



## HPNA Position Statement The Nurse's Role in Advance Care Planning

### Background

Advances in medical technology have empowered healthcare providers across settings with the means to prolong life. Tied to this authority is a responsibility to provide care that is clinically and ethically appropriate. Over time, national awareness of the importance of, and need for, advance care planning (ACP) has increased in response to social campaigns such as Healthcare Decisions Day, the enactment of Federal legislation through the Patient Self-Determination Act (PSDA),<sup>1</sup> and changing health information technology.

Patients make deeply personal and variable healthcare decisions, decisions that may change over the course of an illness or injury trajectory. Hospice and palliative nurses are uniquely positioned to have conversations with patients and families about present and future healthcare interventions, and how those interventions align with patient values, beliefs, and goals.<sup>2</sup> 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.<sup>3</sup>

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.<sup>4,5</sup> Communication and discussion surrounding healthcare decision-making naturally occurs with the development of a therapeutic relationship, and is the foundation for ACP.<sup>6</sup>

Advance care planning is a dynamic process of many discussions whereby patients anticipate and discuss future health states and treatment options.<sup>7</sup> It 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. In ACP, conversations continue to occur over time throughout the course of care to refine and revise decisions.<sup>4,5</sup> ACP discussions emphasize preparing not only for death or serious or life-threatening illness, but

also for potential incapacity.<sup>8</sup> 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.<sup>9</sup>

The prevailing American bioethical approach to healthcare decision-making reflects the preeminence of individual autonomy and personal choice.<sup>10,11</sup> Yet, prior to the PSDA, patients did not have a legally recognized mechanism for establishing written preferences about future care. The ratification of the PSDA reflected a growing public awareness about the use of therapies that were potentially burdensome and could extensively prolong life without enhancing quality of life. The public had concerns about whether individual preferences would be honored by healthcare professionals, stemming from prominent “right to die” legal cases such as those involving Karen Ann Quinlan and Nancy Beth Cruzan.<sup>12,13</sup>

The PSDA legalizes the expression of preferences, especially the preference to forgo treatment. It reinforces an expectation and responsibility for the healthcare provider to follow patient preferences should the patient become incapacitated. The Act provides for two types of written advance directives (ADs): 1) a *Living Will* details a person’s healthcare preferences under specific circumstances and is often, but not always, used to declare a wish to refuse, limit, or withhold life-sustaining medical treatment; and 2) a *Durable Power of Attorney for Healthcare* allows an individual to appoint a healthcare proxy or agent to make decisions on his/her behalf should the person become incapable of doing so. The PSDA federally mandates the use of both documents with parameters and requirements that vary by state.<sup>1</sup>

Despite the advantages of the PSDA and executing ADs, there are limitations. A static, written document is often isolated to preferences identified during a single patient episode or point in time and may not reflect changing preferences in response to serious or life-threatening illnesses.<sup>14</sup> Research conducted by the Agency on Healthcare Research and Quality (AHRQ) showed that, although the PSDA guarantees patients the right to accept or refuse medical treatments and to complete an advance directive, only 50% of the terminally ill patients reviewed had an advance directive in their medical record. Of those completing an advance directive, a mere 12% had input from their physician in its development. In addition, only 65% to 76% of the physicians for the patients in the study were even aware the advance directive existed.<sup>15</sup> Finally, there is evidence that the use of advance directive is growing and that those who completed advance directives received care according to their preferences.<sup>16,17</sup>

The facilitation of ACP discussions, which may include the completion of an advance directive, is inherent in palliative nursing practice. It is through ACP that we provide patient advocacy, support self-determination, and develop a synthesis of patient and family values and beliefs regarding medical treatment that is integrated into the plan of care.<sup>18</sup> When the process of ACP is embedded

in whole systems of care, it potentiates access to palliative care, and reduced hospital admissions and interventionist treatment.

### **Position Statement**

- All patients with capacity have the right to make decisions surrounding medical interventions and preferences in care.
- Palliative nursing standards of practice promote advance care planning with patients and their families.
- Individual hospice and palliative nurses have an ethical responsibility to their patients to ensure a process for the articulation, clarification, and dissemination of advance care planning decisions among care providers.
- Advocacy is a core element within palliative nursing practice supporting patient self-determination and ensuring healthcare preferences are honored.
- A patient's age, maturity, views, attitudes, and behaviors must be taken into consideration when planning care with minors.
- Nurses must be mindful of and sensitive to elements of diversity (e.g., race, culture, ethnicity, religion) when facilitating advance care planning discussions.
- The decision by a patient or family not to engage in advance care planning must be respected.
- All healthcare organizations must incorporate systems that encourage the process of advance care planning as an integral component to promoting quality and optimal outcomes in advanced illness and end-of-life care.
- All healthcare professionals must be educated in the process of advance care planning including the skills necessary to facilitate difficult conversations.

### **Definition of Terms**

*Decisional capacity:* 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.<sup>19,20</sup> An unpleasant subjective sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.<sup>22</sup>

*Healthcare agent or proxy:* a person appointed by the patient to make healthcare decisions if the patient becomes incapable of making her/his own decisions. The

proxy 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 agent or proxy carry the same legal weight as if made by the patient.<sup>10</sup>

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One Penn Center West, Suite 425, Pittsburgh, PA 15276-0109  
Phone (412) 787-9301  
Fax (412) 787-9305  
Website: <http://hpna.advancingexpertcare.org>

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