



# Compassionate responses in emergency department end-of-life care

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End-of-Life Essentials is funded  
by the Australian Government  
Department of Health.

End-of-Life Essentials is based on the Australian Commission on Safety and Quality in Health Care's *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*, and the Commission provides ongoing advice to the project.



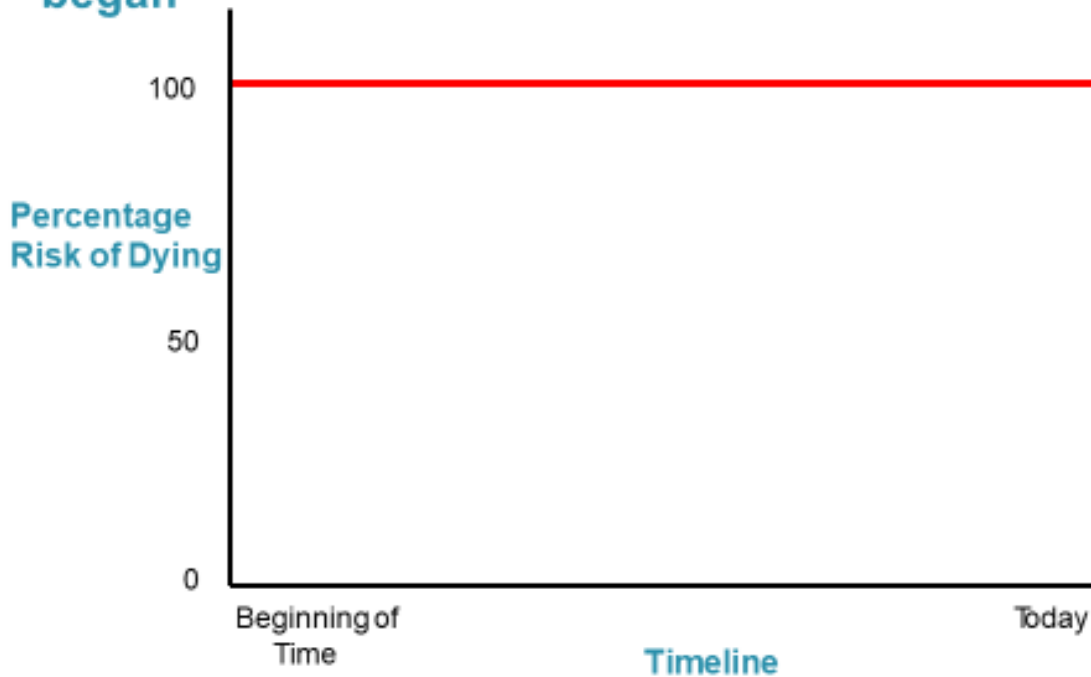
## End of Life

*"People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:*

- Advanced, progressive, incurable conditions;*
- General frailty and co-existing conditions that mean that they are expected to die within 12 months;*
- Existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; or*
- Life-threatening acute conditions caused by sudden catastrophic events."*

Taken from [Australian College for Emergency Medicine](#) Policy on End of Life and Palliative Care in the Emergency Department

## Individual's lifetime risk of death since time began



Metro South Health

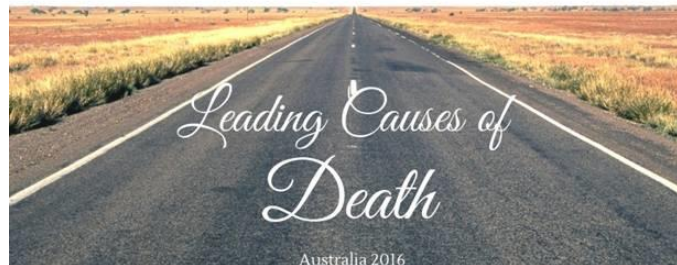
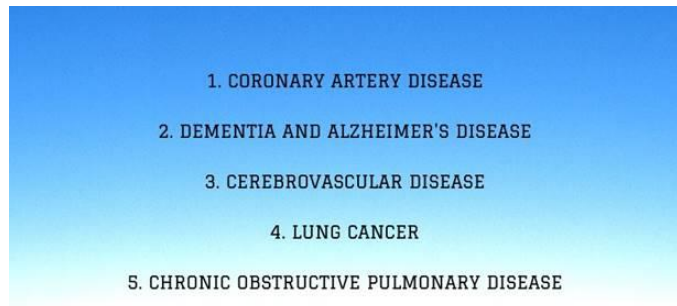
Acknowledgement: Slide from presentation prepared by Professor Liz Reymond "A system for ACP in Queensland", Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying 2019

**end-of-life  
ESSENTIALS**



*education for acute hospitals*

# End of Life in ED



Between 2017 and 2018, there were approximately 8 million presentations to Australian public hospital emergency departments, an increase of 3.4% from the previous year.

A small number of these people die



# 75%

of people in the last 24 months of life present to

# emergency

(at least once)

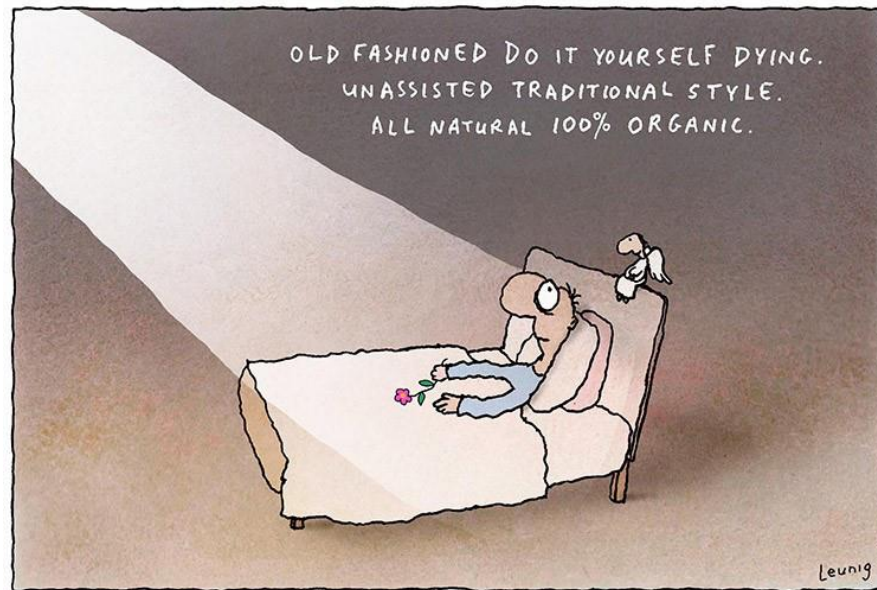
In the last 12 months of life people can have an average of 4 admissions to acute hospitals.

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.



## Last 12 months of life

- 90% of people will spend the last year of their life at home
- Who has been making decisions regarding care to date?
  - E.g. oncologist, neurologist, GP, pall care
- Assumption that someone has had the important conversations
  - Advance Care Planning?
- Who makes decisions here and now?



# What does the literature say?

Eight themes emerged from the literature:

1. Care in the Emergency Department is about living not dying
2. Staff perceive that death is a failure
3. Staff feel underprepared to care for the dying patient and family in this environment
4. There is limited time for safe standards of care
5. Staff stress and distress
6. Staff use of distancing behaviours
7. The care of the dying role is devolved from medics to nurses at the end of life
8. Patients and staff perceive that the Emergency Department is not the preferred place of death



*“Even in the context of a chronic or life-limiting illness, death in the ED can be sudden or unexpected, and therefore a significant traumatic stressor for family members”*

Giles, et al., Nurses' perceptions and experiences of caring for patients who die in the emergency department setting.  
International Emergency Nursing  
<https://doi.org/10.1016/j.ienj.2019.100789>

**Providing  
comfort and symptom relief  
for a patient at the end of life  
is not giving up.**



A formal acceptance by clinicians in the ED that their role is not only *heroic* or *lifesaving* but also to provide care for those beyond rescue is necessary

(Cooper E, Hutchinson A, Sheikh Z, Taylor P, Townend W, Johnson MJ. Palliative care in the emergency department: A systematic literature qualitative review and thematic synthesis. Palliative Medicine 2018; 3299,1443-1454)







## What do patients and families want?

The top five elements identified as important to both patients and their families:

- Effective communication and shared decision making
- Expert care
- Respectful and compassionate care
- Trust and confidence in clinicians
- Minimising burden

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.



## Talking with families / discussing CPR

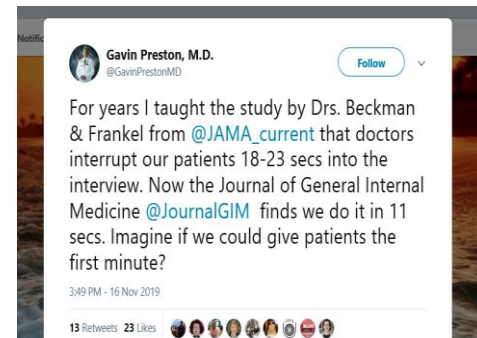
If you assess the patient as not suitable for CPR – that the harm outweighs benefit - you don't need to include CPR in the conversation with the family. However, what if the patient or family asks you directly about resuscitation? How can you respond?

- *“I will provide excellent care (for example, fluids, antibiotics, pain relief etc) but CPR would be harmful. I would resuscitate your relative if I thought that she would have a good outcome - but I will not commence CPR or artificial life support if I believe the outcome is going to be harmful to your Mum. Our focus now is on comfort and allowing for a natural death, I do wish things were different.”*
- *“Our aim is to focus on your comfort. No measures are going to change the course of your illness.”*

Clayton JM, 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 Jun 18;186(12 Suppl):S77-9.



There is no one right way  
to respond to a patient  
who is approaching the  
end of life





## End of Life Essentials (EOLE)

End of Life Essentials (EOLE) is a Commonwealth funded project providing free, evidence-based online, peer reviewed education modules and resources for health professionals working in acute hospitals.

- To date, over 12,000 clinicians have completed the online education and the webpage has attracted over 250,000 visits.
- In December 2018 a module specifically for those working in emergency departments was released.





## Evaluation of ED module

1. Pre- test/post- test data (knowledge, skills, attitude, confidence) are collected routinely for each module.
2. A question 'what is a compassionate response for you in the emergency department'? is asked at the end of this module.

Data were collected from 04 Dec 2018 to 30 Sep 2019.

## Quantitative data

ED module released 4<sup>th</sup> December 2018

- n=528 learners

Professions and workplaces	N	%
Allied Health_Acute Hospital	44	8.3
Allied Health_Other	30	5.7
Doctors_Acute Hospital	16	3.0
Doctors_Other	6	1.1
Nurses_Acute Hospital	296	56.1
Nurses_Other	136	25.8
In Total	528	100.0

### Pre-test /post-test evaluation

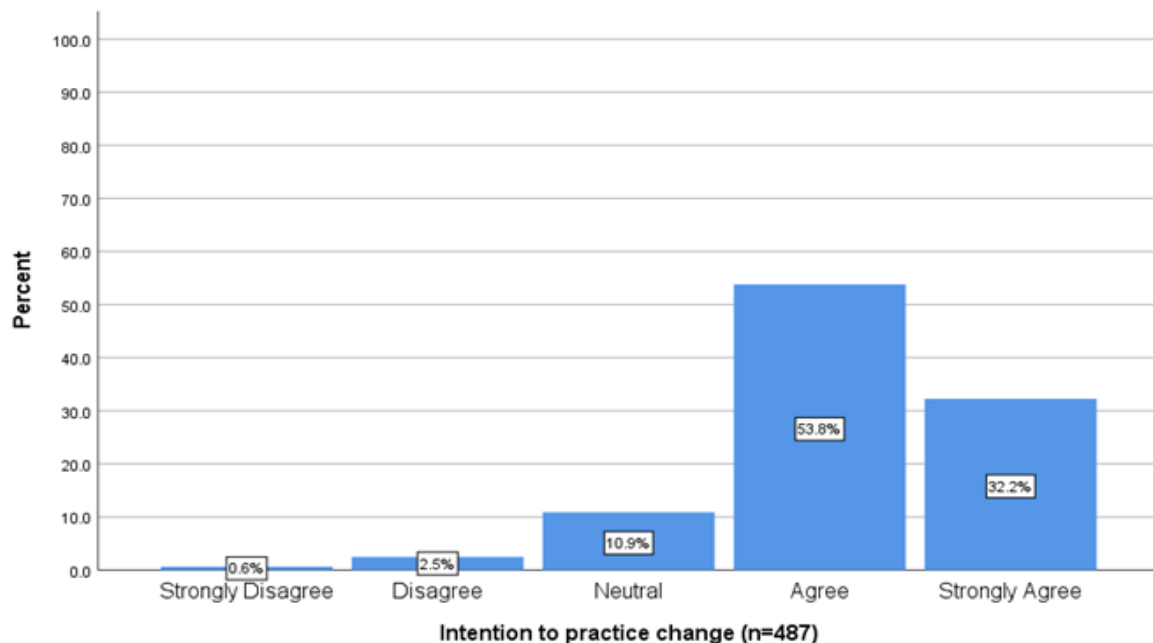
- There were significant improvements on learners' knowledge, skill, attitude and confidence in providing end of life care in the Emergency Department after completing EOLE ED module.
- Wilcoxon Signed Ranks Test indicated that the post-evaluation ranks of knowledge, skill, attitude, and confidence were statistically significantly higher than the pre-evaluation ranks of knowledge, skill, attitude, and confidence



Statements	Pre-evaluation Mean	Post-evaluation Mean	Wilcoxon (Z)	P Value	Effect size
I have sufficient knowledge in providing end-of-life care	3.68±0.94	4.14±0.70	-11.099	<0.001	-0.35
I am skilled in providing end-of-life care	3.66±0.96	4.07±0.79	-10.414	<0.001	-0.34
I have a positive attitude towards end-of-life care	4.08±0.81	4.31±0.69	-7.960	<0.001	-0.26
I am confident in my ability to provide good end-of-life care	3.81±0.88	4.17±0.73	-10.061	<0.001	-0.33

Scores reported are average rating on a five-point Likert Scale: 1= strongly disagree; 2= disagree; 3= neutral; 4= agree; 5= strongly agree. Statistical significance was deemed at  $p<0.05$

## Intention to change practice



The majority of learners strongly agree/agree (32.2%, n=157, 53.8%, n=262) that they intended to change their practice in end-of-life care in the Emergency Department.





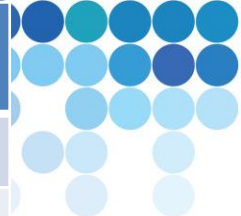
## Qualitative data

*What do you consider compassionate responses to those at the end of life?*




Comments received (n=138) include themes of space, time, privacy, workload and education, as well as compassion, support, empathy, transparency, communication.



Themes/subthemes	No. Participants (%)	Examples Quotes from Participants
<b>Communication skills</b>	167 (43.9%)	
Empathy and understanding	68 (17.9%)	<i>"Showing that I care and want to know and understand their feelings."</i>
Listening	59 (15.5%)	<i>"Listen and don't interrupt."</i>
Questions and information	53 (13.9%)	<i>"Ask them if they have any questions and find out information if you don't know it."</i>
Use of appropriate language (verbal and body)	38 (10.0%)	<i>"Sit at the person's eye level."</i> <i>"Use words that the person can understand."</i> <i>"...always make eye contact, always address family by name."</i>
Respect	35 (9.2%)	<i>"A response that is respectful."</i>
Kindness	30 (7.9%)	<i>"...offer basics such as a cup of tea."</i> <i>"Be patient and kind. Provide an act of kindness no matter how small. Let the patient and family feel important."</i>
Introduce self	26 (6.8%)	<i>"...take the time to introduce myself to both the patient and the family."</i>
Honesty	12 (3.2%)	<i>"Be honest and realistic..."</i>





	<b>Support for staff</b> EOL knowledge and training	41 (10.8%) 27 (7.1%)	<p><i>"More information on End of Life care available for all staff..."</i></p> <p><i>"...make sure everyone is up to date with how to assist at a persons end of life."</i></p> <p><i>"...the need for more training for all clinical staff..."</i></p>	
	<b>Working together/staffing</b>	14 (3.7%)	<p><i>"...to practice and support the staff/team members who have to have these conversations."</i></p> <p><i>"...seek additional support from other team members."</i></p> <p><i>"Have another staff member with you if you feel out of your depth."</i></p> <p><i>"...increased patient staff ratio, staff support."</i></p>	
	<b>Space and privacy</b>	31 (8.2%)	<p><i>"...ensure you provide a space for the patient and family to say what is important to them."</i></p> <p><i>"In the chaotic emergency department - time and space/privacy to speak with the relatives/caregivers as you tell them that someone has died."</i></p> <p><i>"Availability of a side room."</i></p> <p><i>"A quiet place for family to stay with their loved one after death, like a viewing room, but in pleasant surroundings."</i></p> <p><i>"...offer some space also for them to grieve and have a quiet moment."</i></p>	



📶 VoLTE 4G 72% 17:03

☰ NursingTimes 👤

# 'Hello my name is' campaign adopted by 100 plus NHS trusts

02 FEBRUARY, 2015 | BY STEVE FORD



More than 100 NHS organisations – comprising more than 400,000 staff – have signed up to support a campaign improve patient experience, which is being officially rolled out today.



← Tweet

 **Kate Granger**  
@GrangerKate

I'm going to start a 'Hello. My name is...' campaign. Sent Chris home to design the logo...  
[#hellomynameis](#)

4:28 · 01 Sep. 13 · Twitter for iPhone

☰ NursingTimes 👤

The campaign is based on the simple premise of reminding staff to go back to basics and introduce themselves to patients properly.

Dr Granger described it as “the first rung on the ladder to providing compassionate care”.

**#hellomynameis** has made over 2 billion impressions since its conception



One of the activities implemented to foster caregivers' resilience in caring for dying patients is "The Pause." "The Pause" is a 15- to 30-second period of silence at the time of a patient's death shared by the team at the bedside. The purpose is to honor the human life and the efforts of the team. "The Pause" is initiated by the physician or any other team member and participation is voluntary. It is a time to honor and reset.

PubMed

Search term



[Full text](#)

**"Sacred Pause" in the ICU:  
Evaluation of a Ritual and  
Intervention to Lower Distress and  
Burnout.**

Kapoor S, et al. Am J Hosp Palliat Care. 2018.

[Show full citation](#)

**Abstract**

**BACKGROUND:** Increased exposure to deaths in the intensive care unit (ICU) generate grief among ICU staff, which remains unresolved most of the time. Unresolved grief becomes cumulative and presents a risk factor for burnout. "sacred pause" is a ritual performed at patient's death to honor the lost life and recognize the efforts of the health-care team.



## Summary

- Patients at the end-of-life present at Emergency Departments for a variety of reasons and may or may-not have ever discussed their wishes for end of life
- You can provide a variety of services and care for patients with end-of-life needs
- Being able to have conversations about end of life issues is core to providing service
- Compassionate responses can occur in the Emergency Departments
- Being prepared for emotional responses from patients, families, friends, yourself and other staff
- Optimal grieving and bereavement will grow from your compassionate interactions with families and friends



## Summary

- EOLE ED Module has significantly positively impacted on learners' knowledge, skill, attitude, and confidence in providing end of life care in the ED
- The majority (86%, n=419) of learners were intending to change their end of life care practice after completing the ED module.



## Do Not Resuscitate

I can say  
your father is dying.  
I can say  
wishing will not make it so,  
belief doesn't change a thing.

I can say  
love does not conquer all,  
miracles are pretty stories told in church,  
the movies you saw as a child are lies,  
blind hope is not a recipe for success,  
underdogs usually lose,  
death is not the worst thing, it is just  
the last thing.  
But for you that is not true.

I can say  
we have to pretend  
that we can bring him wheezing  
back to you like an old accordion,  
chest pleating in and out,  
singing his customary songs,  
oxygen bumping its hurdy-gurdy way again  
through his ancient heart.

But how can I tell you how  
someone will shout down the hallway, kneel  
frantic on the bed,  
lean his fists against that old breastbone, sharp, frail,  
one onethousand, two onethousand, and count it out.

I can say  
we should not do this.  
He will never be the same.  
I can say  
if it were my father.

I can say  
do not confuse resuscitation  
with resurrection, although  
neither works particularly well.

You look like you are drowning,  
pallid and slow in the waiting room's  
underwater light.

So. Tell me.  
Tell me again.  
Tell me about your father.



## POETRY AND MEDICINE

**Brenda Butka, MD**

JAMA, October 24/31, 2012

Vol 308, No. 16 **1613**





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[//www.endoflifeessentials.com.au/](http://www.endoflifeessentials.com.au/)

