

**"The promotion of the palliative care approach is appropriate for all non-cancer patients.**

**A subset of patients with multiple medical problems or complex palliative care needs will benefit from Specialist Palliative Care."**

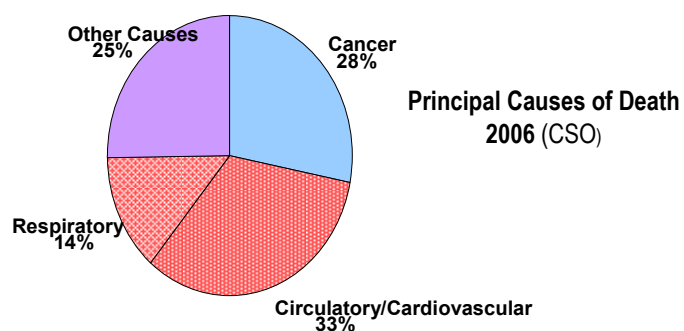
Report of the National Advisory Committee on Palliative Care (NACPC) 2001

## What is Palliative Care?

Palliative care is an approach that improves the quality of life of patients facing problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other symptoms that may be physical, psychosocial and spiritual (WHO)

**Palliative care services are structured in three ascending levels of specialisation:**

- Level 1 – Palliative Care Approach
- Level 2 – General Palliative Care
- Level 3 – Specialist Palliative Care (SPC)



## WHY

### Rationale for Palliative Care for patients with Heart Failure

In 2006 a third of deaths were due to cardiovascular disease in Ireland, and 10,000 people are newly diagnosed with heart failure each year.

The life expectancy for patients with chronic heart failure is worse than common malignancies - except for lung cancer.

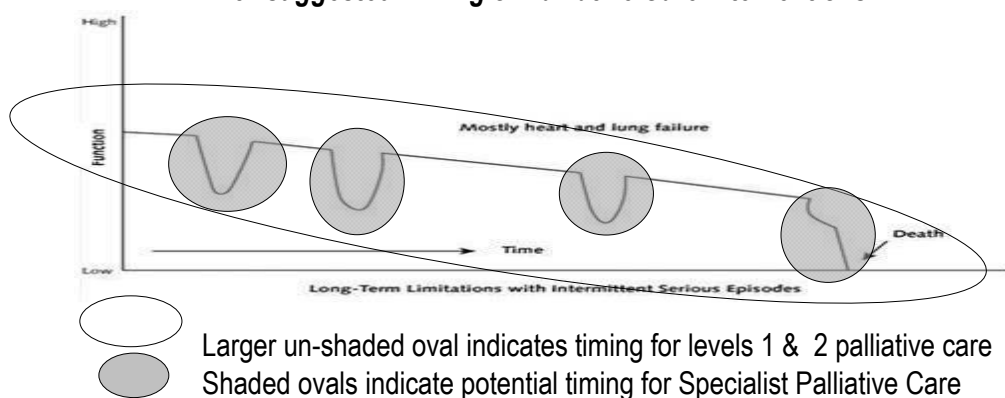
The symptom burden for people with heart failure equals that of people with cancer, may often be of longer duration and can significantly impair their quality of life.

People with heart failure may face complex decisions regarding their health over a long duration and they may confront the fear of death on a number of occasions.

The disease trajectory associated with heart failure can be unpredictable, and this uncertainty can lead to depression, anxiety, social isolation and fear. They can also experience a loss of autonomy and independence in addition to physical symptoms of pain, fatigue, dyspnoea, insomnia and anorexia.

National and international health policy has acknowledged that appropriate levels of palliative care should be available to people with heart failure.

**Diagram representing Heart Failure Disease Trajectory with suggested Timing of Palliative Care Interventions**



### Timing of Palliative Care Intervention

Appropriate levels of palliative care should be available throughout the disease trajectory of people with heart failure, as demonstrated in the diagram above.

Referral to Specialist Palliative Care Services should be considered when there is persistence at NYHA Stage III or IV despite optimal intervention, and patient is not suitable for surgery. Palliative care intervention may be required for physical, psychological or spiritual issues.

### References

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- The diagram is adapted from Lynn et al and is reproduced with the permission of RAND Health

## HOW

### How Palliative Care can be Included in Heart Failure Service Model

- The majority of patients' palliative care needs can be addressed from within heart failure services, with SPC providing support where complex and intractable symptoms persist.

- Palliative care for heart failure should be integrated into routine care in all care settings, with a focus on relieving breathlessness, pain and fatigue; addressing emotional and spiritual issues and to assist with communication about treatment choices and complex end-of-life issues.

- Adopting a palliative approach should facilitate the provision of information for patients and families on disease trajectory, and encourage promotion of patient autonomy and self-

- management to equip patients in dealing with the symptom burden they experience. This can be initiated while the patient is continuing with active disease management.

- UK initiatives have demonstrated that successful integration of palliative care in heart failure service delivery should be based on collaboration between heart failure and palliative care staff and guided by disease policies and end-of-life care strategies.

- A heart failure service model needs to reference the requirement for palliative care across the care settings between primary, secondary and tertiary healthcare

### Palliative Care for All - Recommendations specific to Heart Failure

1. A model of care for people with heart failure which signals the timing and potential of palliative care intervention to be devised, piloted and evaluated, in collaboration between cardiology and SPC professionals
2. A series of fact sheets to be published, for patients and staff, to provide clarity and awareness of the role of palliative care for people with heart failure.
3. Formal and informal education programmes for staff in cardiology and SPC services to support necessary developments.
4. Palliative care to be referenced in all policy material related to heart failure service
5. Development and monitoring systems to be put in place to ensure palliative care services are delivered on the basis of need, not diagnosis.
6. Audit and evaluate services within AGH which provides services to people with heart failure.

## WHAT NEXT

The following action has been prioritised for action and is based on the implementation of the recommendation 1 above.

### Research Project: Establishing a Framework for Palliative Interventions within Heart Failure Services

#### Project Goals

- Identify potential palliative responses in patient pathway of those with heart failure
- Propose, agree and implement mechanisms for inclusion of palliative responses in patient pathway
- Identify key personnel involved in delivering palliative responses
- Provide necessary education materials and training for key personnel
- Provide guidelines to identify when degree of palliative interventions needs to escalate
- Further examine the specific role of Specialist Palliative Care within a heart failure service model
- Evaluate the benefit of palliative interventions from patient, family/carer and staff perspectives
- Recommend service model components based on evaluation.

#### Project Overview

- This development is jointly funded by Irish Hospice Foundation, Irish Heart Foundation and Baxter Foundation with support from HSE.
- Following invitations for expressions of interest, the selected site for research will include Primary Care, Acute General Hospital and SPC services.
- The project will be managed by local medical representatives from Heart Failure services, SPC, Primary Care, Irish Hospice Foundation and HSE.
- The project will be implemented by part-time project officer over a two year period commencing 2009.

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