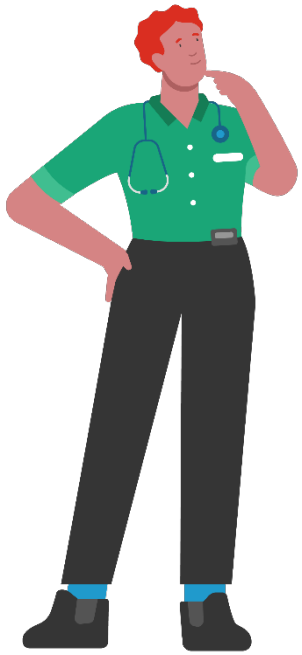
Communication in end-of-life care

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

- Reminder – how and when we die
- Why is it challenging to discuss end of life?
- Confidence and skills in what?
- How to manage conflict



Australians are living longer that ever before

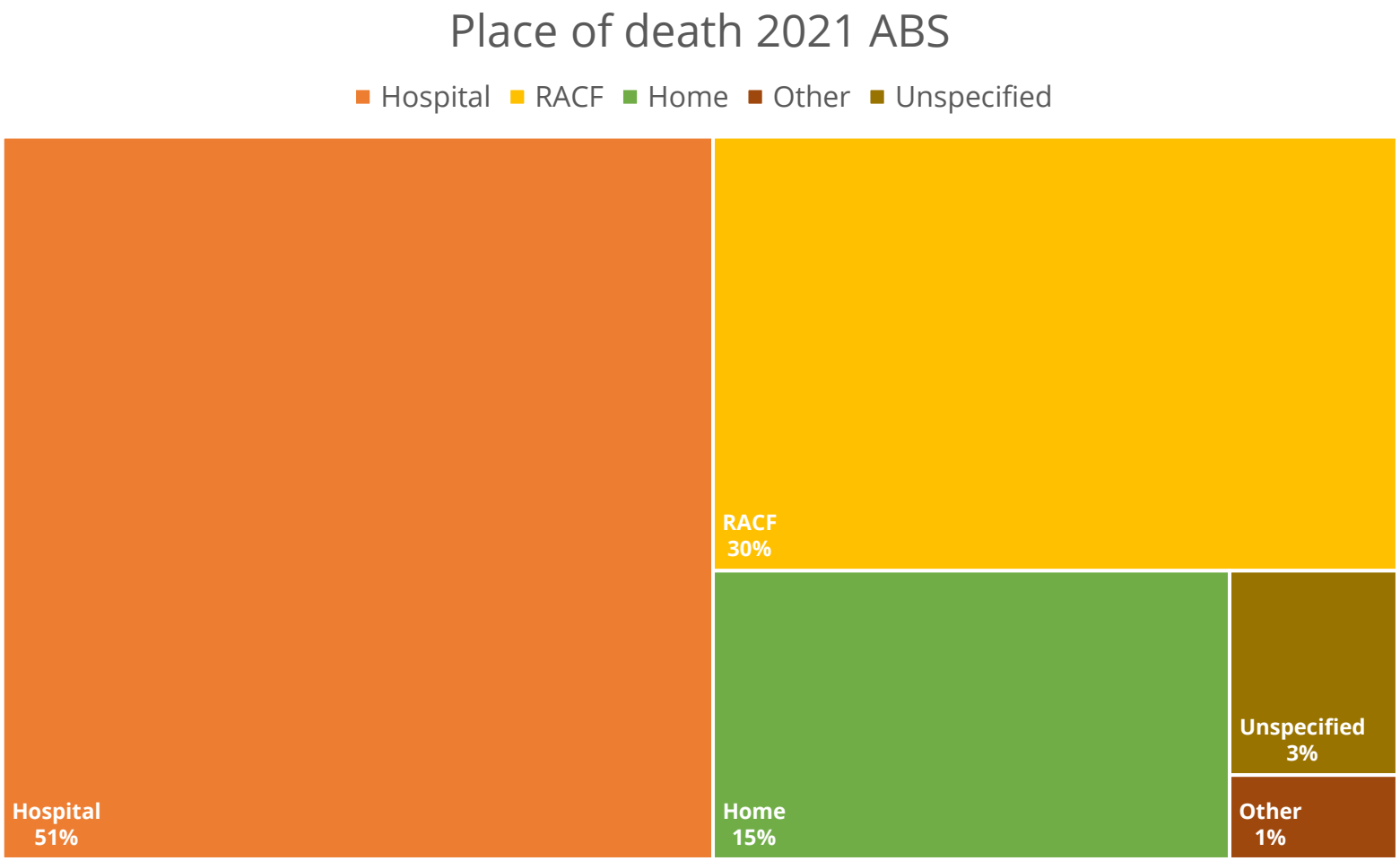
A dramatic shift in the age of when we die –

- We are dying older - median age at death is 80 years for males, and 85 years for females.
- Disability, dementia and comorbidities are prevalent in this age group and substantially reduce quality of life.

AIHW. 2024. Deaths in Australia.

Curtis AJ, Ofori-Asenso R, Gambhir M, McNeil JJ. Mortality among middle-aged Australians, 1960–2010: implications for prevention policy. Med J Aust. 2018;208(10):444-445

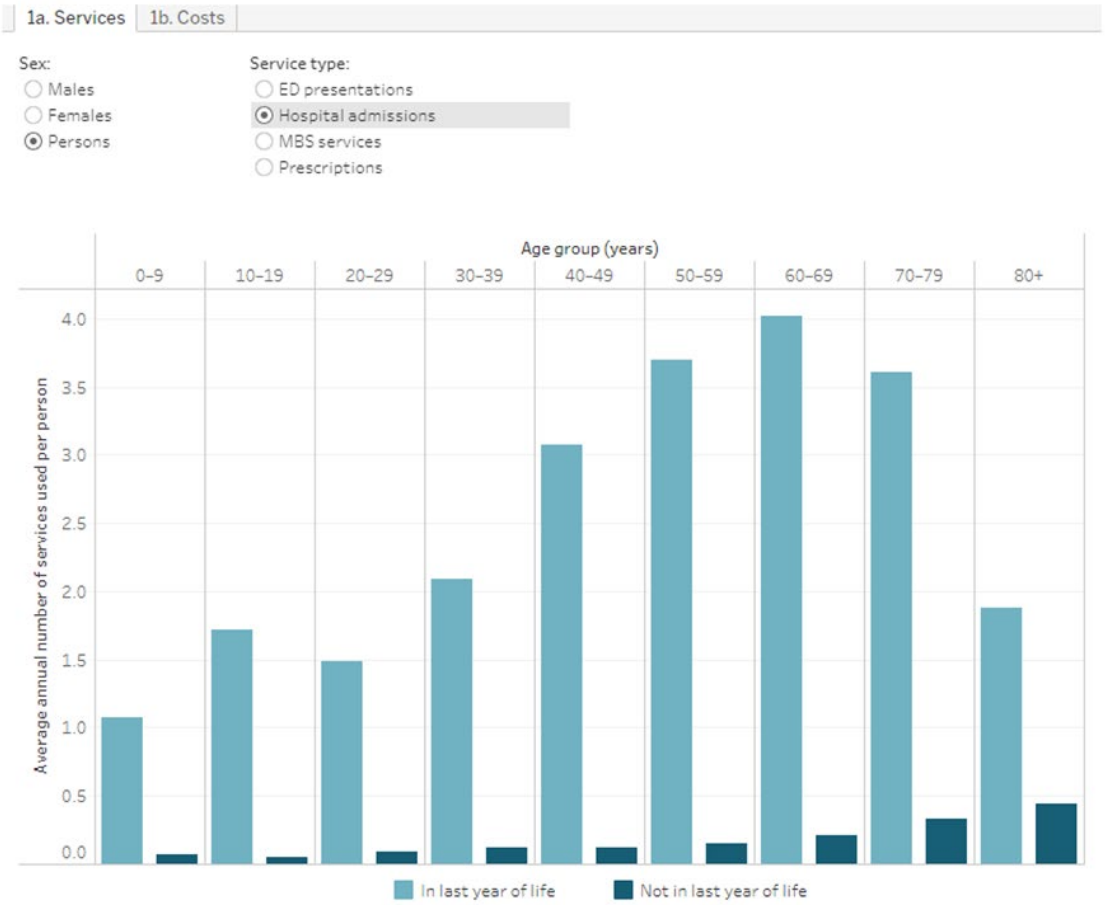
Australians die in health care settings



ABS. 2021. Classifying Place of Death in Australian Mortality Statistics.

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



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.

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

On average 1-4 hospital admissions in the last year of life

And, only 12% of patients have existing advance care plans, recognition of dying is predominantly within the last 48 h of life, with 60% receiving investigations and interventions during this time with late symptom relief. 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 2:540-547

Why is it challenging to 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?

- ABCD Care –attitudes, beliefs, compassion and dialogue – *Chochinov*
- 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 - showing leadership and knowing that end-of-life care is core business.

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What is important at the end of life?

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un et al 2015; Steinhauser et al 2000; Gott et al. 20

A patient's perspective

Key points to remember[1-4]

- 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.

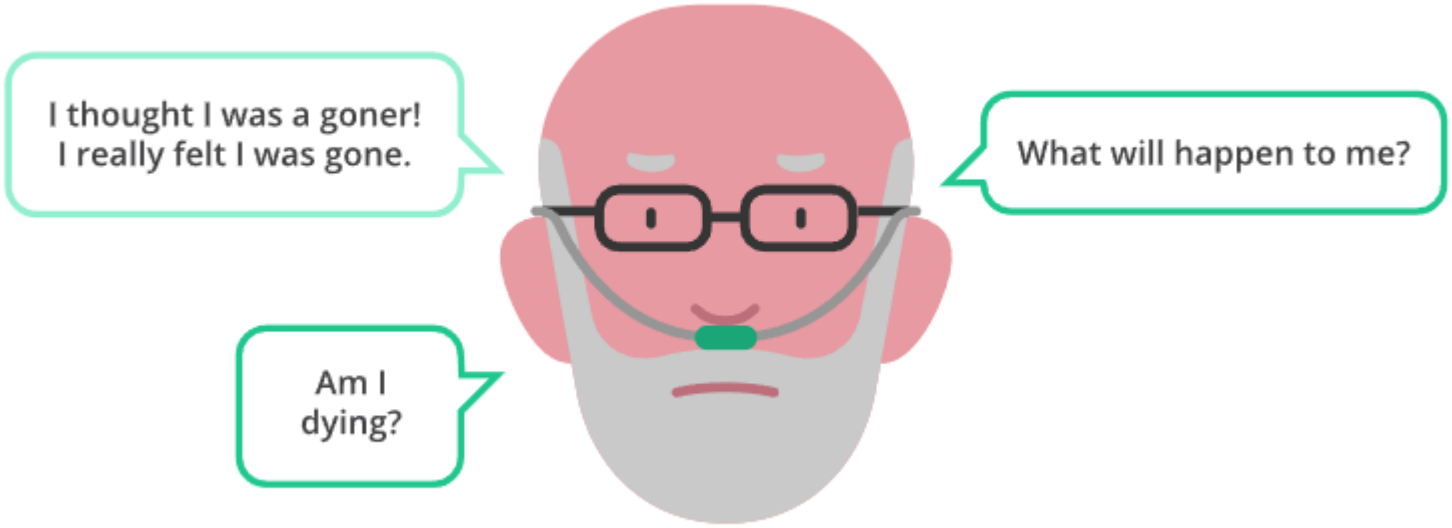
Patient-centred care and communication

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.[6]

Be prepared

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



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.

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.

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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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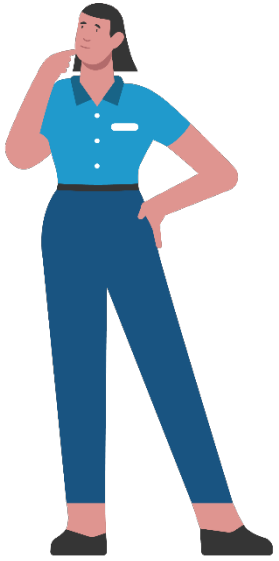
Example questions for you to adopt and adapt

- “What worries you most about your illness?”
- “What are your most important [hopes/expectations] about the future?”
- “As you think about the future 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?”[7]



REMAP

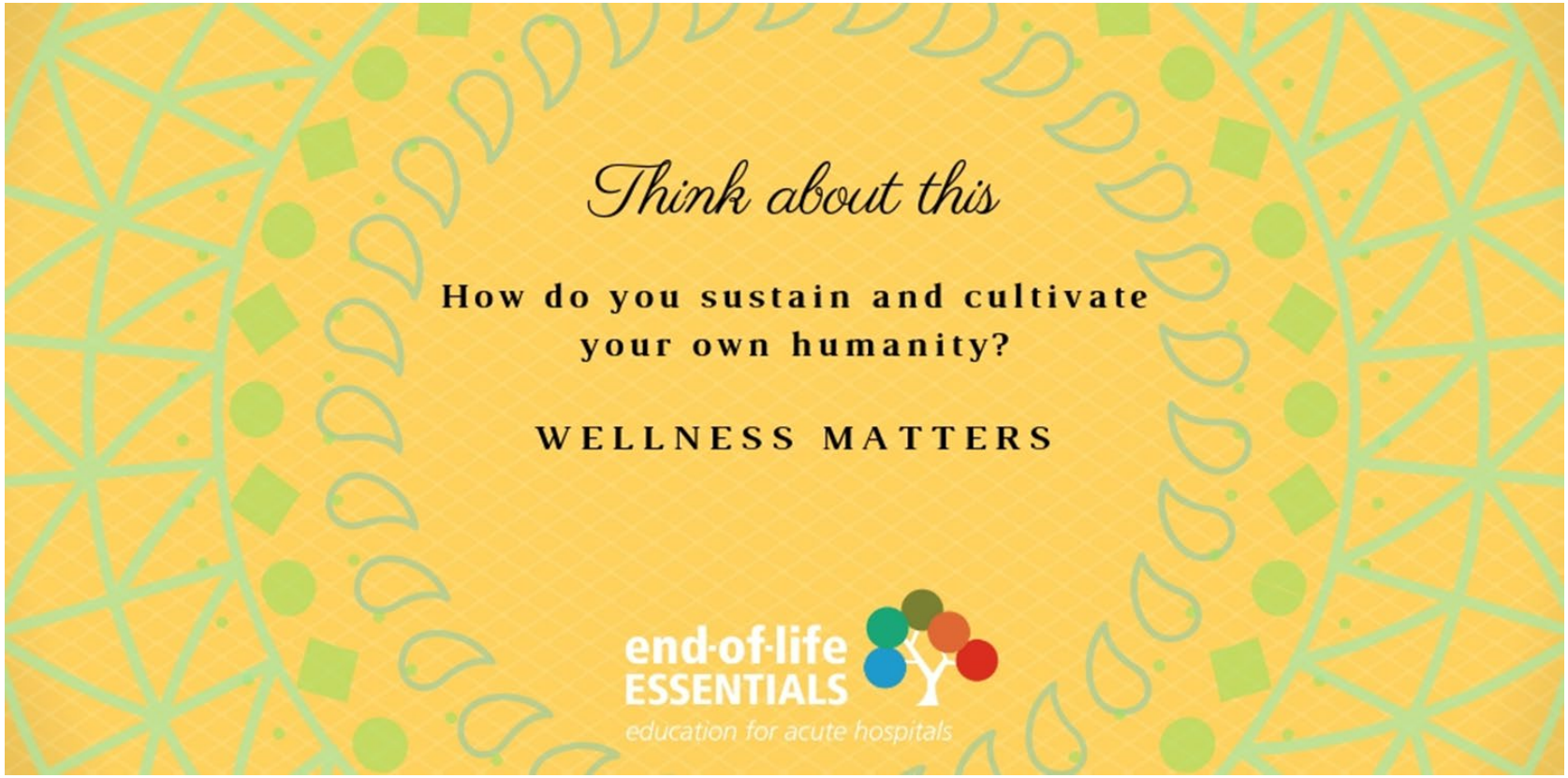
It can help to use a tool like the REMAP framework[8] when discussing end-of-life care with patients.

Adopted from VITAL talk REMAP

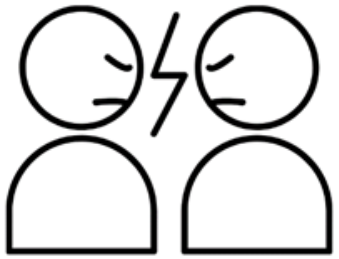

What is one aspect of your communication that you will develop further?

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?



So many complex teams providing complex care to patients with complex needs.



Imagine a patient - Mr Georgiou

A family request that he is told nothing of his diagnosis, advanced head and neck cancer. Importantly, they do not want their father to know he has less than one year to live. The patient, who is fully competent to make his own decisions, has directly asked the nurse *what will happen to me*?

She smiles and answers 'Ah, I think dinner is on its way!' She leaves the room and then pages the RMO to come, fix things up and answer the patient's questions.

The RMO is on his first week with the oncology team and has no idea how to respond. He feels alone. There is no leadership or mentoring about end-of-life care. He avoids the ward.

The nurse, a new graduate feels alone, she never knows what to say. The ward staff are often fatigued at constantly advocating for end-of-life care.

Mr Georgiou feels alone.

He is frightened and exhausted.

He senses he is dying, and he wants to know more.

Maybe no one ever answers Mr. Georgiou's question, he dies with questions unanswered.

All the staff feel disappointed. The rift between the nurses and doctors widens with each death on the ward.

We all want to collaborate, negotiate, have inclusive, emotionally aware conversations and discussions.

Conflict is often seen as unwelcome, however well-managed, respectful responses to conflict has the potential to strengthen team respect and decision-making.

Unresolved conflict and quality care are not compatible.

1. Notice it

ask yourself - are you feeling angry or irritated?

A step-wise approach
Adapted from Back A, Arnold R. Dealing with Conflict in Caring for the Seriously Ill "It Was Just Out of the Question" JAMA March 2005;293:11.

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2. Prepare yourself

am I thinking right?
am I too angry to fully listen?

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3. Find a non-judgemental starting point

what would an impartial third person say this conflict is all about?

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4. Reframe emotionally charged issues

how can I reframe my thoughts and language so to move away from 'Im right'

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5. Respond empathetically

have I responded showing I understand the others feelings and point of view?

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7. If no satisfactory agreement can be reached, get help

who can you call for back up?

The Registered Nurse

The RMO

Mr Georgiou

Speaking up - barriers

- We don’t like to criticise others and especially other disciplines
- Hierarchy/authority in health
- Autonomy of practice
- We don’t want to look ignorant, incompetent, intrusive or negative.

So, we don’t ask questions, don’t admit mistakes, don’t offer ideas and we don’t critique the status quo.

Edmondson AC, Higgins M, Singer S, et al. Understanding Psychological Safety in Health Care and Education Organizations: A Comparative Perspective. *Research in Human Development* 2016; 13: 65-83.

Building Psychological Safety

- Is speaking up!
- Knowing that conflict/difference of opinion happens
- Knowing how to create a climate of openness
- Frame mistakes or uncertainties as learning points
- Acknowledge we are all fallible "*I may have just missed something..*"
- Model curiosity

Edmondson AC, Higgins M, Singer S, et al. Understanding Psychological Safety in Health Care and Education Organizations: A Comparative Perspective. Research in Human Development. 2016;13(1):65-83.

Building psychological safety can take time,
but it can be done to create a culture that values:

Framing issues as learning, this creates a reason for speaking up with ideas.

Sharing with team members that everyone has made mistakes and uses these as a learning or teaching opportunity.

End of Life Care – *therapeutic humility*

Demands of us an ability to manage:

- Complexity – *be confronted and challenged*
- Heightened emotions – *don't avoid, just be*
- Uncertainty – *flexible to not know the right answer*

Chochinov H. Health Care Provider Communication: An empirical model of therapeutic effectiveness. Cancer 2013 May 1;119(9):1706-13.

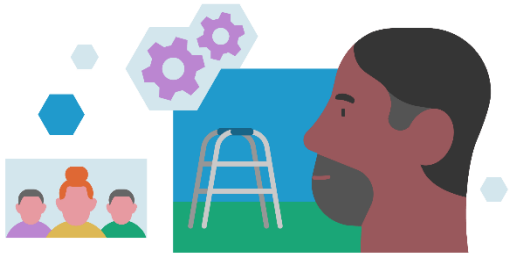
Communication and End of Life Care:

- Begins with us, and a recognition that we will all die, family discussions, work discussions, society discussions.
- Our institutions must recognise that end-of-life care is core business.
- HCPs can increase their capabilities and skills in communication, tolerance of heightened emotions, and great clinical complexity.
- Skilled handling of conflict can be an opportunity to create a culture of trust and learning.

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' self care

Which modules should I complete next?



Teams and Continuity for the Patient

Planning End-of-Life Care – Goals of Care

Bereavement Care

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