



HPNA Position Statement Advance Care Planning

Background

Advances in medical technology have provided an array of treatment options available to patients that make extension of life possible, and various treatment options at the end of life available. Patients make deeply personal and variable health care decisions, decisions that may change over the course of an illness or injury trajectory.

Advance care planning is a dynamic process of many discussions whereby patients anticipate and discuss future health states and treatment options.¹ Advance care planning includes three components: 1) the delegation of a surrogate decision-maker to make health care decisions should the patient choose that person to make decision or the patient lacks decision-making capacity; 2) advance directives, and 3) orders to limit life sustaining treatment known as POLST/MOLST (provider/physician orders for life sustaining treatment).

Advance care planning is an essential part of palliative care and should begin well before a healthcare crisis, such as at the first patient encounter, during an initial consultation, or at the disclosure of a serious or life-threatening illness or injury.² Conversations continue to occur over time throughout the course of care to refine and revise decisions.^{3,4} ACP discussions emphasize preparing not only for death or serious or life-threatening illness, but also for potential incapacity.⁵ This is especially important when considering the needs of patients in relation to age and cultural, ethnic, and religious diversity, including discussions with children based on their level of maturity, ability to understand, and status under statutory law.⁶

The American Nurses Association's (ANA) position statement, *Nursing and the Patient Self-Determination Act*, supports the nurse's role as a patient advocate who supports the identification of healthcare preferences, which was supported by the 2010 ANA position statement *Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life*. The statement asserts that it is a responsibility of the nurse to facilitate the process of informed healthcare decision-making for patients.^{3,4} Communication and discussion surrounding healthcare decision-making naturally occurs with the

development of a therapeutic relationship, and is the foundation for ACP.⁷ The ANA-HPNA Palliative Nursing Scope and Standards states informed health care decision making is a core tenet of palliative nursing.⁸

The 2017 ANA-HPNA Call for Action statement asserts that it is a responsibility of the nurse to facilitate the process of informed healthcare decision-making for patients.⁹ 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, and make a plan to receive care that is consistent with their values. Hospice and palliative nurses are uniquely positioned and have expertise to facilitate meaningful conversations with patients and families about present and future health care, and how those interventions align with patient values, beliefs, and goals. Nurses who facilitate these discussions give the patient and family an opportunity to say the things that matter to them, including expressions of hope and meaning in life.¹⁰

However, more than 70% of patients who need to make the end-of-life decisions, lack decision-making capacity.¹¹ In such a situation, healthcare providers turn to family members to make the decisions for their loved ones. When there have been no advance care planning conversations between the patient and family, family members are left to make decisions regarding life-sustaining treatment without input from the patient or with no intimate knowledge of the patient's wishes. There are many deleterious consequences when patients and their family members do not engage in advance care planning before nearing the end of life, and therefore are unprepared for end-of-life decision making. Patients may not receive care that they would have desired at the end of life.^{11,12} Family members or surrogate decision makers experience severe psychological distress during and after the end-of-life decision making.^{13,14}

Hospice and palliative nurses are uniquely positioned to facilitate such meaningful conversations with their patients. The Palliative Nursing Summit report states that nurses should take a lead role in providing more community education and training related to advance care planning.¹⁵ Nurses serve as resources as well as educate and become resources to other nurse clinicians and healthcare providers to fulfill the responsibility to advocate for patients to receive care that is concordant with their values.¹⁶

Position Statement

The Hospice and Palliative Nurses Association believes nurses take a leading role in advance care planning through the education of patients, families, and other healthcare professionals and its implementation in everyday practice.

Clinical Practice

- Advance care planning is a central tenet of person-centered care.
- Patients have the right to receive care that is consistent with their values and preferences.

- Advocacy is a core element of nursing practice supporting and respecting patient values and ensuring their healthcare preferences are honored.
- The decision made by a patient or family not to engage in advance care planning must be respected.

Education

- Nurses must be educated in advance care planning and trained for the skills necessary to facilitate difficult but critical conversations.
- Nurses have the responsibility to facilitate advance care planning to advocate for their patients.
- Nurses must be mindful of and sensitive to elements of diversity (e.g., race/ethnicity, culture, religion) when facilitating advance care planning discussions.

Policy

- Healthcare organizations must incorporate systems that encourage advance care planning as an integral component of quality care for individuals with advanced illness and their families.

Definition of Terms

Advance care planning: A process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. This process can start at any time and be revisited periodically, but it becomes more focused as health status changes.¹⁷

Advance directives: Patient-initiated documents including living wills and documents that name a health care agent.¹⁷

- *Living will:* This is a statement about the kinds of medical care a person does or does not want under certain specific conditions (often “terminal illness”) if no longer able to express those wishes.
- *Durable power of attorney for health care:* (This name may vary by states: e.g., proxy, healthcare representative) Identifies the person (the health care agent) who should make medical decisions in case of the patient’s incapacity.

Decisional capability: Decisional capacity refers to the ability of a person to make decisions. Adults are presumed capable unless declared incompetent by a court of law or a judge. Some states require two physicians to determine decisional capacity of a particular person. Decisional capacity is specific to a point in time and a specific decision. A clinical evaluation of capacity centers on a person’s ability to 1) take in information; 2) understand the relevant information and apply it to his/her own condition; 3) have insight into the condition and consequences of treatment options; 4) be able to communicate the decision and reasoning for choices.^{18,19}

Medical orders: Medical orders are created with and signed by a healthcare professional, usually a physician (in some states, a nurse practitioner or physician assistant), for someone who is seriously ill. Because they are actual medical orders, other health professionals, including emergency personnel, are required to follow them.¹⁷

- *Physicians order for life sustaining treatment (POLST) or medical order for life sustaining treatment (MOLST) etc.:* POLST covers a range of topics likely to emerge in care of a patient near the end of life.
- *Do-not-resuscitate (DNR), do-not-intubate (DNI), do-not-hospitalize (DNH) orders:* Medical orders covering specific treatments that are written in a healthcare facility, but do not cross care settings.

Surrogate decision maker: A person appointed by the patient to make healthcare decisions if the patient becomes incapable of making his/her own decisions. The surrogate decision-maker has a responsibility to act in accordance with the known preferences of the patient; if the preferences are not specifically known, the responsibility is to act on similar known preferences of the patient. Decisions made by the surrogate decision-maker carry the same legal weight as if made by the patient. Also known as *healthcare agent* or *proxy*.²⁰

References

1. Centers for Disease Control and Prevention. *Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself*. Atlanta, GA; 2012. <https://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>. Accessed October 6, 2017.
2. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care. 3rd ed*. Pittsburgh, PA: NCP; 2013. www.nationalconsensusproject.org/Guidelines_Download2.aspx. Accessed October 6, 2017.
3. American Nurses Association. *ANA Position Statement: Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life*. Silver Spring, MD; 2016. www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources/Ethics-Position-Statements/EndofLife-PositionStatement.pdf. Accessed October 7, 2017.
4. Seymour J, Almack K, Kennedy S. Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative Care*, 2010;9:4.
5. Johnstone MJ, Kanitsaki O. Ethics and advance care planning in a culturally diverse society. *J Transcult Nurs*, 2009;20(4):405-416.
6. President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment*. Washington, DC: U.S. Government Printing Office; 1983.

7. Kolarik RC, Arnold RM, Fischer GS, Tulskey JA, et al. Objectives for advance care planning. *J Palliat Med*, 2002;5(5):697-704.
8. American Nurses Association and Hospice and Palliative Nurses Association. *Palliative Nursing Scope and Standards*. Silver Spring, MD; 2014.
9. American Nurses Association and Hospice and Palliative Nurses Association, Professional Issues Panel. *Call for Action: Nurses Lead and Transform Palliative Care*. Silver Spring, MD; 2017.
<http://nursingworld.org/CallforAction-NursesLeadTransformPalliativeCare>. Accessed October 6, 2017.
10. Fried T, Bullock K, Iannone L, O'Leary J. Understanding advance care planning as a process of health behavior change. *J Am Geriatr Soc*, 2009; 57(9), 1547-1555.
11. Silveira MJ, Kim, SYH, Langa, KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*, 2010;362(13), 1211-1218.
12. Song MK, Ward SE, Hanson LC, Metzger M, Kim S. Determining consistency of surrogate decisions and end-of-life care received with patient goals-of-care preferences. *J Palliat Med*, 2016;19(6), 610-616.
13. Chiarchiaro J, Buddadhumaruk P, Arnold RM, White DB. Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients. *Ann Am Thorac Soc*, 2015;12(10), 1528-1533.
14. Detering KM, Hancock AD, Reader MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: Randomized controlled trial. *BMJ*, 2010;340, c1345.
15. Hospice and Palliative Nurses Association. *Palliative Nursing Summit*. 2017. Pittsburgh, PA. <http://advancingexpertcare.org/palliative-nursing-summit/>. Accessed October 6, 2017.
16. Izumi, S. Advance care planning: The nurse's role. *Am J Nurs*, 2017;117(6), 56-61.
17. Institute of Medicine. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington DC: The National Academy Press; 2014.
www.nationalacademies.org/hmd/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx. Accessed October 7, 2017.
18. Applebaum, PS. Assessment of patients' competence to consent to treatment. *N Engl J Med*, 2007;357:1834-1840.
19. Simpson C. Decision-making capacity and informed consent to participate in research by cognitively impaired individuals. *Appl Nurs Res*, 2010; 24(4):221-6.
20. President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research. *Making Healthcare Decisions: The Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship*. Washington, DC: U.S. Government Printing Office; 1982.

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