Palliative care for patients with advanced heart failure

Karen J Hogg
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Overview

• What is the difference in the provision of palliative care for patients with heart failure and cancer?
• Why is palliative care for patients with advanced heart failure so important?
• What happens when we do not consider a collaborative cardiac/palliative approach?
• Barriers
• Drivers for change
• Core components of care
Why is palliative care important?

- **Poor Prognosis**
  - 30-40% patients diagnosed with heart failure are dead within 1 year

- **Ongoing symptoms despite treatment**
  - High symptom burden

- **Complexity of care**
  - Elderly
    - Multiple co-morbidities
  - Rx options increasing in complexity
  - Variety of social care issues
  - Social & family care burden is high

- **Poor understanding about heart failure & its implications**
  - Many patients are not told they have “heart failure” or don’t understand what that means
  - “Expectation gap”
Why is palliative care important?

- Poor Prognosis
- Ongoing symptoms despite treatment
- Complexity of care
- Poor understanding

Uncoordinated care
Why is palliative care important?

- Poor Prognosis
- Ongoing symptoms despite treatment
- Complexity of care
- Poor understanding about heart failure

Uncoordinated care →

- Aspects of care left unmanaged →
  - Poor QoL

Hospital admissions (prolonged) ↔ readmissions →

Death in hospital
Why do we need palliative care?

• Patients with heart failure
  – Inequity of access to palliative care services
    • UK survey of patients receiving palliative care (1997-98)
      – 1094 patients had cardiac disease
      – 62499 patients had a cancer diagnosis
    • The National Council for Palliative Care (2005)
      – “Patients dying of advanced heart failure remain disadvantaged compared to peers with cancer in terms of symptom control, management, communication and access to palliative care support networks”
  – Less likely
    • Involved in health care planning & end of life discussions
    • Access to social and financial supports
    • Placed on palliative care register

Allen et al. JAMA 2008;299:2533-42
Murray et al. BMJ 2002; 325: 929-932
What is the difference in the provision of palliative care for patients with heart failure and cancer?

- Despite poor prognosis
- High symptom burden
- Recurrent prolonged admissions
- Poor QoL
- Complex social needs
- Multi-morbidity
- High carer strain

The provision of palliative care is not routinely offered or provided.
What is the difference in the provision of palliative care for patients with heart failure and cancer?

- **Better understanding** of when the right time is to start a palliative approach when patients have cancer
- **Greater acceptance** from patients and families that palliative care is a part of cancer treatment
What happens when we don’t consider a collaborative cardiology & palliative care approach?

- **CASE 1: YC** (68yr old female)
  - Ischaemic cardiomyopathy with severe LVSD
    - Late presentation MI complicated by VF arrest aged 50
  - Multiple comorbidities
    - Poorly controlled Type 1 DM
    - Hypertension
    - Mild renal impairment
    - COPD (Smoked 40-60 cigarettes per day)
  - Management
    - Shared care local cardiology team, Tx team, HFLN & 1^o^ care team
    - Optimal doses of evidence based medical therapy
    - CRT-D
    - Not for cardiac Tx
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• 8yrs after index event before she had 1st HF admission
• Over the next 3 years
  – 12 admissions with HF (300 bed days)
  – 4 admissions with shocks from device
    • Single shocks deteriorated to multiple shocks
  – Worsening symptoms
    • Struggling with ADL
    • Housebound unkempt and depressed
    • Leg ulcers with recurrent cellulitis
    • Cachectic
  – Symptomatic hypotension & renal impairment
    • Medical therapy reduced
What happens when we don’t consider a collaborative cardiology & palliative care approach?

- **Final admission**
  - Pulmonary oedema and shocks from CRT-D
  - Multiple attempts at central line access
  - IV Frusemide & IV Amiodarone
  - 21 shocks from CRT-D & external defib prior to death
  - Failed attempts at overdrive pacing
  - Anaesthetist was called to discuss admission to ITU
  - Family were not present
  - Died in CCU in the procedures room

- **Discussion with the family**
  - “shocked” – didn’t realise how unwell she was
  - “hospital admissions & shocks from device were signs that this would happen so soon?”
  - “were the shocks prior to death painful?”
  - Issues surrounding the care for her son with learning difficulties
Outcome

• Despite good “cardiology” care
  – Poor QoL
  – Uncoordinated care including towards EoL
  – Uncomfortable & undignified death in hospital
  – Discharges from device hours prior to death
  – Family viewed her predictable death as a “sudden death”
    • Unsupported
    • Many unresolved issues mainly related to
      – Poor planning & communication
Death in hospital

Definitive cardiology decisions

Clinical decline at a ceiling of therapy

- Frequent admissions
- Increasing symptom burden
- Discharges from defibrillator
- Clinically forced reduction in HF Rx
- Anorexia, weight loss & cachexia

Cardiology Therapeutic Strategies

- No early identification
- No clear documentation of ceiling of Rx
- Poor communication & coordination
- Focus on technical care & prevention of death only
- No intervention to improve QoL
- No ACP/device plan
- No autonomy
- No realistic choice for care or EoL care
- No realistic choice for care or EoL care
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• **Case 2: 74yr old male**
  – Secondary prevention ICD following OOHVF arrest
  – Severe LVSD
    • EF 19%, NYHA III, QRSd 104ms
    • Ischaemic aetiology
    • No discharges from device since implant 4 years ago
    • Tolerated good medical therapy
    • Reasonable QoL restricted only by SOB on exertion
    • Good family support
  – Co-morbidities including COPD, DM, RA
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• **Dx with pancreatic Ca**
  – 2 month history of back pain
  – Surgeons – not for intervention
  – Oncology – palliative Rx
    • During his Rx he developed persistent diarrhoea
    • Found attendance at clinic appts impossible
      – 3 DNAs HFLN service: Subsequently discharged from FU
      – DNA 2x device FU – reappointed
      – Routine cardiology clinic - junior member of staff
      – Bloods done from oncology – relative hypokalamia (2.8-3.3)
      – Anorexic and lost weight quickly - cachectic
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• Family called ambulance on the day he died
  – “recurrent fits” which he had been having for the past few days
    • Discharges from his device
    • Died within a few hours of hospital admission in A&E
    • Device was deactivated 7 mins prior to death
    • Last shock was 12 mins prior to death
Lack of early identification → Poor inter-specialty communication

Restrictive system policies (DNA) → Failure to plan (MACP, device)

Uncoordinated care → Death in hospital & unnecessary shocks prior to death
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• **Case 3: 81yr old female**
  – Moderate – severe LVSD
  – Secondary prevention CRT-D (defibrillator)
  – Severe mitral regurgitation
  – Moderate COPD
  – DM, IHD, AF, anaemia, CKD III, arthritis
  – Limited mobility & housebound
  – 12 admissions over past 18 months with HF
What happens when we don’t consider a collaborative cardiology & palliative care approach?

- **Final admission**
  - Heart failure
    - Slow progress with fairly aggressive medical Rx
  - Complicated
    - LRTI and subsequent acute on chronic kidney injury
    - CVA with left hemiparesis
  - Progressively declined
    - Worsening renal function
    - Spending increasing time asleep
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• Clinical plan
  – Ward doctor spoke with family
    • Patient was dying and would be for symptom Mx
    • Aim now was to keep her comfortable
  – Patient’s defibrillator was deactivated
  – DNACPR form was completed
  – Daily ward rounds by ward team and 2x weekly consultant ward rounds
  – Remained comfortable and died peacefully overnight
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• **Outcome**
  – Patient died 21 days later in hospital
  – Family expedited a formal complaint
    • Relative had been starved to death
    • They felt traumatised “we were told that our mother was dying but they were wrong she lived for weeks”
    • “Once we were told she was dying nobody spoke to us and nobody did anything”
    • “I don’t think the doctors even saw her anymore, just the nurses”
    • “We were avoided, nobody came near us, we had to approach the nurses for information”
    • “If my mum had known she was dying she would not have wanted to die in hospital”
No early identification

No ACP/device plan

No preferences & priorities of care

Poor management of prolonged dying

No management of patient and families expectation

No mechanism at ward level for “information rounds”
What happens when we don’t consider a collaborative cardiology & palliative care approach?

**Case 4: 84yr old male**

- Chronic HF with moderate LVSD
- 2° prevention ICD following VF arrest 15yr ago
  - No therapies since implant
  - Generator change 5 years ago
  - Sub-pectoral generator due to general weight loss
  - Regular follow up with cardiac physiologist
- 1 year ago admitted to NH due to worsening dementia
  - Issues regarding transport to attend for ICD checks
  - Medical review due to concerns about a prominent lead
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• Listed & admitted for elective generator change
  – Towards the end of the list
  – Admitted after the team had gone down to theatre
  – On the ward for most of the day
    • Fasting
    • Disorientated & agitated
    • Family distressed to see father upset
What happens when we don’t consider a collaborative cardiology & palliative care approach?

• Outcome:
  – Procedure cancelled
    • Active ICD was no longer in his best interests
  – Patient given a sandwich which he didn’t eat and water which he threw on the floor
  – Transferred back to the NH
  – GP called due to level of agitation
  – Family submitted a formal complaint
    • “why was this decision not made earlier?”
• Early identification changing circumstances

• ACP, device plan or ceiling of therapy

• Unnecessary transfer from NH for a procedure not required
• Unnecessary stress and upset for patient & family
• Complaint
Without a collaborative cardiology & palliative care approach

- No planning or pathways of care
- No cardiological & holistic assessment for patients and families
- No planning or pathways of care
- Death in hospital
- Bereavement care

- Poor understanding of palliative care & no mechanism for identifying patients with palliative care needs
- General lack of engagement with the process

Progressive deteriorating condition with an unpredictable trajectory
What is missing?

- Provision of integrated cardiology and palliative care

“Palliative care should be integrated in all settings and by all hospital specialties”

WHO 2014
Barriers

Unmet need for end of life care in heart failure

“Discomfort was not necessarily greatest in those dying from cancer; patients dying of heart failure, or renal failure, or both, had the most physical distress”

Hinton JM. The physical and mental distress of the dying. QJM 1963;32: 1-21
Barriers

- Terminology
  - End of life care
  - Palliative care
  - Supportive care
  - Terminal care
  - Care of the dying
BARRIERS

Cardiology perspective:

• Only appropriate for patients
  – Cancer
  – Facing imminent death where the time lines are clear
    • We have to know when patients are going to die

• Impact on HF treatments
  – De-escalation of medical Rx
  – Deactivation of device therapy
  – Not for any further escalation of Rx

• Focus is very much about death

• Difficulty with prognostication
  – “When is the right time?”
Barriers

Onset of incurable cancer

Time

Functional status

Good

Poor

Increased need for palliative care services

Death

Time to plan

Adapted from Murray, S. A et al. BMJ 2005;330:1007-1011
Understanding what palliative care means & identification of patients with palliative care needs

“The physician who can foretell the course of the illness is the most highly esteemed”

Hippocrates

D = clinical decompensation

Sudden cardiac death

Intervention: CRT

Death

Adapted from Murray, S. A et al. BMJ 2005;330:1007-1011
Drivers for change and what’s new
Drivers for change

• The National Council for Palliative Care (2005)
  – “Patients dying of advanced heart failure remain disadvantaged compared to peers with cancer in terms of symptom control, management, communication and access to palliative care support networks”

• WHO 2007
  – “Palliative care should be accessible for malignant and non-malignant disease”

• WHO 2014
  – Palliative care should be integrated in all settings and by all hospital specialties
ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012

The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology

Developed in collaboration with the Heart Failure Association of the ESC

Authors/Task Force Members: John J. V. McMurray (Chairperson) (UK), Stamatis Adamopoulos (Greece), Stefan D. Anker (Germany), Angelo Auricchio (Switzerland), Michael Böhm (Germany), Kenneth Dickstein (Norway), Volkanar Falk (Switzerland), Gerasimos Filippatos (Greece), Cândida Fumara (Portugal), Miguel Angel Gomez-Sanchez (Spain), Tiny Johanna (Sweden), Lars Kober (Denmark), Gregory Y.H. Lip (UK), Aido Pietro Maggioni (Italy), Alexander Parhamenok (Ukraine), Bernhard M. Pieske (Austria), Bogdan A. Pepine (Romania), Per K. Rennevik (Norway), Frans H. Rotten (The Netherlands), Jurgen Schwitter (Switzerland), Petar Seferovic (Serbia), Jozina Stojkovic (Poland), Pedro T. Trindade (Switzerland), Adrian A. Yous (The Netherlands), Andreas Zeiner (Germany).

ESC Committee for Practice Guidelines (CPG): Jeroen J. Bax (Chairman of the ESC) (The Netherlands), Robert Beagle (Belgium), Christian de Backer (France), David Debacker (France), Helmut Engeli (Switzerland), Martin Engeli (Switzerland), Jan Fagard (Belgium), Christian Funck-Brentano (France), David Haddad (France), Cyril Mailleau (France), Bogdan A. Pepine (Romania), Zoltan Prach-Torres (Elizabeth), Vito Stefanelli (Italy), Per-Arne Slemroth (Norway), Michael Tasko (Poland), Adam Tawil (Poland), Ali Vasisht (UK).
Priority 5: Heart Failure

Aim:  To improve the journey of care for patients with heart failure by developing a whole system approach to the delivery of care.

Background:  Heart Failure services are generally progressing well across Scotland despite some residual difficulties in relation to resources. However, as the incidence of heart failure rises in line with the aging population the impact on individuals and the healthcare system is becoming increasingly problematic. Improvement in the quality of care and implementation of readily accessible treatment throughout the patient journey would greatly increase patients' quality of life with associated efficiencies for healthcare system.

In addition, there is an increasing body of evidence that patients with heart failure have similar or worse symptoms burden, morbidity and mortality compared to patients with cancer. Patients with cancer have well developed, formalised palliative care services provided by appropriately trained staff to address their needs. Despite the obvious equivalent need, patients with heart failure do not. There is clear national and international policy and guidelines all stating that palliative care should be provided for patients with advanced disease including heart failure. Although many areas around Scotland are now making significant progress in relation to developing palliative care and anticipatory care planning for patients with heart failure, we still have a long way to go.

Actions:
1. Improve identification, diagnosis and long-term management of patients with heart failure.
2. Improve patient centred flow into, through, between and out of hospital.
Drivers for change

Caring Together Programme
Better end of life care for patients with heart failure

National Heart Failure & Palliative Care Clinical Education Programme
Core components of care

- Understanding what palliative care means & early identification
- Cardiology, holistic assessment & management
- Coordination of care & communication: MDT working, planning & pathways of care
- Education & Research

Patient centered care
Core components of care in practice

Identification

• Case 6: 72yr old male
  – Severe aortic stenosis and LVSD
  – Previous pneumonectomy for lung cancer
  – Prostatic carcinoma
  – AF, IHD, CRT-D
  – Referred for TAVI and rejected on basis of lung Ca
  – Referred for AV balloon valvuloplasty
    • Complicated by AV endocarditis & subsequent severe AI
    • Recurrent hospital admissions with pulmonary oedema and sepsis
Core components of care in practice

Identification

• Over the next 3 months at a ceiling of therapy
  • Maximal tolerated medical Rx
  • Not for TAVI
  • Following BAV resulting in severe AI
• **6 hospital admissions to cardiology**
  • Pulmonary oedema and sepsis
  • 5 cardiologists (not including those related to TAVI)
  • 84 bed days (*92% of total time in hospital*)
  • Reducing Ex tolerance and ability to carry out ADLs
Core components of care in practice

Identification

- Discharge home following 6\textsuperscript{th} admission:
  - Simple standard discharge letter with minimal useful information
  - No definitive decisions
  - No planning or discussion with GP
  - No OT or home assessment (patient lives in a flat)
  - No consideration of the palliative care needs or any needs of the patient and his family
  - No discussion or documentation of patient’s preferences of care
  - No anticipatory care planning or out of hours consideration
  - No management plan to manage his inevitable symptoms or CRT-D
Core components of care in practice

Identification

• **Outcome:**
  – Patient was readmitted to hospital within 72 hours of discharge with pulmonary oedema
  – Admitted for a further 21 days
  – Discharged as his last admission

  • *Simple standard discharge letter with minimal useful information*
  • *No definitive decisions*
  • *No planning or discussion with GP*
  • *No OT or home assessment (patient lives in a flat)*
  • *No consideration of the palliative care needs or any needs of the patient and his family*
  • *No discussion or documentation of patient’s preferences of care*
  • *No anticipatory care planning or out of hours consideration*
  • *No management plan to manage his inevitable symptoms or CRT-D*
Cardiology Therapeutic Strategies

No early identification

Ceiling of treatment
Recurrent hospital admissions
Increasing symptom burden despite optimal Rx
Anorexia, Wt Loss, Cachexia

Death in hospital
WHO Definition of Palliative Care

• Palliative care is an **approach**
  – **improves the quality of life of patients and their families** facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of **early identification** and impeccable **assessment and treatment of pain and other problems, physical, psychosocial and spiritual**

• provides relief from pain and other distressing symptoms

• intends neither to hasten or postpone death

• offers a **support system to help patients live as actively as possible until death**

• offers a support system to help the family cope during the patient’s illness and in their own bereavement

• uses a **team approach to address the needs of patients and their families**, including bereavement counselling, if indicated

• will **enhance quality of life**, and may also positively influence the course of illness

• is **applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life**, and includes those investigations needed to better understand and manage distressing clinical complications.
"Cure then care model"

"Integrated care model"
Identification of patients with palliative needs
Where could we have identified this patient?

72yr old male
Severe AS
BAV - Mod-Severe AI
Endocarditis
Recurrent pulmonary oedema

Heart Failure Treatment
Palliative Care
Symptom triggers & Hospitalisations

Time
Death
What are the main principles of identification of patients with palliative care needs?

- Optimal or near optimally tolerated heart failure therapy
  - No significant disease modifying options
- Ongoing symptoms and or hospitalisations
- Other complex issues
- LVSD or Non-LVSD

In due course palliative care scoring mechanism may be developed
- Needs based assessment
# Early identification of palliative care needs

**Will not**

- Stop active treatment or access to appropriate treatments
- Focus on death

**Will facilitate**

- Open & honest conversations
- Interventions to improve QoL
  - Managing symptoms
  - Supports for patient & family
- Anticipatory care planning
  - MACP/ Device plans
- A focus on living and QoL whilst preparing for an unknown time between now and death to improve QoC at that time
**CORE COMPONENTS OF CARE: ASSESSMENT**

EARLY IDENTIFICATION LVSD or Non-LVSD HF patients: Refer using SCI gateway/email

| GP | HFLN | GIM | COTE | CARD | AHFU | ACHD |

**ASSESSMENT**

![Cardiologist](cardiologist.png) \[\rightarrow\] **HF & PC specialist nurse**

- **HF management optimised**
  - Medical Rx: ACE-I/ARB, BB, MRA, S/V
  - Rhythm management and device therapy
  - Consideration of cardiac Tx
- **Fluid balance: diuretic adjustment**
- **Symptom management:**
  - Cardiac and non-cardiac
- **Holistic assessment for patient and carer**

**Additional supports**

- Long term conditions & finance
- Spiritual care
- Clinical psychology
- SPC
- Day services hospice
  - Breathlessness
  - Fatigue
  - Anxiety
  - Depression
  - Physio & OT
  - Alternative therapies
  - Patient & support grps
HEART FUNCTION & SUPPORTIVE CARE SERVICE

IDENTIFICATION

GP  HFLN  GIM  COTE  CARD  AHFU  ACHD

ASSESSMENT

Cardiologist  HF & SC specialist nurse  Finance & Benefits

INTEGRATED & COORDINATED CARE

Integrated HF&SC approach

COMMUNICATION & PLANNING

Case Manager  Care Plans  Network of care
An approach to care
“Coordination & communication

- Following assessment all patients will have:
  - **Tailored care plan**
    - HF Management plan
    - Medical Anticipatory care plan (MACP)
  - **Case manager**
    - HFLN for LVSD
    - HF&PC specialist nurse for non-LVSD
  - **Network of care “communication hub”**
    - Primary & secondary care teams
  - **Pathways of care**
    - Managing inevitable decline
    - Defibrillator deactivation
# Medical Anticipatory Care Plan

## Caring Together: Medical Anticipatory Care Plan

**Caring Together Programme**

**DEPARTMENT OF MEDICAL CARDIOLOGY**

Heart Function and Supportive Care Clinic

Glasgow Royal Infirmary

Level 3

Walton Building

84 Castle Street

Glasgow G4 0SF

**Consultant:**

Dr Karen J Hogg

### Caring Together Medical Anticipatory Care Plan

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<th>Patient and Main Carer Details</th>
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**Care Manager Details:**

**Diagnosis List:**

**Current Medications:**

**Changes to medications**

**Medications to stop:**

**Medication Intolerance:**

**Device details:** Applicable / Not applicable

**Medical and Symptom Management Considerations:**

### Priorities of Care

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### Current Place of Care:

**Preferred place of care:** 1.

### Medical Status if appropriate:

**DNA / CPR Status:**

**Intensive Care Referral:** Not Appropriate

**General line access:** Not Appropriate

**Appropriate maximal medical therapy:**

- Intra-aortic balloon Pump (ABP): Yes / No
- IV Inotropes: Yes / No
- IV Diuretics: Yes / No
- SC Diuretics: Yes / No
- Oral medications: Yes / No

Transfer to hospital in the event of acute deterioration (specify if at all possible)

### Key Professional Services Currently Involved:

**NAME:** Consultant Cardiologist GRI

**NAME:** Care manager

**NAME:** Other Consultant

### Key Professional Services to be considered if condition or situation changes:

### Significant Conversations

**Patients Understanding of current situation:**

**Carers Understanding of current situation:**

### Helpful/Emergency Contact Numbers:

**Cardiology GRI:**

**NHS 111:**

**DN:**

### Consent

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Medical Anticipatory Care Plan

**Patient ACP**
- Patient held & led document
- Documents patients’ priorities of care

**Medical ACP**
- Led by healthcare professional in conjunction with patient
- Designed to guide patient care in different care settings in context of patients’ priorities of care
<table>
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<th>Summary medical history</th>
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<td>Current &amp; anticipated Medical, Device &amp; Symptom management plan</td>
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- Type of device
- VT burden & programming
- ATP v shocks
- Deactivation plan if appropriate
- Generator change policy
- Contact details

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*Note: The table contains information specific to medical history and care management, including patient details, care manager information, and emergency contact numbers.*
Medical Anticipatory Care plans match preferred place of care & reduce hospital admissions

K Hogg & SMM Jenkins
Medical Anticipatory Care Plans prevent hospital admissions
European Heart Journal (2012) 33 (Abstract supplement) 483-484
Outcomes from use of MACP

• Reduction in hospital admissions & length of stay
• Matched PPC/D:APC/D
• Patients and families found the MACP
  – Helpful
    • Coordination of care, initiation & completion of difficult conversations
  – Did not find the conversations distressing
  – Appropriate post conversation support
  – Promoted patient autonomy with realistic care choices
• GPs/DN/HFLN/Paramedical staff
  – Helpful medical & decision making guide to facilitate good supportive & EoL care
  – Corner stone to the development & functioning of the network of care
Pathways of care

- Integral component of coordination of care
- Dovetail into the care plans
- Provide
  - Clear direction of care
  - Ensure what should be done, is done regardless of the underlying knowledge of the disease process
- Provide a means to compare current practice against
Pathways of care

Deteriorating patient at a ceiling of Rx

Device Deactivation pathway

Hospital inpatient care

Secondary care supported community care
PATHWAYS OF CARE:
Progressive disease & symptom decline

HOSPITAL BASED REACTIVE CARE

PROACTIVE INTEGRATED COMMUNITY CARE

DECLINE

TRIGGERS

WHO TO CONTACT & HOW
(direct access)

HOME

CARE HOME

PROVIDE SPECIALIST HEART FAILURE & HOSPICE ENABLED CARE IN DIFFERENT SETTINGS

HOSPITAL

HOSPICE

WHAT YOU OFFER HAS TO BE REALISTIC & APPROPRIATELY SUPPORTED
**Heart failure & symptom Mx plan**
- Breathlessness, nausea, anxiety
- Constipation
- Peripheral and abdominal oedema
  - High dose oral & SC diuretics
- Generalised pain
- Skin management

**Planning & coordination**
- Ceiling of treatment
- Preferences & priorities of care
- DNACPR documentation
- Device deactivation plan
  - ICD deactivated at home
  - CRT remained active
- Palliative care register
- Case manager
- Network of care

**Communication**
- Emergency contact numbers
- Clinical portal
- Out of hours
Overall outcome

• After his 7th discharge & referral to the service
  – Lived for a further 4 months
  – No further hospital admissions
    • Previous 3 months in hospital most of the time
    • There were medical issues which were managed within the network of care to provide care at home
  – Coordinated care with supported care choices
    • Comfortable and dignified time at home with family
    • Family felt supported to cope with his decline and death at home
  – Bereavement care for his family following his death
• **Identify** patients based on their needs rather than specific prognosis

• **Improves QoL and QoC**
  - Symptom management
  - Holistic care and support
  - **Coordinated care & communication**
  - Financial & legal **support**

• **Planning** regardless of unpredictability

• Promotes supported patient autonomy

• **Realistic choice** for care & EoL care
“The components of cardiac palliative care are not difficult but changing practice is...........”
Summary

• **Who to identify?**
  – Heart failure (LVSD or non-LVSD)
  – Ongoing symptoms and/or hospitalisations despite optimal or near optimal therapy

• **How to refer?**
  – SCI gateway
    • Marked for my attention (in bold), note palliative (bold)
    • Email
    • Telephone my secretary
Summary

• What will we do?
  – Cardiology & holistic assessment of patient & family
  – Identify case manager
  – Develop patient specific care plan/MACP
  – Direct contact details
  – Greater flexibility for review as needed
  – Secondary care integration with primary care
    • Help support end of life care in the patients’ preferred place of care based on needs rather than specific prognosis
What do we want to achieve?

Early identification based on needs

Core components of HF&PC care provided by specialist HF enabled integrated community care teams

Realistic care choices

Improved QoL

Joint medical anticipatory care planning

Good EoL care
# What do we want to achieve?

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