End of Life Care – A National Policy Perspective
END OF LIFE CARE – A NATIONAL POLICY PERSPECTIVE

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WHO IN THE ROOM HAS A DOCUMENTED ADVANCE CARE DIRECTIVE OR GUARDIANSHIP ORDER?

- Yes
- No
WHO HAS DISCUSSED THEIR END OF LIFE WISHES WITH THEIR FAMILY MEMBERS?

- Yes
- No
OUTLINE OF TALK

1. Australian Commission on Safety and Quality in Health Care

2. Choosing Wisely Australia

3. Other national movements
Deaths for younger people are now rare; about two-thirds of Australians die between the ages of 75 and 95. Most of these deaths are expected, yet we are not taking the opportunity to help people plan to die well.

When asked, most people have clear preferences for the care they want at the end of their life. But rarely do we have open, systematic conversations that lead to effective End of Life Care plans. Most people do not discuss the support they would like as they die.

Population ageing!
Number of people aged 65 years and over is projected to exceed the number of children aged 0-14 years by 2030 (ABS, 2014). Over the next 40 years, the number of people aged 85 years and over is expected to increase four-fold.
Of this cohort, it is estimated that up to 85% will die as a result of a chronic illness.

The default medical position ‘to do everything to save life, no matter what’ addresses the wishes of only a minority. In a large survey, only 7 per cent of Australians 75 years and over wanted all possible medical intervention compared to 61 per cent who strongly opposed any intervention that prolonged life in poor health or resulted in a poor quality of life (Corke, 2015).
MAJOR CHALLENGE: END OF LIFE CARE

- Inadequate resourcing of palliative care services
- Ill equipped acute care sector for dying
- Lack of understanding of people’s wishes
- Few people have developed a plan for the end of life care

  8%  717 ICU patients
  11% 183 dead patients Canberra Hospital
  14% 2400 people sampled
  31% 1670 people sampled

- Increasing use of medical emergency teams to help make EOL decisions
- Delayed comfort care and prolonged suffering

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1 Anstey M Personal Communication 2015, 2 Burke B Personal Communication 2015
3 White B et al Internal Medicine Journal 2014; 975-980
4 Commonwealth Fund 2014,
5 Jones et al Critical Care Medicine 2012; 40: 98-103
EXPLANATIONS

- Modern medicine focuses on curing rather than accepting death as natural
- “Death denying culture” for patients/families/healthcare professionals
- Inexperienced junior medical staff (eg: 600 junior doctors and 600 deaths/year)
- End of life conversations are confronting and difficult
- Hospital processes provide little time for deep and meaningful conversations
“To describe the elements that are essential for delivering safe and high quality end of life care in acute care settings”
Overview of the 10 essential elements of EOL care

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<thead>
<tr>
<th>PROCESSES OF CARE</th>
<th>ORGANISATIONAL PREREQUISITES</th>
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<tr>
<td><strong>1. PATIENT CENTRED CARE</strong></td>
<td><strong>6. LEADERSHIP &amp; GOVERNANCE</strong></td>
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<tr>
<td>Patients are part of decision making about end-of-life care</td>
<td>Policies and systems for end-of-life care</td>
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<tr>
<td><strong>2. TEAMWORK</strong></td>
<td><strong>7. EDUCATION &amp; TRAINING</strong></td>
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<tr>
<td>Clinicians work together to provide end-of-life care</td>
<td>Clinicians have the skills and knowledge to provide end-of-life care</td>
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<td><strong>3. GOALS OF CARE</strong></td>
<td><strong>8. SUPERVISION &amp; SUPPORT</strong></td>
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<td>Clear goals improve the quality of end-of-life care</td>
<td>Clinicians providing end-of-life care are supported</td>
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<td><strong>4. USING TRIGGERS</strong></td>
<td><strong>9. EVALUATION &amp; FEEDBACK</strong></td>
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<tr>
<td>Triggers identify when patients need end-of-life care</td>
<td>The quality of end-of-life care is measured and improved</td>
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<td><strong>5. RESPONDING TO CONCERNS</strong></td>
<td><strong>10. SUPPORTING SYSTEMS</strong></td>
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<tr>
<td>Clinicians get help to rapidly respond to patient suffering</td>
<td>Systems align with NSQHS Standards to improve outcomes</td>
</tr>
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</table>
GUIDING PRINCIPLES

- Patient Centred Communication
  series compassionate conversations to arrive at shared decision making
- Teamwork and Coordination of Care
  team needs to be interdisciplinary, work effectively and supported
- Components of Care
  processes should be in place to support individualised end of life care
- Use of Triggers to Recognise Patients approaching End of Life
  recognition systems in acute care settings
- Response to Concerns
  easy to access to rapid assessment by suitably skilled care provider
Recognition systems in acute health services should aim to identify patients at two critical points:

- When a patient is likely to die in the medium term (next 12 months) but episodes of acute clinical deterioration may be reversible

- When a patient is likely to die in the short term (days to weeks or current admission) and clinical deterioration likely to be IRREVERSIBLE
GUIDING PRINCIPLES

- Leadership and Governance requirement for leadership and governance systems
- Education and Training end of life care education and training for all care providers
- Supervision and Support for Interdisciplinary Team Members facilities should help access peer support, mentoring and supervision
- Evaluation, audit and feedback requirement for ongoing monitoring of effectiveness of end of life care systems and processes and needs to address quality of death
WHO HAS HAD TRAINING IN HAVING END OF LIFE DISCUSSIONS WITH PATIENTS/FAMILY MEMBERS?

- Yes
- No
Develop **tools** and **resources** to support safe and high-quality end-of-life care in acute healthcare settings to assist health service organisations and clinical teams to translate the End of Life Consensus statement.
TOOLS AND RESOURCES

• Data to understand practice
• Data to inform and measure change
• Crowd source resources to improve care
• Triggers to recognise dying
• Goals of Care Forms
• Teaching and learning packages:
  • Recognising dying
  • Goals of care
  • Empathic conversations
DATA TO INFORM IMPLEMENTATION

- Examine performance regarding end-of-life care
- Undertake single centre data collection: Canberra
  - Quantitative data collection tool (processes and outcome)
  - Qualitative data collection tool (healthcare professionals)
- Determine validity and use
- Pilot in 8 hospitals representing a tertiary, metro, private,
- Inform national data collection tool

- Note: difficulty in retrospective ascertaining appropriateness
Starting a national conversation about tests, treatments and procedures that provide no benefit and in some cases may cause harm

Focused on high quality care, supporting conversations between the consumer and clinician

Based on the best available evidence and what care is truly needed

Part of a global movement to assess low value care
Supporting both consumers and clinicians to have conversations about appropriate care

Consumer resources for website

Engaging with consumer organisations

FIND OUT WHICH TESTS, TREATMENTS AND PROCEDURES YOU SHOULD QUESTION

REACHING CONSUMERS
For emergency department patients approaching end-of-life, ensure clinicians, patients and families have a common understanding of the goals of care.
For patients with limited life expectancy (such as advanced cardiac, renal or respiratory failure, metastatic malignancy, third line chemotherapy) ensure patients have a ‘goals of care’ discussion at or prior to admission to ICU and for patients in ICU who are at high risk for death or severely impaired functional recovery, ensure that alternative care focused predominantly on comfort and dignity is offered to patients and their families.
Do not delay discussion of and referral to palliative care for a patient with serious illness just because they are pursuing disease-directed treatment.

Do not delay conversations around prognosis, wishes, values and end of life planning (including advance care planning) in patients with advanced disease.

WHY: Evidence shows that advance care planning conversations improve patient and family satisfaction with care and concordance between patients’ and families’ wishes, reduce the likelihood of patients receiving hospital care and the number of days spent in hospital, and increase the likelihood of receiving hospice care.
End-of-life care projects across Australia

The Commonwealth, state and territory governments across Australia are increasing their focus on improving the safety and quality of end-of-life care.

The links below provide information on the work that is happening across Australia.

Disclaimer: These links are provided for convenience only and should not be construed as an endorsement by the Commonwealth of Australia; conversely, omissions should not be construed as non-endorsement.

Commonwealth

National Palliative Care Program

The Australian Government funds a range of projects aimed at improving palliative care education and training for health and aged care workers, and raising awareness of end of life choices.

Australian Capital Territory
Australian Capital Territory

Palliative Care – Health professionals

Respecting Patient Choices

Palliative Care – Consumers

The ACT Government website contains information for consumers and health professionals about palliative care services and advance care planning.

New South Wales

Agency for Clinical Innovation – Palliative and End of Life Care Blueprint

This online resource aims to guide services and Local Health Districts in constructing their own, localised models of care.

Clinical Excellence Commission – End of life Program

The End of Life program aims to introduce a state-wide approach to end-of-life care in NSW.

Northern Territory

Palliative Care – NT

Information for consumers and health professionals on palliative care services in the Northern Territory

Queensland

Statewide strategy for end-of-life care

The Queensland Government launched a statewide strategy for end-of-life care in May 2015.

South Australia

End of life care for health professionals
South Australia
End of life care for health professionals
Information for health professionals on end of life options, including policies and procedures:

- Advance Care Directives for health professionals
- Consent to medical treatment for health professionals
- Resuscitation Plan 7 Step Pathway

Tasmania

Palliative Care – Tasmania

Information for patients and health professionals on palliative care programs and the Healthy Dying Initiative in Tasmania. Includes:

- Advance Care Planning
- Medical Goals of Care Plan
- Palliative Care Service Delivery Model

Victoria

End of life Care – Victoria

Information on advance care planning and palliative care services in Victoria.

Greater say for Victorians: Improving end of life care

The Victorian Government is conducting inquiry into end of life choices that is due to report in May 2016.

Western Australia

WA Cancer and Palliative Care Network

Information and resources on palliative and end-of-life care.
Information for patients, families and carers

How should care be given at the end of life? Information for patients and their families and carers

If you are a patient, family member, carer, consumer or consumer advocate, this information sheet has been developed to give you useful information about how care should be provided to people at the end of life in hospitals.

For more information on advance care planning visit the following websites:

Advance Care Planning Australia

Start2Talk

My Values

https://www.safetyandquality.gov.au
Tools and resources for health services

Infographic: Essential elements for safe and high-quality end-of-life care

- Highlights the ten essential elements for safe and high-quality end-of-life care. Download the picture and share it with your colleagues to start a conversation about how to deliver the highest-quality end-of-life care.

Fact sheet – End-of-life Care and the NSQHS Standards

- Includes information about how implementing the Consensus Statement can help your organisation to provide evidence for accreditation against actions in the NSQHS Standards.

The Commission engaged the Centre for Health Service Development based at the University of Wollongong to perform a rapid review of the literature to identify existing work and inform the development of indicators to measure the safety and quality of end-of-life care in acute hospital settings.

- Rapid review of the literature to inform the development of quality and safety indicators for end-of-life care in acute hospitals (PDF 1MB) (Word 589KB)

The Commission is developing additional tools and resources to support safe and high-quality end-of-life care in acute healthcare settings including:

- Survey and audit tools for measuring the quality of end-of-life care in hospitals. These are currently being piloted in a major teaching hospital. This project will be expanded to several other pilot sites before being evaluated and released for public use.

- Fact sheets to help organisations to implement the actions in the National Consensus Statement: Essential elements for safe and high-quality end-of-life care. Check the Commission website or sign up to the newsletter for details on these as they are released.
MOVING FORWARD

"I encourage you to hope for and expect the best, but it is also wise to prepare for the worst."

Anthony Back
Annals of Internal Medicine, 2003
End of Life Care is Everyone’s Responsibility

1. **People** to talk about their wishes for End of Life Care with family and loved ones at the kitchen table – not in the intensive care unit when it’s too late. Encourage people to document their choices of care and initiate a conversation with their health professional.

2. **Communities** to build capacity to become compassionate and support people to live well and die well in partnership with health professionals through a health promoting approach to End of Life Care.

3. **Health providers** to initiate honest, timely and culturally-sensitive conversations with patients so they are a routine part of healthcare delivery. Establish a dedicated Medicare reimbursement system to facilitate of End of Life Care conversations and planning.

4. **Universities, colleges and training organisations** to help health professionals, across all chronic care and complex care specialities, have difficult conversations and improve end of life communication with patients, families, and colleagues.

5. **Policy makers** to acknowledge End of Life Care as a national health priority, promote public awareness programs and fund End of Life Care conversations with dedicated medicare item numbers.

6. **Employers** to better support staff who are living with an advanced illness, carer responsibilities or grief, and help them have conversations about their options and choices.

7. **Media** to demystify dying and help normalise the experience for the general public. Greater public discussions about the limits of healthcare as end of life approaches informs the public about their options and helps them translate these into personal choices.

8. **Researchers** to conduct randomised trials examining new approaches and models for enhancing conversations. These trials would include measures of the frequency and quality of end of life discussions, perceived control, quality of life, and pain/symptom management. Combined with a cost-benefit analysis, provide the data needed for a reimbursable End of Life Care management strategy.
DOCTOR

PATIENT

SYSTEM

Time
Communication training
Billing??

Recording of info
Flow of information
Whose responsibility?

Health Literacy
Impetus for planning
To find out more or become involved:

- [www.choosingwisely.org.au](http://www.choosingwisely.org.au)
- [twitter.com/ChooseWiselyAu](http://twitter.com/ChooseWiselyAu)
- [@choosingwisely@nps.org.au](http://@choosingwisely@nps.org.au)

[matthew.anstey@health.wa.gov.au](mailto:matthew.anstey@health.wa.gov.au)

Futile Care and End of Life Matters

A Symposium by the Western Australian Audit of Surgical Mortality

Tuesday, 15 November 2016

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<td>James Atken</td>
<td>Chairman</td>
<td>Introduction</td>
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<td>Hon Jim McGinty AM</td>
<td>Former WA Minister of Health and Attorney General</td>
<td>Parliament’s role in End of Life matters</td>
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<tr>
<td>Dr Penny Flatt AO</td>
<td>Former CEO Brightwater Care Group</td>
<td>The aged care sector’s role in preparing for the End of Life</td>
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<td>Dr Matthew Anstey</td>
<td>Senior Medical Advisor Australian Commission on Safety and Quality in Health Care</td>
<td>End of Life care - a national policy perspective</td>
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<td>Dr Tim Paterson</td>
<td>Consultant in Intensive Care</td>
<td>Proceeding in borderline cases</td>
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<td>Mr Stephen Honeybul</td>
<td>Consultant Neurosurgeon</td>
<td>Futile care or no treatment</td>
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<td>Dr Zaza Lyons</td>
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<td>Mr Albie Lyons</td>
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<tr>
<td>James Atken</td>
<td>Chairman</td>
<td>Discussion (to conclude at 8.30pm followed by refreshments)</td>
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This activity qualifies for 3 RACS CPD points in Maintenance of Knowledge and Skill