



Palliative Care Conversations: Finding compassion and clarity in challenging situations

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Presenters

- Facilitated by Distinguished Professor **Patsy Yates**, Program of Experience in the Palliative Approach (**PEPA**)
- Associate Professor **Kim Devery**, Lead **End-of-Life Essentials**
- Associate Professor **Mark Boughey**, Director of Palliative Medicine, St Vincent's Hospital Melbourne and Deputy Director, Centre for Palliative Care – **CarerHelp**



We acknowledge and pay our deepest respect to the past, present and future Traditional Custodians and Elders of the many lands on which we work and live, and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.





From your experience, what do patients and families want from their communication with nurses?



What aspects of communication do you find most challenging in palliative care? What makes it challenging?

Perspectives of Patients and Families: A Recent Systematic Review

Open and honest information

However, this open and honest communication can also trigger anxiety, stress, and existential disruption.

Health-care professionals aligning to the patient's and relative's process of uptake and coping with information

Clear and understandable language

Leaving room for positive coping strategies

Committed health-care professionals taking responsibility
Empathy

Recognition of relatives in their role as caregiver

Engel M, Kars MC, Teunissen SCCM, van der Heide A. Effective communication in palliative care from the perspectives of patients and relatives: A systematic review. *Palliative and Supportive Care*. 2023;21(5):890-913. doi:10.1017/S1478951523001165

Ascertain a patient or family member's perspective before offering your own

- *Do you know her preferences of the kind of quality of life she would want?*

Where possible, mirror the language of the patient or family

Create opportunities to discuss the future

- *Do you worry about what's coming?*
- *If you- supposing- I mean this is just supposing, supposing you had got infected or were to get infected*

Be clear about uncertainty

- *This looks like the last days probably...We have learned that we have no idea to predict how many.*

Display sensitivity

- *I know it's not always the easiest thing to uh to chat about.*

Observations from Practice: A Scoping Review

Ekberg, S., Parry, R., Land, V. *et al.* Communicating with patients and families about illness progression and end of life: a review of studies using direct observation of clinical practice. *BMC Palliat Care* **20**, 186 (2021).
<https://doi.org/10.1186/s12904-021-00876-2>

Workshop Learning Outcomes

- Gain practical skills to help you communicate confidently and effectively with patients and their families in palliative care settings.
- Develop strategies for facilitating communication among healthcare professionals and healthcare teams in palliative care contexts, fostering collaboration and multidisciplinary.
- Find out more about the range of free, palliative care education and training opportunities for nurses.

One Example of an Education and Training Initiative:

PEPA and PEPA Aged Care

Funded by the Australian Government Department of Health and Aged Care

PALLIATIVE CARE EDUCATION & TRAINING COLLABORATIVE



PCC4U

PALLIATIVE CARE
CURRICULUM FOR
UNDERGRADUATES

PEPA

Program of
Experience in the
Palliative Approach



Indigenous Program
of Experience in the
Palliative Approach

Funded by the Australian Government Department of Health

PEPA and PEPA Aged Care

- To improve access to high quality palliative care for all Australians as they require it
- To enhance the capacity of health professionals to deliver a palliative care approach
- To develop confidence, knowledge and skills in the palliative approach to care
- Through:
 - Funded clinical workforce placements or workshops
 - Integration of learning into the workplace
 - Establishing networks of support



PEPA and PEPA Aged Care

- **PEPA Aged Care** is an extension of the PEPA Project which has been funded to:
- Improve the knowledge, skill and confidence of the aged care workforce to practice a palliative approach to care for all people and their families in aged care contexts.
- Enhance the support networks of the aged care workforce to connect and interact with specialist palliative care.



PEPA Aged Care is facilitated by experienced Nurse Educators providing individualised learning experiences across a range of aged care settings.

What will PEPA do?



Provide individualised learning experiences for non-specialist health and aged care workers across rural, remote, and metropolitan settings using an experiential learning model.



Enhance linkages between specialist and non-specialist service providers to improve the quality and coordination of palliative care for people in any setting.



Provide mentoring resources and development opportunities, to increase the capacity of each organisation's workforce to support team members to learn more about palliative care.



Palliative Care Nurses Association Conference 2024

Palliative Care Conversations: Finding compassion and clarity in challenging situations

Associate Professor Kim Devery



Funded by the Australian Government Department of Health and Aged Care

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





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.**



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

- 3,201 responses
- *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 life and 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.*



ABCD Care – Harvey Chochinov

Framework to enhance patient dignity. Taking a look at our own preconceived notions is a deeply personal but necessary exercise

A- Attitude - How would I be feeling in this person's situation? Am I aware how my attitudes toward the person may be affecting him or her?

B – Behaviour - Use language that the person can understand. When within hearing distance, never speak about the person's condition in terms he or she cannot understand.

C – Compassion - Compassion isn't something a person knows – it's something a person feels. It is a deep awareness of the suffering of another, coupled with the wish to relieve it. Find your role models

D – Dialogue - At this time in your life, what are the things that are most important to you, or that concern you most?

<https://dignityincare.ca/en/>



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.



Communication with patients

“Am I dying? I don’t want to die” (said while weeping)

A novice response maybe: You are doing so well, (trying to buoy the patient, while avoiding more emotion, don’t want to upset the patient)

A more experienced approach maybe: leaning into the emotion



The NURSE mnemonic

N - Name it

“...it sounds like you’ve been worried about what’s going on...”

U - Understand the core message:

“...if I understand you correctly, you are worried about what to say to your family and how they will react...”

R - Respect /Reassurance at the right time:

“...I’m really impressed that you’ve continued to be independent ...”.

S - Support:

“... would you like to talk more to me about this...”

E - Explore:

“... I notice that you’re upset, can you tell me what you’re thinking?”

The NURSE mnemonic has been reproduced from Back A, Arnold R, Tulsky J. Mastering communication with seriously ill patients: balancing honesty with empathy and hope. Cambridge University Press; 2009 Mar 2.

Communication between health care professionals/teams advocating for the people you are caring for.

Imagine: you have assessed that the patient needs an urgent pain review, you ask a team member to review the patient. The response is:

"I think she will be fine. Let's leave her overnight and review her in the morning."

Novice responses maybe: to feel powerless = moral distress, to be angry and blame the person/team member, to concede = give up.

An experienced approach may be to negotiate:

Negotiation

Step	Self-assessment questions	What to say to a colleague
1. Notice the conflict	<i>Am I feeling angry or <u>irritated</u> or bored?</i>	This is an internal reflective step
2. Prepare <u>yourself</u> - Get into a 'ready to negotiate' state of mind. - Examine the <u>situation</u> - Decide on the purpose of working through the conflict	<i>Am I too angry to fully listen?</i> <i>Am I still thinking I am right?</i> <i>What information do I need to know?</i> <i>What are the consequences of not addressing this conflict?</i>	These are an internal reflective step
3. Find a <u>non-judgemental</u> starting point	<i>What would an impartial third person say that this conflict <u>is</u> about?</i>	<i>"Let's start with the big picture – what we are hoping for in <u>Mrs X's</u> situation"</i>
4. Reframe emotionally charged issues	<i>How can I describe the issues so that it is something that we both need to work together on?</i> <i>Am I moving on to the 'me against you' stance?</i>	<i>"I am concerned that <u>Mrs X</u> is in pain now and that the current pain management is not adequate until the morning."</i>
5. Respond empathetically	<i>Have I given explicit feedback that shows I understand the other person's feelings?</i>	<i>"I can hear that you must be really busy"</i>
6. Look for options that meet the needs of both parties	<i>Does this option address that other person's and <u>my</u> concerns?</i>	<i>"I can gather the information you require to assess <u>Mrs X</u>, would that assist you? Is there someone else we can call to assist here?"</i>
7. If no satisfactory agreement can be reached, get help	<i>What resources exist to help you in your <u>organisation</u>?</i>	<i>"<u>I</u> think it would be helpful to have another impartial person help us discuss what is best"</i>



Communication with colleagues and teams

Effective health care and excellent end of life care teams allow and respect differences of opinion.

Team members feel psychologically safe to speak up, to suggest that a patient is at the end of life or wishes a review of their health care.



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.



eLearning Topics, example

- Dying, a normal part of life
- Patient-centred communication and shared-decision making
- Recognising end of life
- Goals of care
- Teamwork
- Responding to concerns
- ED – EOLE Care
- Paeds – EOLE Care
- Imminent death
- Chronic complex conditions – EOLE Care
- States of mind at the end of life



Your turn to communicate! How do you respond?

Patient - *"Am I dying? I don't want to die"* (said while weeping)

Colleague - *"I think she will be fine. Let's leave her overnight and review her in the morning."*



Thank you



Communicating with caregivers



Here for You

Sarah Richards, Ngiyampaa woman, born on Gadigal land (May 2022)

What is CarerHelp?

CarerHelp is an online resource developed to support Australians who are caring for someone towards the end of life.

www.carerhelp.com.au

- Funded by the Australian Government Department of Health and Aged Care through a National Palliative Care Project grant since 2017
 - 1st **CarerHelp** 2017-20 website launched in 2019
 - 2nd **CarerHelp Diversity** 2020-23,
 - 3rd **CarerHelp Rural Connect** 2023-26
- Reached over 80,000 new users!





- St V's CPC team
 - Professor Peter Hudson – Centre for Palliative Care, SVHM, and University of Melbourne
 - A/Prof Mark Boughey – SVHM Palliative Care Service & Centre for Palliative Care
 - Dr Tina Thomas – Project Manager Centre for Palliative Care
 - Di Saward RN - Centre for Palliative Care
- Flinders University
 - Professor Jennifer Tieman & team
- Carer's Australia (2017-2023)
- National Rural Health Alliance (2023 -)
- Grief Australia (2023 -)
- National Reference Group (2017-)

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Carer Pathways - CarerHelp

The support

Your role as carer is so important. We provide you with the information, tools, and resources you need to succeed.

When carers are ready for their role, everybody benefits.

Pathway 1: When Someone Needs Care

Pathway 2: Caring When Death Is a Possibility

Pathway 3: Preparing for Dying

Pathway 4: When the Person Is Dying

Pathway 5: After Caring

[Find out more on Carer Resources](#)



Communities

Resources developed for specific communities are now available.

[Aboriginal and Torres Strait Islander](#)

<https://www.carerhelp.com.au/tabid/5635/Default.aspx>

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The support you need to

Your role as carer is so important. Find reliable and trustworthy information, tools, and resources with CarerHelp. When carers are ready for their role, everybody benefits.

[Find out more on Carer Resources](#)

Communities

Resources developed for specific communities are now available.

[Aboriginal and Torres Strait Islander](#)

Recognising Dying



When you are ready, call the doctor or health care team to verify the death. If you are in the hospital or aged care facility contact one of the staff members.

[Download PDF version \(261KB\)](#)

On this page:

[How will I know when they are dying?](#)
[How will I know when death has occurred?](#)

How will I know when they are dying?

Knowing that someone is now in the last days of their life can be difficult. There are some common indications that death may be very near. These may include:

- Large portions of the day being spent in bed
- Inability to move freely out of the bed or chair
- Difficulty swallowing solid foods
- Sleeping for long periods of time
- Not talking very much

Occasional confusion

CarerHelp Knowledge

[After The Death](#)
[Being An LGBTQIA+ Carer](#)
[Can I Trust This Information?](#)
[Caring For The Dying Person](#)
[Caring For Yourself At The Bedside](#)
[Checklist And Plan For Moving Forward](#)
[Common Emotions At The End Of Their Life](#)
[Emotional Care Of The Seriously Ill Person](#)
[Financial Matters](#)
[Helplines For Carers](#)
[How To Access Subsidised Home Care Support Services Through My Aged Care](#)
[Injections And Syringe Drivers](#)
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[Managing Communications](#)
[Question Prompt List](#)
[Recognising Dying](#)
[Relationships And Children](#)
[Responding To A Request To Die](#)
[Setting Up The Health Care Team](#)
[Tips For Managing Common Symptoms At End Of Life](#)
[Tips For Staying Well](#)
[Tips For Visiting – Engaging With](#)

Communicating with caregivers

Why focus on communication skills?

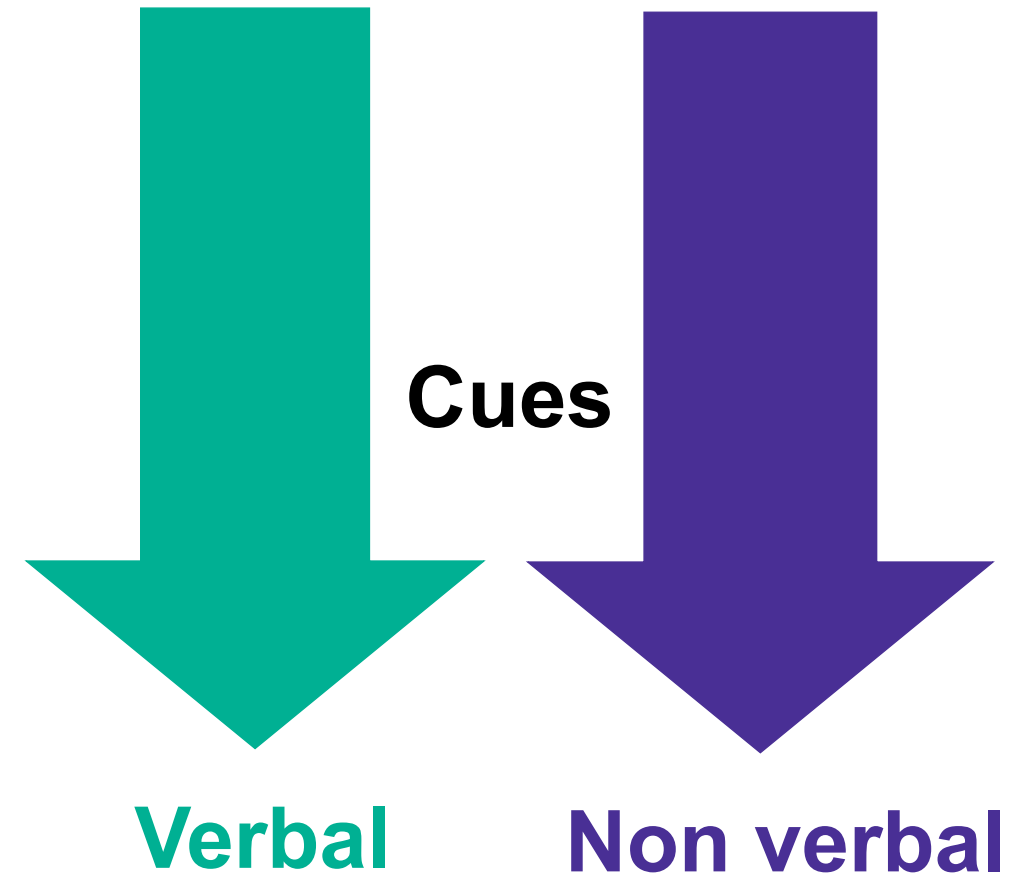
- Fundamental part of how we interact and care for **patients & carers**
- Improves **patient and caregiver satisfaction** of care
- Can **facilitate trust** and establish a therapeutic alliance
- Improves health literacy, processes of **shared understanding** and decision making
- Is not inherent or innate – **skills can be learnt** to help healthcare providers manage in situations that can be challenging



Chichirez & Purcarea, 2018, J Med Life
Sany et al. 2020, BMC Health Services Research

Facilitating conversations

- Open ended questions
- Non-medical language
- Active Listening
- Pauses/use of silence
- Minimal prompts/encouragement
- Summarising



Goldberg et al 1993; Wilkinson 1991; Maguire et al 1996; Zimmerman et al, 2003

Issues to consider in communication

- ❖ initiating the interview
- ❖ gathering information
- ❖ explanation and planning
- ❖ building the relationship
- ❖ summary & recommendations

Cues

ANGER

(raised voice, flushed, no eye contact, won't sit down, sarcasm, dismissive comments, integratory questioning)

SADNESS

(flat, teary, little bodily movement, eyes downcast, sighing, holding someone, hunched/closed posture)

ANXIETY

(rapid speech, restless, nervous laughter, distracted, needing excessive reassurance, fidgeting, tired/sleep disturbance, dyspnea, impaired concentration/decision making)



SPIKES

Framing a conversation

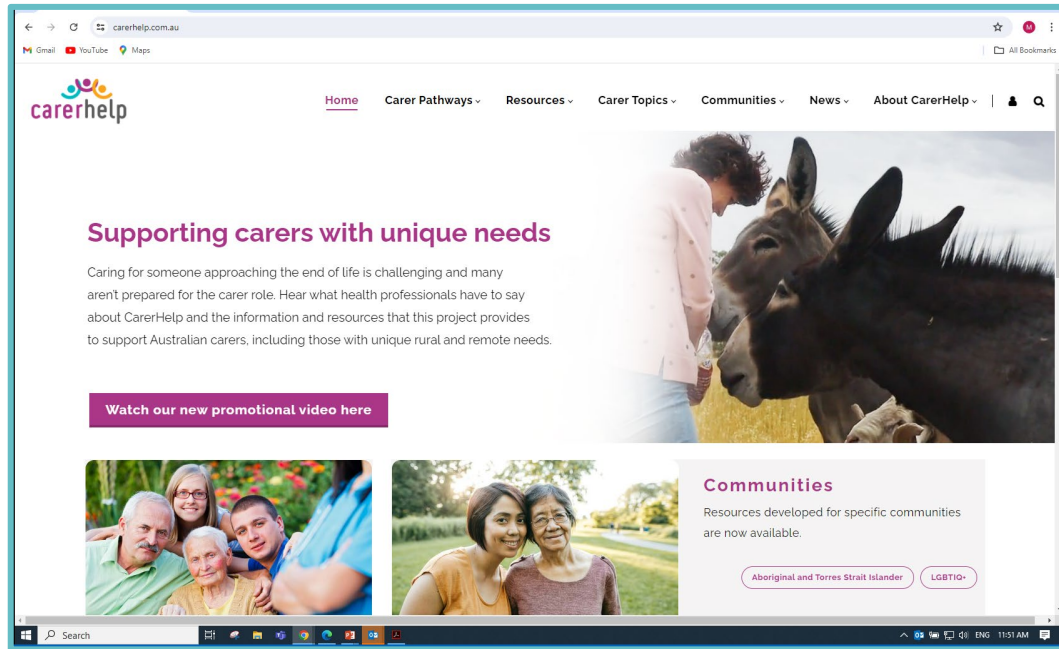


S	SET UP	It would be good to hear from Do you think you could show me
P	PERCEPTION	How do you see the situation
I	INVITATION	Can we talk about how you are feeling
K	KNOWLEDGE	What would you like to know
E	EMPATHY AND EMOTION	NURSE
S	SUMMARY AND STRATEGY	Can I check back on what we have covered

Now its your turn to communicate **again**

- Engaging a carer to understand and recognise their needs
- Engaging a carer to help them advocate for their loved one





www.carerhelp.com.au

Links from:

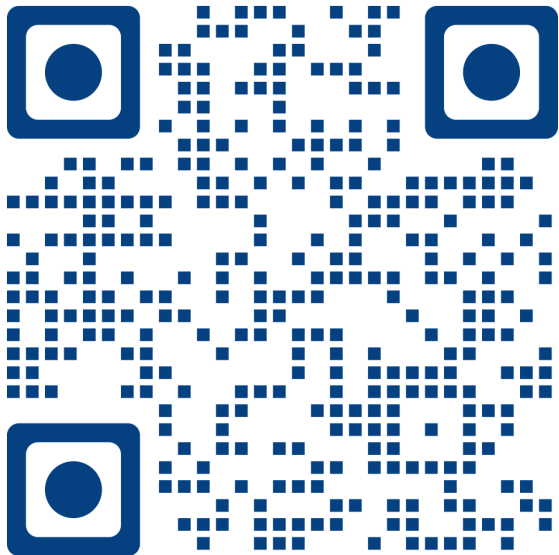
- Health Direct
- Carer's Gateway
- Care Search
- WellMob
- Cancer Australia
- Palliative Care Australia
- Dementia Australia



Questions

Education and training

- For course information and resources to build your skills, visit:



“Death can be confronting, and it will give you the confidence to be able to deal with these situations.”
Brigitte Karle, Aged Care Nurse Practitioner

Free palliative care education and training

 health.gov.au/palliative-care-education

Thank you

