Palliative Care

Ensuring death with dignity epitomizes the foundation of our care and reflects the heart of team. It demands the best of us.

Dying at Home.
Sarah Dillwyn's Deathbed, by Charles Robert Leslie

HPNA
Hospice & Palliative Nurses Association
Advancing Expert Care in Serious Illness

Call for Action:
Nurses Lead and Transform Palliative Care

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Disclosure

Thank you for this invitation to speak. This education content is not influenced by any commercial interests, relevant relationships or conflicts.

Personal Disclosures include:

- *My family, Jim and Silas, are my blessings*
- *I am a Gullah Historian*
- *I have a passion for writing*
- *I am committed to improving culturally effective care at end of life*
- *I scaled a 30-foot gully at the age of 12 with a rope in the middle of a downpour to rescue a baby calf and return her to her mother. My mother threw me the rope.*

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Anticipated Outcomes of this Activity

At the conclusion of this educational activity, participants will self-report:

intent to change practice by applying evidence based strategies to address his/her greatest opportunities to help *nursing transform the care and culture of serious illness* within his/her distinct practice setting.

Palliative Nursing Summit

- In May of 2017, leaders of 26 nursing organizations met in Washington, D.C. to develop a collaborative agenda and action plan for primary palliative nursing.
- The summit was convened by the Hospice and Palliative Nurses Association (HPNA) and the American Nurses Association under the theme, “Nurses Leading Change and Transforming Palliative Care.”
- The objective of the summit was to create a collaborative national agenda for primary palliative nursing.
- The ultimate goal is to ensure that patients with a serious illness and their families have access to primary palliative nursing care whenever and wherever they need it.

Palliative Nursing Summit

Assertions

- The 2017 ANA-HPNA Call for Action asserts that it is a responsibility of the nurse to facilitate the process of informed healthcare decision-making for patients.
- Nurses who facilitate these conversations give the patient and family an opportunity to:
  - reflect and say the things that matter to them, including expressions of hope and meaning in life
  - make a plan to receive care that is consistent with their values.

Help Me Understand: Palliative Nursing?

- Palliative nursing is delivered at the same time as other curative and life-prolonging treatments, and it is not limited to the terminally ill.
- Hospice is a component of palliative nursing that is focused on the care of the terminally ill who have opted to stop curative, life-prolonging treatments.
- The fundamental aspects of palliative nursing are communication and the coordination of care within and across various settings.
- Palliative nursing is the foundation to ***respecting patient's end of life choices.***

Help Me Understand: Difference Between Advance Care Planning and Advance Directives

- Advance Care Planning – a process:
  - Helps the person answer the question, "What medical treatment is right for me?"
  - Depends on the person's values and preferences and cannot be accurately predicted by hcp or family without discussion
  - Exploration of treatment options
  - Process is on-going – not a snapshot in time
  - May or may not include completion of an advance directive
- Advance Directives – a document:
  - Documents patients complete while in possession of decisional capacity about treatment options in the event they lose capacity in the future

Respecting Patient Choices Advance Care Planning

Benefits of Advance Care Planning (ACP) for Patients with Serious Illnesses

- Higher rates of completion of **A**dvance **D**irectives (AD)
- Increased likelihood that clinicians and families are knowledgeable and respect patient choices
- A reduction in hospitalization at the end of life
- The receipt of less intensive treatments at the end of life
- A decrease in futile treatments
- Increased utilization of hospice services
- Increased likelihood that a patient will die in their preferred place

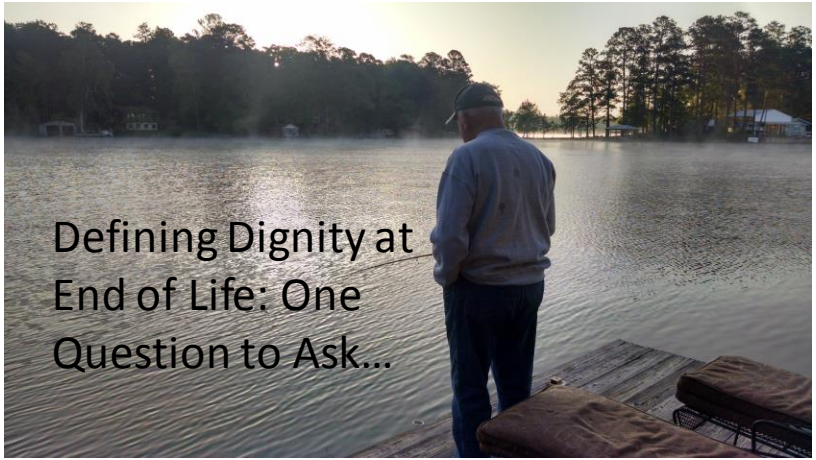
Current Status of Advance Care Planning (ACP) in the United States

- **80%** of people think ACP is important but only **25%** have recorded their wishes
- **90%** of participants think talking to their healthcare provider is important, but only **20%** actually have do so
- Less than **50%** have talked to their family about their wishes

The Dignity Question

The Dignity Question: Self-Reflection Exercise – 3 Minutes

"What do I need to know about you as a person to give you the best care possible?"



There is no wrong answer to this question.

Think about how you see yourself. Think about how your loved ones would describe you.

The answer to this question leads to a greater understanding of the needs, desires and identity of you, as the person, beyond the you, as the "patient."

So, how would you answer the following question?

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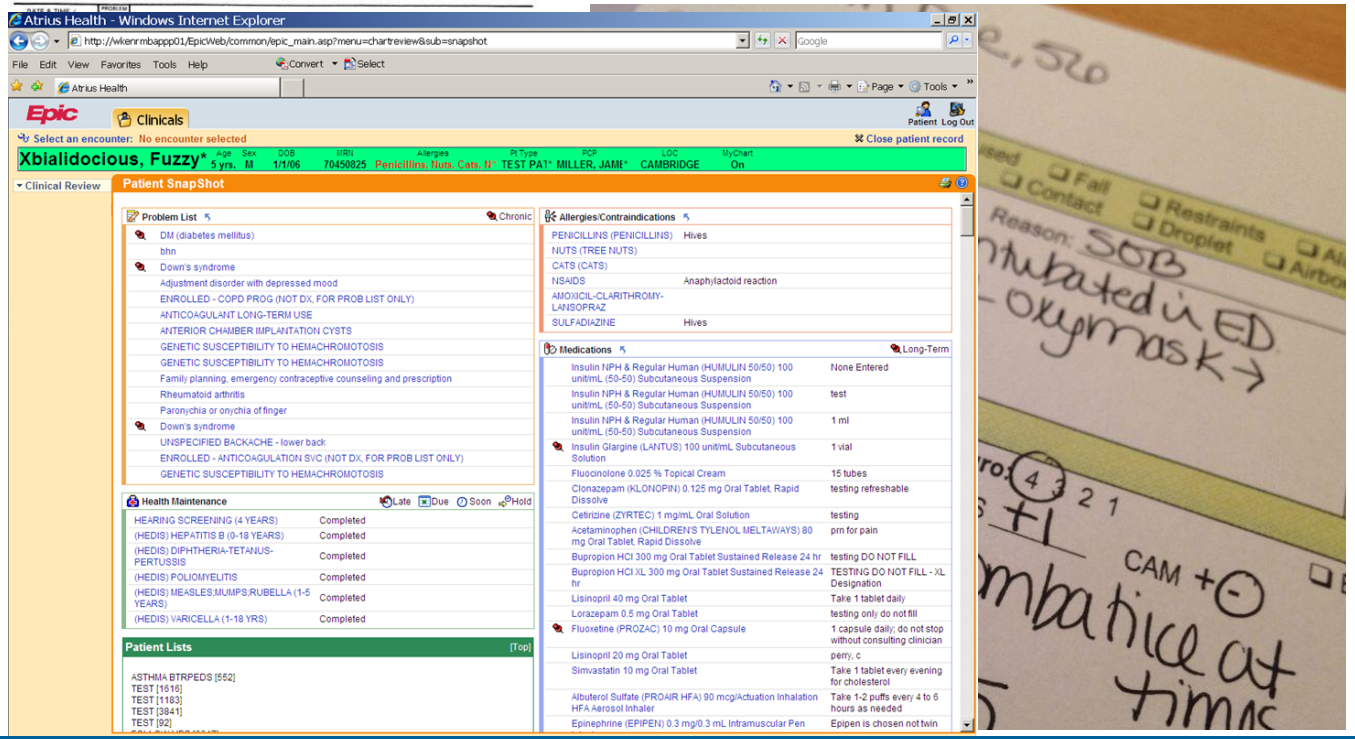
http://www.pallimed.org/2017/11/defining-dignity-at-end-of-life-one.html

Why is palliative care important at this particular moment in health care?

- We are in an environment of increasingly depersonalized health care



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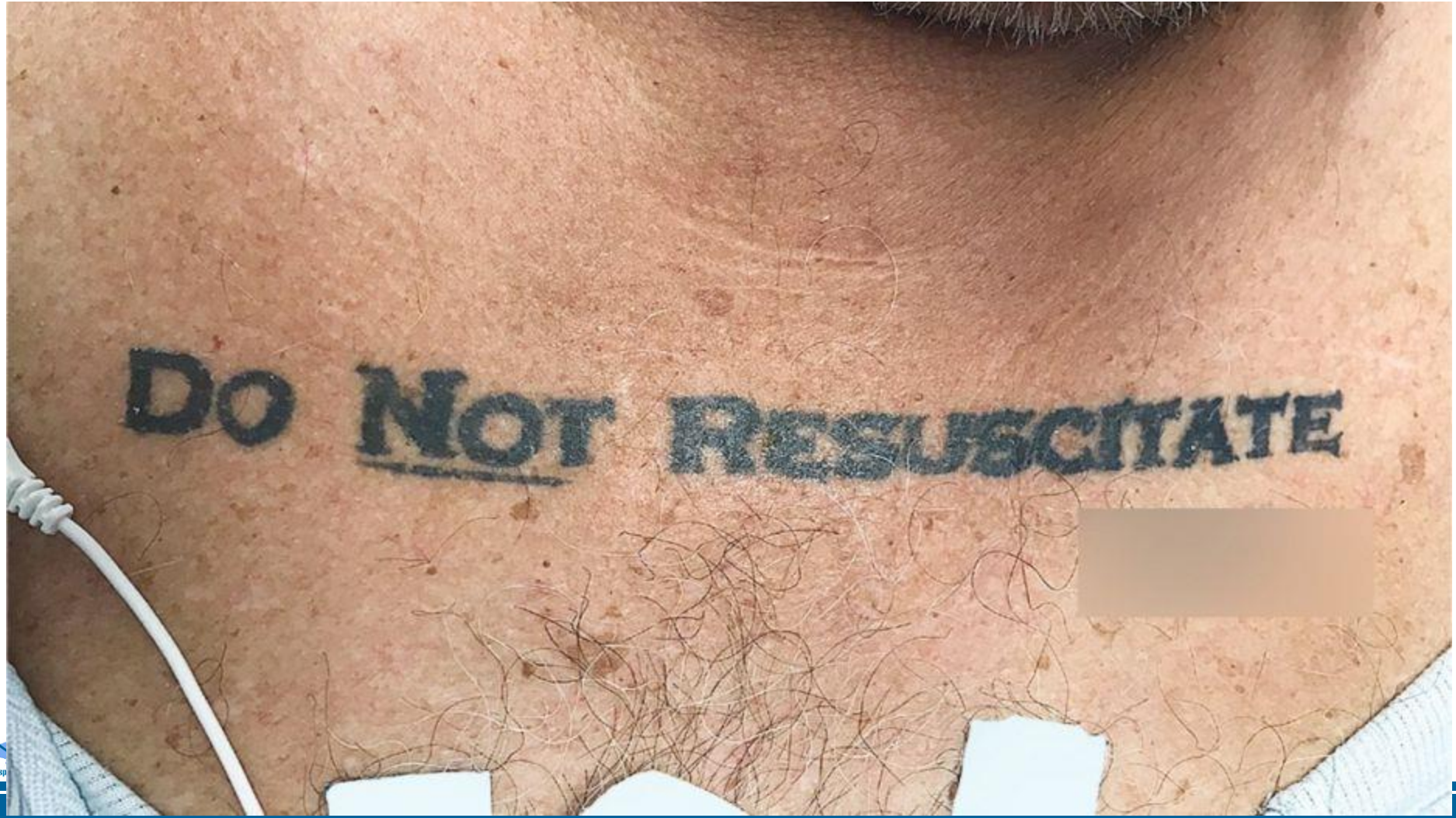
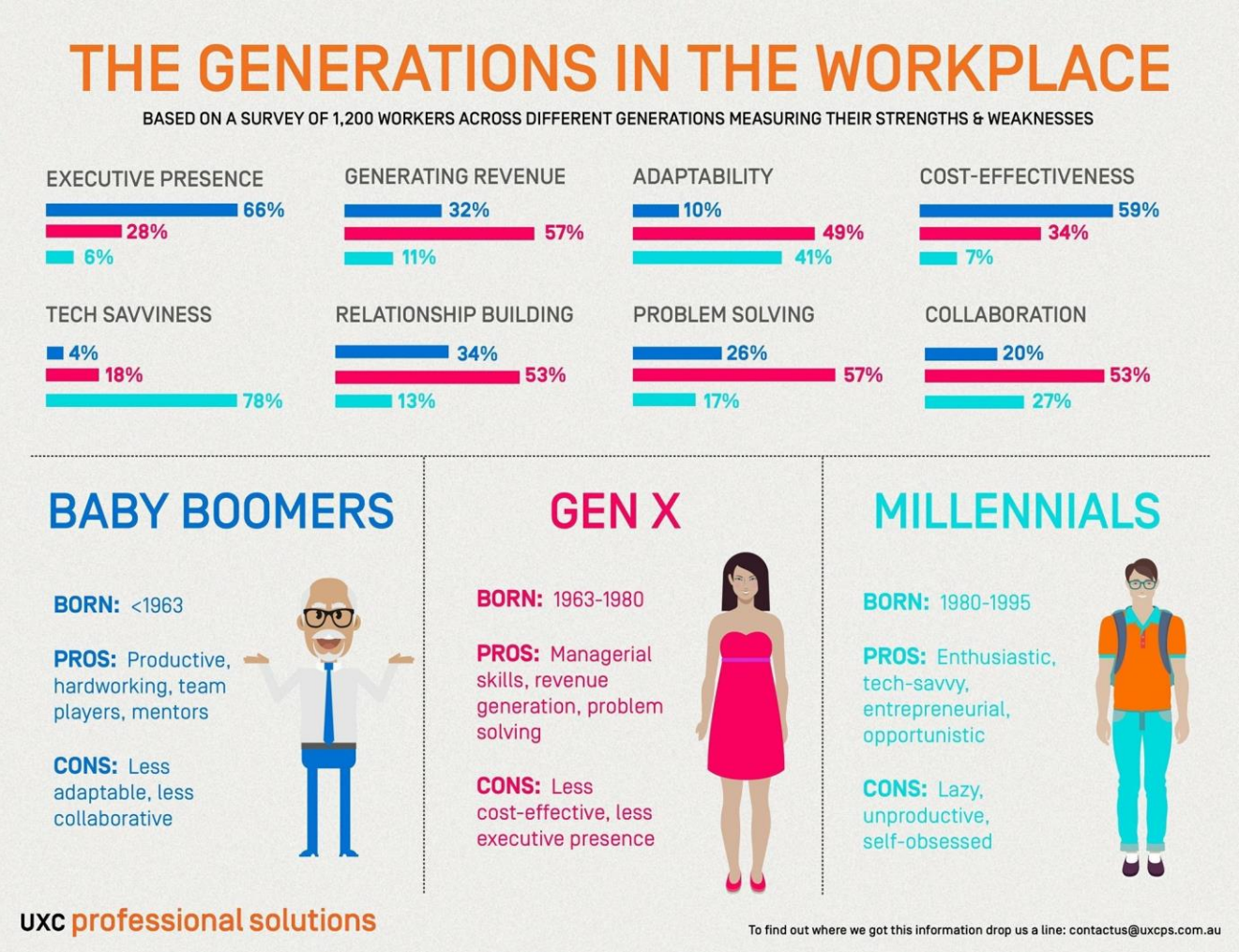
Why is palliative care important at this particular moment in health care?

- Despite (and some times because of) significant advances in life saving technologies, we have a larger population who needs palliation of symptoms from treatment.


DO NOT RESUSCITATE

Why is palliative care important at this particular moment in health care?

- There is a major shift in the generational values and culture of patients and caregivers.



https://www.youtube.com/watch?v=1B3otefmrjA

http://zdoggmd.com/

Nursing has long been committed to peaceful death, and many nurses harbor concerns about futility in medical services for the dying.

Advanced care planning (ACP) is not a discussion that should take place as a patient lays dying, but is instead a conversation that needs to take place much sooner. RN case managers have the experience, philosophy, advocacy and relationship skills to comprehensively address advanced care planning for end-of-life decision making.

Mary Jo Borden, APRN-BC, CCM, MSN

Incorporating Primary Palliative Nursing into Case Management Practice

- Understand the natural trajectory of illnesses and critical decision making points.
- Discuss advance care planning, goals of care, issues of advanced disease, and provide psychosocial support for clients and their families of varying cultures.
- Understand hospice and palliative care services, eligibility, and how to access these services in individual practice and community settings.
- Attend to population specific concerns across the life span: pediatrics, geriatrics, underserved populations.
- Understand community resources.

Dahlin 2015

An Evidence-Based Approach to Advance Care Planning

- Step 1: Appropriate for all adults regardless of health care status: nomination of a health care proxy (surrogate)
- Step 2: Appropriate for patients likely to die within a year: focuses on specific treatments such as CPR, ventilation, artificial hydration and nutrition
- Step 3: Appropriate for patients with symptomatic chronic illness: assist patient and surrogate to understand treatment benefits, **burdens** and to develop a more detailed advance care plan

Burdensome Interventions Self-Assessment Exercise

Burdensome Interventions Self-Assessment Exercise

Exercise Instructions

This activity allows 2 minutes to complete learner self-assessment exercise. Circle one response per intervention.

Rank the following interventions according to which are the least to the most burdensome using 4-point Likert scale of 0 (least) to 3 (most):

0 = least burdensome, not a problem
1 = not much of a burden
2 = somewhat burdensome
3 = most burdensome, very problematic

Intervention	Likert Scale 0 (least burdensome) to 3 (most burdensome)			
	0	1	2	3
Vital Signs Twice Daily				
Diagnostic Tests				
ET Tube to Ventilator				
Daily Weights				
Peripheral Lab Draws				
NG Tube				
Oxygen per Nasal Cannula				
IV/SC/IM Infusion Therapy				
Positioning/Transfer				
Tube Feedings				

Case Mangers as Primary Palliative Nurses: Knowledge and Skills

- *Reflect and self-assess* your individual experiences with end of life and their impact both personally and professionally to increase resilience
- *Recognize* that advance care planning conversations inform your understanding the patients values and allow you to explore the future with the patient and family
- *Understand* how to elicit permission to begin conversations about advance care planning
- *Advocate* goals of advance care planning conversations for the patient and family
- *Differentiate* future opportunities for advance care planning and distinguish them from the present – "that was then, this is now…."
- Reiterate and communicate

Strategies: Listen and Encourage Discussion

- Health care providers should open the conversation then listen more than they speak
- Allow for discussion of the patient's health status, likely treatment choices and outcomes
- Pay attention to non-verbal communication
- Expect the patients/families to need repetition and have HCPs provide a consistent message
- Recognize the importance of hope
- Encourage shared decision making if appropriate
- Support the patient/family decision

"Hope for the best, prepare for the worst. I believe we may be pretty close to the best we hoped for. "

Strategy: Review ACP with hospitalized patients

- It can be difficult to determine when and how to review ACPs with hospitalized patients (timing makes a difference!)
- It is recommended to do on admission and when the patient's condition changes
- An assessment of decision making capacity is needed at the same time
- Structure the discussion in terms of overall treatment
- Engage the patient or surrogate in the discussion (what would the patient desire **IF** s/he experiences clinical deterioration)
- Discussion is essential (provision of educational materials is NOT enough and the give and take of discussion is necessary)

Completing the process

R
D
D
R

- Reiterate preferences
- Document preferences
- Disseminate patient's choices
- Revisit decisions regularly

In Review

Advance Care Planning

Current State	Ideal State
Focus on right to refuse treatment	Focus on thoughtful preplanning **conversations**
Once form is complete, process is considered finished.	Asking about existing documents as a baseline/starting place for conversations, not an end point
Commonly, provide a form for the patient to complete independently	Majority of assistance is focused on ACP engagement and guided conversation
If completing advance directive form with patient, not validating agent's acceptance or understanding of role	Ensuring agent's acceptance of role and ability to honor pt's wishes even if not in agreement with those wishes AND documenting this in ACP note/Advance Directive

Conclusion

- Nurses have a profound role in the care of individuals and families living with serious and life altering illness or injury.
- Nurses are often the first to recognize palliative care issues, needs, and associated distress.
- Nurses play an essential role in advocating for palliative care services for individuals and families, whether by delivery of direct care or team referral processes.
- Nurses can educate consumers about the characteristics and value of palliative care.

Nursing has long been committed to peaceful death, and many nurses harbor concerns about futility in medical services for the dying. Advanced care planning (ACP) is not a discussion that should take place as a patient lays dying, but is instead a conversation that needs to take place much sooner. RN case managers have the experience, philosophy, advocacy and relationship skills to comprehensively address advanced care planning for end-of-life decision making.

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Delivered Outcome of this Activity

I hope that you will self-report intent to change **your** practice by applying evidence based strategies to address **your** greatest opportunities to help *nursing transform the care and culture of serious illness* within **your** distinct practice setting as a result of this activity.

Healing Hands
My hands that delivered babies,
patted their tender feet,
now cradle the dying and bereaved,
bear witness to final sacred breaths.
Tired and cracked,
washed and scrubbed,
my hands restore memories,
soothe and calm.
They wipe away a tear
and burst forth in song.
My heart has taught my hands
to fold in prayer
and open to grace.

Poet:
Summa Palliative Care Team
Summa Health System
Akron, Ohio

Design:
Ian McCullough
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Visual Communication Design

"Please share with me what I need to know about you, as a person, to give you the best care possible."

http://www.pallimed.org/2017/11/defining-dignity-at-end-of-life-one.html