Developing an End-of-Life Framework
Taking the gamble out of end-of-life care

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Why?

How does a terminally ill patient with clearly documented limitations of care on previous admissions, return to hospital only to have full resuscitation efforts for 30 mins on a Saturday night before he is pronounced dead?

This is the question his family asked.

Adverse event and patient feedback investigations showed us that the quality of the end-of-life care people received was like a roll of the dice …
Before the project

Mortality review – acute wards:

• **15%** Patients had no resuscitation plan in place at time of death;

• **21%** Patients did not have a resuscitation plan completed until late in their admission – often only within hours or days of death;

• **23%** of deaths - End of life decision was made by either the MET team or ICU doctors

• **24%** patients had the Liverpool care pathway (being trialled) in place at time of death.

• ACP in Residential aged care only
A Framework

• Comprehensive,
• Integrated,
• Coordinated

- To take the gamble out of end-of-life care
We needed to hear from the experts…

Review of the literature;

Ethics approval then ..

What is end of life care like here at BHS?
• We asked 13 bereaved families (2013)

What does good end of life care look like to you?
• We set up focus groups with Doctors, Nurses, Allied Health staff and Consumers from BHS and from medical services outside BHS. (N=25)
• Consumer focus group (N=7)
Key Themes

• Preparation for death
• The care experience
• The dying experience
• Follow up after death
• Communication
Framework scope

Well
Diagnosis
Progression
Dying
Death
Post death

Initial scope
Culture, values behaviour

Advance Care Planning
Identifying people at risk of deteriorating or dying
Goals of care planning
Care of the dying management plan
Bereavement

Communication
Goals of Care

Introduced May 2014

An alternative to the ‘DNR’ approach

• Changed the focus of the discussion of limitations of treatment
• The role of the Medical Emergency Team
• Language: “Palliative” – not just active dying;
• Reviewed July 2015

Acknowledgements:
• Southern Tasmania area health network
• Dr Barbara Hayes, Northern Hospital
Firstly –

Documents correct ‘Person Responsible’ and Medical Enduring Power of Attorney if appointed

Documents whether patient has done any advance care planning
### LIMITATION OF MEDICAL TREATMENT

**B** Goal of Care: CURATIVE OR RESTORATIVE but following treatment limitations apply. *(Tick ONE)*

- **NOT FOR CPR**
  - but is for intubation for respiratory failure
  
- **NOT FOR CPR or INTUBATION**
  - but is for all other appropriate ACTIVE MANAGEMENT

⇒ **For CODE BLUE/MET CALL**

⇒ **NOT for CODE BLUE** (if cardiac arrest)

⇒ **For MET CALL**

\[Specific notes (eg inotropes, non-invasive ventilation):\]

**C** Goal of Care: PALLIATIVE. Treatment aim is symptom management and Quality of Life.

- **NOT FOR CPR or INTUBATION**
  - Optimise symptom control

⇒ **NOT for CODE BLUE** (if cardiac arrest)

⇒ **For MET call**

⇒ **Not for MET call**

⇒ **For Palliative Care Response** (distressing symptoms)

⇒ **Consider Palliative care referral**

\[Specific notes (eg antibiotics, IV fluids):\]

**D** Goal of Care: COMFORT DURING DYING – TERMINAL CARE (prognosis is assessed to be hours or days)

- **NOT FOR CPR, INTUBATION, VENTILATION**

⇒ **NOT for CODE BLUE**

⇒ **For Palliative Care Response**

⇒ **Commence Care of the Dying Management Plan**

\[Specific notes:\]
Then and now

Timely discussion of goals of care
Excl Paediatrics, Obstetrics and Short stay

<table>
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<th>Within 48hrs %</th>
<th>&gt;48hrs %</th>
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<td>51</td>
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<tr>
<td>Jul-15</td>
<td>75</td>
<td>12</td>
<td>13</td>
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Care of the Dying Management Plan (CDMP)

- Commenced when Goal of Care is D (patient is actively dying)
- Offers best chance of dying well
- Multidisciplinary
- Involves patient and family
- First question: “Do you want to die at home?”
- July 2014
Advance Care Planning

• Respecting patient choices
• Assoc. Prof Bill Silvester – Steering group member
• Developing the model for BHS – regional area has advantages (lesson from Barwon Health)
• Focus on primary care and community programs
• Education for facilitators already in place
• Partnering with a GP practice as a pilot.
• Business case 2015 -
Advance care Planning - evidence

Assoc Prof Bill Silvester

- Improves care, including end-of-life care
- Improves patient & family satisfaction with care
- Reduces stress, anxiety and depression in the surviving relatives
- Has also been shown to reduce moral distress among healthcare providers
- Reduces ineffective or unwanted costly care at end of life, without increasing mortality.
Advance care planning

Improves

- Quality of death
- Likelihood that a person’s wishes will be complied with by family & medical carers
- Likelihood of a person dying in their preferred place
- Patient and family satisfaction with care
- Family preparedness for what to expect during the dying process
“Tests and investigations are our failure to have the courage to have a difficult conversation”

Dr Ranjana Srivastava
Medical Oncologist
Author

Hot topic - the challenge of the difficult conversation
Communication

- Evidence suggested we needed to offer explicit communication skills training – opportunities for junior staff to observe skilled communication by senior clinicians is limited
- *Discussing goals of care* workshop developed at BHS
- Experiential (role play with an actor) and didactic
- Pitched to Registrars at this stage
- Introduced in April 2015
- A work in progress ..
EoL Framework

More than a roll of the dice …

• Over 90% patients who die have a goals of care plan in place within 48hrs of admission.
• Over 80% patients who die now are for either comfort measures and symptom management (Goal of care C) or terminal care (Goal of Care D) rather than curative or restorative.
• 80% of those who die in subacute are on CDMP
• CDMP use in acute after 3 month roll-out is still a work in progress - not yet embedded.
Next steps ..

- Roll out the Framework document;
- Advance Care Planning – business case and collaborations with primary care and other organisations;
- Building capability for having the difficult conversation – Communication Skills Training for medical staff.
- GoC form review analysis
- CDMP sustainability
- Considering our role with bereavement;
- Goals of care and CDMP for Residential Aged Care – being trialled currently
- Repeating interviews
- Significant opportunities for research ...
Not yet there but we’re on our way...
Questions?