

End of Life Care Opportunities

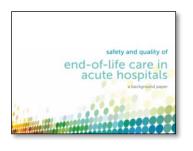
Kim Devery - Lead

Deb Rawlings – Co-lead





AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE







- <u>End of Life Essentials</u> education for acute hospitals funded by the Department of Health. Free, evidence-based, peer reviewed by over 50 clinicians around Australia
- Education modules were built around areas of knowledge gap identified in the 2015 ACQSHC's consensus statement ¹
 - First 6 modules released in 2016
 - ED, Chronic Complex Illness, Imminent Death, Paediatrics end of life new states of mind
 - 23,000 doctors, nurses and allied health registered



































eLearning Topics

- Dying, a normal part of life
- Patient-centred Communication and Shared-decision making
- Recognising end of life
- Goals of Care
- Team Work
- When things aren't going well
- ED EOLE Care
- Paeds EOLE Care
- Imminent Death
- Chronic Complex Conditions EOLE Care
- States of Mind at the end of life



100 years ago

Respiratory illness
Diphtheria
Gastrointestinal diseases
Influenzas



Life expectancy for a person born 1920 = 59.2 years (ABS)

Photo -

Australian War Memorial

ADELAIDE, SA, 1920. NO 4 WARD, KESWICK MILITARY HOSPITAL, ADELAIDE, SOUTH AUSTRALIA, IN 1920.





- Around two thirds of Australian die 75-95 years of age
- Estimated 70% of all deaths are expected
- Numbers of Australians who die each year will double in the next 25 years²
- Think about the population you provide service for in terms
 of age and other....
 end-of-life

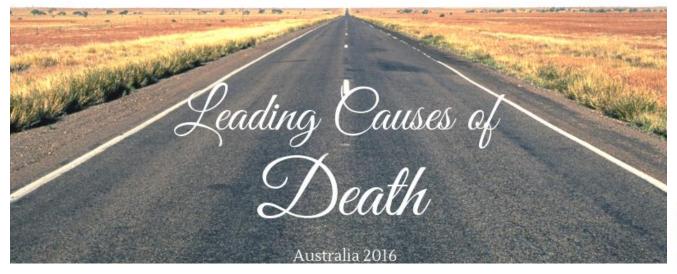
1. CORONARY ARTERY DISEASE

2. DEMENTIA AND ALZHEIMER'S DISEASE

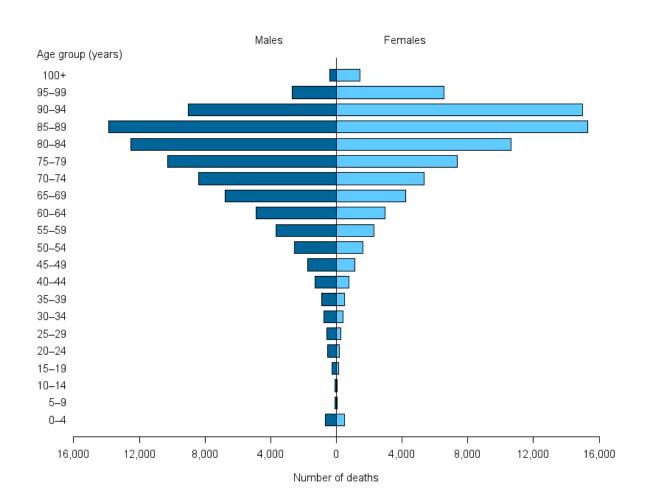
3. CEREBROVASCULAR DISEASE

4. LUNG CANCER

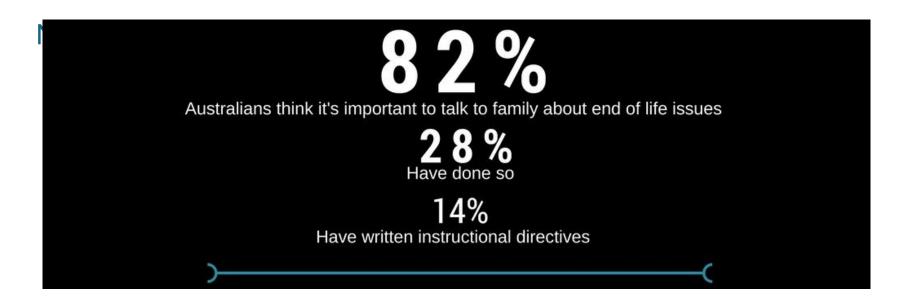
5. CHRONIC OBSTRUCTIVE PULMONARY DISEASE











Figures from

- 3. Palliative Care Australia, http://dyingtotalk.org.au/
- 4. End-of-life Law in Australia, QUT





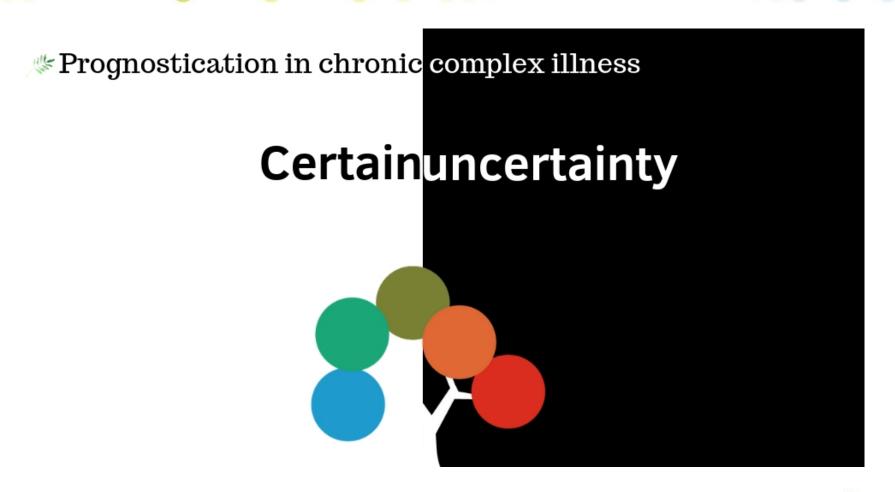
So?

Patients are poorly prepared for their future (and may not know for example, their chronic complex illness will end their lives).

Hospital HCP (where 54% Australians die) are excellent at prolonging life but the ACQSHC work has identified that not so good at recognising end of life or providing EOL care.

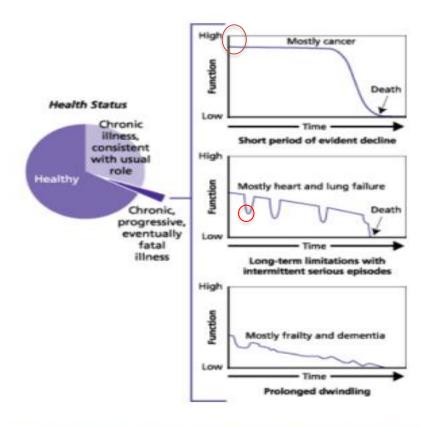
Early identification of end of life is recommended by WHO as key to providing quality and safe care.







Patterns of end of life – When are we aware?



Lynn, J., Adamson, D.M. (2003). Living well at the end of life: adapting health care to serious chronic illness in old age, Rand Health White Paper WP 137. California: Rand Corporation. Retrieved March 28 2016, Reproduced with permission.





Some complex chronic illnesses have poorer prognoses than many cancers

Advanced congestive heart failure with severe symptoms has a one year mortality of 30-40%. However, the illness has an unpredictable pathway. While some patients recover from acute episodes of deterioration, unpredictably 15-20% of other patients die a sudden death. ⁶

EOLC=1-2 years before death (ACQSHC) allows choice and shared care





The patient may ask you.

You may have updates from consultants.

You've discussed with the team.

You've used a tool.



BE

PREPARED!

for unexpected questions and comments from patients

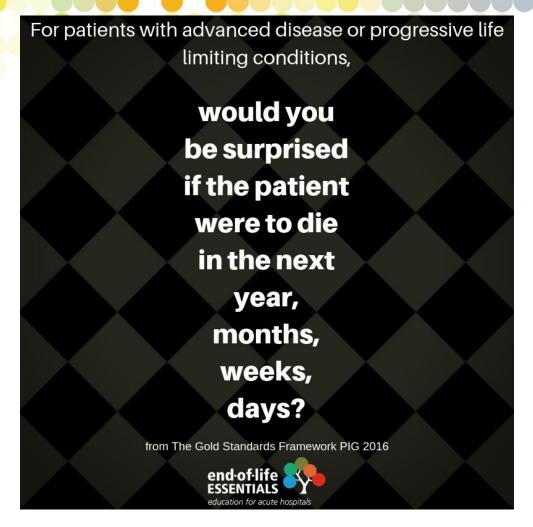
I thought I was going to die!

what will happen to me?

is this the end?

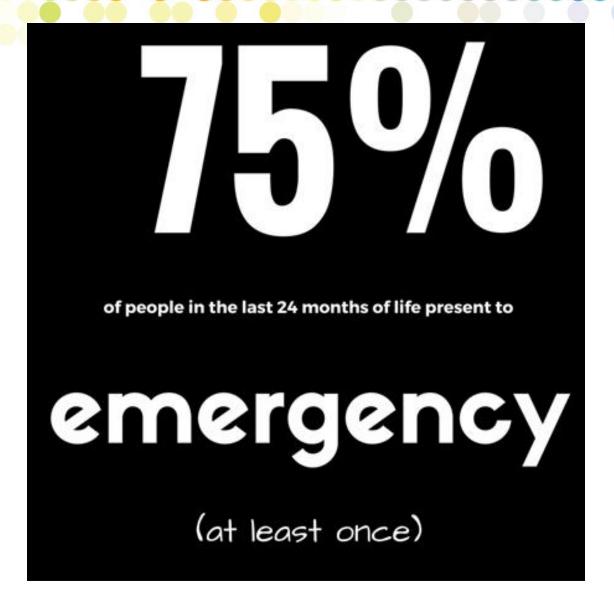






Also SPICT

Mayo Clinic Fifth Vital Sign - Nurses' pattern recognition and sense of worry can provide important information for the detection of acute physiological deterioration Romero-Brufau S, Gaines K, Nicolas C, JohnsonM, Hickman J, Huddleston J, The fifth vital sign? Nurse worry predicts inpatient deterioration within 24 hours, JAMA Operation for acute hospitals



New South Wales Department of Health. <u>Guidelines for end-of life care and decision-making (163KB pdf)</u>. Gepartment of Health; 2005 Mar.



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really?

an average of

4 hospital admissions in the last 12 months of life



Challenging - health care professionals may be initiating discussions with patients who have never spoken to anyone about their end of life wishes

Limited undergraduate preparation and limited post graduate for end of life care in acute care settings⁵





Skill set 7

- Expanded tolerance for clinical ambiguity/uncertainty
 - Prognosis for an individual is inexact
- Tolerate strong emotions
 - Suffering, moral distress, grief and loss
- Accept complexity
 - Physical, spiritual, emotional and social care needs



Some patients will wish to know everything, other patients only some things and a smaller group will not want to know details about end of life at all - so ask.





End of life conversations

enables choice & planning







Offer to discuss the future

"Some people like to know everything that is going on with them and what may happen in the future, others prefer not to know too many details. What do you prefer?"

Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Med J Aust 2007; 286(12): S79-S108





Adapt and adopt

"I know that often people expect doctors to know what is going to happen, but in truth we can often only take educated guesses and can often be quite wrong about what the future holds, and especially how long it is. What we can be sure about is . . . and what we don't know for sure is . . ."

"We've been talking about some treatments that are really not going to be effective now and that we don't recommend you use. But there are a lot of other things we can still do to help and support you and make sure you are as comfortable as possible."1

"What are your most important [hopes/expectations] about the future?"

"As you think about the future and that you may not have a very long time to live, what is most important to you? Are there any aspects of your life that you want to attend to?"

"What are the things you most want to invest your time and energy in?" "What are the things you want to do in the time you have?" "Is there any particular event that you are looking forward to?"

Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Med J Aust 2007; 286(12): S79-S108. © Copyright 2007 The Medical Journal of Australia – reproduced with permission.

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REMAP

STEPS

Reframe why the status quo isn't working.

we're in a different place

I can see you're really concerned about X

Map the future

Given this situation what's most important for you?

Align with the patient's values

As I listen to you, it sounds like the most important things are . . .

Plan medical treatments that match patient values

Here is what I can do now that will help you do
those most important things



LISTEN TO HOW PATIENTS AND THEIR FAMILY/CARERS ARE EMOTIONALLY AND PHYSICALLY

reacting and responding to treatments & interventions





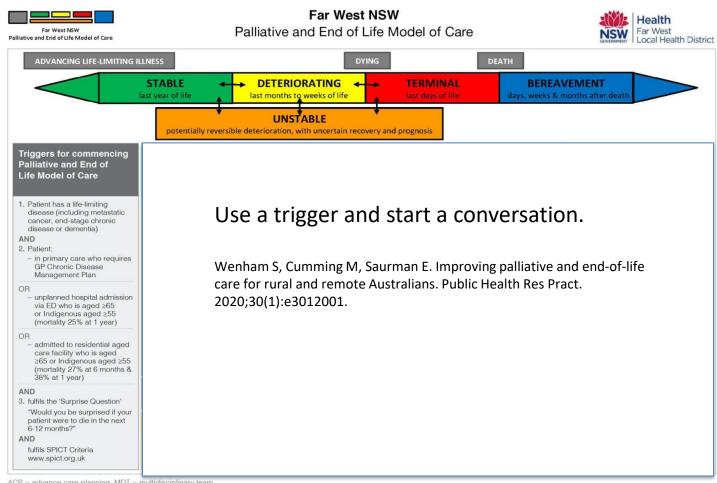
Remoteness

Palliative Care provision is inconsistent across Australia particularly in rural and remote regions. People living in rural and remote areas may have delayed access to services, issues with transport and fewer resources. This means that all health professionals have a role to play in providing and-of-life care.

What does this mean for you?



Remoteness



ACP = advance care planning, MDT = multidisciplinary team

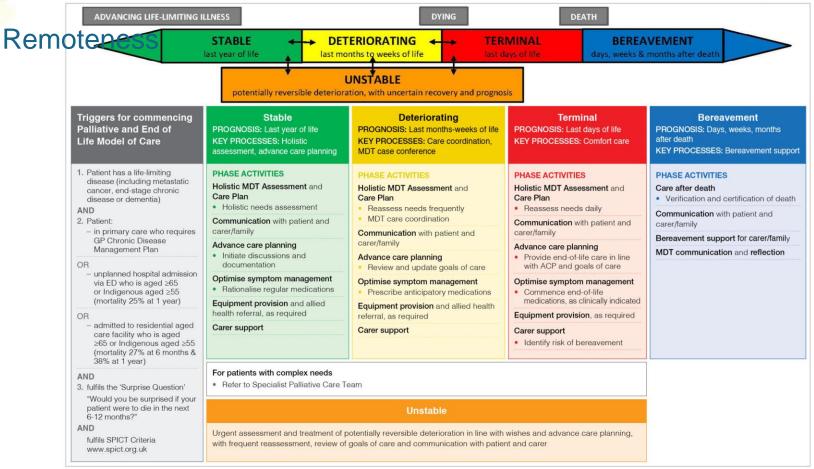


a This is a simplified version of the Model15 with high-level phase activities only; the complete Model is available online: https://www.wnswphn.org.au/epaf/epaf-healthcare-professionals



Far West NSW Palliative and End of Life Model of Care





ACP = advance care planning, MDT = multidisciplinary team

a This is a simplified version of the Model15 with high-level phase activities only; the complete Model is available online: https://www.wnswphn.org.au/epaf/epaf-healthcare-professionals

Wenham S, Cumming M, Saurman E. Improving palliative and end-of-life care for rural and remote Australians. Public Health Res Pract. 2020;30(1):e3012001.

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Resources

The Royal Australian College of General Practitioners (RACGP) aged care clinical guide (Silver Book) - Part B Older people in rural and remote communities assists GP's working in rural and remote areas to understand the barriers and has a checklist for the newly arrives GP.

CRANAplus is the peak professional body for the remote and isolated health workforce of Australia. They have a Position Paper: Palliative Care (Endorsed by PCNA).

The Australian General Practice Network (AGPN) developed a Rural Palliative Care Program Resource toolkit which is available within the <u>CareSearch Grey literature</u> <u>database</u>.

From the National Rural Health Alliance: Fact Sheet 34 - Palliative care in Rural and Remote Areas (2012). (969kb pdf) Explains what palliative care service may look like in rural and remote areas.

From the Palliative Care Bridge website. Listen to Dr Sarah Wenham talk about rural palliative care.

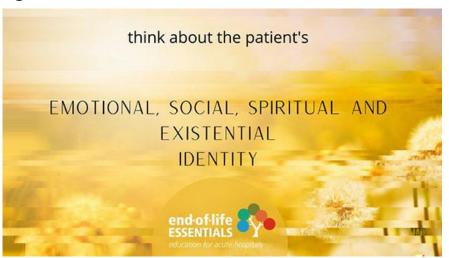
ESSENTIALS

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Common psycho-existential responses to end of life

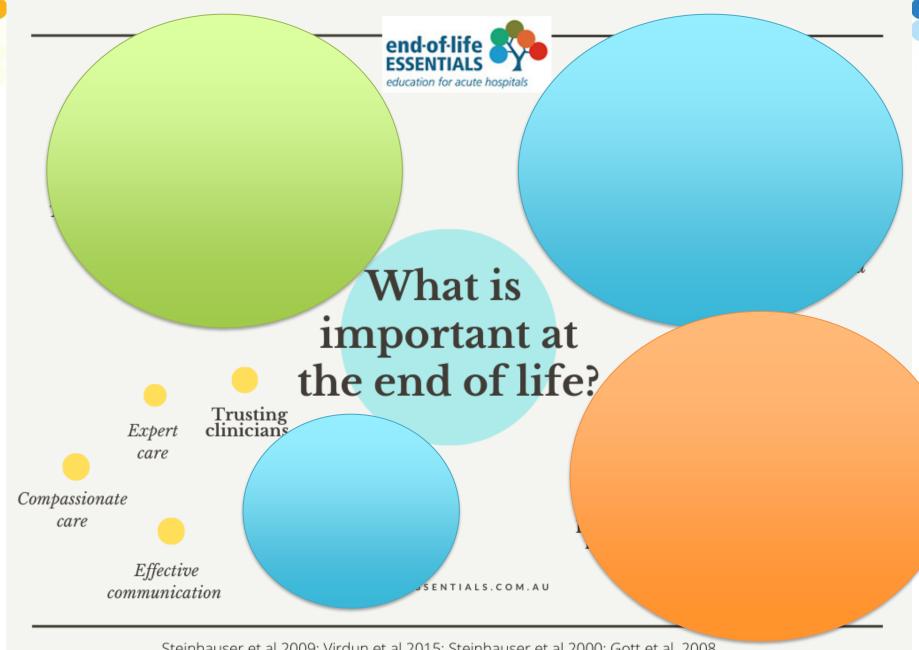
Most Australians die a expected death after a normal course of chronic complex illness, around the age of 75 years of age.

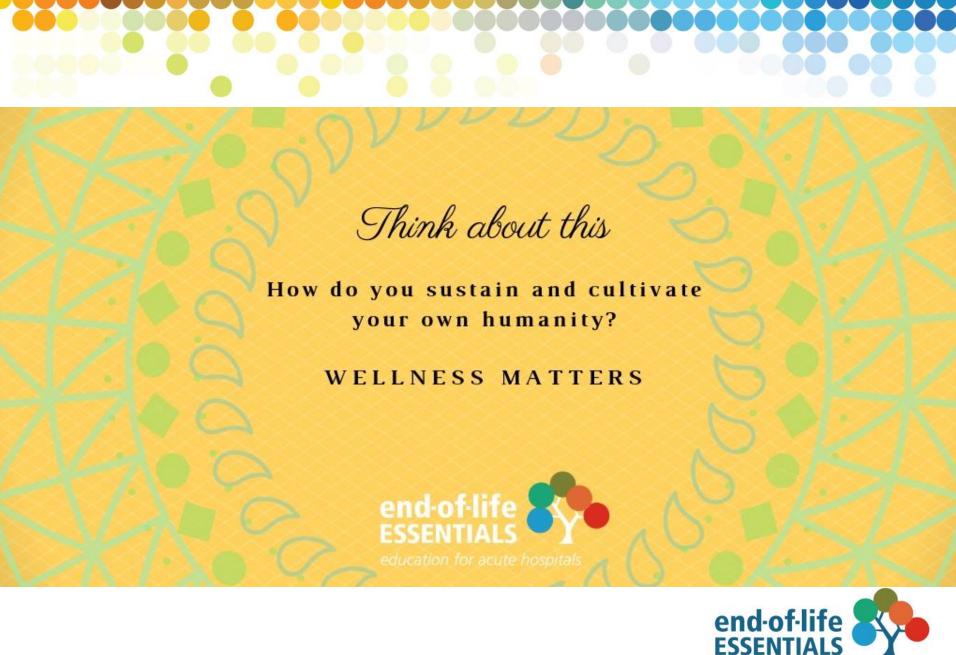
Frailty
Loneliness
Multiple losses
Very individual
Fear, grief, guilt, hope, denial, anger and sadness



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However, many clinicians will report that most people approach the end of their lives the same way they have lived; thus, not everyone is overcome with and focussed on negative emotions. There are ebbs and flows to the sadness and the joys of life when people approach death.







Caring for yourself

Headspace Australia
Beyond Blue
Guiding their way back
Beyond Blue Beyond Now

Black Dog Institute
myCompass Personalised Self-Help Tool
Lifeline
Chat Crisis Support - 13 11 14

Crisis Chat 7pm-12pm

Crisis Text 6pm-12am: 0477 13 11 14

Suicide Call Back Service - Online and video chat: 1300 659 467

QLife for LGBTIQ+: 1800 78 99 78

Kids Helpline: 1800 551 800

Mensline: 1300 78 99 78

Open Arms for Veterans and their families: 1800 011 046





Gwandalan National Palliative Care Project

This project aims to improve access and the quality of palliative care service delivery for Aboriginal and/or Torres Strait Islander people throughout Australia, by providing a suite of tailored education and training materials to support cultural safety within palliative care services.





<u>Specialist Palliative Rural Telehealth</u> <u>service: Information for clinicians.</u> <u>Queensland Health</u>

PallConsult is funded by Queensland Health and has been designed to boost the ability of local healthcare teams to deliver patient-centred palliative care, especially in rural and remote parts of the State.

Palliative care support line for clinicians
SA Health

The Palliative Care Advice Service
Health Vic

<u>PEPA</u> Program of Experience in the Palliative Approach





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communication, say the word 'dying' emotional insight, honesty, dignity & compassion professional mindset, confidence, self care person-centred care, respect the patient, their family and wishes

Professional practice, *identify end-of-life triggers*. *Telling the truth with kindness*

Rawlings D, Devery K, Poole N

Improving quality in hospital end-of-life care: honest communication, compassion and empathy, *BMJ Open Quality* 2019;**8:**e000669. doi: 10.1136/bmjoq-2019-000669

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Rural remote and very remote

The learners of EOLE include doctors, allied health professionals and nurses. Most of them are from major cities and work in acute hospitals in all states and territories in Australia.

Learners from remote and very remote areas showed higher proportion of module completion than learners from the major cities, which seems to indicate that End-of-Life Essentials as an important online resource for health professionals working in the remote areas.





Data Analysis

- Using the AUSTRALIAN STATISTICAL GEOGRAPHY STANDARD (ASGS) REMOTENESS STRUCTURE
- All analyses were conducted using SPSS version 25.00
- A value of P <. 0.05 was considered statistically significant.
- The significance of differences in single module completion status was tested by Cochran's Q test
- The significance of differences in proportion of Module completion status among learners from different residential areas was tested by Pearson Chi-Square Tests









- Australian Commission on Safety and Quality in Health Care. (2015) *National Consensus Statement:* essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC.
- 2 Swerissen, H and Duckett, S., 2014, Dying Well. Grattan Institute
- 3 Palliative Care Australia, http://dyingtotalk.org.au/
- White B, et al, (2014) *Prevalence and predictors of advance directives in Australia*, Internal Medicine Journal, 44:10.
- 5 Croxon L, Deravin L, Anderson J. Dealing with end of life—New graduated nurse experiences. *J Clin Nurs*. 2018;27:337–344. https://doi.org/10.1111/jocn.13907
- Glare P, Sinclair C, Stone P, Clayton J, (2015) Predicting survival in patients with advanced disease, in Oxford Textbook of Palliative Medicine, (Cherny N, Fallon M, Kassa S, Portenoy R, Currow D eds) Oxford University Press.
- 7 Chochinov H (2013) Health Care Provider Communication: An empirical model of therapeutic effectiveness. Cancer, May 1;119(9):1706-13. doi: 10.1002/cncr.27949.





www.caresearch.com.au/EndofLifeEssentials



