Compassionate responses in emergency department end-of-life care

Rawlings, Devery, Morgan, Tieman, Yin

end-of-life ESSENTIALS

education for acute hospitals

CARESEARCH® palliative care knowledge network

Flinders UNIVERSITY

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

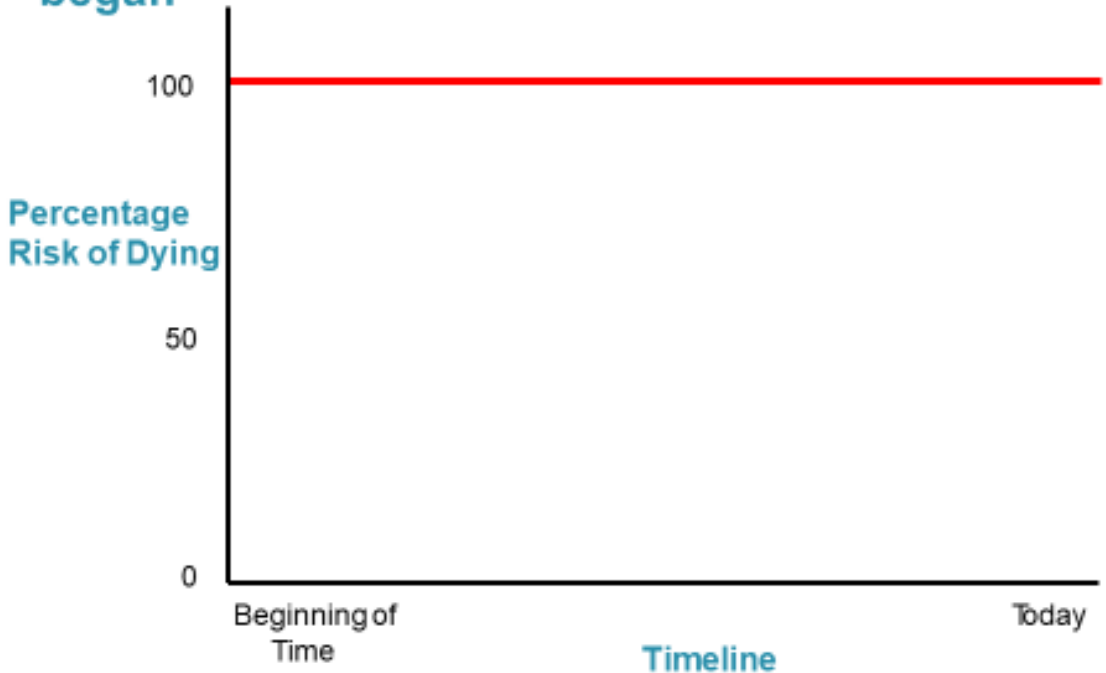
"People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- *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

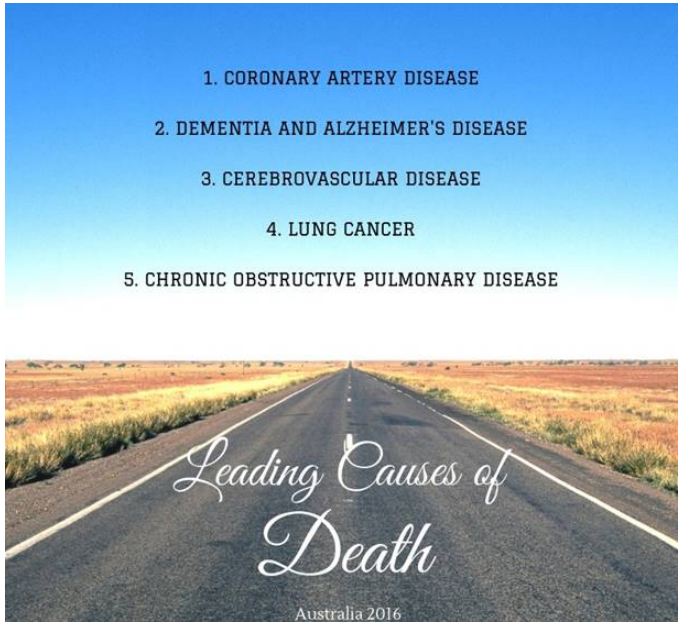
end-of-life ESSENTIALS
education for acute hospitals

Individual's lifetime risk of death since time began



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

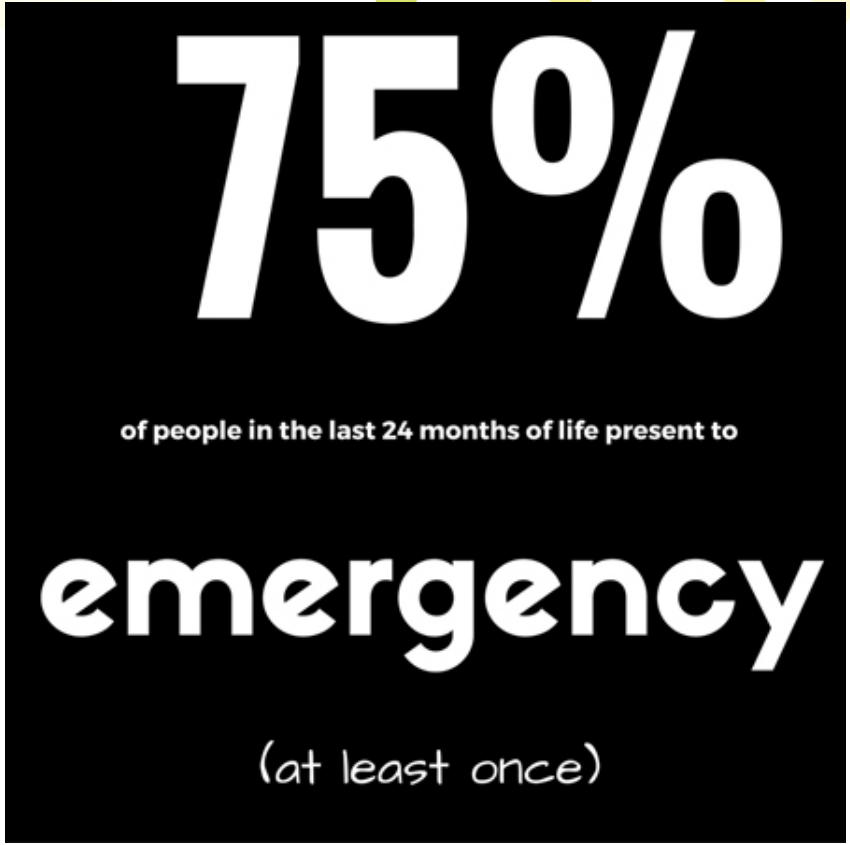
End of Life in ED



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

end-of-life ESSENTIALS
education for acute hospitals



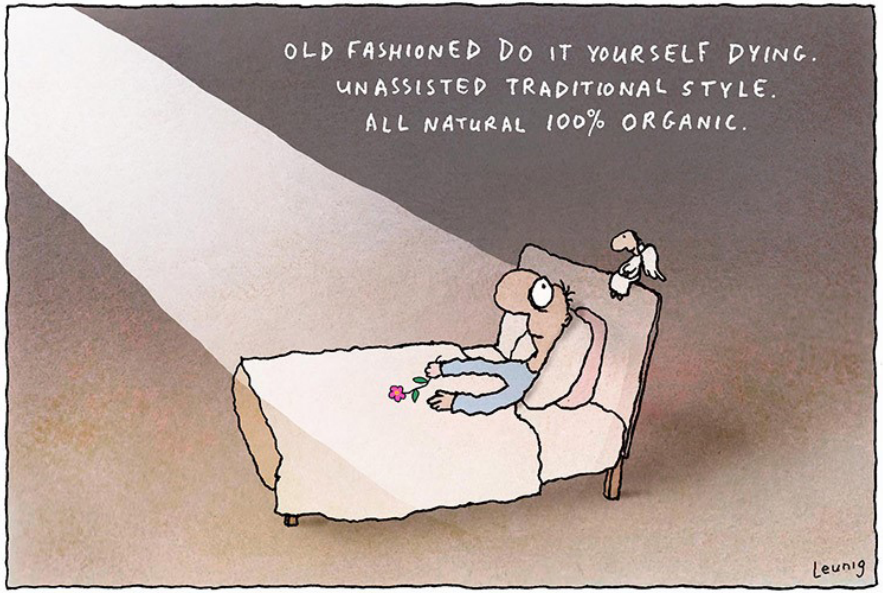
In the last 12 months of life people can have an average of 4 admissions to acute hospitals.

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.

end-of-life ESSENTIALS
education for acute hospitals

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?



end-of-life ESSENTIALS
education for acute hospitals

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

International Journal of Nursing Studies 85 (2018) 106–117

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/locate/ijns

Exploring the quality of the dying and death experience in the Emergency Department: An integrative literature review

Kay J. McCallum[a,*], Debra Jackson[b], Helen Walthall[a], Helen Aveyard[a]

[a] Oxford Brookes University, United Kingdom
[b] Oxford Brookes University, Oxford University Hospitals NHS Foundation Trust, Oxford Health, University of Technology Sydney, Australia, Health Education England Thames Valley, United Kingdom

ARTICLE INFO

Keywords:
Integrative literature review
Emergency department
Death and dying
Nursing
Carers

ABSTRACT

Aim: The aim of this integrative literature review was to explore the quality of the dying and death experience in the Emergency Department from the perspective of staff and carers.
Background: Death in the Emergency Department is common. Understanding the quality of the death and dying experience of patients and their family members is crucial to building knowledge and improving care.
Design: Systematic integrative literature review reported following the PRISMA guidelines.
Data sources: Pubmed, Cumulative Index to Nursing and Allied Health Literature, Magonline (internurse), and the Cochrane library. Articles used were published in English during 1990- 2017.
Review method: Appraisal and thematic analysis.
Results: Sixteen articles are included. Eight themes emerged from the literature: *care in the Emergency Department is about living not dying, staff perceive that death is a failure, staff feel underprepared to care for the dying patient and family in this environment, there is limited time for safe standards of care, staff stress and distress, staff use of distancing behaviours, the care of the dying role is devolved from medics to nurses at the end of life, and patients and staff perceive that the Emergency Department is not the preferred place of death*
Conclusion: There are areas of concern about end of life care in the Emergency Department. To improve practice and to ensure that a good death occurs, further research is needed. There is a need to understand more about the experience of caregivers when a relative or friend dies in the Emergency Department.

end-of-life ESSENTIALS
education for acute hospitals

"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.

end-of-life ESSENTIALS
education for acute hospitals

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)

end-of-life ESSENTIALS
education for acute hospitals

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.

end-of-life ESSENTIALS
education for acute hospitals

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?

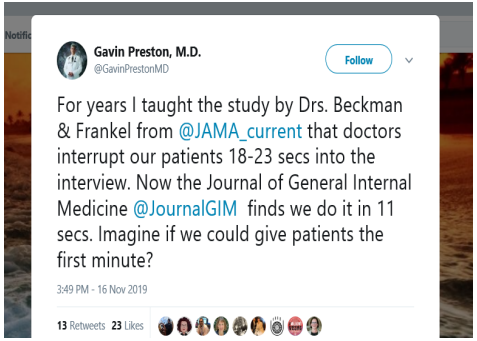
- *"I will provide excellent care (for example, fluids, antibiotics, pain relief etc) but CPR would be harmful. I would resuscitate your relative if I thought that she would have a good outcome - but I will not commence CPR or artificial life support if I believe the outcome is going to be harmful to 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.

end-of-life ESSENTIALS
education for acute hospitals

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



end-of-life ESSENTIALS
education for acute hospitals

end-of-life ESSENTIALS
education for acute hospitals

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.

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-2019-00066

end-of-life ESSENTIALS
education for acute hospitals

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.

end-of-life ESSENTIALS
education for acute hospitals

Quantitative data

ED module released 4th 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

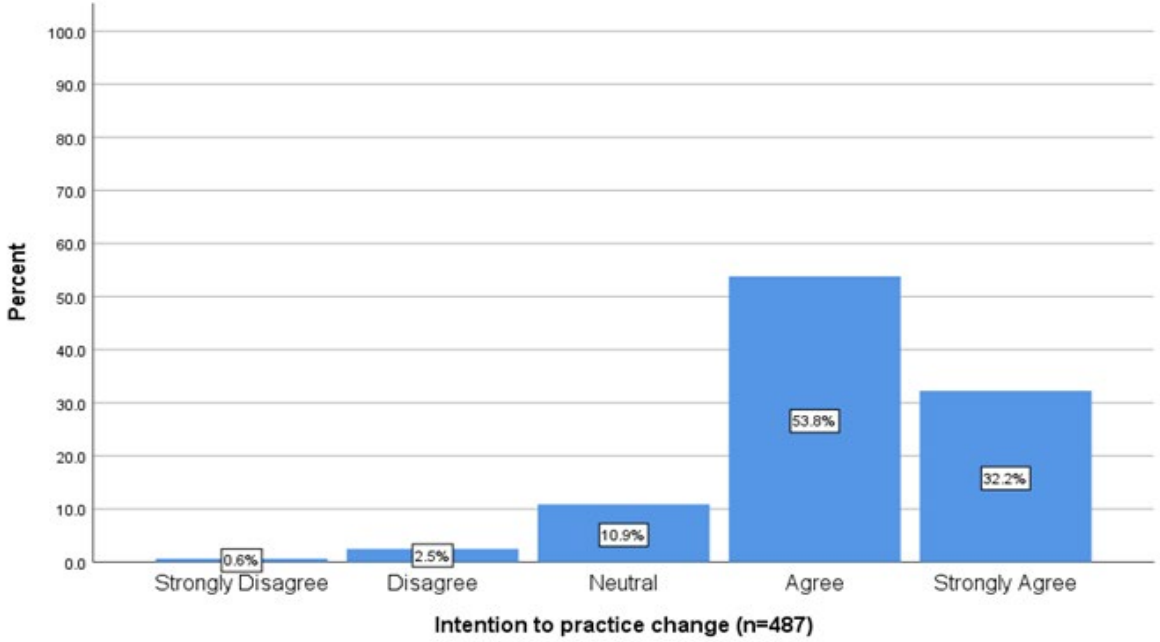
end-of-life ESSENTIALS
education for acute hospitals

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 $p<0.05$

end-of-life ESSENTIALS
education for acute hospitals

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.

end-of-life ESSENTIALS
education for acute hospitals

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.

end-of-life ESSENTIALS
education for acute hospitals

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

Care for the patient	**104 (27.4%)**	
Understanding and prioritising individual EOL needs and wishes	70 (18.4%)	*"Family and patient feel they are being heard and asked about their wishes."*
Comfort care, reassurance, and pain management	40 (10.5%)	*"…reassuring the patient that this place gives the best care."* *"…prioritising comfort."*
Care for the family	75 (19.7%)	
Emotional support	53 (19.4%)	*"Taking the time out to talk to families and explain process. Provide TLC."*
Referral to support services	16 (4.2%)	*"…access to supports explored whilst in the hospital and when family leave."*
EOL resources	12 (3.2%)	*"More resources available to support families - during their time in hospital (e.g rest and washing facilities, access to food and drink, information pamphlets) information on practical assistance afterwards (e.g. funeral arrangements, benefits and legal elements)."*
Time	53 (13.9%)	*"… the need to take time when the ED is busy."* *"Being able to feel that you have the time to give to the relatives/caregivers, when you work in such a busy environment."* *"…let relatives take as much time as they need to say goodbye."* *"Being present, not being rushed."*

hospitals

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

hospitals

‘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.

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”.

Tweet

Kate Granger
@GrangerKate

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

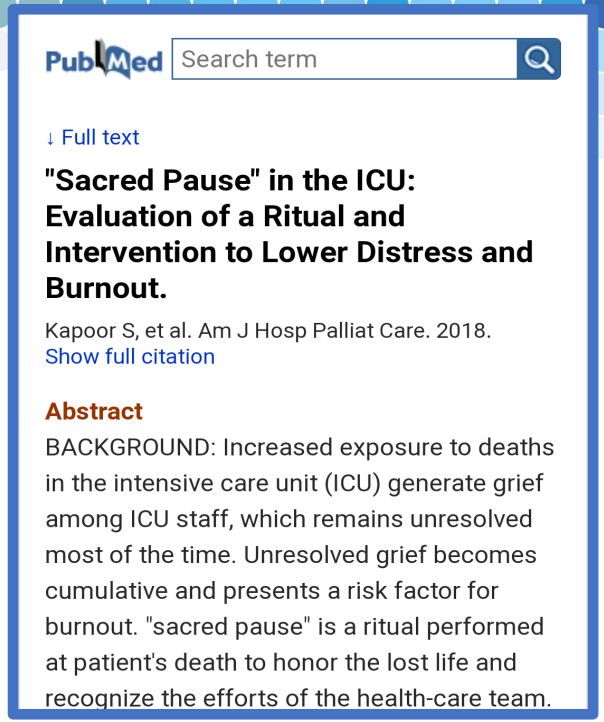
4:28 · 01 Sep. 13 · Twitter for iPhone

#hellomynameis has made over 2 billion impressions since its conception

end-of-life ESSENTIALS
education for acute hospitals

Dr Kate Granger 31 October 1981 – 23 July 2016

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.



end-of-life ESSENTIALS
education for acute hospitals

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

end-of-life ESSENTIALS
education for acute hospitals

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.

end-of-life ESSENTIALS
education for acute hospitals

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**

end-of-life ESSENTIALS
education for acute hospitals

End of Life Essentials would like to thank the many people who contribute their time and expertise to the project, including members of the National Advisory Group and numerous peer reviewers.

//www.endoflifeessentials.com.au/

end-of-life ESSENTIALS

education for acute hospitals