Government of **Western Australia**
Department of **Health**

Great Expectations – Planning for expected deaths in acute health settings

Setting the scene

Professor Geoffrey Dobb, on behalf of
Professor Gary Geelhoed, CMO, Executive Sponsor

Clinical Senate, March 2015

Photo courtesy of Pablo Yáñez, http://www.modernstills.com

Setting the scene

Personal account of trying to care for MG

- MG, in his late 60's had been diagnosed with a lymphoma in 2012
- Treatment included chemotherapy, radiotherapy and a BMT
- Recurrence late 2014: repeat chemo and BMT
- Quite severe graft vs host disease
- Re-presented with low grade fever, increasing SOB, cough
- Nil cultured but treated with multiple anti-infectives
- 3 days increasing SOB, tachypnoea, worse oxygenation
- Referred to ICU: CPAP, BiPAP, possible intubation (?)
- 2 days continuing deterioration: 'trial of steroids', not palliation
- 3 days continuing deterioration: highly symptomatic
- Finally family meeting, including haem-oncology: palliation very late

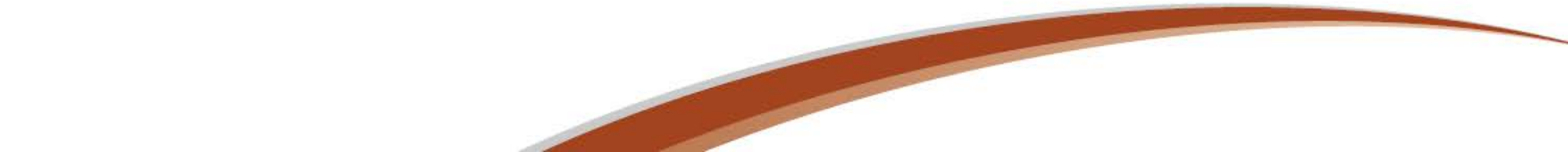
The story so far …

2008

Clinical Senators debated the topic '*Patients, Clinicians, the Law and Decisions for End of Life Care*', in anticipation of legislative changes related to the passing of Acts Amendment (Consent to Medical Treatment) Act 2008. This legislation provided a new framework for improving the quality of end of life care.

2014

Prof Gary Geelhoed, CMO, and the Palliative Care Network - end of life care in acute care settings identified as a priority for improvement



The main question for Senators to consider today:

How can we better respond to patient clinical deterioration and plan for expected deaths in acute health settings?

Driving change: Government policy

End of life care is on the national health agenda:

- **National Safety and Quality Health Service Standard 9 –** Recognising and responding to clinical deterioration in acute health care

- **National Palliative Care Strategy 2010 –** Supporting Australians to live well at end of life
  - **Goal 1** – to significantly improve the appreciation of death and dying as a normal part of the continuum
  - **Goal 2** – to enhance community and professional awareness of the scope of and benefits of timely and appropriate access to palliative care services
  - **Goal 5** – to build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care

- The shared views of experts – Consensus Statements:
  - ACSQHC National Consensus Statement – Essential elements for recognising and responding to clinical deterioration
  - ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill

Consensus Statements: the shared views of experts

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The need for change:
End of life care in the acute health sector

- Increased demand in the provision of end of life care – changing patterns of disease
- Gaps in the provision of quality and safety in end of life care
- Inadequate recognition of dying
- Need for increased awareness that better end of life care starts before the terminal phase
- A responsibility to improve end of life care for patients and their families
- Clear mandate for transformative, system-wide, cultural change around end of life care in acute settings in WA

The need for change 2:
End of life care in the acute health sector

- High number of hospital admissions and ED presentations in last 12 months of life
- High percentage of deaths in acute care settings
  - 58.9% of hospital separations in WA
  - National survey - 68% of patients wish to die at home
- Dying in Australia is more institutionalised than in the rest of the world
- People want to die to at home, however most spending in the last year of life is in hospital and residential care
- Each year over $2 billion is spent on older people who die in hospital
- Costs are highest for those who die as acute in-patients – 48 per cent of identified hospital and aged care costs

The need for change:
Improving end of life care for patients and families/carers

- Patients are facing a dilemma between quality and quantity of life
- The need to avoid unnecessary interventions at end of life
- The importance of timely referral to palliative care
- Planning for a ‘good death’ – good care at end of life can help to reduce distress for both patients and their families/carers
- Opportunity to have timely and honest conversations
- Opportunities to have wishes respected and establish goals of care
- Opportunities to initiate Advance Care Planning

Current initiatives

Continuum for End of Life Framework:

- Recognises that the need for better care starts before the terminal phase of life, and includes four phases:
  - Advancing Disease
  - Increasing Decline
  - Last Days of Life
  - Bereavement
- Currently being developed by the OCMO and the Palliative Care Network
- Key strategy within the PCN election commitment funding 2013-17
- Involves increased recognition of patients with chronic diseases and their future care needs
- Aims to enhance communication with patients to facilitate advance care planning
- Aims to improve the quality and appropriateness of care provided towards end of life.

Current initiatives (cont'd)

- The *Care Plan for the Dying Person* – a replacement document for the WA Liverpool Care Pathway, rolling out to existing health sites by July 2015 (65 metropolitan and regional health sites currently use the WA lcp)
- *Advance Health Directive/Advance Care Planning*
  - A joint initiative with the Palliative Care Network and the Office of the Chief Medical Officer to inform both consumers and health professionals about advance care planning and the advance health directive.
  - Advance Care Planning is the process and Advance Health Directive is the tool to facilitate documentation of end of life wishes.
- *Talking about end of life* – in Residential Aged Care Facilities:
  - RACF palliative link teams are trained to recognise patients with palliative care needs and the concepts of advance care planning.
  - program has been implemented in 70% RACFs in the Perth metropolitan area
  - expanding to regional areas in 2015

My perspective

- Recognising disease trajectory is an important clinical skill
- Determining a patient's goals of treatment is an essential part of every admission
- Talking about end of life care is a learnable skill
- The potential for organ and tissue donation should always be considered

Healthcare needs to be judged, not just by the lives saved, but by the quality of death for those they can't save

The problem

- End of life discussions often start too late
- Hard work, emotionally demanding, takes time
- Culture of ‘fighting’ disease
  - Recognising possibility of death = failure
- Few advance directives
- Fear of the legal system – doctors
- Unrealistic expectations, guilt

Thank you.