End Stage Heart Failure

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PAH HFS

Heart Failure

- Chronic, progressive disease – major contributor to morbidity and mortality world-wide\(^1\)
- Most common cause of admissions in those >65 years\(^1\)
- QOL often worse than those with other chronic disease\(^2\)
- Cluster of symptoms and debilitation which worsens with each hospitalisation\(^3\)
- 38% die within 1 year of diagnosis and 60% die within 5 years\(^4\)

1. Stewart et al. 2010 Population impact of heart failure and the most common forms of cancer. Circ Cardiovasc Qual Outcomes
4. NHS Information Centre. National Heart Failure Audit 2010
HF Terminology based on LVEF.

- **HFrEF** – Heart Failure with Reduced Ejection Fraction
  - EF < 50%
  - Clear evidence of improved morbidity and mortality with evidence based therapies

- **HFpEF** – Heart Failure with Preserved Ejection Fraction
  - EF > 50%
  - Increased filling pressures
  - Increased Ventricular wall thickness


Proportion of HFrEF and HFpEF

Steinberg et al. Circulation 2012;126:65–75
Prevalence of heart failure in Australians aged ≥ 45 years

Estimated Burden of Heart Failure in Australia

AUSTRALIANS AFFECTED BY HEART FAILURE

Current Burden (2013)

<table>
<thead>
<tr>
<th>Metric</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Australians aged ≥ 45 years with an advanced form of HF (HF with reduced ejection fraction [HFrEF])</td>
<td>476,382</td>
</tr>
<tr>
<td>Number of HF related emergency hospitalisations per annum</td>
<td>147,347</td>
</tr>
<tr>
<td>Total days in hospital</td>
<td>1,006,113</td>
</tr>
<tr>
<td>Cost of in-patient care per annum</td>
<td>$1.82 billion</td>
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<tr>
<td>Cost of community care per annum</td>
<td>$567 million</td>
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<tr>
<td>Total health care expenditure</td>
<td>$2.68 billion</td>
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Planning for future (2020)

<table>
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<tr>
<th>Metric</th>
<th>Value</th>
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<tbody>
<tr>
<td>Projected number of Australians aged ≥ 45 years with an advanced form of HF (HFrEF)</td>
<td>582,366</td>
</tr>
<tr>
<td>Projected total health care expenditure</td>
<td>$3.76 billion</td>
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Ahamed et al. 2015 Rediscovering Heart Failure Summit Report and Recommendations
Highly Malignant Condition


Pathophysiology

- Disabling and ultimately fatal syndrome characterised by maladaptive compensatory mechanisms:
  - neuroendocrine activation
  - cytokine activation
  - salt and water retention,
  - progressive multi-organ failure

HF Treatment

- Designed to counteract the Maladaptive Compensatory Mechanisms

- Irrefutable prognostic evidence of the benefit of HF medical therapy
  - ACE I, B-Blockers, MRA(Spironolactone)
  - These drugs also alleviate symptoms, reduce hospitalisations and improve QOL

- Diuretics important throughout trajectory by alleviating peripheral oedema and preventing pulmonary oedema

- ICD (Defibrillator) and CRTD (pacemaker/defibrillator) reduce mortality and improve symptoms (CRTD)

- Co-morbid conditions adequately treated
  - Reversible causes of HF identified and treated

Gadoud et al 2013 Palliative Medicine 27(9):822-829
HF Treatment

Effect of Adding Medications/Devices

Survival

Years

0 1 2 3 4 5

+ ICD

+ Aldo Blocker

+ β Blocker

+ACEI

Baseline

Trajectory of heart failure

• Characterised by periods of stability with episodes of decompensation
• 79.5% patients have a gradual progression
• Sudden death can occur at any stage
• Patients co-morbidities affect the trajectory
• Unique to each individual

Mortality

- 50% of deaths sudden (less severe stages)\(^1\)
  - Arrhythmias / ischaemic events
  - Reported to have had good QOL in month prior to death
- 10-20% die within 30 days of diagnosis\(^2\)
- Chronic HF deaths 50% at 4 years\(^2\)
- Progressive pump failure most common in advanced HF\(^1\)
  - Disabling symptoms similar prevalence to Ca
  - Fatigue, breathlessness, limited mobility, social isolation, poor QOL, complex medication regimen, significant impact on family / caregivers

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What do we know???

- There is a significant Burden from HF to individuals and the community
- Current treatments work but……..

People *eventually* Die from HF

- Significant symptom burden toward end of life
- Difficult to determine when people will die

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Prognostication and HF

- Extremely Difficult\(^1\)
  - Most prognostic indicator tools have not been found to be useful
  - BNP measurement has greatest prognostic potential

- NYHA Classification major gauge of disease severity – 1 year mortality estimates\(^2\)
  - Class II 5-10%
  - Class III 10-15%
  - Class IV 30-40%

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1. Gadoud et al 2013 Palliative Medicine 27(9)822-829
Variables associated with mortality

- Worsening LV dysfunction despite therapy
- Cardiac Hospitalisation - *triples 1 year mortality*
- Frequent re-admissions
- Failure to respond to / Intolerant of therapies (B-blockers ACE I) - *increased 4 month mortality*
- Cachexia
- End organ failure
- Frequent life threatening arrhythmias resistant to Rx
- Elevated creatinine & urea
- Hyponatraemia
- Anaemia – *16% increase in mortality*
- Systolic BP < 100 and Pulse >100 - *doubles 1 year mortality*
- Orthopnoea
- Multiple co-morbidities
- Terminal cancer

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**ESHF Non-Acute Care Management  Patient Identifiers**

| Identifiers of Patients with End Stage Heart Failure ¹ |  
|---|---|
| 1. Patient with NYHA class IV Heart Failure consistently – (Unable to carry on any physical activity without discomfort. Symptoms of CHF present at rest, “severe CHF”)* | ☐ |
| **And** |  
| 2. Not suitable for any further procedural interventions (eg. revascularisation with coronary bypass surgery, coronary angioplasty, valve surgery, BIV pacing or cardiac transplantation). | ☐ |
| **Plus, meets at least one of the criteria below** |  
| 3. Increasing heart failure symptoms despite maximum tolerated heart failure therapy including diuretics, ACE inhibitors and beta-blockers, as indicated. | ☐ |
| 4. Worsening or irreversible end organ damage (including cardiac cachexia). | ☐ |
| 5. Repeated hospital readmissions with deteriorating heart failure, ventricular arrhythmias or cardiac arrest. | ☐ |

¹ New York Heart Association (NYHA) Classification for Congestive Heart Failure cited in National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand. Guidelines for the prevention, detection and management of chronic heart failure in Australia, 2006; 11.

The Surprise Question: “Would you be surprised if this patient died within the next 12 months?” ²

² Murray et al 2011. Using the Surprise Question can identify people with advanced heart failure and COPD who would benefit from a palliative approach Palliative Medicine

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Marks et al 2015 Palliative Care Network Wisconsin [www.mypcnow.org](http://www.mypcnow.org)
Palliation

- **Palliative care:**
  - approach that improves 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

  World Health Organization

- **Extra layer of support**

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**Model for Palliative Care**

Not Quite!

- WHO recommends PC early in the course of the illness
- Difficulties with “Too Early or Too Late” referrals
  - Average time from PC referral to death - 21 days
- Less than 10% of patients with HF receive palliative care
- Less than 12% of US hospice admissions for HF patients

1. Gelfman et al 2014 Engaging Heart Failure Clinicians to increase palliative referrals: Overcoming Barriers, Improving techniques. Journal of Palliative Medicine
2. NHPCO Facts and Figures 2012 Hospice Care in America. National Hospice and Palliative Care Organization

Barriers to Palliative care for HF - Clinicians

- Unsure of how to discuss prognosis and unpredictable course
- Fear of destroying hope
  - “Prognostic Paralysis” - conversations don’t happen
- Medical Model focussed on prevention of death
  - Don’t want to seem to have “failed” “lost the patient”
- Lack of understanding of palliative approach
  - Belief this is just for “end of life”
  - How to effectively collaborate
- Lack of clear responsibility

Ziehm et al 2016 Palliative Care for patients with heart failure: facilitators and barriers – a cross sectional survey of German health care professionals BMC Health Services Research 16:361
Lindahl et al 2014 Overcoming Barriers to Palliative Care Referral for Patients with Advanced Heart Failure. Journal of the American Heart Association
### Barriers to Palliative Care for HF – Patient / Family

- Belief HF Benign condition
- Patients and their families are insufficiently informed of the terminal nature of their condition
- Wish to focus on active ongoing treatment
- Rollercoaster like trajectory where there are numerous “Saves”
- No other alternative than to access hospital care for poorly controlled symptoms
- Do not wish to discuss end of life issues

### Barriers to Palliative Care for HF – System

- Funding Model
- Lack of specialist palliative care resources
- Funding Model
- Silo approach to health care
- Funding Model
Potential of PC and HF

- Evidence base still in development for PC and HF but…….
- Likely to improve clinical outcomes
  - Improve pain
  - Improve symptom control
  - Clarity of goals of care
  - Guiding Rx decisions to meet the goals

Gelfman et al 2014 Engaging Heart Failure Clinicians to increase palliative referrals: Overcoming Barriers, Improving techniques. Journal of Palliative Medicine

Hope for the best, plan for the worst

Proposed Model

- Collaborative management of the patient by HF and PC specialist teams
- PC team treats symptoms, offers emotional support
- HF team continues evidence based therapies and treats exacerbations
- Jointly engage in “Goals of Care” and “End of Life” discussions

Gelfman et al 2014 Engaging Heart Failure Clinicians to increase palliative referrals: Overcoming Barriers, Improving techniques. Journal of Palliative Medicine
Issues

- Assessment
- Symptom Management
- Clarifying EOL choices
  - where? how? what to expect?
- Supporting Family

Symptoms

- Patients with heart failure have:
  - symptoms as severe and distressing as those of cancer patients
  - multiple symptoms requiring frequent, ongoing assessment and evaluation of interventions

Beemster et al. 2013, Referral to Palliative care in COPD and other chronic diseases: A population based study. Resp Med
Approach

- Same approach to symptom management as for all PC patients

<table>
<thead>
<tr>
<th>Physical</th>
<th>Psychological</th>
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<tbody>
<tr>
<td>Pain assessment</td>
<td>Depression*</td>
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<tr>
<td>Dyspnoea</td>
<td>Reflection on life and events</td>
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<tr>
<td>Nausea</td>
<td>Delirium**</td>
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<tr>
<td>Anorexia</td>
<td>Confusion</td>
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<tr>
<td>Functional impairment</td>
<td>Fear and anxiety***</td>
</tr>
<tr>
<td>Bowel and bladder function</td>
<td>Concerns for future</td>
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<tr>
<td>constipation</td>
<td>Quality of life****</td>
</tr>
<tr>
<td>Odour</td>
<td>Cultural significance of death and dying</td>
</tr>
<tr>
<td>- consider presence of ascral edema due to immobility</td>
<td>Cultural requirements for management of death</td>
</tr>
<tr>
<td>- Assess for potential drug effects (eg, diprosim toxicity)</td>
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<tr>
<th>Social</th>
<th>Emotional</th>
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<tbody>
<tr>
<td>Financial status</td>
<td>Depression*</td>
</tr>
<tr>
<td>Abuse</td>
<td>Reflection on life and events</td>
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<tr>
<td>Life change</td>
<td>Delirium**</td>
</tr>
<tr>
<td>Ability to self care</td>
<td>Confusion</td>
</tr>
<tr>
<td>Adherence with lifestyle</td>
<td>Fear and anxiety***</td>
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<tr>
<td>recommendations</td>
<td>Concerns for future</td>
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<tr>
<td>Fear for dependents</td>
<td>Quality of life****</td>
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<td>Care burden</td>
<td>Cultural significance of death and dying</td>
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<tr>
<td>Place of death</td>
<td>Cultural requirements for management of death</td>
</tr>
<tr>
<td>Current advance care directive</td>
<td>Cultural significance of death and dying</td>
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</table>

Davidson et al 2010 CHF in general practice Australian Family Physician

Assess history of presenting condition

- Not a physical assessment but helps to target what you are looking for
  - Breathing
    - NYHA (functional)
    - Orthopnoea / PND
  - Pain
    - Chest pain
    - other
  - Appetite
  - Dizziness light headedness
    - When does it occur
Fluid intake
Salt intake
Medication compliance
Daily Weight
- Loss / gain

Functional Assessment NYHA

- Class I
  - No symptoms with ordinary activity
- Class II
  - Symptoms with ordinary activity
- Class III
  - Symptoms with less than ordinary activity
- Class IV
  - Symptoms with any physical activity or at rest
Functional Assessment –

- PND / Orthopnoea - How many pillows are you sleeping on?
  - Is this usual for you?
  - Has there been a change to this recently?
- Do you wake at night feeling short of breath?
  - Does this make you sit up out of bed to get your breath back?

Assessment – Dyspnoea

- Physical assessment and identification of congestion
- Respiratory Exam
  - Position the patient upright sitting / standing
  - Listen over one spot and then move the stethoscope to the same position on the opposite side and repeat.
    - This makes use of one lung as a source of comparison for the other.
- Fluid build up is usually heard in the lower lobes, it can be bilateral or unilateral
- Crackles heard on inspiration
  - Sound like hair being rubbed together
  - Report position where sound no longer heard
    - (bibasal crackles to midzone / fine crackles to lower left base)
- Consolidation (effusion / collapse / infection)
  - Decreased breath sounds corresponding with same area
Treatment - Dyspnoea

- Continue HF specific meds unless not tolerated
  - Treat congestion with diuretics -IV / SC may be considered
  - Alleviate symptoms, reduce admissions, improve QOL
    - ACE I, B-Blocker, MRA, Diuretic, Digoxin

- Current evidence-based approaches to dyspnoea
  - Oral, transdermal or parenteral opioids
  - Palliative oxygen (readily available for heart failure)
  - Anxiolytics

- Non-medical management
  - Calm reassurance, Explanation, Fresh cool air (fan or window), Reposition, Relaxation, Distraction, Energy conservation, Activity management

Assessment – Oedema (Fluid Status)

- Have you noticed any swelling?
  - Are your shoes / socks tighter, do they leave a mark?

- Are your clothes tighter / looser have you had to change the mark on your belt

- Have you put on weight?
Oedema Assessment

- Check for presence of Oedema to lower extremities
- Oedema can involve scrotum, abdomen and sacral areas
- To determine presence of pitting oedema:
  - Push on the area for 10 seconds

<table>
<thead>
<tr>
<th>Grade</th>
<th>Depth (mm)</th>
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<tbody>
<tr>
<td>1+</td>
<td>2</td>
</tr>
<tr>
<td>2+</td>
<td>4</td>
</tr>
<tr>
<td>3+</td>
<td>6</td>
</tr>
<tr>
<td>4+</td>
<td>8</td>
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Oedema Treatment

- Diuretics
  - Oral, IV, SC
- Continue HF medications
Assessment - Pain

- The pain can be cardiac or non-cardiac
- Often reported as pain all over the body
- Causes of cardiac pain
  - angina and oedema,
- Causes of non-cardiac pain
  - related to comorbidities and medical interventions

Treatment - Pain

- Cardiac Pain
  - Long acting nitrates – patches / tablets
  - Opioids
- Non-cardiac pain
  - Simple Analgesia trialled first
  - **NO NSAIDS**
  - Opioids
- Non-pharmacologic approaches
  - repositioning, relaxation, distraction, and alternative approaches, including pet therapy, music therapy, and aromatherapy.
**Fatigue**

- Emotional and cognitive dimensions influence fatigue
- Comorbidities contribute
  - anaemia, infection, cachexia, and/or medications
- Psychological and situational factors.
- Management of fatigue is challenging and requires multidimensional strategies.
  - Alleviate other symptoms to allow for rest
  - Energy conservation techniques
  - Exercise both active and passive
    - minimises oedema, breathlessness, decreases risk of other complications related to immobility.

**Depression**

- Medications to help treat depression include SSRIs
- Tricyclic antidepressants are avoided, potential for hypotension and arrhythmias
- Non-pharmacologic interventions
  - psychosocial and spiritual support
Gastrointestinal Disturbances

- Gastrointestinal symptoms common
  - nausea / vomiting, constipation, incontinence
- Antiemetics to relieve nausea
- Aperients may be required
  - particularly if opioids are prescribed.
- Anorexia common
- Cachexia managed with
  - increased calorie intake
  - dietary supplements
  - small frequent meals

Caregiver Burden

- Carer fatigue
- Depressive symptoms
- Decreased QOL
- HF and PC clinicians can collaboratively offer solutions

Gelfman et al 2014 Engaging Heart Failure Clinicians to increase palliative referrals: Overcoming Barriers, Improving techniques. Journal of Palliative Medicine
EOL decisions

- What do patients want?
- Where would they prefer to be?
  - Home
  - Hospice/PC Unit
  - Hospital
- How will the disease progress?
- What to expect?

(Foster) Realistic hope

- Be honest without being blunt or giving too much detail
- Do not give misleading information to positively influence hope
- Reassure that support with symptoms is available
- Explore day to day ways of coping and realistic goals and wishes
Withdrawal of treatment

- Withdrawing and withholding treatments is a challenging decision
- Generally, the aim should be to maintain core CHF drugs for as long as possible as they assist in decreasing symptoms
- Avoid diagnostic tests unless there is clear intent to act upon the results

Medication Withdrawal

- The decision to withdraw or withhold medication should be based on a comprehensive clinical assessment
- If a treatment goal is to reduce the number of tablets – consider withdrawing drugs such as digoxin and statins
- Determine the risk / benefit ratio for Anticoagulation
Defibrillator Deactivation

- The decision to deactivate implantable cardiac defibrillators should ultimately be that of the patient.
- Decision undertaken in consultation with the patient, their family members and cardiologist.
- Defibrillator does not prolong life.
- Reassure that the pacing function will still work.

Integrated Strategy (Wish –List)

- A palliative approach should run in parallel with conventional HF treatment.
- We need a dynamic process responsive to individual need.
- Allowing for optimisation of HF therapy and management of more difficult symptoms.
  - HF and PC specialist input and care.
  - Seamless transition to appropriate team as required.
- Palliative approach should be discussed at pertinent points in trajectory.
  - Diagnosis.
  - 1st hospitalisation.
  - Progression of the condition (refractory symptoms).

Gadoud et al 2013 Palliative Medicine 27(9)822-829
Conclusion

“To cure sometimes, relieve often, and comfort always”
- Anonymous 16th century physician:

Aggressive symptom management, psychosocial and spiritual support help to prevent suffering and lead to a peaceful, dignified death