

# End of Life Care for Heart Failure: Challenges and Opportunities

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# Outline of talk

- Why heart failure?
- End of life care for heart failure: challenges
- End of life care for heart failure: opportunities
- Conclusions

# Heart Failure

- Definition:

A complex clinical syndrome with typical symptoms (e.g. dyspnoea, fatigue) that can occur at rest or on effort that is characterised by objective evidence of an underlying structural abnormality OR cardiac dysfunction that impairs the ability of the ventricle to fill with or eject blood (particularly during exercise) Krum, 2006

# Common causes

- Ischaemic heart disease (present in >50% of new cases)
- Hypertension (about two thirds of cases)
- Idiopathic dilated cardiomyopathy (around 5-10% of cases)

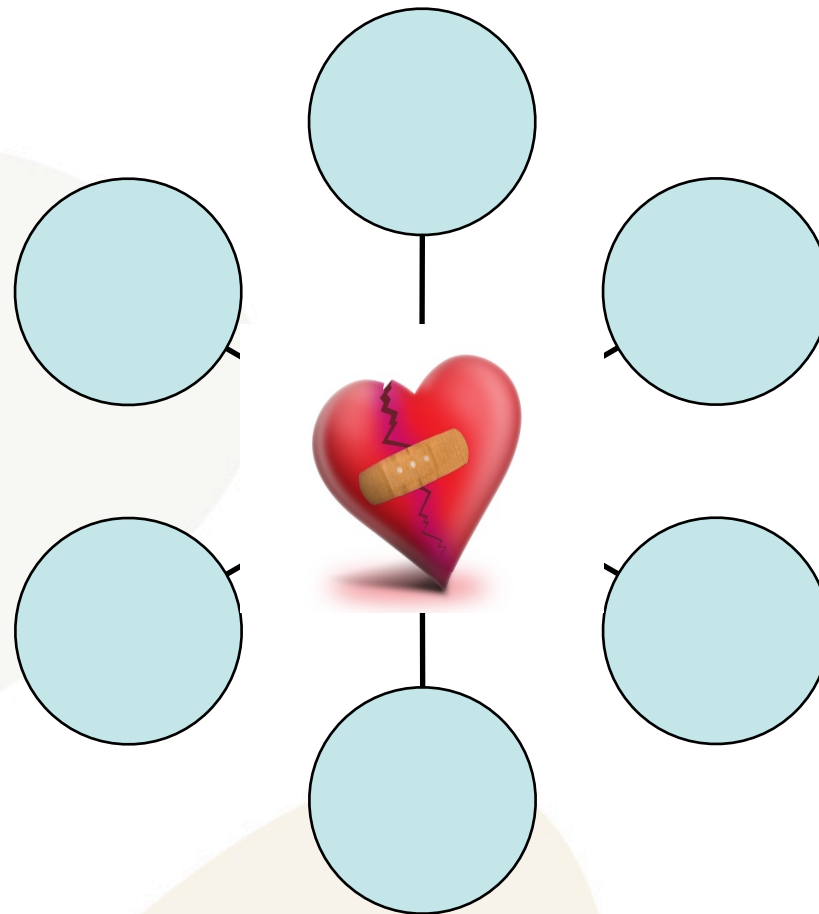
# Epidemic

- Incidence is increasing (affects 1 in 1000 people each year, increasing by 10% a year)
- Prevalence is increasing (over next 20 years expected to rise by 20%)
- Accounts for approximately 5% of all medical admissions

[http://www.dh.gov.uk/en/Publicationsand](http://www.dh.gov.uk/en/Publicationsand%20statistics/Publications/PublicationsPolicyAnd%20Guidance?DH-4094275) statistics?Publications/PublicationsPolicyAnd Guidance?DH-4094275

<http://www.healthcarecommission.org.uk/-/db/-/documents/pushing-the-boundaries.Improving-services-for-patients-with-heart-failure-200707042319.pdf>

# Prototypical palliative care domains



# Palliative care needs

- Physical

SOB, lack of energy, dry mouth, drowsiness, pain Solano, 2006, Blinderman, 2008,

- Psychological

Anxiety, depression Rutledge, 2006, Opasich, 2008

- Social

Social needs may be neglected Clausen, 2005

- Spiritual

Spiritual concerns may be ignored Bekelman, 2007

- Information and communication

Rarely discuss end of life care preferences Selman, 2007, Harding, 2008

# Heart failure pts accessing SPC

- Ireland National Survey O'Leary 2008  
100% response rate  
5-10% of overall activity
- UK national survey Gibbs, 2006  
59% response rate  
Mean number of patients whose main problem was heart failure under a SPC service was 2.2(0-53)

# Mismatch between need and uptake



need



uptake

# Mismatch between need and uptake



need



uptake

# Mismatch between need and uptake



need



uptake

# Challenge of end of life care

- Elderly population with multiple co-morbidities
- Overstated palliative care needs of heart failure patients
- How to measure good end of life care
- Lack of evidence for specialist palliative care in heart failure
- Unpredictable heart failure disease trajectory
- Divergent professional paradigms of care

# Palliative care needs

## Early study limitations:

- Retrospective / chart reviews
- Proxy based assessments
- Heterogeneity of patient selection
- Variable definition and measurement of symptoms
- Ad hoc care rather than current reference standard of care

# HF disease management programme

- Multidisciplinary coordinated care incorporating principles of
  - Patient self care
  - Symptom monitoring
  - Medication monitoring Holland, 2005
- Proven to:
  - Improve life expectancy
  - Improve quality of life
  - Reduce hospital stay Stewart, 2003

# Comparative study

## Aim:

To examine in depth the palliative care needs of patients with advanced heart failure and to compare them with a cohort of cancer patients deemed to have specialist palliative care needs O'Leary, 2009

# Methodology

- Face to face semi-structured interviews
- Qualitative – open ended questions
- Quantitative – validated questionnaires  
NEADL, ESAS, HADS, SF-36
- Ethical approval

# Needs

Both cohorts were statistically indistinguishable for:

- symptom burden
- emotional distress
- quality of life
- satisfaction ratings
- medical and community supports
- information and communication needs

# Valued aspects of care

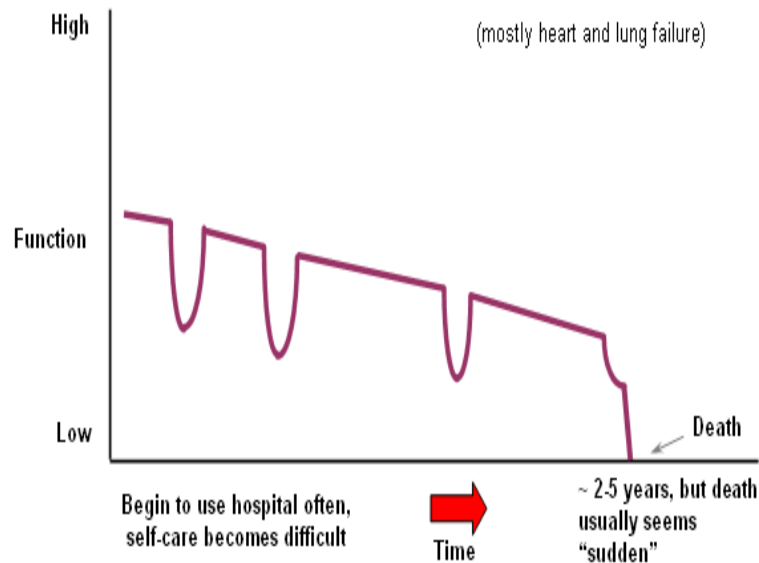
- Close supervision
- Medication monitoring
- Ease of access to service
- Telephone support
- Key worker

# Palliative transition point

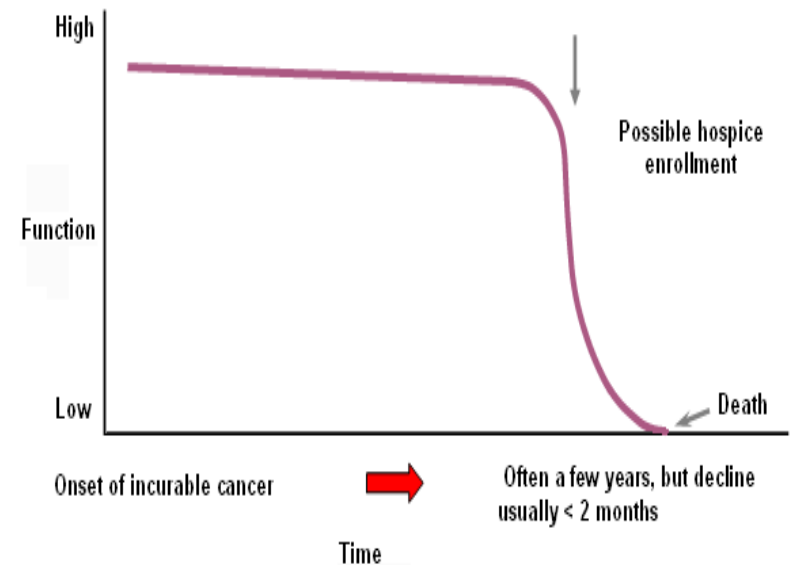
- Deteriorating despite optimum multidisciplinary support
- Increasing fatigue
- Increasing functional dependence
- Low ejection fraction
- Recurring hospitalisations
- Emotional distress
- Carer fatigue
- Patient request

# Challenge – unpredictable trajectory

Organ System Failure Trajectory



"Cancer" Trajectory, Diagnosis to Death



# Palliative transition

Evidence of irreversible and ever declining health status:

- Simple clinical acumen
- Progressive renal dysfunction
- Greater than 5% non-fluid related weight loss (cachexia)
- Escalating diuretic dose requirement

# Palliative Trigger

## Triggers:

- Episode of decompensation within 6 months despite optimal tolerated therapy
- Occurrence of malignant arrhythmias
- Need for frequent or continual intravenous therapies
- Chronic poor quality of life
- Intractable NYHA class 4 symptoms
- Signs of cardiac cachexia Jaarsma 2009

# Position statement from Heart Failure Association of the European Society of Cardiology

## **Stage 1: Chronic disease management phase (NYHA 1-3)**

Goals of care include active monitoring, effective therapy to prolong survival, symptom control, patient and carer education, and supported self management

Patients are given a clear explanation of their condition including its name, aetiology, treatment, and prognosis

Regular monitoring and appropriate review according to national guidelines and local protocols

## **Stage 2: Supportive and palliative care phase (NYHA 3-4)**

Admission to hospital may herald this phase

A key professional is identified in the community to coordinate care and liaise with specialist heart failure, palliative care, and other services

The goal of care shifts to maintaining optimal symptom control and quality of life

A holistic, multidisciplinary assessment of patient and care needs takes place

Opportunities to discuss prognosis and the likely course of the illness in more detail are provided by professionals, including recommendations for completion of an advance care plan

Out of hours services are documented in care plans in the event of acute deterioration

## **Stage 3: Terminal care phase**

Clinical indicators include, despite maximal treatment, renal impairment, hypotension, persistent oedema, fatigue, anorexia

Heart failure treatment for symptom control is continued and resuscitation status clarified, documented, and communicated to all care providers

An integrated care pathway for the dying may be introduced to structure care planning

Increased practical and emotional; support for carers is provided, continuing to bereavement support

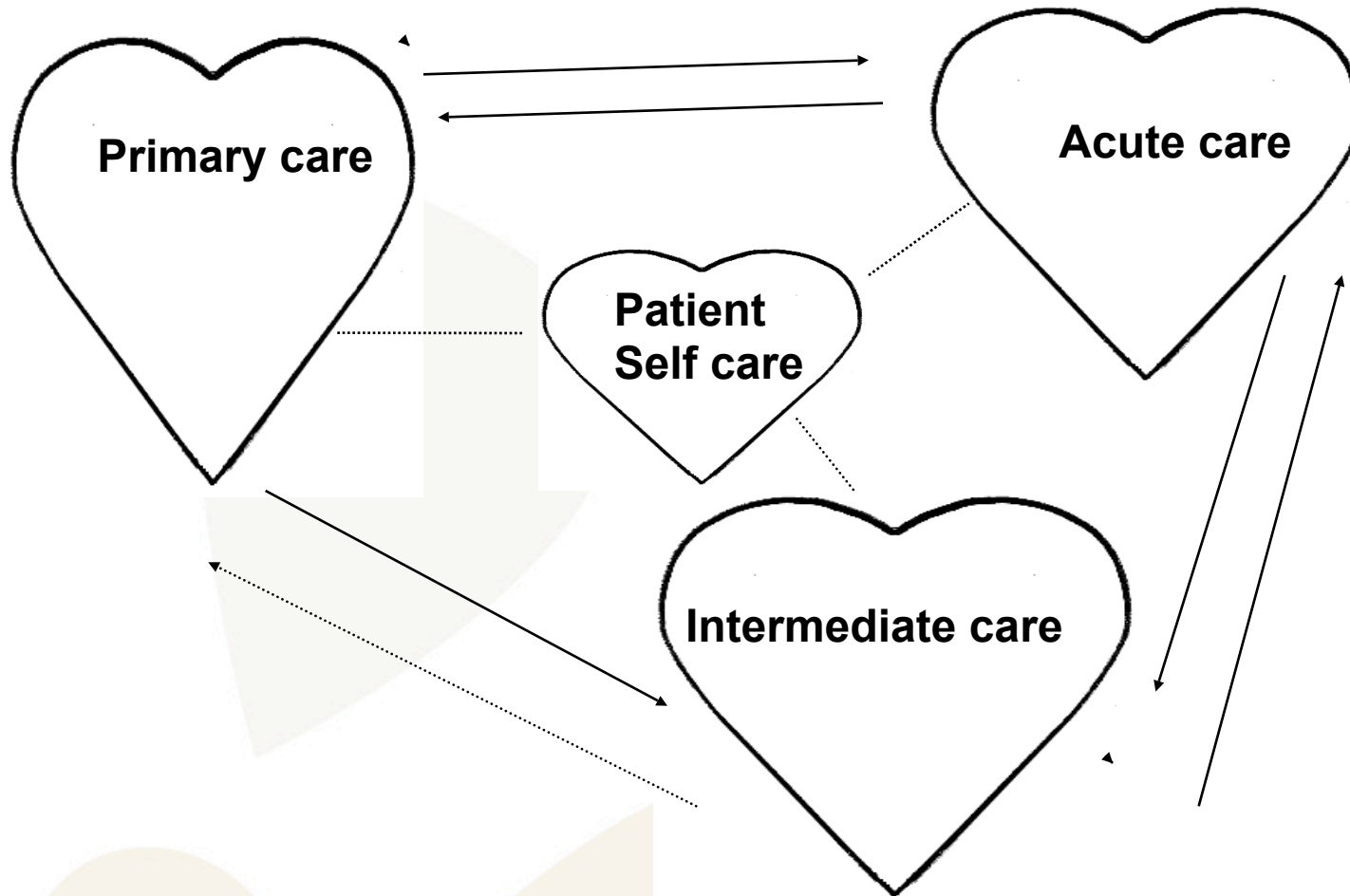
Provision of and access to the same levels of generalist and specialist care for patients in all care setting according to their needs

# Models of palliative care for heart failure



- Heart failure specialist care aligned with palliative care consultancy
- Heart failure-oriented palliative care services

# Heart failure pathway



# Opportunities

- NHS Institute for Innovation and Improvement - Focus on Heart Failure 2009
- Highlight the ideal pathway and key characteristics that optimise quality and value for patients with heart failure

# Challenges



# Opportunities/Challenges

Specialist Palliative Care  
when you need help most



# Conclusions



## Top down

Policy

Strong leadership - Equity of access

Mutual education



## Bottom up

Teachable moment – domino effect

Building good working relationships locally

Heart failure journey – palliative triggers

Thank you

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*when you need help most*

