

# Communication in End-of-life care

End-of-Life Essentials (EOLE) is a National Palliative Care Project funded by the Australian Government Department of Health, Disability and Ageing, and delivered by Flinders University.

1. Reminder – how and when we die
2. Why is it challenging to discuss end of life?
3. Confidence and skills in what?
4. End-of-Life Essentials
5. One thing to change in practice to deliver effective end-of-life care (eolc)



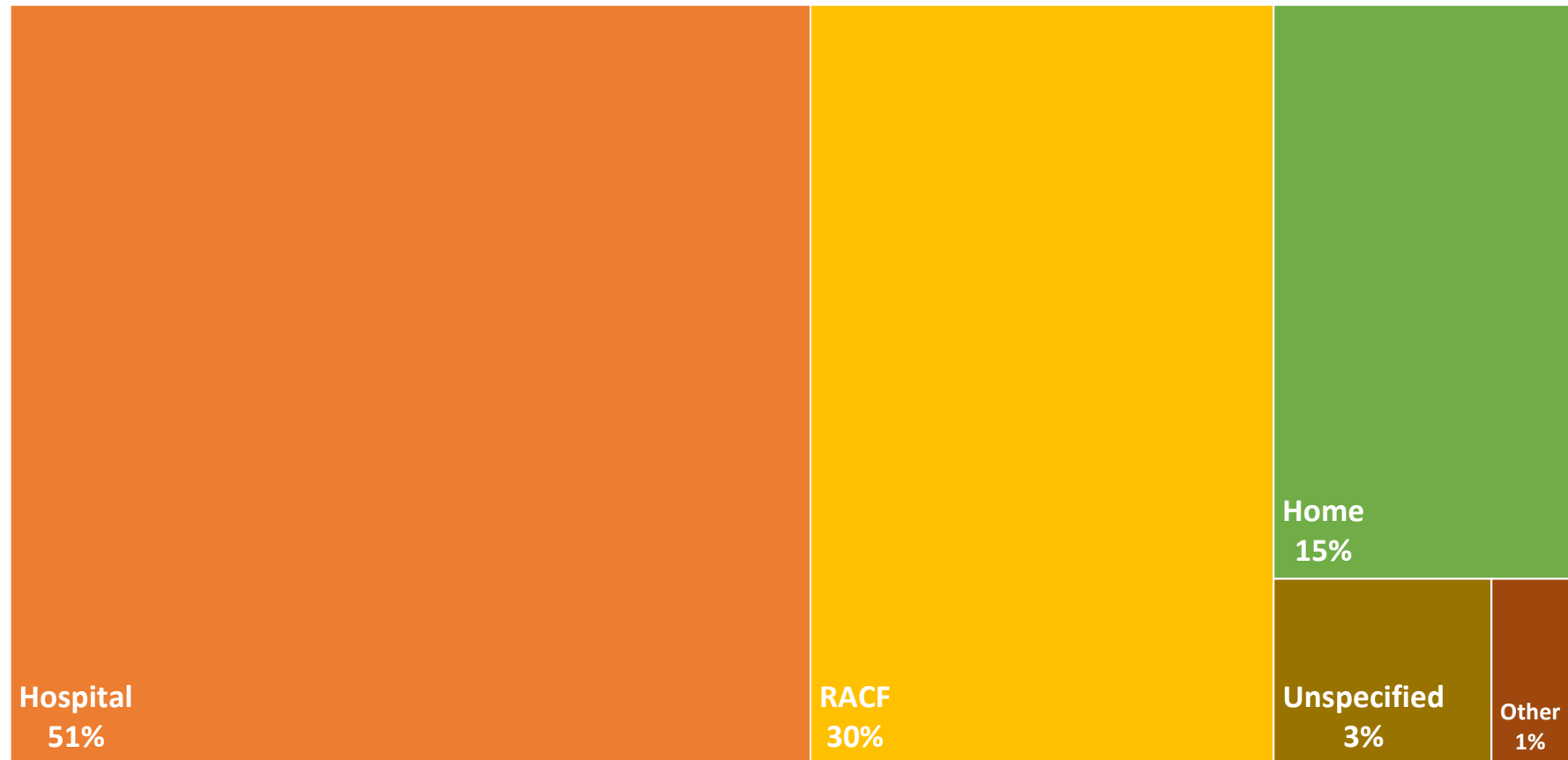
# Australians are living longer than ever before

- A dramatic shift in the age of when we die:
  - In 1970 half of men died before the age of 70 years, in 2010 only 18% of men had died before 70.
  - Similarly, 28% of women had died before 70 and this has fallen to 11%.
  - Disability, dementia and comorbidities are prevalent in this age group and substantially reduce quality of life.

*Andrea J Curtis, Richard Ofori-Asenso, Manoj Gambhir and John J McNeil, Mortality among middle-aged Australians, 1960–2010: implications for prevention policy, Med J Aust 2018; 208 (10): 444-445. || doi: 10.5694/mja17.00852*

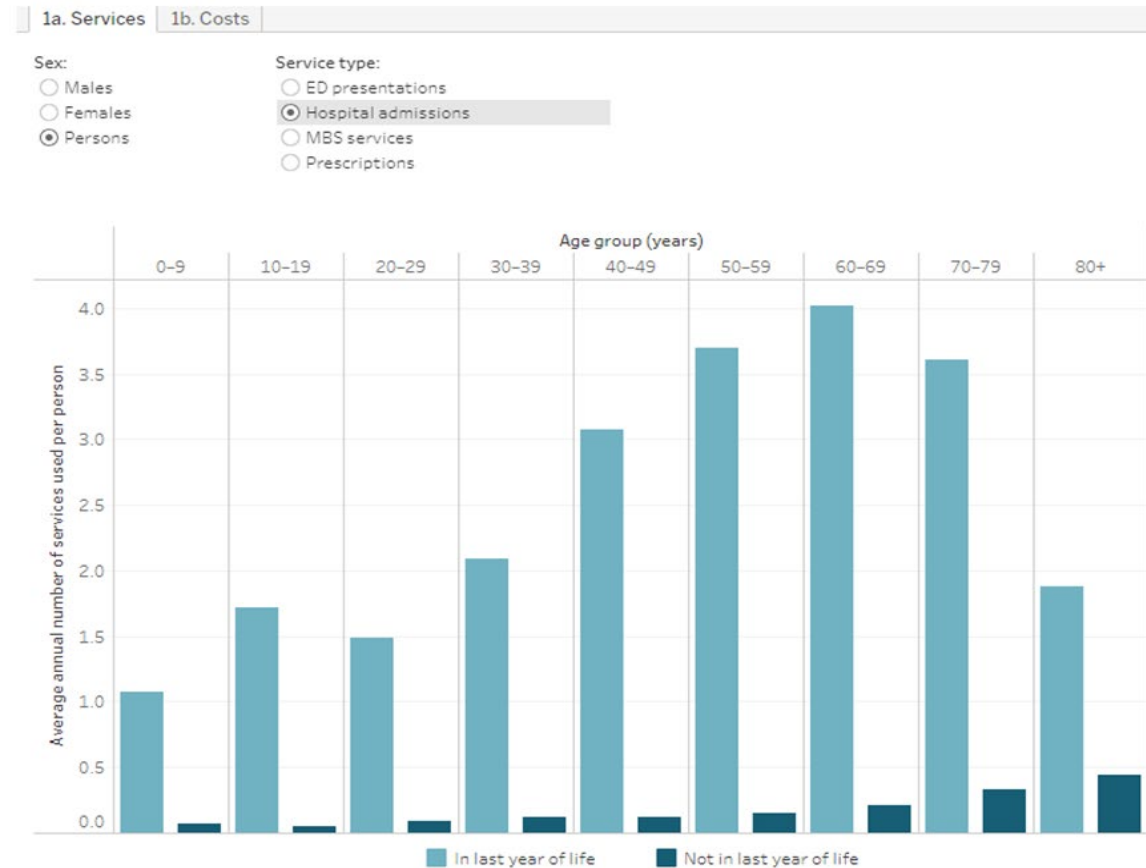
# Australians die in health care settings

PLACE OF DEATH 2021 ABS



# AIHW 2022 – The last year of life: patterns in health service use and expenditure

Figure 1: Average annual number of health services used (a) and costs (b) per person by sex, age, service type and whether in last year of life



<https://www.aihw.gov.au/reports/life-expectancy-deaths/the-last-yr-of-life-health-service-use-patterns/contents/health-service-use-and-costs-in-the-last-year-of-l>

Notes:

1. Analysis for the *In last year of life* group includes services used by this group in the 12 months before their death. This includes services used between 1 July 2010 and 31 December 2016, presented as average number of services used, per person.
2. Analysis for the *Not in last year of life* group includes services used by this group between 1 July 2010 and 31 December 2016, presented as average number of services used per person over a 12-month period.

## On average 1-4 hospital admission in the last year of life.

In the largest Australian study of hospital deaths (1693 inpatients) reveals **only 12% of patients have existing advance care plans**, recognition of death is predominantly within the last 48 hours of life, with 60% receiving investigations and interventions during this time with late symptom relief.

Decisions to involve palliative care or start conversations about supportive care often happened in the last 48 hours of life. Recognition of dying happens hours or days prior to death \*

**Enormous opportunities to recognise end of life, meet needs and develop goals of care.**

\*Mitchell I, Lacey J, Anstey M, Corbett C, Douglas C, Drummond C, Hensley M, Mills A, Scott C, Slee JA, Weil J, Scholz B, Burke B, D'Este C. Understanding end-of-life care in Australian hospitals. Aust Health Rev. 2021 Jun 2. doi: 10.1071/AH20223.

# Why is it challenging to plan and discuss end of life?

- Medical and health care successes mean that often patient deterioration is slow, punctuated by acute deterioration with only some recovery. Patient function very slowly deteriorates over time. Dying takes time.
- Doctors, nurses and allied health professionals have entered their professions to improve patient ill health & function and make people feel better.
- It's a mindset shift to move from active management of illness to End-of-Life care in a busy hospital environment.

So often identification of end of life is left till hours or days before death.

# Confidence and skills in what?

- Identifying the end of life in patients
- Talking about the end of life
- Talking with our teams
- Looking after ourselves and each other
- For hospitals and organisations - they show leadership and know that end of life care is their core business

What is  
important at  
the end of life?

ENDOFLIFEESSENTIALS.COM.AU

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

## Key points to remember<sup>1-4</sup>

- Offering to discuss end-of-life issues will not cause harm to your patients.
- Anxiety for patients and clinicians is normal when discussing end-of-life issues.
- No matter your role or where you work, you can make a huge difference by giving patients and their families the chance to talk and prepare for the end of life.



# Patient-centred care and communication

The following concepts define patient-centred care:

- Informing and involving patients and those important to them
- Eliciting and respecting patient preferences
- Engaging patients in the care process
- Treating patients with dignity
- Designing care processes to suit patient needs, not providers
- Ready access to health information
- Continuity of care.<sup>6</sup>



## A patient's point of view



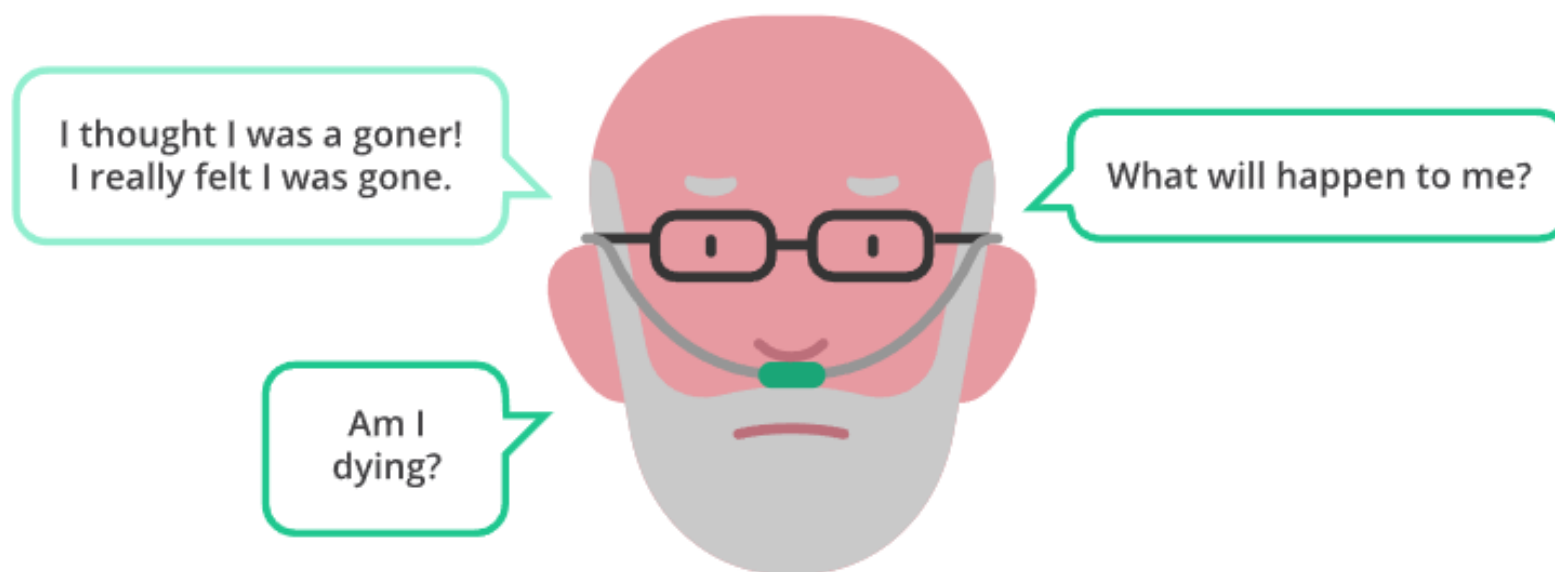
[CLICK THIS LINK](#)



To watch 'The Patient's Perspective' animation, featuring a patient with cancer. How often do you consider the patient as a person with a life, family, and vulnerabilities?

# Be prepared

Unexpected questions or comments from patients and families are common...



## Case study: Joan



[CLICK THIS LINK](#)

To watch the film 'I thought I was going to die', featuring a patient, Joan.

Spend a few moments now and consider how you would respond to the patient in the film.

Be honest. [How would you respond?](#)

If you feel comfortable, share and discuss in a group.

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.**

## How do you know when to discuss end-of-life care?



- The patient may directly ask you.
- You may have updates from consultants and your team.
- You've discussed with the team.
- You've used a tool like the SPICT.

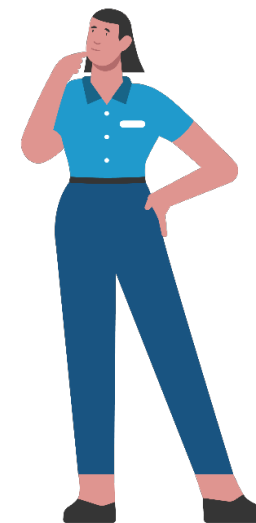
# Tips for facilitating conversations with patients



- Use plain language.
- Offer repeated explanations as requested.
- Show the patient that they have your full attention.
- Invite the patient to have a support person with them.
- Respect the patient's need for privacy.
- When speaking with the patient, be seated at a comfortable distance at the patient's eye level.<sup>4</sup>

# Example questions for you to adopt and adapt

- “What worries you most about your illness?”
- “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?”
- “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?”<sup>7</sup>



# REMAP

A graphic titled 'REMAP' with 'STEPS' in the center. The background is a light blue gradient with a wavy pattern at the bottom. The text is white and black. The steps are: 1. Reframe why the status quo isn't working. we're in a different place. 2. Expect emotion and empathise. I can see you're really concerned about X. 3. Map the future. Given this situation what's most important for you? 4. Align with the patient's values. As I listen to you, it sounds like the most important things are ... 5. Plan medical treatments that match patient values. Here is what I can do now that will help you do those most important things.

**REMAP**

STEPS

Reframe why the status quo isn't working.  
*we're in a different place*

Expect emotion and empathise  
*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 . . .*

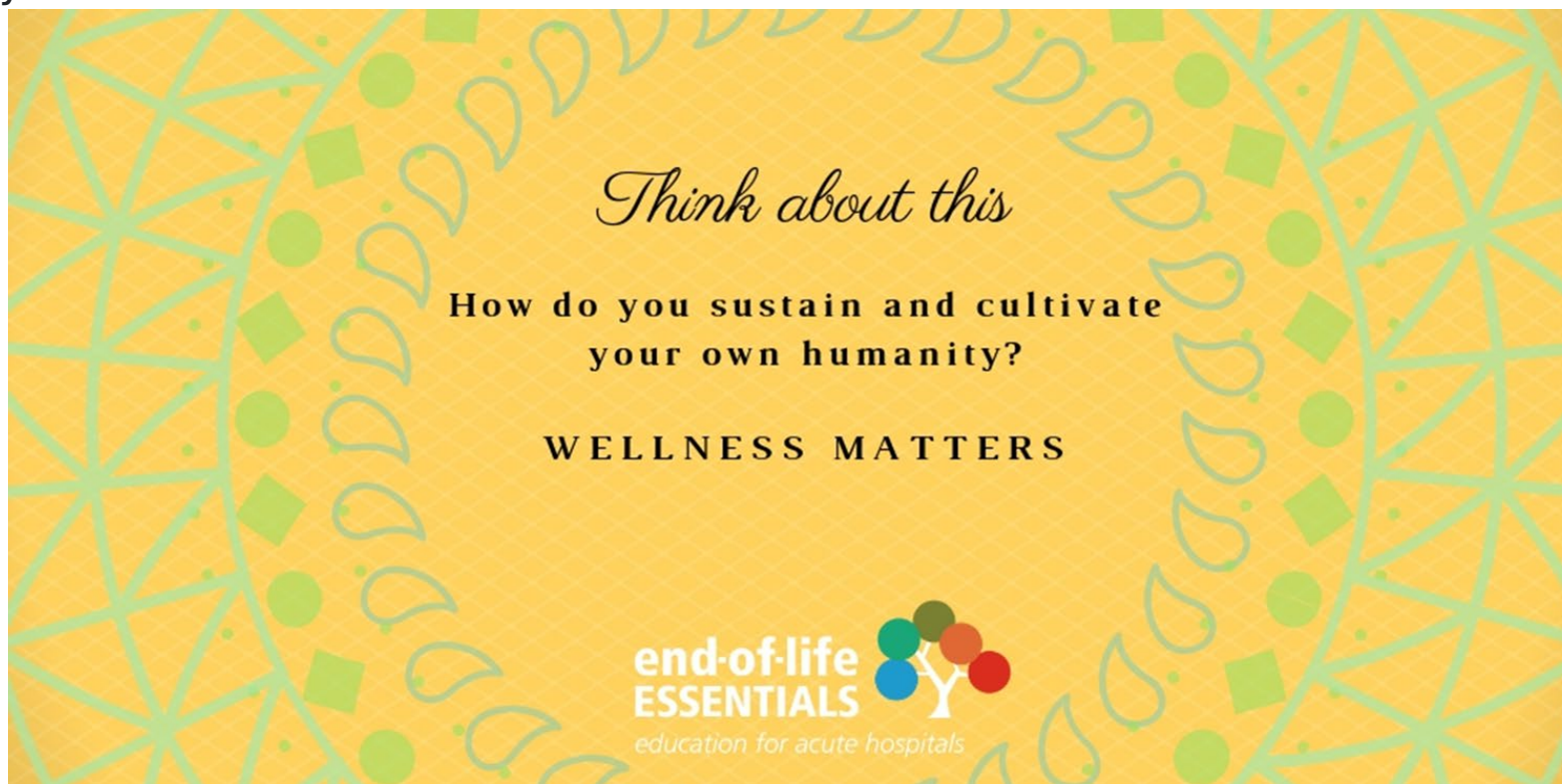
Plan medical treatments that match  
patient values  
*Here is what I can do now that will help you do those most important things*

It can help to use a tool like the REMAP framework<sup>8</sup> when discussing end-of-life care with patients.

**What is one aspect of  
your communication  
that you will develop  
further?**

## Self-care reminder

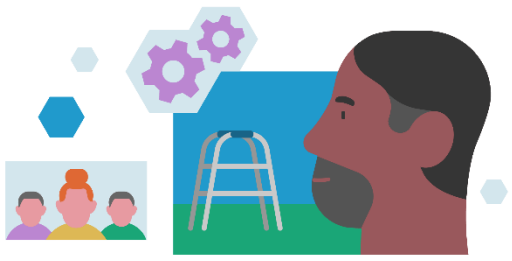
Providing care to dying patients can be stressful. It is important to evaluate your own health and emotions, practicing self-care when possible. Who and what are your supports within your workplace and more broadly?



## Summary

- You can make a huge difference by giving patients and families the chance to talk and prepare for the end of life.
- You can prepare for unexpected but common questions from patients and families, such as *'What will happen to me?'* *'Is this the end?'*
- Resources are available for you to extend your practice by adapting and adopting end-of-life care skills.
- End-of-Life Essentials advocates proactive approaches to [professionals' quality of mental health](#).

# Which modules should I complete next?



Teamwork and Escalating Concerns



Goals of Care at the End of Life



Bereavement Care



# References

1. Fried TR, Bradley EH, O'Leary J. [Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians.](#) J Am Geriatr Soc. 2003 Oct;51(10):1398-403.
2. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. [Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment.](#) JAMA. 2008 Oct 8;300(14):1665-73.
3. Block SD. [Perspectives on care at the close of life: psychological considerations, growth, and transcendence at the end of life: the art of the possible.](#) JAMA. 2001 Jun 13;285(22):2898-905.
4. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. [Factors considered important at the end of life by patients, family, physicians, and other care providers.](#) JAMA. 2000 Nov 15; 284(19):2476-82.
5. Meier DE, Back AL, Morrison RS. [The inner life of physicians and care of the seriously ill.](#) JAMA. 2001;286(23):3007-3014.  
doi:10.1001/jama.286.23.3007
6. Robb G, Seddon M. [Quality improvement in New Zealand healthcare. Part 6: keeping the patient front and centre to improve healthcare quality.](#) N Z Med J. 2006 Sep 22;119(1242):U2174.
7. 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.
8. VitalTalk. [Transitions/Goals of Care: Addressing Goals of Care: Using the REMAP tool.](#) 2019.