

### Role delineation is vital when working in the home

- Prior to launch of the service a meeting to establish parameters is recommended between the palliative care team, primary care colleagues and the cardiology team.
- Some palliative care medical services co-manage with cardiology or primary care, some are purely consultative, and some palliative care services function as the attending service in the home.

### A strong relationship with cardiology and primary care is essential for the success of the program and for its optimization

- Care coordination is best accomplished with all specialties involved during regular patient care meetings.
- Operational communication is also vital for discussing changes in protocols and practice personnel. This could happen via a quick phone meeting between point people and goes a long way to ease communication channels.

### Emergencies

- A strategy for handling emergencies should be set up. If your service is not available 24/7, an off-work hours plan needs to be in place.

### Data

- Clinical and operational data, patient/family satisfaction and referring entity satisfaction should be collected and reviewed routinely.

### Additional support from cardiology is essential if palliative care becomes involved with Ventricular Assist Device (VAD) patients.

**Monitor expected outcomes: improved continuity and quality of care decrease in ER visits and hospitalization, increased adherence to patient goals, improved patient and provider satisfaction.**

## Summary: Lessons Learned and Best Practices

- A well-coordinated team is required, preferably with a shared electronic medical record.
- Frequent team meetings allow other insights and techniques; each home setting is unique and requires attention and respect for the environment.
- Focus should be on keeping the patient comfortable and meeting patient/family goals, versus just avoiding hospitalizations. Some hospitalizations may be appropriate.
- Prevention and preventative plans are vital.
- Home is where the heart is; figuring out how to eliminate obstacles for patients is part of the terrain.
- Social interactions and being able to give to others in some way is good medicine.
- Efficiencies are obtained through having an office nurse coordinator to work with the palliative care provider(s). A nurse, who triages phone calls, provides clinical input, assists with care coordination and managing referrals maximizes the provider's time.
- Relationships develop in a different way when in the home; resiliency and self-care must be part of this work.

## References:

1. Go AS, Mozaffarian D, Roger VL, Benjamin EJ, Berry JD, et al. Heart disease and stroke statistics—2013 update: a report from the American Heart Association. *Circulation*. 2013;127:e6–e245.
2. Shah AB, Morrissey RP, Baraghoush A, Bharadwaj P, Phan A, Hamilton M, Kobashigawa J, Swarcz ER. Failing the failing heart: a review of palliative care in heart failure. *Rev Cardiovasc Med*. 2013; 14(1):41-8.
3. Chatterjee K, Massie B. "Systolic and Diastolic Heart Failure: Differences and Similarities", *Journal of Cardiac Failure* Vol 13 No 7 2007.
4. Shah AB, Udeoji DU, Baraghoush A, Bharadwaj P, Yennurajalingam S, Schwarz ER. An evaluation of the prevalence and severity of pain and other symptoms in acute decompensated heart failure. *J Palliat Med*. 2013 Jan;16(1):87-90. doi: 10.1089/jpm.2012.0248. Epub 2012 Dec 28.
5. Udeoji DU, Shah AB, Bharadwaj P, Katsiyiannis P, Schwarz ER. Evaluation of the prevalence and severity of pain in patients with stable chronic heart failure. *World Journal of Cardiology*. 2012;4(8):250-255. doi:10.4330/wjc.v4.i8.250.
6. Ahmed A. DEFEAT – Heart Failure: A Guide to Management of Geriatric Heart Failure by Generalist Physicians. *Minerva medica*. 2009;100(1):39-50.
7. Howlett JG, McKelvie RS, Arnold JMO, et al. Canadian Cardiovascular Society Consensus Conference guidelines on heart failure, update 2009: Diagnosis and management of right- sided heart failure, myocarditis, device therapy and recent important clinical trials. *The Canadian Journal of Cardiology*. 2009;25(2):85-105.
8. Thompson KA, Philip KJ, Barbagelata A, Schwarz ER. Review article: the new concept of interventional heart failure therapy--part 1: electrical therapy, treatment of CAD, fluid removal, and ventricular support. *J Cardiovasc Pharmacol Ther*. 2010 Jun;15(2):102-11. doi: 10.1177/1074248410366447. Review.
9. Thompson KA, Philip KJ, Simsir S, Schwarz ER. The new concept of "interventional heart failure therapy": part 2--inotropes, valvular disease, pumps, and transplantation. *J Cardiovasc Pharmacol Ther*. 2010 Sep;15(3):231-43. doi: 10.1177/1074248410369111. Epub 2010 Jul 1. Review.





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**NHPCO**

1731 King Street  
Alexandria, VA 22314

tel. 703.837.1500 | [nhpco.org](http://nhpco.org)