

ANA Position Statement: Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life

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Column

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Purpose

The purpose of this ANA position statement is to articulate the roles, responsibilities, and opportunities for nurses providing care for patients at the end of their lives, and for their families. This statement also provides direction for nurses to support patients and families in recognizing and adapting to a patient's impending death. Nurses are responsible for recognizing patients' symptoms, taking measures within their scope of practice to administer medications, providing other measures for symptom alleviation, and collaborating with other professionals to optimize patients' comfort and families' understanding and adaptation. Throughout this position statement, the term *family* includes those linked by biology or affection; family is whomever the patient defines it to be.

Statement of ANA Position

Nurses are obliged to provide comprehensive and compassionate end-of-life care. This includes recognizing when death is near and conveying that information to families, surrogates, or health care agents. Nurses should collaborate with other members of the health care team to ensure optimal symptom management and to provide support for the patient and the patient's family.

Nurses and other health care providers have a responsibility to establish decision-making processes that reflect physiologic realities, patient preferences, and the recognition of what, clinically, may or may not be accomplished. Establishing goals of care for *this* patient at *this* time may provide a framework for discussion about what care should be provided. This process often involves collaboration with palliative care, ethics, and legal/risk management.

Recommendations

While the dying process is an expected part of our human experience, the introduction of technology has created ethical challenges. Nurses in all roles and specialties must be knowledgeable about the ethical boundaries and ethical principles that guide end-of-life care. Being knowledgeable about primary palliative care is important so the nurse can take steps toward improving care and support at the end of life. Over the past 20 years, much has been learned about how end-of-life care can be improved. Opportunities still abound for nurses and other health care providers to continue to advance the care of patients and families. Recommendations for improvements in practice, education, research, and administration include:

Practice

- Strive to attain a standard of primary palliative care so that all nurses have basic knowledge of palliative nursing to improve the care of patients and families.
- All nurses will have basic skills in recognizing and managing symptoms, including but not limited to pain, dyspnea, nausea, and constipation.

- Nurses will be skilled in having discussions about death and will collaborate with the care teams to ensure that patients, families, surrogates, and health care agents have current and accurate information about the possibility or probability of a patient's impending death.
- Nurses will be knowledgeable about their state's statutes governing end-of-life care and the implications, if any, of those statutes for the scope of nursing practice.
- Nurses will offer resources about advance directives.
- Nurses will routinely ask patients about their health care preferences, who they would want to speak for them if they cannot speak for themselves, and whether they have executed an advance directive.

Education

- Institutions and schools of nursing will integrate precepts of primary palliative care into curricula to include specific ethics content across the lifespan.
- Those who practice in secondary or tertiary palliative care will have specialist education and certification in the specialty area.
- Nurses will advocate for additional education in academic programs and work settings related to ethics education and palliative care, including symptom management, supported decision-making, and end-of-life care, focusing on patients, families, surrogates, and health care agents.
- Those who practice in pediatric settings will have adequate education and training to partner with families/guardians, and as appropriate to involve patients in age- and developmentally appropriate decision-making and language when communicating about end-of-life care.
- Educational programs will incorporate knowledge, skills, and tools to support nurses' integrity and well-being in providing palliative and end-of-life care.

Research

- Support the development and implementation of a targeted research agenda that examines the ethical, clinical, and care delivery questions that are relevant to end-of-life nursing practice across the lifespan.
- Increase the integration of evidence-based dimensions of end-of-life care, including the ethical domain across the lifespan.
- Assess the effectiveness of care in order to develop evidence-informed best practices across the dimensions of end-of-life care and across the lifespan, including the ethical, physical, psychological, spiritual, and interpersonal.
- Assess end-of-life interventions to understand the impact on nurses' integrity and well-being when they are providing end-of-life care.

Administration

- Advocate for facilities and institutions to support the clinical competence and professional development that will help nurses provide dignified and compassionate end-of-life care and support of the bereaved.
- Establish a standard of palliative care that will be available to patients and families from the time of diagnosis of a serious illness or an injury.
- Support the development of comprehensive palliative care services across the lifespan and in all practice settings.
- Create policies, protocols, and guidelines that support nurses in providing comprehensive palliative care and bereavement support.
- Develop, implement, and evaluate mechanisms to recognize ethical concerns and to respond to the impact of moral suffering clinicians may experience in providing quality end-of-life care.

Background

The reality of a patient's imminent death is typically very difficult for patients and families. Choices about the most appropriate health care at the end of a person's life often address whether specific treatments are likely to benefit the patient. These choices may have a quality-of-life dimension. Nurses are frequently able to provide guidance for patients and

families confronting difficult decisions and adapting to painful realities.

It is common for a patient's death to follow the withdrawal of potentially life-prolonging therapies (e.g., ventilator support, medically provided nutrition and hydration, dialysis, vasopressors or inotropes, chemotherapy, antibiotics, etc.). There is no ethical, moral, or legal difference between stopping a therapy and never starting it.

Nurses are obligated to provide care that includes the promotion of comfort, relief of pain and other symptoms, and support for patients, families, and others close to the patient. While nurses should make every effort to provide comprehensive symptom management at the end of life, it is never ethically permissible for a nurse to act by omission or commission, including but not limited to medication administration, with the intention of ending a patient's life. (For more information regarding guidance on ethical decision-making in response to a patient's request for medical aid in dying, see the position statement [The Nurse's Role When a Patient Requests Medical Aid in Dying](#)).

Nurses can often play a pivotal role in supporting patients and families through the decision-making process that precedes death. Nurses are ideally positioned to contribute to conversations about end-of-life care, including maintaining a focus on the patient's preferences and values, and to establish mechanisms to respect all patients' inherent dignity. There are times when the preferences of the family do not represent, or conflict with, the preferences of the patient. In those cases, the nurse's primary responsibility is to provide care and support to the patient and to respect the patient's autonomy while continuing to support the family as they adjust to their loved one's impending death.

In the context of neonates, children, and adolescents, additional ethical complexities impact the care and support of this population at the end of life. It is often presumed that children who have not reached the legal age of decision-making do not have capacity to participate in their advance care planning. Individuals of any age who have the capacity to do so ought to be included in crucial decisions about their end-of-life care. Working with neonates, children, and adolescents at end of life adds a level of complexity to ethical deliberation that can cause nurses moral angst. Cases involving this population may have significant impacts on the nurse providing care and support at the end of life. With guidance and the expert opinion of the nurse, palliative care team, and other members of the interdisciplinary team, end-of-life care for children can be meaningful for all involved.

History/Previous Position Statements

- 2010 Position Statement: Registered Nurses' Roles and Responsibilities in Providing Expert Care and Counseling at the End-of-life
- 2003 Position Statement: Pain Management and Control of Distressing Symptoms in Dying Patients
- 1994 Position Statement: Active Euthanasia
- 1994 Position Statement: Assisted Suicide
- 1991 Position Statement: PSDA (Patient Self-Determination Act)

Supportive Material

Code of Ethics for Nurses with Interpretive Statements (2015): Provision 1, Interpretive Statement 1.4, titled "The Right to Self Determination," affirms the nurse's role and responsibility in providing care and support at the end of life:

The importance of carefully considered decisions regarding resuscitation status, withholding and withdrawing life-sustaining therapies, forgoing nutrition and hydration, palliative care, and advance directives is widely recognized. Nurses assist patients as necessary with these decisions. Nurses should promote advance care planning conversations and must be knowledgeable about the benefits and limits of various advance directive documents. The nurse should provide interventions to relieve pain and other symptoms in the dying process consistent with palliative care standards and may not act with the sole intent of ending a patient's life (p. 3).

Similarly, Nursing's Social Policy Statement: The Essence of the Profession (2010) states:

All registered nurses are educated in the art and science of nursing, with the goal of helping individuals, families, groups, communities, and populations to promote, attain, maintain, and restore health or to experience a dignified death (p. 19).

This position statement also builds on the following ANA and Hospice and Palliative Nurses Association documents and position statements:

- Nursing: Scope and Standards of Practice (2021)

- Palliative Nursing: Scope and Standards of Practice: An Essential Resource for Hospice and Palliative Nurses (2021)
- Position Statement: Nursing Care and Do-not-resuscitate (DNR) Decisions (2020)
- Position Statement: Nutrition and Hydration at the End-of-life (2017)

Guidance and Support for Patients and Families at the End of Life

Nursing care includes not only disease management but also attention to physical comfort and the recognition that patients' well-being also comprises psychological, interpersonal, and spiritual dimensions. Nurses should have the knowledge and skills to manage pain and other distressing symptoms for patients with serious or life-limiting illness, and to collaborate with patients and their families in palliative and end-of-life care decision-making.

Palliative care refers to aggressive symptom management, supported decision-making, and end-of-life care. *Primary palliative care* refers to the knowledge and skills of palliative care that all providers should have, including basic symptom management, the ability to support decision-making (based on accurate physiologic data), and the ability to provide support for patients and families. *Secondary palliative care* refers to the use of consultant specialists with expert knowledge in palliative care to improve care of patients and families. *Tertiary palliative care* refers to the academic medical centers where specialist knowledge for the most complex cases is practiced, researched, and taught. This is the same model used to enhance cardiovascular, renal, neurologic, or other dimensions of patient care.

Clinical decision-making is first based on the physiologic realities of the patient's condition. These physiologic realities frame the options for decision-making. Is the goal to cure this patient? Is the goal to help the patient live well with a serious illness? Do we know that this patient is likely to die soon from this illness? The patient and family must know what is possible and what can no longer be accomplished. Health care providers must acknowledge, and then provide, this information in clear terms to the patient and family. The information should be shared when the health care team recognizes that the condition is terminal or that death is near. Once physiologic parameters have been used to frame options, then patient preferences can be elicited based on clinical realities.

The recognition of the timing and need for end-of-life care may come at different times for varying members of the health care team, as it does for patients and families. Providers' failure to recognize that a patient is close to death may deprive patients of the opportunities that can occur at the end of life. Failure to recognize when a patient is dying and to inform the patient may also keep patients from responsibilities related to dying, such as writing a will or addressing financial obligations. It is also important for the nurse to inquire whether the patient desires chaplaincy services so their spiritual needs can be addressed.

Providers are responsible for identifying options that can no longer benefit the patient. Decision-making should involve targeted questions. Providers should focus on goals of care rather than on specific questions, such as whether vasopressors should be used. Decision-making should focus on patient preferences. Questions address realities, possibilities, and preferences. One such question is, "What would your mother want if she were able to talk with us?" (e.g., feeding tube for a person with dementia, chemotherapy for someone with poor functional status). But if the patient has advanced dementia, a case in which percutaneous endoscopic gastrostomy (PEG) tubes are not indicated, the option for a PEG should not be offered. That is, just because a technology exists does not mean it should always be offered. This includes machines such as ventilators and continuous renal replacement therapy and such therapies as blood transfusions and nasogastric tube feedings.

These discussions cannot occur in isolation. Nurses function as part of a care team and typically as one part in the continuum of care. Establishing the goals of care is a process undertaken by the teams caring for the patient.

Advance Care Planning and Anticipatory Counseling

Advance directives are an expression of the patient's preferences for medical care that are based on a person's values and beliefs. Advance directives come into play when those who have completed them are unable to, or choose not to, speak for themselves. Advance directives also include identification of a surrogate, someone who will represent *the patient's preferences* in decision-making.

Examples of advance directives include durable powers of attorney for health care, do-not-resuscitate/do-not-attempt-resuscitation orders, medical/physician orders for life-sustaining therapy (MOLST, POLST), informal documents of preference, or other health care proxies. While a written document is often helpful, a patient's statements to a loved one or to a health care provider can also be used to represent patient preferences if the patient is unable to participate in decision-making.

Ideally, advance directives reflect a process of conversations that the patient had and decisions that the patient made while the patient still had decision-making capacity. Advance directives, at their best, reflect discussions among the patient's family, surrogate, and health care provider about the patient's preferences for health care in the context of serious illness.

Advance care planning discussions may be initiated in the outpatient setting. It is typical for patients with advanced chronic illness to receive care in outpatient settings at some point during their last year of life. The recognition of the terminal nature or phase of an illness is an ideal impetus for discussions about patient preferences and the identification of a surrogate. Coordination of these efforts is especially important with patients living with conditions such as advanced cancer, dementia, HIV/AIDS, end-stage renal disease, chronic heart failure, and neurodegenerative disease.

For children and adolescents, it is often assumed that withholding information about death can protect them. However, more recent research indicates that both children and families benefit from truthful disclosure in a developmentally appropriate manner. "As we look at the process of including children in advanced [sic] care planning, two natural poles emerge. On the one end there are neonates. They are defined nearly exclusively through the lens of their family's narrative and the framework of expectations in the minds of their parents. On the other end of the spectrum there are mature minors who develop the ability to process and participate in end-of-life planning" (Sholas, 2020, p. 100).

Discussions regarding patient preferences often begin within families rather than with a health care provider. The nurse may be able to ask whether the patient has an advance directive or has expressed preferences about medical care in the event of serious illness.

Many tools exist to help patients and families with decision-making. For example:

- Caring Info is a website that has a list of each state's advance directives. <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>
- The American Cancer Society has a page that provides guidance for the development of an advance directive. <http://www.cancer.org/treatment/findingandpayingfortreatment/understandingfinancialandlegalmatters/advancedirectives/advance-directives-setting-up-a-good-adv-health-care-directive>
- AARP has guidance for individuals and families on developing an advance directive. <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>
- The U.S. Advance Care Plan Registry is a site at which people can register their advance directives. This allows the document to be accessed by providers or hospitals in the event that the document is necessary but not available. <https://www.usacpr.com/individuals-families/how-the-registry-works/>
- Courageous Parents Network is a platform that empowers and supports families and providers who are caring for children with serious illness. <https://courageousparentsnetwork.org>

Summary

Nurses' roles and responsibilities with respect to care at the end of life are grounded in the fundamentals of excellent practice and clinical ethics. While often rewarding, care of patients and families when a person is dying is demanding work that requires the nurse to marshal professionalism and compassion while honoring the nurse's personal integrity.

The provision of excellent end-of-life care requires, first, an excellent knowledge of the pathophysiology of terminal illness or injuries. Based on this knowledge, it is up to providers to construct clinical options for this patient. This almost always means that some options are not available. Excellent, skilled, precise communication is essential for patients and is just as important for families. Based on the options that are constructed by clinicians, patient preferences (or the surrogate's representation of patient preferences) should be elicited.

One of the greatest challenges of end-of-life care in the 21st century is not offering care that cannot benefit the patient. This will require the involvement and support of all levels in the health care system, from those who directly provide patient care to the administrators and regulators who address more system-based issues. Providers must feel assured that they will be supported in not offering care that cannot benefit the patient. Nurses and others must have the knowledge and communication skills to explain to patients, and more often to families, why organ transplantation, chemotherapy, CPR, or an IV cannot help this patient and therefore should not be provided.

Finally, the systems to provide end-of-life care where people die must be consistently available without causing a severe depletion of family resources. Excellence in end-of-life care is complex. Understanding of its components has evolved tremendously. These references and resources can be used to help nurses, other health care providers, administrators, policymakers, and, most important, patients and their families.

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Resources

Many resources are available for patients and families, as well as for nurses and other health care providers. These resources do not represent all available but are meant to serve as an initial guide to some of the topics introduced in this position statement.

End-of-Life Nursing Education Consortium

The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve palliative care. To date, over 20,500 nurses and other health care professionals, representing all 50 U.S. states plus 88 international countries, have received ELNEC training through these national courses and are sharing this new expertise in educational and clinical settings. <https://www.aacnnursing.org/ELNEC>.

Growth House, Inc.

Growth House, Inc., offers “free access to over 4,000 pages of high-quality education materials about end-of-life care, palliative medicine, and hospice care, including the full text of several books. We provide education both for the general public and health care professionals.” <https://caringcommunity.org/self-help/compendiumsguides/growth-house/>.

Hospice and Palliative Nurses Association

The Hospice and Palliative Nurses Association (HPNA) works “to transform the care and culture of serious illness, with a focus on closing the gap in what could be a critical shortage of hospice and palliative professionals needed to care for the aging Baby Boomer population.” HPNA provides education, opportunities for certification, and leadership for nurses providing care for patients with serious illness. <http://www.hpna.org>.

National Consensus Project for Quality Palliative Care

“The purpose of the National Consensus Project for Quality Palliative Care is to promote the implementation of Clinical Practice Guidelines that ensure care of consistent and high quality, and that guide the development and structure of new and existing palliative care services.” <https://www.nationalcoalitionhpc.org/hcp/>.

National Hospice and Palliative Care Organization

NHPCO “is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.” <http://www.nhpco.org>.

Respecting Choices

Respecting Choices is a program developed within the Gunderson Health Care System, the purpose of which is to change the way care is provided so that advance care planning is a regular component of care across all parts of the health care system. <http://www.gundersenhealth.org/respecting-choices>.

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