

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

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

The Future of Population Health:
Nurses Leading Change and Transforming Care

Communication & Advance Care Planning | Coordination of Care | Pain & Symptom Management

The Palliative Nursing Summit took place May 12, 2017, and was hosted by the George Washington University School of Nursing in Washington, DC.

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.

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 **Advance Directives (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

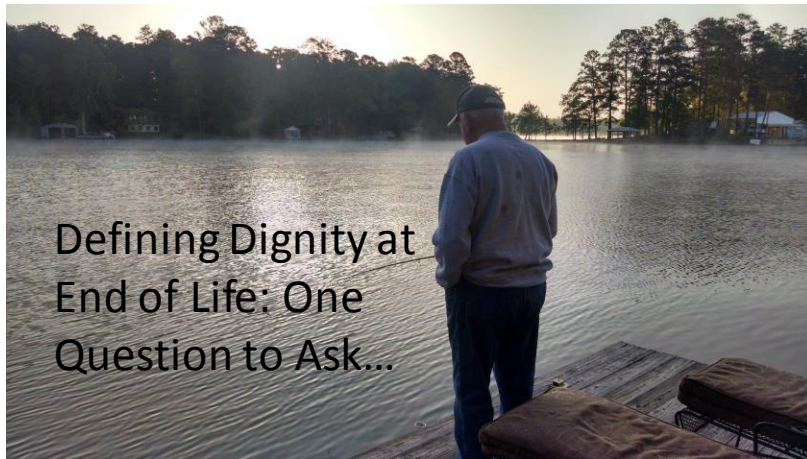
Current Status of Advance Care Planning (ACP) in the United States

- **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?”



Defining Dignity at
End of Life: One
Question to Ask...

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?

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

- We are in an environment of increasingly depersonalized health care



A screenshot of a Windows Internet Explorer browser displaying the Epic Atrius Health patient portal. The browser address bar shows a URL starting with 'http://www.mhapp01.EpicWeb/Common/epic_main.asp?menu=chartreview&sub=snapshot'. The Epic logo is visible at the top left of the page.

The patient information section shows:

- Select an encounter:** No encounter selected
- Patient Name:** Xbialdocious, Fuzzy
- Age:** 5 yrs. **Sex:** M **DOB:** 1/1/06 **MRN:** 70450825
- Location:** Penicillins, Nuts, Case N
- Test Pat:** MILLER, JAMM
- City:** CAMBRIDGE
- MyChart:** On

The **Patient SnapShot** section is expanded, showing the following tabs and content:

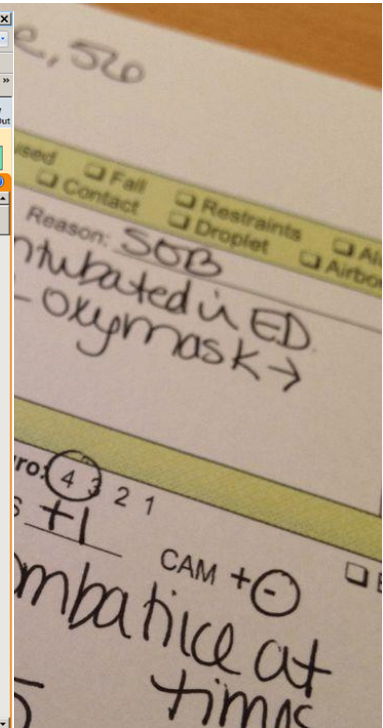
- Problem List:** 5 items. Includes DM (diabetes mellitus), Down's syndrome, Adjustment disorder with depressed mood, ENROLLED - COPD PROG (NOT DX, FOR PROB LIST ONLY), ANTICOAGULANT LONG-TERM USE, ANTERIOR CHAMBER IMPLANTATION CYSTS, GENETIC SUSCEPTIBILITY TO HEMACHROMOTOSIS, GENETIC SUSCEPTIBILITY TO HEMACHROMOTOSIS, Family planning, emergency contraceptive counseling and prescription, Rheumatoid arthritis, Paronychia or onychia of finger, Down's syndrome, UNSPECIFIED BACKACHE - lower back, ENROLLED - ANTICOAGULATION SVC (NOT DX, FOR PROB LIST ONLY), GENETIC SUSCEPTIBILITY TO HEMACHROMOTOSIS.
- Allergies/Contraindications:** 5 items. Includes PENICILLINS (PENICILLINS) Hives, NUTS (TREE NUTS), CATS (CATS), NSAIDS Anaphylactoid reaction, AMOXICIL-CLARITHROMY- LANSOPRAZ SULFADIAZINE Hives.
- Medications:** 5 items. Includes Insulin NPH & Regular Human (HUMULIN 50/50) 100 unit/mL, (50-50) Subcutaneous Suspension (None Entered), Insulin NPH & Regular Human (HUMULIN 50/50) 100 unit/mL, (50-50) Subcutaneous Suspension (test), Insulin NPH & Regular Human (HUMULIN 50/50) 100 unit/mL, (50-50) Subcutaneous Suspension (1 ml), Insulin Glargine (LANTUS) 100 unit/mL, Subcutaneous Solution (1 vial), Fluocinolone 0.025 % Topical Cream (15 tubes), Clonazepam (KLONOPIN) 0.125 mg Oral Tablet, Rapid Dissolve (testing refreshable), Ceftriaxone (ZYRTEC) 1 mg/mL Oral Solution (testing), Acetaminophen (CHILDREN'S TYLENOL MELTAWAYS) 80 mg Oral Tablet, Rapid Dissolve (prn for pain), Bupropion HCl 300 mg Oral Tablet Sustained Release 24 hr (testing DO NOT FILL), Bupropion HCl XL 300 mg Oral Tablet Sustained Release 24 hr (testing DO NOT FILL - XL Designation), Lisinopril 40 mg Oral Tablet (Take 1 tablet daily), Lorazepam 0.5 mg Oral Tablet (testing only do not fill), Fluoxetine (PROZAC) 10 mg Oral Capsule (1 capsule daily; do not stop without consulting clinician), Lisinopril 20 mg Oral Tablet (per day), Simvastatin 10 mg Oral Tablet (Take 1 tablet every evening for cholesterol), Albuterol Sulfate (PROAIR HFA) 90 mcg/actuation Inhalation HFA Aerosol Inhaler (Take 1-2 puffs every 4 to 6 hours as needed), Epinephrine (EPIPEN) 0.3 mg/0.3 mL Intramuscular Pen (Epipen is chosen not twin).

The **Health Maintenance** section shows a list of screenings and their completion status:

Screening	Status
HEARING SCREENING (4 YEARS)	Completed
(HEDIS) HEPATITIS B (0-18 YEARS)	Completed
(HEDIS) DIPHTHERIA-TETANUS- PERTUSSIS	Completed
(HEDIS) POLIO/MEASLES	Completed
(HEDIS) MEASLES/MUMPS/RUBELLA (1-5 YEARS)	Completed
(HEDIS) VARICELLA (1-18 YRS)	Completed

The **Patient Lists** section shows a list of patients:

Patient Name
ASTHMA BTRPEDS [552]
TEST [1616]
TEST [1163]
TEST [3841]
TEST [92]



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.

THE GENERATIONS IN THE WORKPLACE

BASED ON A SURVEY OF 1,200 WORKERS ACROSS DIFFERENT GENERATIONS MEASURING THEIR STRENGTHS & WEAKNESSES

EXECUTIVE PRESENCE



GENERATING REVENUE



ADAPTABILITY



COST-EFFECTIVENESS



TECH SAVVINESS



RELATIONSHIP BUILDING



PROBLEM SOLVING



COLLABORATION



BABY BOOMERS

BORN: <1963

PROS: Productive, hardworking, team players, mentors

CONS: Less adaptable, less collaborative



GEN X

BORN: 1963-1980

PROS: Managerial skills, revenue generation, problem solving

CONS: Less cost-effective, less executive presence



MILLENNIALS

BORN: 1980-1995

PROS: Enthusiastic, tech-savvy, entrepreneurial, opportunistic

CONS: Lazy, unproductive, self-obsessed



UXC professional solutions

To find out where we got this information drop us a line: contactus@uxcps.com.au



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

The screenshot shows the ZDOGG MD website. The header includes a logo with a heart rate line, the text "ZDOGG MD Slightly Funnier Than Placebo", and navigation links: VIDEOS, ABOUT, SPONSOR, EVENTS, BOOK Z, and a search icon. The main content area is split into two panels. The left panel shows a video player with a scene of a man in a blue shirt kneeling on a rooftop under a cloudy sky. The text "Ain't The Way to Die" is overlaid on the video, with "Die" in red. The right panel features a portrait of a bald man in blue medical scrubs with a stethoscope around his neck, smiling. The background of the right panel is a collage of medical-related images.

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.

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

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):

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

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 Managers 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

- Reiterate preferences

D

- Document preferences

D

- Disseminate patient's choices

R

- Revisit decisions regularly

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
Kent State University
Visual Communication Design

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