What is needed to provide a heart failure & palliative care service, who should provide it and what are the challenges?

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What is needed to provide a Heart Failure & Palliative Care service

- **Identify unmet need**
- **National & International guidelines and policy**
- **Acceptance and willingness from health boards to support an approach to care**
  - Improve QoC, QoL and QoEoL care
  - Coordinates care
    - Reduces hospital admissions
    - Reduces length of stay
  - Provide choice for elderly and patients with HF towards EoL
  - Equity of access to palliative care services based on need

- **Pathways of care**
What is needed to provide a Heart Failure & Palliative Care service

Step 1: Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion
- Agreeing care plan and regular review of needs and preferences
- Assessing needs of carers

Step 2: Assessment, care planning and review
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 3: Coordination of care
- High quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 4: Delivery of high quality services in different settings
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 5: Care in the last days of life
- Recognition that end of life care does not stop at the point of death
- Timely verification and certification of death or referral to coroner
- Care and support for carer and family, including emotional and practical bereavement support

Step 6: Support for carers and families
Information for patients and carers
Spiritual care services
Who should provide palliative care for patients with advanced heart failure?
Caring Together Programme

Heart Failure team

General Practice & community teams

Palliative care team
Other Models

Palliative care team

General practice & community teams

Cardiology
Core Components of Care

• Understanding of the approach to care
  – Patient & problem centred care
  – Palliative care can occur in parallel to heart failure
  – Needs based rather than diagnosis or prognosis
  – Being able to predict death is not necessary to manage symptoms
  – Dynamic and responsive triggered by symptoms
Core Components of Care

• Range of expertise within multidisciplinary team
  – Cardiology
  – Specialist Palliative Care
  – Primary care
  – Access to social, occupational & religious services

• Core Skills
  – Heart failure assessment & management
  – Generalist palliative care
  – Communication skills
Core Components of Care

• **Time**
  – Facilitate priorities of care

• **Communication network between 1º and 2º care & collaborative working between cardiology and palliative care**
  – Coordinated care plans
  – Care manager to coordinate care
  – Palliative care register
  – Patient & carer information

• **Provide supportive care through all phases of care**
  – Assessment & management
  – End of life
  – Bereavement

• **Provide coordinated care in different care settings**
Core Components of Care

• *Structured locally* to allow flexibility to fit
  – Local resources, expertise and need

• *Ensure equity of access* to the core components of a heart failure & palliative care integrated service
What are the challenges?
Challenges

• General
  – Financial climate & limited resources
    • Service redesign
  – Integrate & utilise knowledge and skills of two specialities at different ends of spectrum
  – Heart failure managed by cardiologist
    • Mortality & symptom burden similar or worse than many cancers
    • Unacceptable for patients with heart failure to be managed by anyone other than cardiologist and heart failure team
Challenges

• Identification & prognostication
  – Change focus from prognostication of death to identification of ongoing symptoms & “triggers”

• Engagement with integrated approach to care
  – Time
    • Understanding what palliative care means & can offer
    • Palliative care in conjunction with cardiology therapeutic strategies intended to prolong life is appropriate and additive
    • Palliative care available for patients based on need

• Local coordination of core components of care
Challenges

• Improve public awareness of heart failure & perception of palliative care & hospices
  – Specialist care
  – Management of ongoing symptoms
  – Access to financial, social, & spiritual support
  – Option to be involved in end of life care decisions
  – Continue to change negative connotations associated with palliative care and hospices
  – Prioritise investment in public awareness
    • Needs & entitlement of patients with advanced heart failure
    • What palliative care can offer
Challenges

• Managing patient & family expectations
  – Therapeutic strategies become more sophisticated
    • Potentially increasing the ceiling of therapy
    • Definitely increasing patient and family expectations
  – Parallel palliative care and heart failure approach

• Equity of access for other cardiology patients
  – Recurrent ischaemia despite Rx
  – Adult Congenital Heart Disease
  – Recurrent malignant arrhythmias
  – Non-LVSD HF including valvular heart disease
Challenges

- **Patient who cannot attend out-patients**
  - Too sick
  - Geography
  - Social circumstances

- **Collaborative research**
  - Interesting & relevant to both cardiology and palliative care
  - Characterisation cohort of patients & their needs
  - Identification & prognostication – where should the focus lie?
  - Models & methods of care
  - Evaluation of the intervention

Combination factors
Challenges

- Equity of access & delivery of care in different care settings
- Collaborative research
- General
- Identification & Prognostication
- Managing expectations
- Local coordination of core components of care
- Engagement with integrated approach to care
- Public awareness of heart failure
Summary

• **Unmet need** to provide palliative care for patients with heart failure

• **Clear guidance** that palliative care should be provided

• **Hub and spoke model with core components of care**
  – Incorporating service redesign
  – Core components of integrated care structured locally

• **Identify and manage challenges**

• **Equity of access to palliative care services** based on need rather than diagnosis or prognosis