Equity of well-timed end-of-life care, practical considerations.

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The Australian Commission on Safety and Quality in Health Care (ACSQHC) has supported EOLE since it commenced in 2015

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Let's begin at the end

We will all die

All patients will die

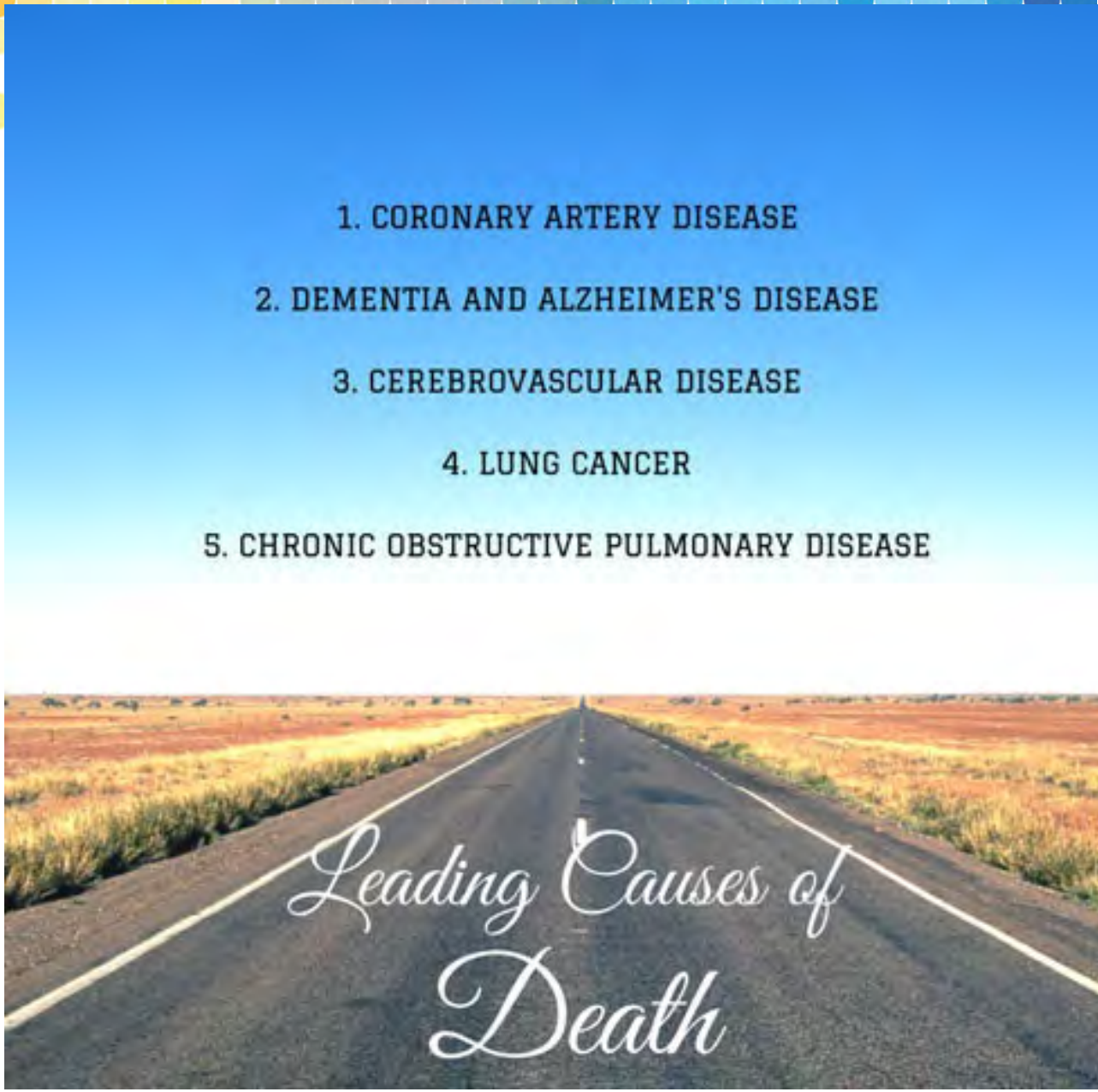
Dying, a normal part of life – how do we get this right every time?

Discussions regarding the future with patients & the challenges of communicating

Importance of teamwork – nurses supporting equitable and quality health care at the end of life

What do we die of?

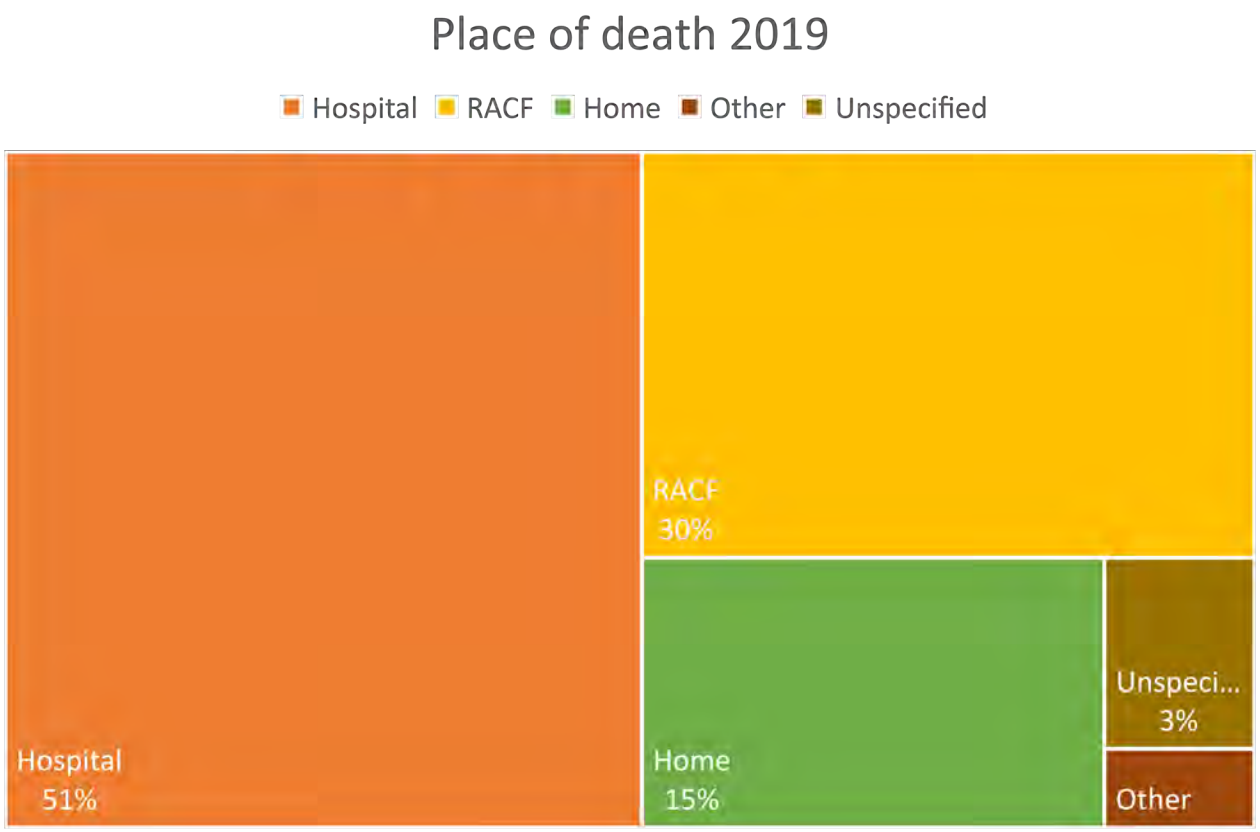
AIHW 2016
Leading Causes of Death



- 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 18 years

- **The Grattan Report *Dying Well 2014***

Where do we die?



ABS - Classifying Place of Death in Australian Mortality Statistics, published 2021

So, most Australians will predictably die in very old age, probably in hospital of chronic complex illnesses.

Should we plan and talk about dying?

- Empowering patients & families to plan their lives
- Honestly transferring information about the patient to the patient.
- Euphemisms – need to avoid misunderstandings

"*Everyone kept saying Mum was 'really sick'. I wish someone said that really sick meant dying, because then I could have been there*"

Patients in your service and care

May ask you about your beliefs

May be very curious about their own future

May not want to discuss dying or prognosis

May want to know *everything*

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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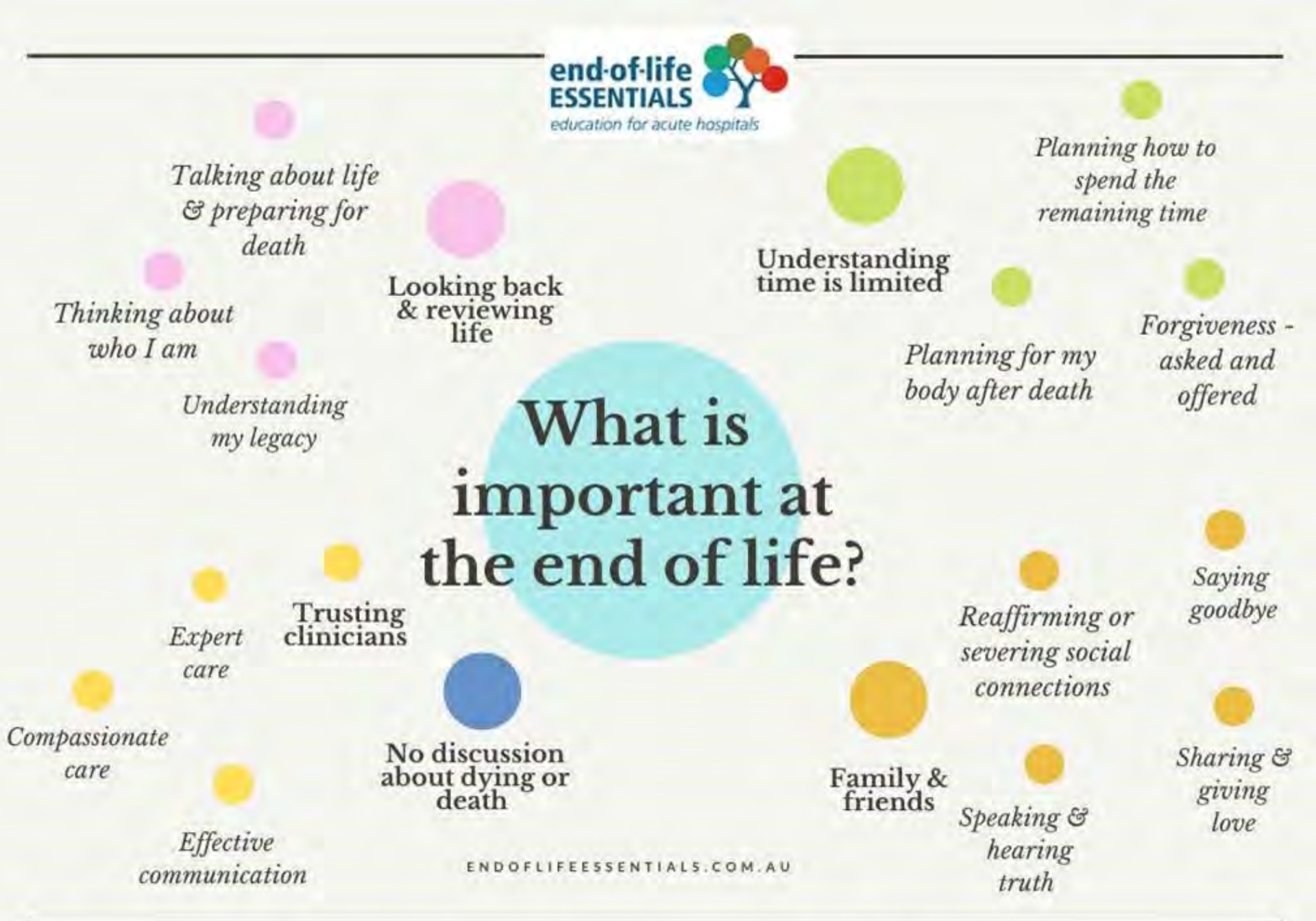


Steinhauser et al 2009; Virdun et al 2015; Steinhauser et al 2000; Gott et al. 2008

individual preferences

I'd like to die in my sleep

I'd like to drop dead on the tennis court

I want to die at home in my own bed

I just don't want to think of it!

VAD – another element to consider

Able or novice in EOL care?

Do you empower patients to direct own care or do you mainly focus on health professional decision making?

Can you recognise when patients could be approaching end of life or do you see all ill health as a fixable biomedical problem?

Do you see eolc as urgent care or do you miss signs and patterns of end of life

Are you able to have critical conversations about dying or are you still learning?

How should nurses respond in order to provide equity in well timed end-of-life care?

Tomorrow, the one thing I can change to more appropriately provide end-of-life care is…'

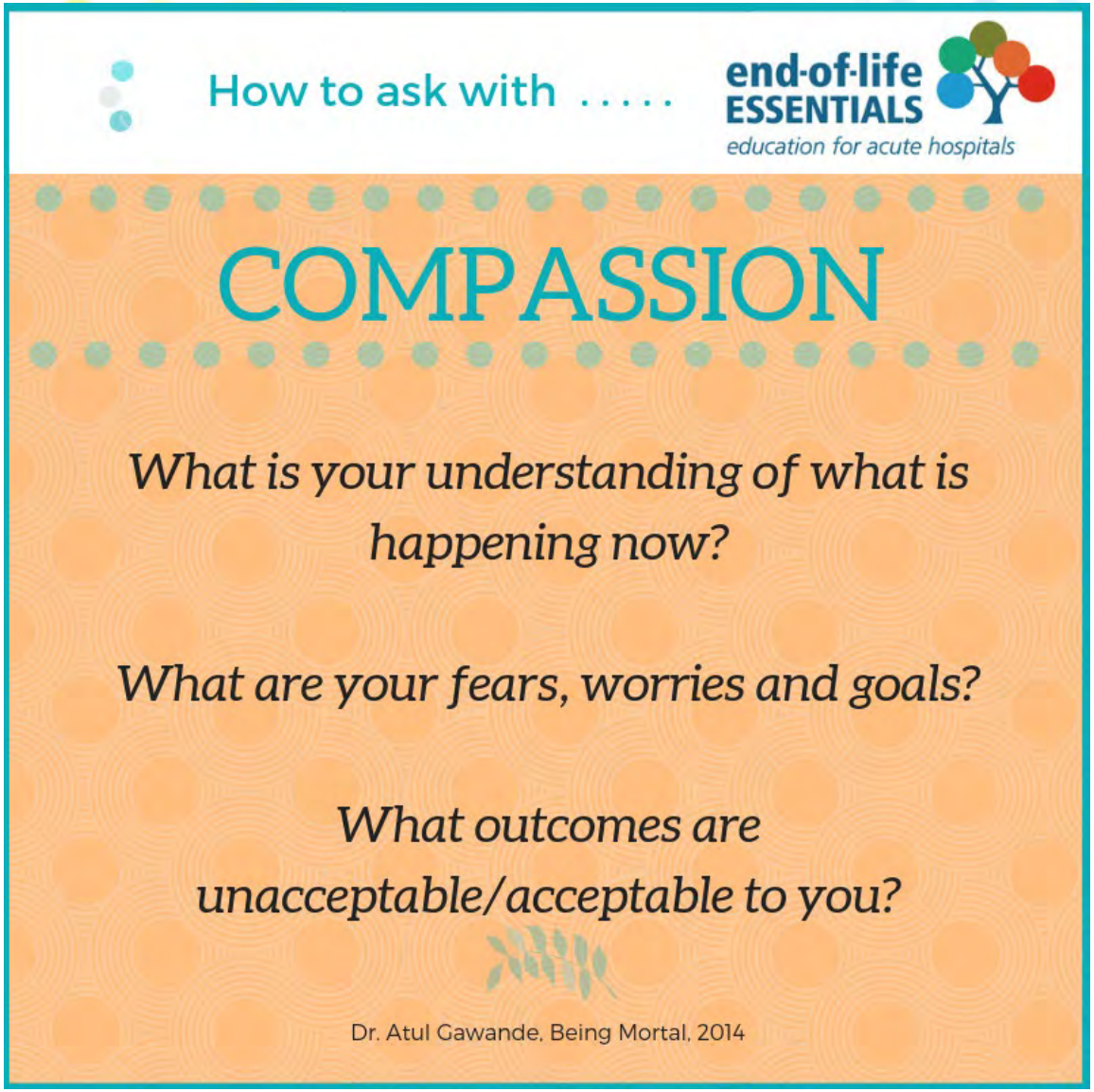
- 3,201 responses
- Curb my own avoidance
- Communicate more, better, listen, manage conflict
- Compassion – recognising another person's suffering and acting to relieve
- Empathy – understanding and sensitivity to another
- Dignity – valuing and respecting another
- Honesty – responding to patient questions
- Respecting patient wishes – even if they are different to my own
- Advocacy – stopping the conveyer belt so patients can hop off

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

One thing to change in your practice…

- *Pull up a chair*
- *Not fear the words 'die' and 'death' when communicating with unwell patients when they question me.*
- *Being more self-aware of my thoughts, feelings and what is coming out of my mouth. To not be nervous about open communication and having meaningful conversations with people about death.*
- *Listen to my patient, treat respectfully and with dignity. Don't rush in to 'fix' the issue, it may not be fixable, raise false hopes. Be truthful and be kind.*
- *Continue to be brave and talk about death and dying within the context that it is not something that we as a society necessarily do very well and that it doesn't have to be something to be frightened of talking about.*

Seek training



Discussions about the future

We don't tend to talk about EOL

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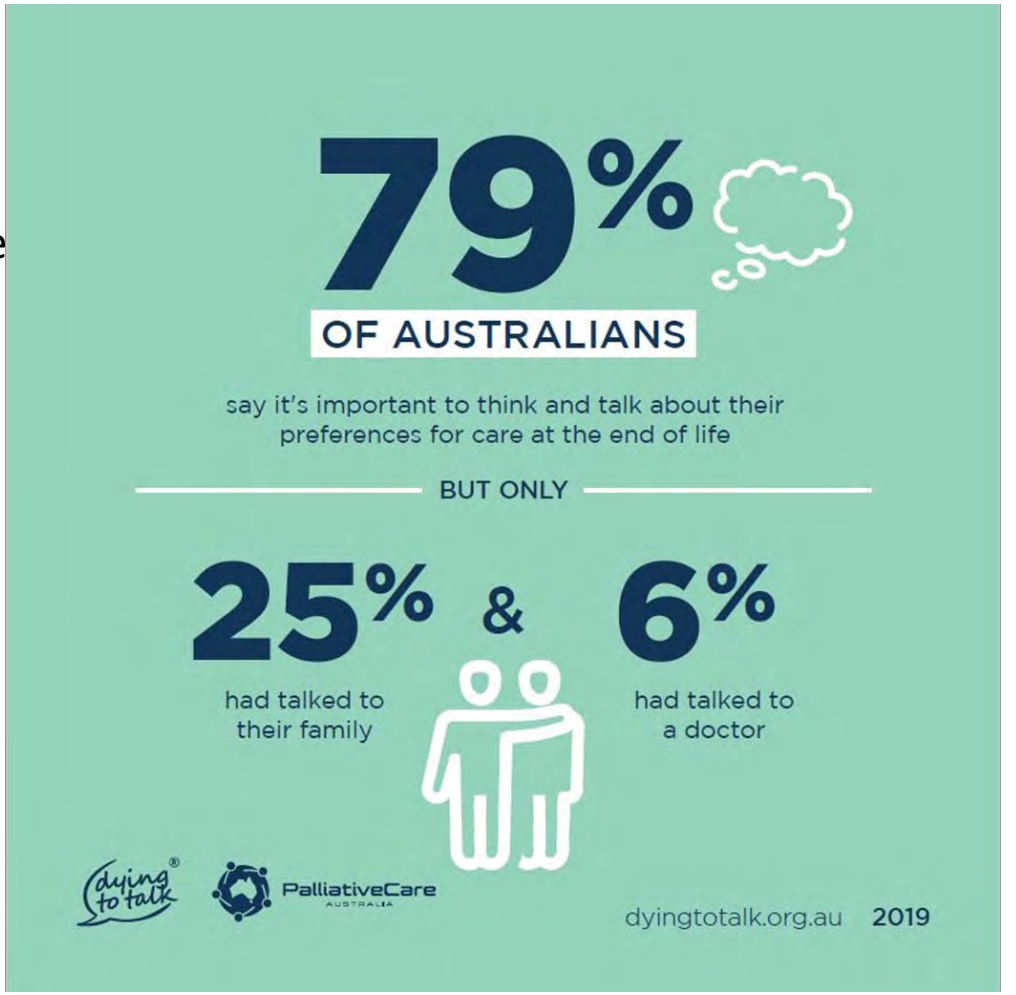

Patients say they wish for:

- honest communication with their health care teams
- the ability to prepare for life's end
- feeling listened to
- being aware of their physical condition

Virdun C, Luckett T, Davidson PM, Phillips J. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. Palliat Med, 2015 Oct: 29(9):774-96.

Discussions regarding the future with patients

- Do we tippy-toe?
- Do we invite patients into our teams in order to make decisions?
- Do we focus on therapeutic interventions more than goals of care
- What are the challenges?

Quality care = negotiating GoC

'What are the hardest or most challenging things about negotiating GoC with patients and families?'

- (421 responses)
- differing views and opinions;
- challenges to understanding;
- managing emotions;
- initiating the EOL conversation and
- lack of professional knowledge or capacity.

Devery K. Winsall M, Rawlings D, A qualitative study exploring challenges and solutions to negotiating goals of care at the end of life in hospital settings, International Journal for Quality in Health Care, Volume 34, Issue 4, 2022, https://doi.org/10.1093/intqhc/mzac089

Results

Almost half of responders discussed the challenge **differences in individual views, opinions, ideas, goals, and plans** posed when negotiating GoC.

Not just between patients and families but patients, families and health care professionals. AND between **members of the health care team**

Results

Challenges - patient and family understanding, either of the patient's condition or prognosis.

Challenges with dealing and managing emotions.

Difficult to navigate the distress and heightened emotions of the patient and family, and some mentioned challenges regarding their own emotions in these situations.

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 – *accept to not know the right answer*

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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Recommendations for practice based on study findings

Effective communication skills and techniques are important when negotiating goals of care.

Your organisation, unit or ward and team must all agree that end-of-life care is core business.

Planning ahead

WOULD YOU LIKE TO DISCUSS WHAT THE FUTURE MIGHT LOOK LIKE?

who would you want to make your medical decisions if you were unable to?

What does a good day look like for you? What do you wish for?

what do you value most in life?

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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

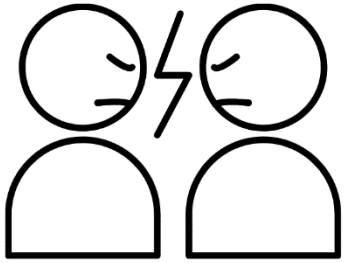
Here is what I can do now that will help you do those most important things

VITAL talk

Teamwork – nurses supporting equitable and quality health care at the end of life

Importance of Teams

Australian Commission on Safety and Quality in Health Care
& National Safety and Quality Health Service Standards



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

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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.

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Mr Georgiou feels alone.

He is frightened and exhausted.

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

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Can you guess what will happen next?

Maybe no one ever answers Mr. Georgiou's question, he dies without sharing what matters most to him.

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

TO BE CONTINUED….

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How many of you

work in cohesive and well functioning teams?

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Conflict happens

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.

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Unresolved conflict and quality care are not compatible.

Oscillating between providing life prolonging care and quality end-of-life care, requires healthcare teams to be highly nimble to continually assess patients and treatment intent, plan appropriate goals of care and navigate provision of care in fast-paced complex environments.

The potential for conflict is high.

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Addressing conflict

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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1. Notice it

ask yourself - are you feeling angry or irritated?

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2. Prepare yourself

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

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 'I'm 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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6. Look for solutions that meets the needs of both parties

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

who can you call for back up?

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So what happens with Mr Georgiou's case?

The registered nurse on the medical ward calls and speaks to the RMO. She discusses with the RMO the complex issue around disclosure of prognosis to Mr Georgiou – she says she realises the family don't wish their father to know he has less than one year to live.

She reframes her own emotions of fear and unease and says she knows there is no easy responses or a way to fix the situation quickly.

Empathically, she acknowledges that the RMO is new to the service, and says it would be helpful to discuss Mr Georgiou's question with the medical team.

The RMO replies that he will come to the ward and discuss the best way to approach Mr Georgiou's question. Meanwhile, the RMO asks a colleague for advice and he admits to himself, he doesn't know what to do.

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Barriers to speaking up

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.

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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: 65-83.

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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.

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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
- Responding to concerns
- 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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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 (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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So, equity of well-timed 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.

Nurses can increase their capabilities and skills in communication, tolerance of heighten emotions and great clinical complexity.

Skilled handling of conflict can be an opportunity to create a culture of trust and learning

End-of-Life Essentials

Online peer review and evidence based education

Implementation toolkits – how to change practice

Training Resources for educators

Accreditation resources for hospitals planning on meeting the NSQHS Standards to provide a nationally consistent level of care consumers can expect from health services.

End-of-Life Essentials advocates proactive approaches to professionals' quality of mental health.

There are many ways to access information and support about your wellbeing and mental health. Here are some suggestions from Australia:

Headspace Australia

Beyond Blue

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

Nurse and Midwife Support

Doctors' Support

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Ultimately equity is giving patients and families the knowledge health care teams control. To empower people to make their own choices. Allowing people to give and share love at the end of life, manage ever decreasing time and to say goodbye.

Thank you for listening