**CRANAplus– Webinar**
**9 November 2021**

# End of Life Care Opportunities

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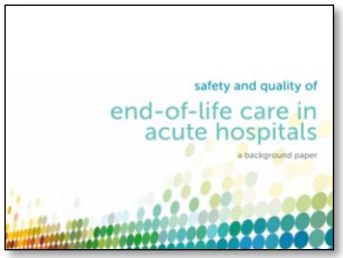
Flinders UNIVERSITY

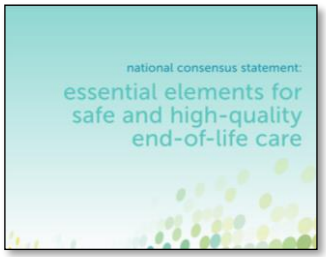
end-of-life ESSENTIALS®

*education for acute hospitals*

Funded by the Australian Government Department of Health

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE




NSQHS STANDARDS

- **End of Life Essentials** – 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**

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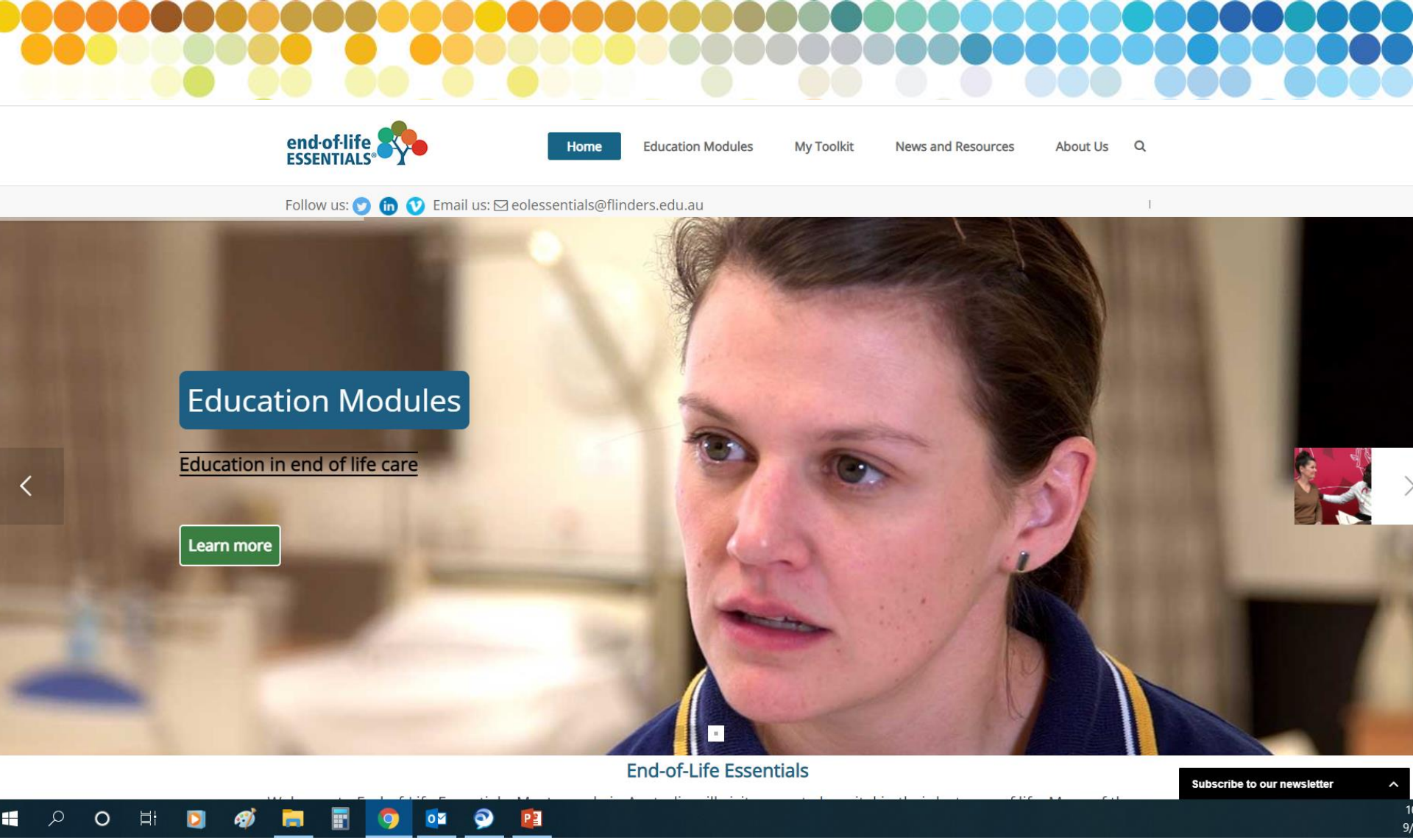


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# eLearning Topics

- 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

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# 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.

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- 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 years[2]
- Think about the population you provide service for in terms of age and other….

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The Gratten Report *Dying Well 2014*

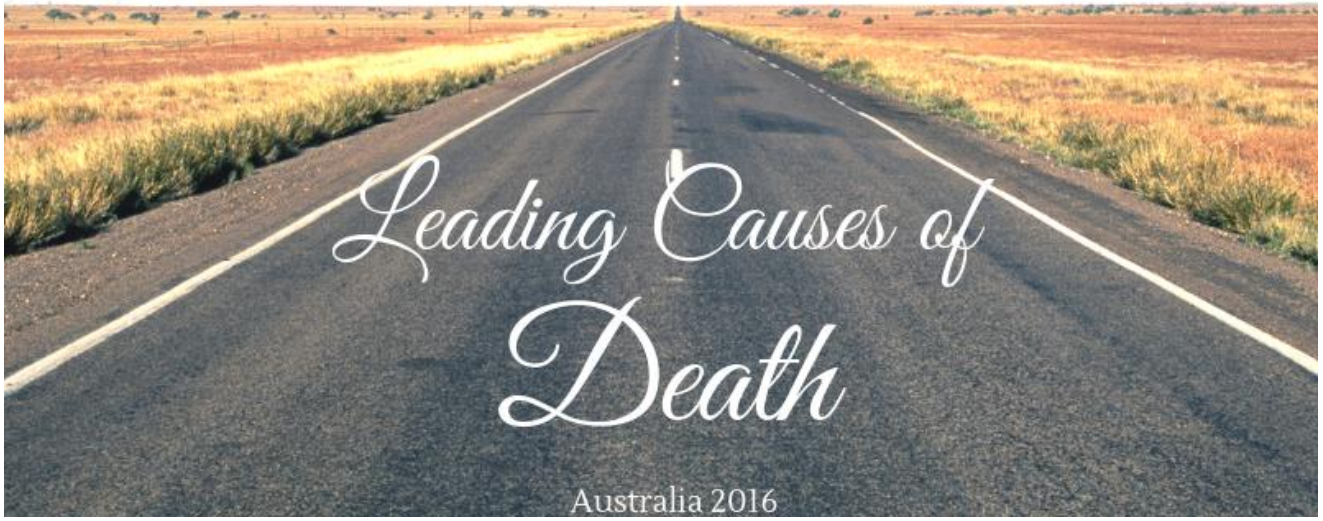
1. CORONARY ARTERY DISEASE

2. DEMENTIA AND ALZHEIMER'S DISEASE

3. CEREBROVASCULAR DISEASE

4. LUNG CANCER

5. CHRONIC OBSTRUCTIVE PULMONARY DISEASE

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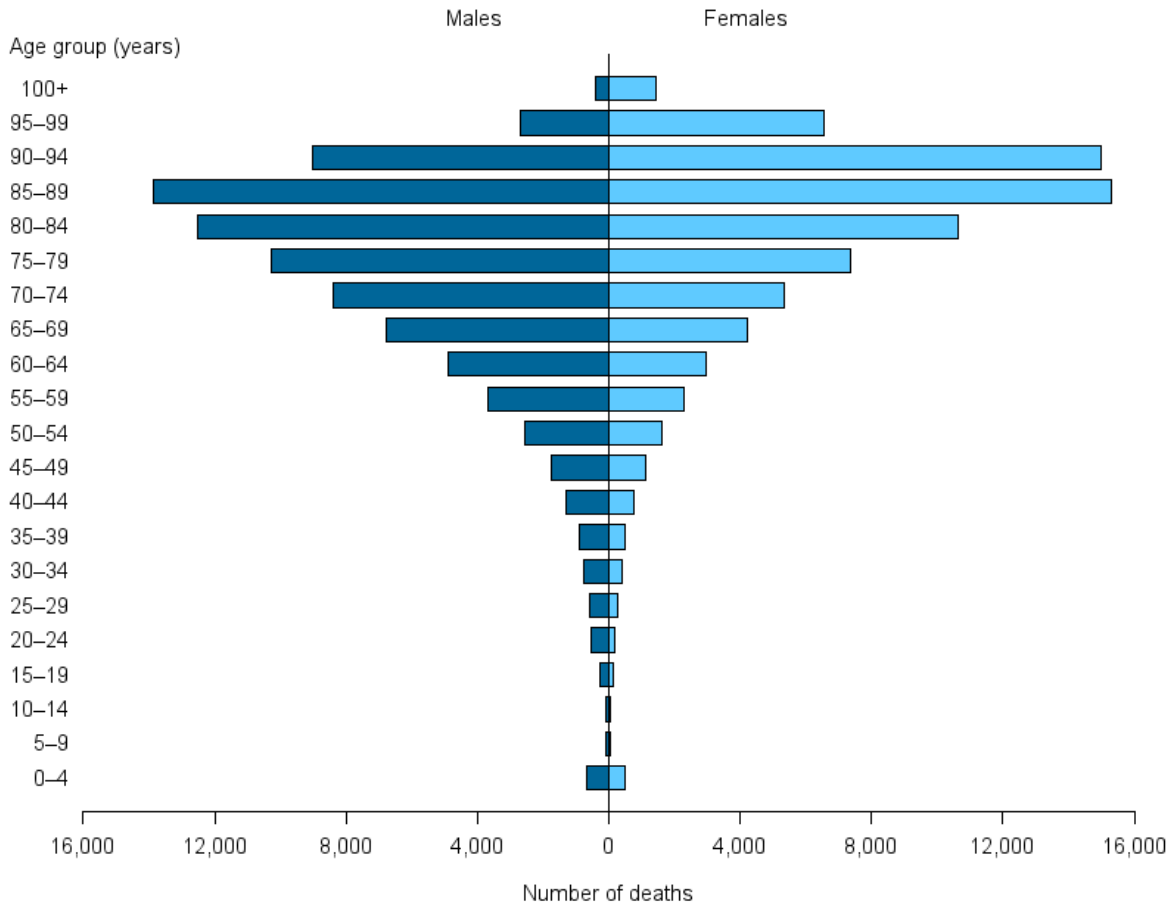


AIHW 2016

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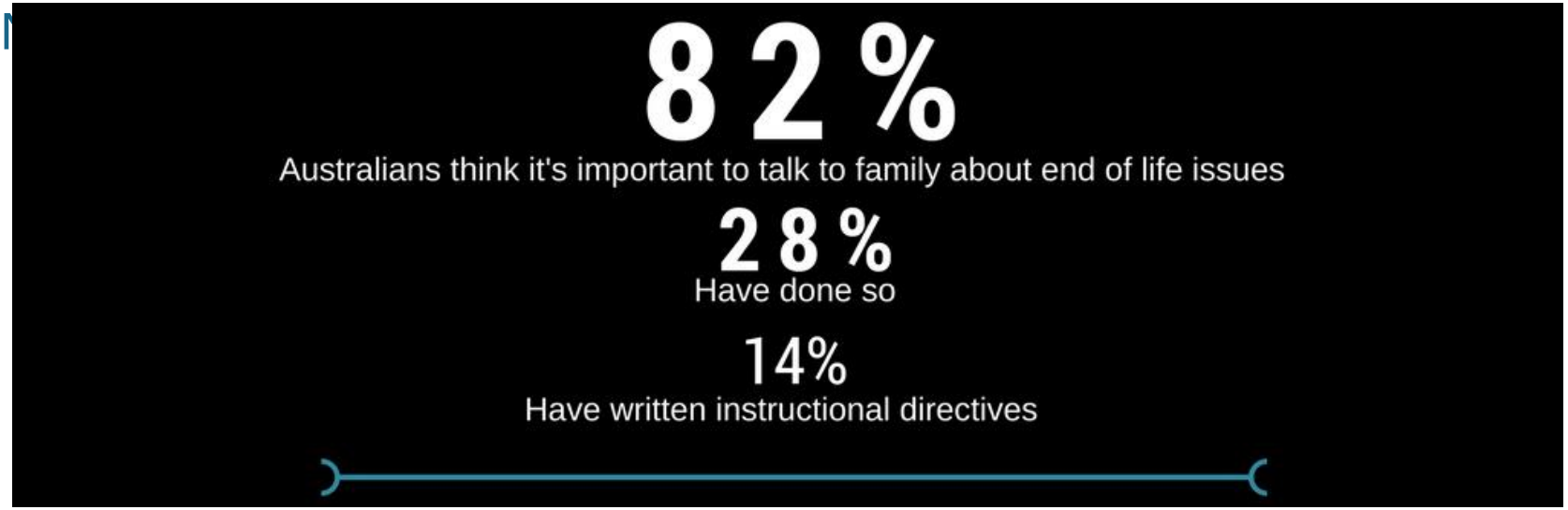


*Figures from*

*3. Palliative Care Australia, http://dyingtotalk.org.au/*

*4. End-of-life Law in Australia, QUT*

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## 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.

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Prognostication in chronic complex illness

# Certainuncertainty

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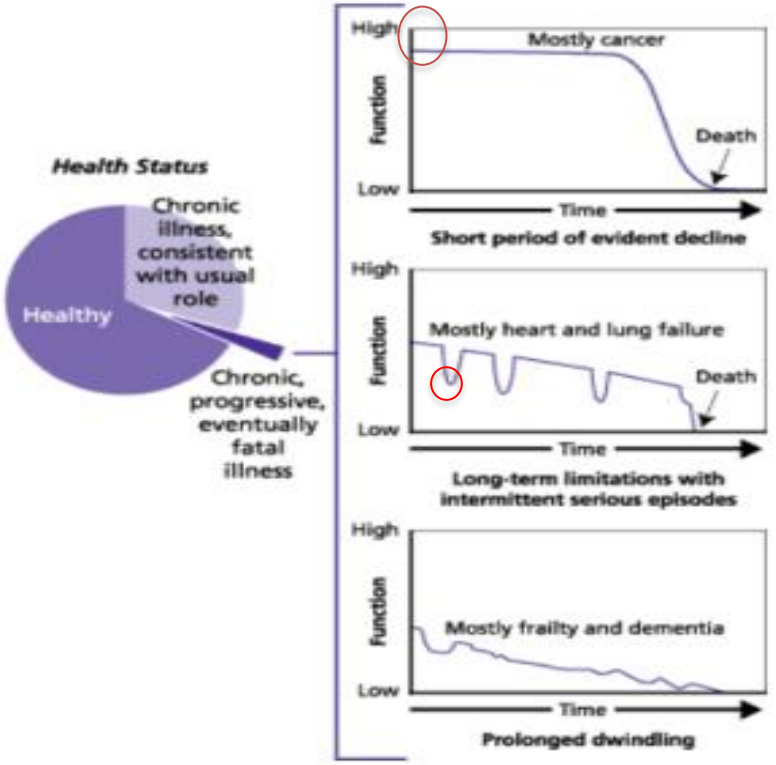
# Patterns of end of life – When are we aware?




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.

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# When does end of life begin?

**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

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## How do we know when to discuss EOLC?

The patient may ask you.

You may have updates from consultants.

You've discussed with the team.

You've used a tool.

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# 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?

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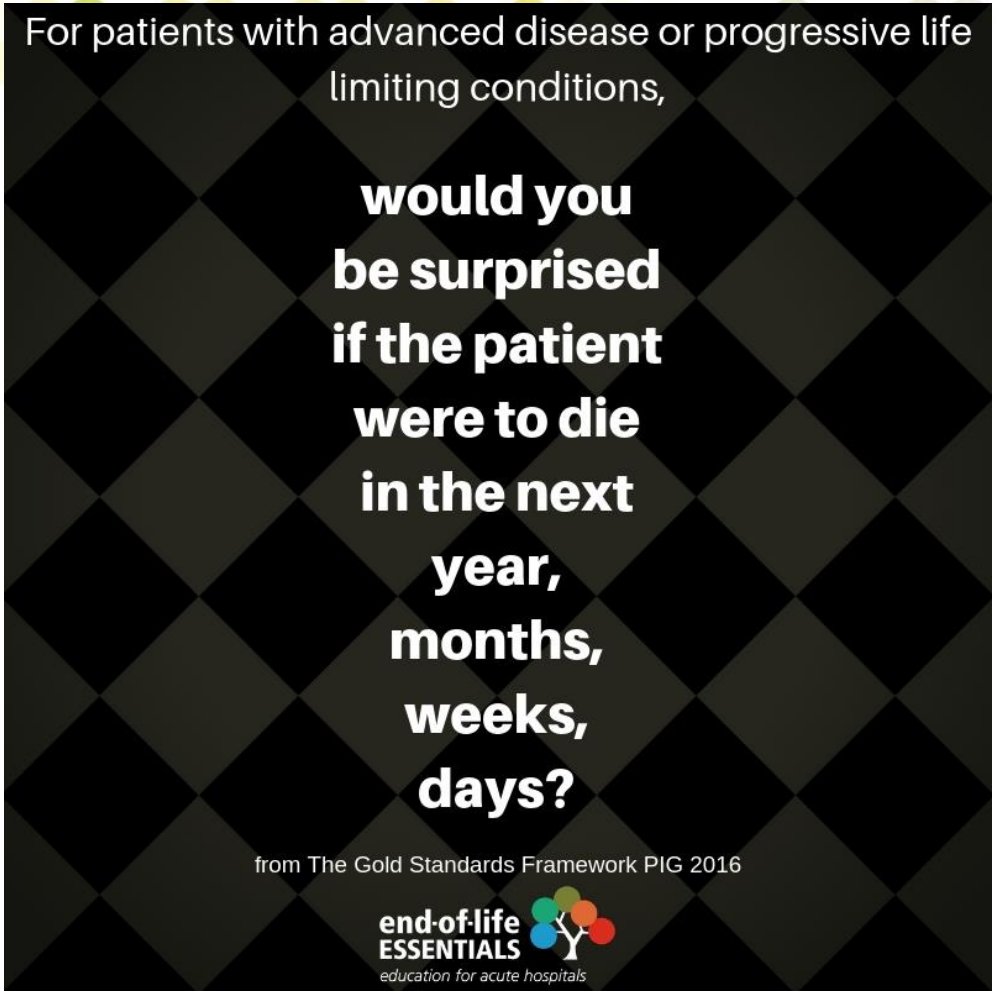


**Also**

**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 Open*,

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New South Wales Department of Health. Guidelines for end-of life care and decision-making (163KB pdf). Gladesville (NSW): NSW Department of Health; 2005 Mar.

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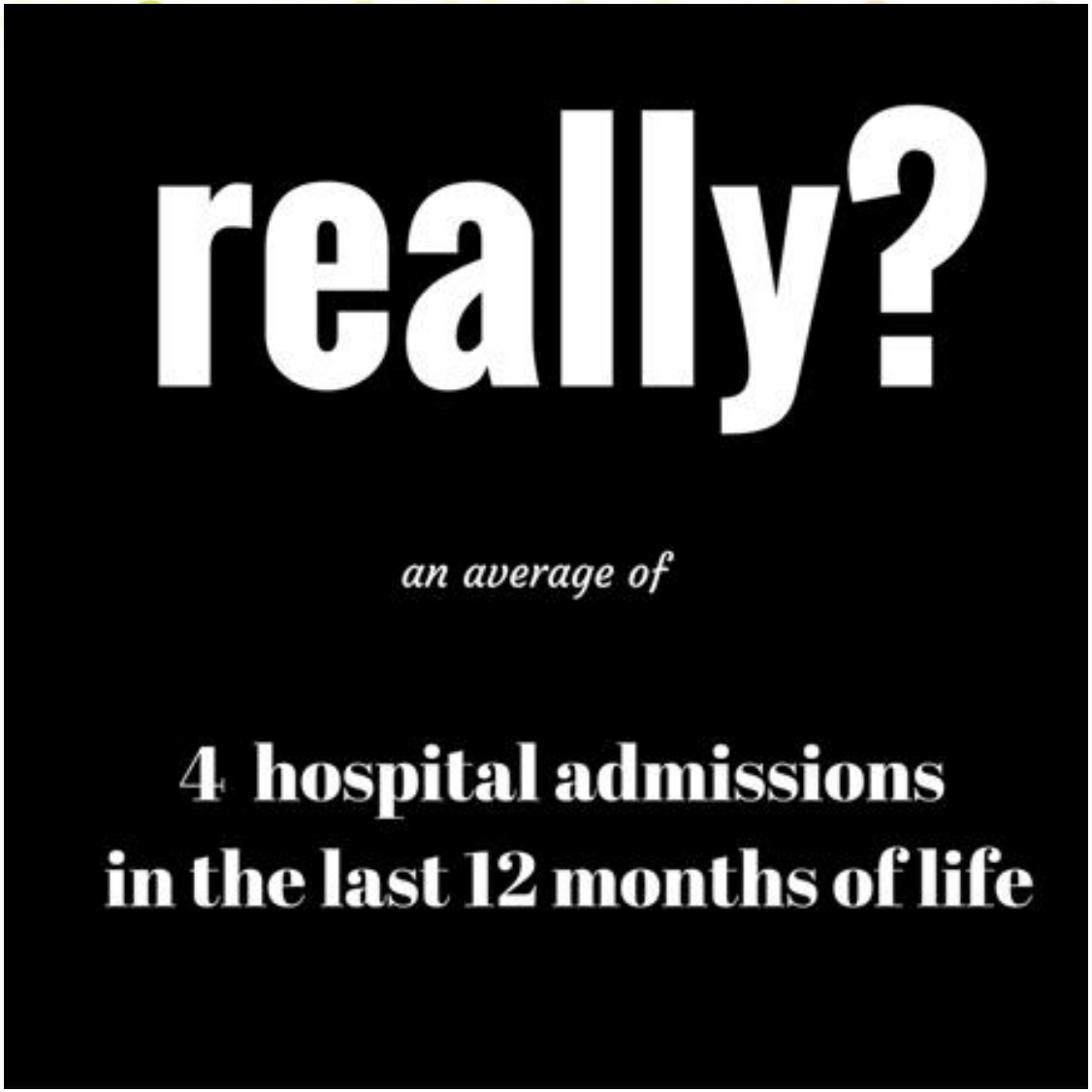


Agency for Clinical Innovation (ACI). Fact of Death Analysis 2011/12 – Use of NSW public hospital services in the last year of life by NSW residents (720KB pdf). Chatswood (NSW) ACI;2015 Sep.

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End-of-life Care

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 settings[5]

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# 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

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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.


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# End of life conversations

enables

choice & planning

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What can you do?

# 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

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# 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?"



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# REMAP

STEPS

**Reframe why the status quo isn't working.**

*we're in a different place*

**Expect emotion and emphathise**

*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*

Adopted from VITAL talk

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

*reacting and responding to treatments & interventions*

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## 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?

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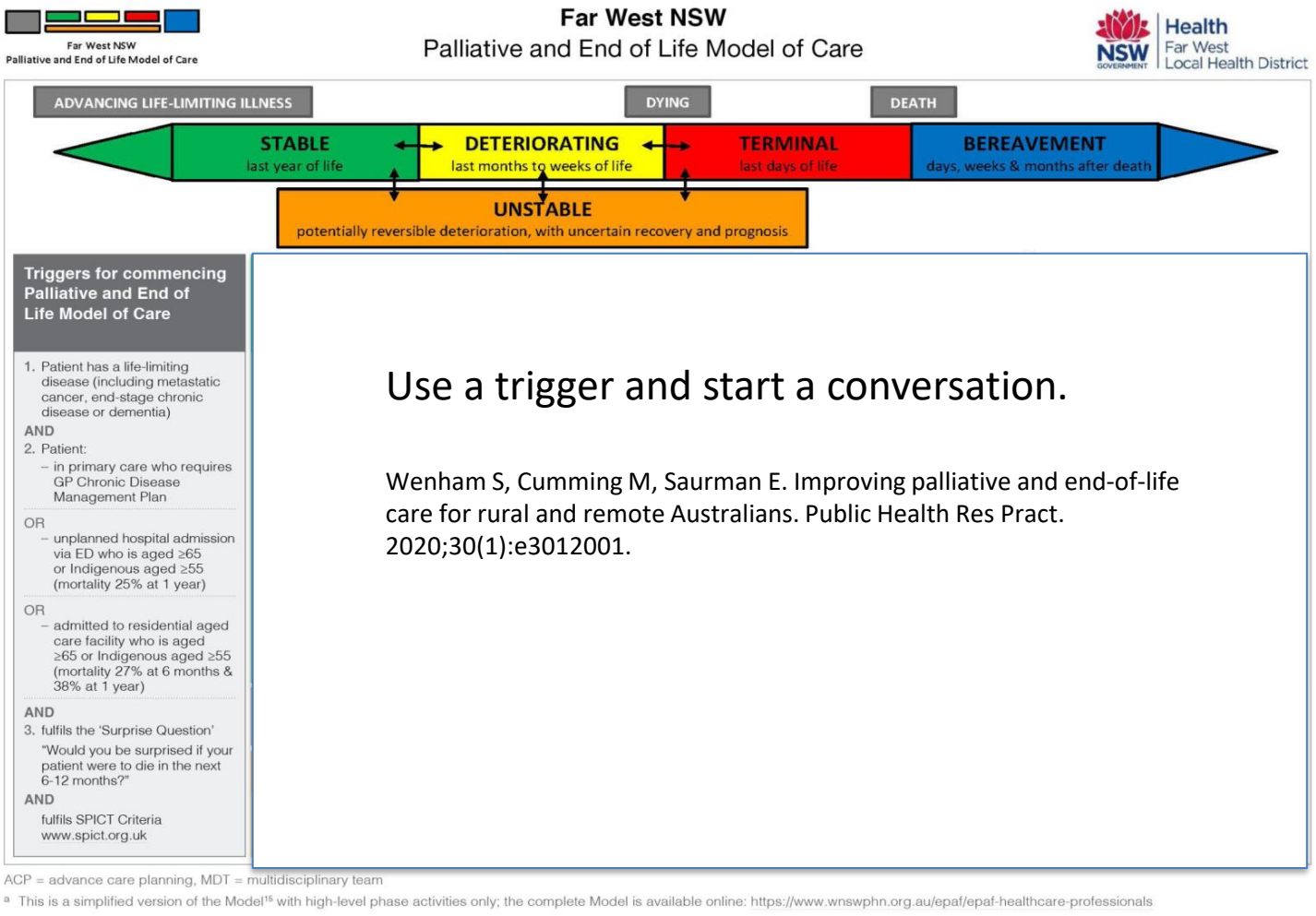
# Remoteness

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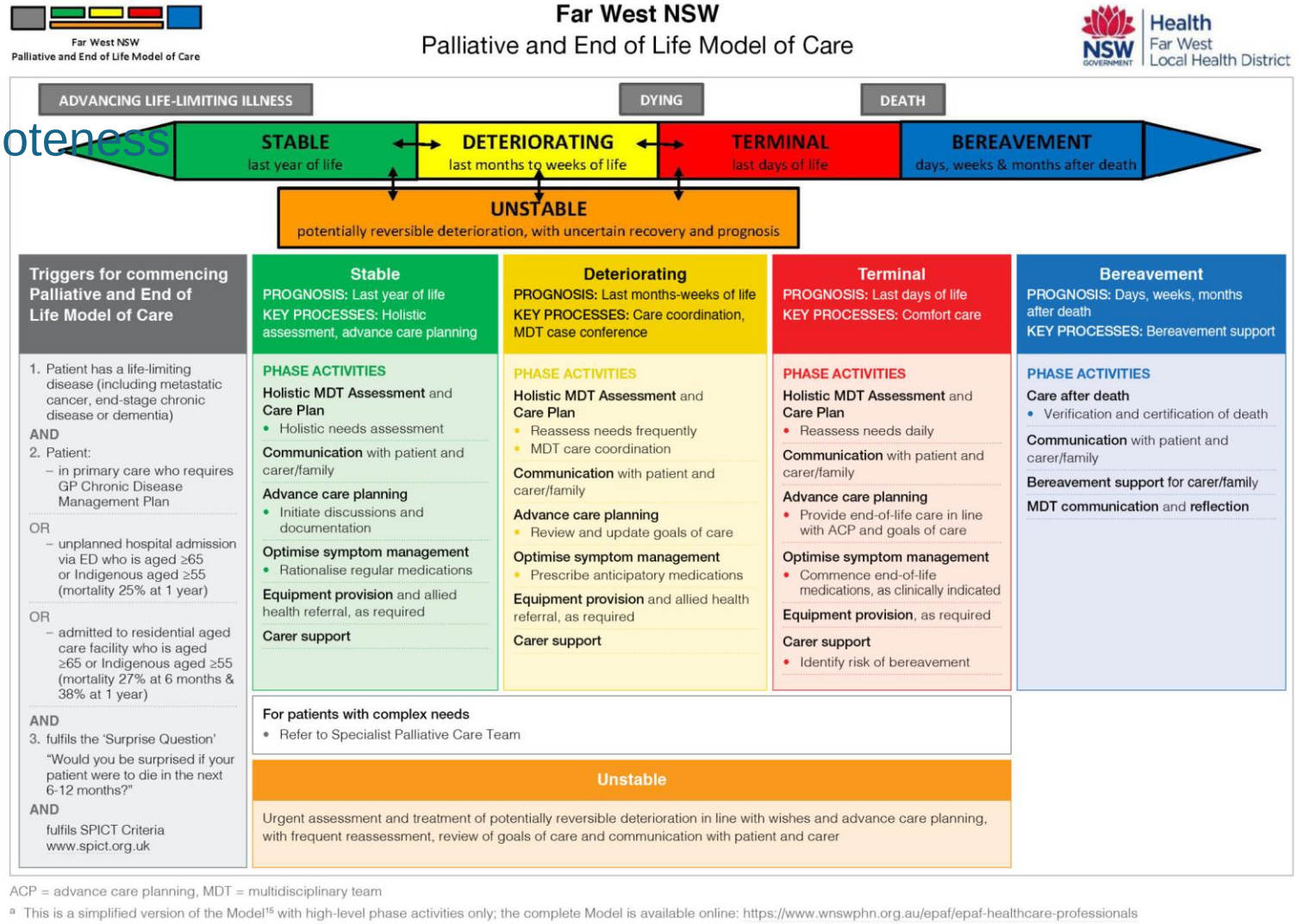
Remoteness




ACP = advance care planning, MDT = multidisciplinary team

[a] This is a simplified version of the Model[15] 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 CareSearch Grey literature database.

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.

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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.

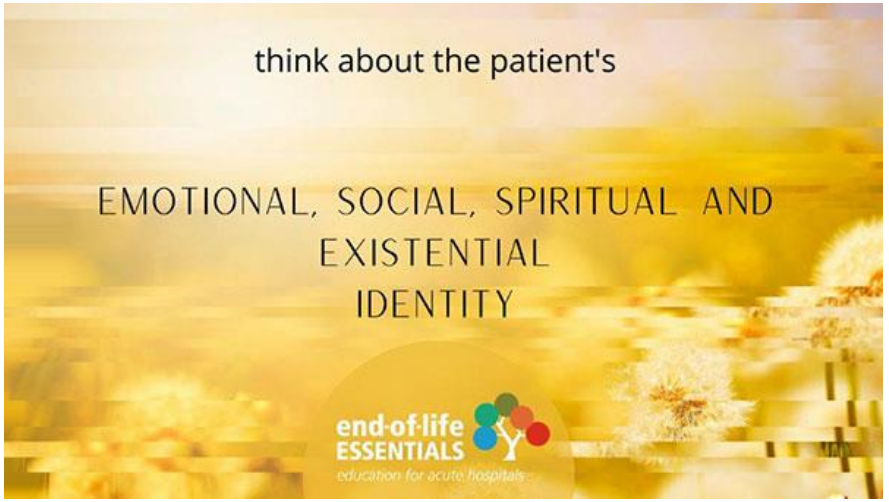
Frailty

Loneliness

Multiple losses

Very individual

Fear, grief, guilt, hope, denial, anger and sadness




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.

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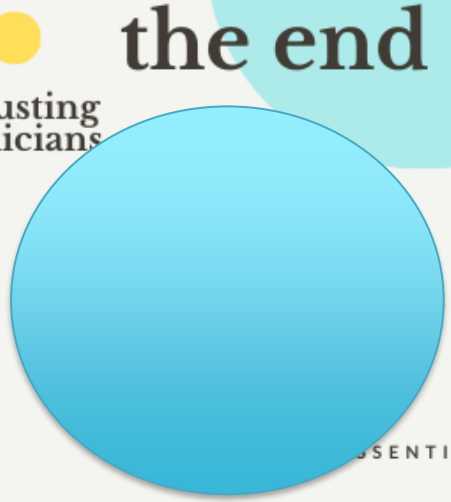
# What is important at the end of life?

*Expert care*

Trusting clinicians

*Compassionate care*

*Effective communication*





Steinhauser et al 2009; Virdun et al 2015; Steinhauser et al 2000; Gott et al. 2008

*Think about this*

**How do you sustain and cultivate your own humanity?**

**WELLNESS MATTERS**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# 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

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## Where to find quality free resources and services

**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.

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# Where to find quality free resources and services

Specialist Palliative Rural Telehealth service: Information for clinicians. Queensland Health

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

PEPA Program of Experience in the Palliative Approach

CARESEARCH®
palliative care knowledge network

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# eLearning Topics

- Dying, a normal part of life
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- States of Mind at the end of life

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## Changes to clinical practice

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.

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# 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

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# References


1 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/*

4 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

6 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.


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End-of-Life Essentials would like to thank the many people who contribute their time and expertise to the project

www.caresearch.com.au/EndofLifeEssentials

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