

Nurses' Roles and Responsibilities in Providing Care and Support at the End of Life

Effective Date: 2016
Status: Revised Position Statement
Written by: ANA Center for Ethics and Human Rights
Adopted by: ANA Board of Directors

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.

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. Nurses should collaborate with other members of the health care team to ensure optimal symptom management and to provide support for the patient and 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 experts in decision-making, such as ethics committees or palliative care teams.

Recommendations

Over the past twenty 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 for patients and families. In an IOM report, authors wrote, "At present, the U.S. health care system is ill designed to meet the needs of patients near the end of life and their families. The system is geared to providing acute care aimed at curing disease, but not at providing the comfort care most people near the

end of life prefer. The financial incentives built into the programs that most often serve people with advanced serious illnesses—Medicare and Medicaid— are not well coordinated, and the result is fragmented care that increases risks to patients and creates avoidable burdens on them and their families” (Institute of Medicine, 2014, p. 330). Recommendations for improvements in practice, education, research, and administration listed here are steps that nurses can take to overcome some of these barriers.

Practice

1. Strive to attain a standard of primary palliative care so that all health care providers have basic knowledge of palliative nursing to improve the care of patients and families.
2. All nurses will have basic skills in recognizing and managing symptoms, including pain, dyspnea, nausea, constipation, and others.
3. Nurses will be comfortable having discussions about death, and will collaborate with the care teams to ensure that patients and families have current and accurate information about the possibility or probability of a patient’s impending death.
4. Encourage patient and family participation in health care decision-making, including the use of advance directives in which both patient preferences and surrogates are identified.

Education

1. Those who practice in secondary or tertiary palliative care will have specialist education and certification.
2. Institutions and schools of nursing will integrate precepts of primary palliative care into curricula.
3. Basic and specialist End-of-Life Nursing Education Consortium (ELNEC) resources will be available.
4. Advocate for additional education in academic programs and work settings related to palliative care, including symptom management, supported decision-making, and end-of-life care, focusing on patients and families.

Research

1. Increase the integration of evidence-based care across the dimensions of end-of-life care.
2. Develop best practices for quality care across the dimensions of end-of-life care, including the physical, psychological, spiritual, and interpersonal.
3. Support the use of evidence-based and ethical care, and support decision-making for care at the end of life.
4. Develop best practices to measure the quality and effectiveness of the counseling and interdisciplinary care patients and families receive regarding end-of-life decision-making and treatments.
5. Support research that examines the relationship of patient and family satisfaction and their utilization of health care resources in end-of-life care choices.

Administration

1. Promote work environments in which the standards for excellent care extend through the patient’s death and into post-death care for families.
2. Encourage facilities and institutions to support the clinical competence and professional development that will help nurses provide excellent, dignified, and compassionate end-of-life care.

3. Work toward a standard of palliative care being available to patients and families from the time of diagnosis of a serious illness or an injury.
4. Support the development and integration of palliative care services for all in- and outpatients and their families.

Background

The proximal reality of a patient's 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 ultimately likely to benefit the patient. These choices may have a quality-of-life dimension. Nurses are frequently in a position to provide guidance for patients and families confronting difficult decisions and adapting to painful realities.

It is not uncommon for a patient's death to follow the withdrawal of potentially life-prolonging therapies (e.g., ventilator support, dialysis, vasopressors or inotropes, chemotherapy, antibiotics, etc.). There is no ethical, moral, or legal difference between stopping a therapy and never starting it. Providers should never start a therapy they are not willing to discontinue.

Decisions about care at the end of a person's life often involve quality-of-life considerations. 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. Throughout this position statement, the term "family" includes those linked by biology or affection; family is whomever the patient says it is. While nurses should make every effort to provide aggressive 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.

Decision-making for the end of a patient's life should occur over years rather than just in the minutes or days before a patient's death. Nurses can be a resource and support for patients and families at the end of a patient's life and in the decision-making process that precedes it. Nurses are often ideally positioned to contribute to conversations about end-of-life care and decisions, including maintaining a focus on patients' preferences, and to establish mechanisms to respect the patient's autonomy.

There are times when the preferences of the family do not represent, or are in 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 struggle to adjust to the impending reality of the patient's death. Standards for excellent care for patients at the end of life should be evidence based, and should integrate national and international standards of care.

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 with-drawing 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 HPNA documents and position statements:

- Nursing: Scope and Standards of Practice (2015)
- Palliative Nursing: Scope and Standards of Practice: An Essential Resource for Hospice and Palliative Nurses (2014)
- Position Statement: Forgoing Nutrition and Hydration (2011)
- Position Statement: Nursing Care and Do Not Resuscitate (DNR) and Allow Natural Death (AND) Decisions (2012)

Nurses’ roles and responsibilities for care at the end of life are grounded in the fundamentals of excellent practice and clinical ethics. Respect for patient autonomy is an important dimension of clinical decision-making, including at the end of life. 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.

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 work 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. *Specialist palliative care* refers to the use of consultant specialists with expert knowledge in palliative care to improve care of patients and families. This is much the same model as is 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 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 need for and timing of 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 and tell when a patient is dying may also keep patients from responsibilities related to dying, such as writing a will or addressing financial responsibilities.

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 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 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 (CRRT), and such therapies as blood transfusions and NG 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 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 that person is unable to, or chooses not to, speak for her- or himself. 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 diseases.

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

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

- 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 in developing an advance directive. http://www.aarp.org/relationships/caregiving-resource-center/info-11-2010/lfm_living_will_and_health_care_power_of_attorney.html
- The U.S. Living Will 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. <http://uslwr.com/formslist.shtm>

Summary

The provision of excellent end-of-life care requires, first and foremost, 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 twenty-first 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 importantly, patients and families.

References

Agency for Health Care Research and Quality. (2013). AHRQ report examines the effect of quality improvement interventions on palliative care. Retrieved from <http://www.ahrq.gov/news/newsletters/research-activities/13jan/0113ra32.html>.

Agency for Health Care Research and Quality. (2013). Decision modeling can demonstrate potential trade-offs between survival and quality of life in advance directives. Retrieved from <http://www.ahrq.gov/news/newsletters/research-activities/13jan/0113ra8.html>.

- Agency for Health Care Research and Quality. (2013). Surgeons are more reluctant to withdraw postoperative life support for patients with complications from surgeon error. Retrieved from <http://www.ahrq.gov/news/newsletters/research-activities/13feb/0213ra8.html>.
- Agency for Health Care Research and Quality. (2014). Advance care planning, preferences for care at the end of life. Retrieved from <http://www.ahrq.gov/research/findings/factsheets/aging/endliferia/index.html>.
- Aging with Dignity. (2015). *Five wishes*. Retrieved from <https://agingwithdignity.org/five-wishes>.
- Almack K., Seymour J., Bellamy G. (2010). Exploring the impact of sexual orientation on experiences and concerns about end-of-life care and on bereavement for lesbian, gay and bisexual older people. *Sociology* 44, 908-924.
- American Association of Colleges of Nursing. (2015). End-of-Life Nursing Education Consortium (ELNEC). Retrieved from <http://www.aacn.nche.edu/el nec/about/fact-sheet>.
- American Association of periOperative Registered Nurses. (2014). Position statement on Perioperative Care of Patients with Do Not Resuscitate or Allow Natural Death Orders. Retrieved from <https://www.aorn.org/-/media/aorn/guidelines/position-statements/posstat-dnr-w.pdf>.
- American College of Surgeons. (2014). Statement on advance directives by patients: "Do not resuscitate" in the operating room. *Bulletin of the American College of Surgeons* 99(1), 42-43.
- American Nurses Association. (2010). *Nursing's social policy statement: The essence of the profession*. Silver Spring, MD. Retrieved from <http://www.nursingworld.org/social-policy-statement>.
- American Nurses Association. (2010). *Position Statement: Forgoing Nutrition and Hydration*. Retrieved from <http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements>.
- American Nurses Association. (2010). *Position Statement: Nursing Care and Do Not Resuscitate (DNR) and Allow Natural Death (AND) Decisions*. Retrieved from <http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements>.
- American Nurses Association. (2013). *Position Statement: Euthanasia, Assisted Suicide, and Aid in Dying*. Retrieved from <http://nursingworld.org/euthanasiaanddying>.
- American Nurses Association. (2015). *Code of Ethics for Nurses with Interpretive Statements*. Silver Spring, MD. Retrieved from <http://www.nursingworld.org/code-of-ethics>.
- American Society of Anesthesiologists. (2013). *Ethical guidelines for the anesthesia care of patients with do-not-resuscitate orders or other directives that limit treatment*. Retrieved from <http://www.asahq.org/~media/sites/asahq/files/public/resources/standards-guidelines/ethical-guidelines-for-the-anesthesia-care-of-patients.pdf>.
- Au, D., Urdis, E., Engelberg, R., Diehr, P., Bryson, L., Reinke, L., Curtis, R. (2012). A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest*, 141(3), 726-735. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3415164/pdf/110362.pdf>.
- Berlandi, J., Duncan, J. (2008). Perioperative DNR orders, palliative surgery, and ethics. *Perioperative Nursing Clinics*, 3(3), 223-232. doi:10.1016/j.cpen.2008.04.001.
- Bolt, E., Hagens, M., Willems, D., Onwuteaka-Philipsen, B. (2015). Primary care patients hastening death by voluntarily stopping eating and drinking. *Annals of Family Medicine*, 13(5), 421-428. doi:10.1370/afm.1814.
- Brinkman-Stoppelenburg, A., Rietjens, J., ven der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28(8), 1000-1025. doi:10.1177/0269216314526272.
- Campbell, M. (2014). "It's not time": Delayed hospice enrollment. *Journal of Palliative Medicine*, 17(8), 874-875. doi:10.1089/jpm.2014.9415.

Chicago-Kent College of Law. (1989). Cruzan by Cruzan v. Director, Missouri Department of Health. Retrieved from <https://www.oyez.org/cases/1989/88-1503>.

Cornell University Law School Legal Information Institute. (2003). Requirements for providers, Title 42, Chapter IV, Subchapter G, Part 489, Subpart I, Section 489.102. Retrieved from <https://www.law.cornell.edu/cfr/text/42/489.102>.

Cornell University Law School Legal Information Institute. (2011). Certification of Terminal Illness, Title 42, Chapter IV, Subchapter B, Part 418, Subpart B. Retrieved from <https://www.law.cornell.edu/cfr/text/42/418.22>.

Cornell University Law School Legal Information Institute. (2012). Conditions of Participation, Title 42, Chapter IV, Subchapter G, Part 482, Subpart B, Section 482.13. Retrieved from <https://www.law.cornell.edu/cfr/text/42/482.13>

Coyne, P., Lyckholm, L., Bobb, B., Blaney-Brouse, D., Harrington, S., Yanni, L. (2013). Managing pain with algorithms: An opportunity for improvement? Or: The development and utilization of algorithms to manage acute pain. *Pain Management Nursing*, 14(4), e185-e188. doi:10.1016/j.pmn.2011.10.005.

Curtis, R., Engelbert, R., Bensink, M., Ramsey, S. (2012). End-of-life care in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine*, 186(7) 587-592. doi:10.1164/rccm.201206-1020CP.

Ford, D., Koch, K.A., Ray, D.E., Selecky, P.A. (2013). Palliative and end-of-life care in lung cancer. *Chest*, 143(5_ suppl):e498S-e512S. doi:10.1378/chest.12-2367.

Gundersen Health System. (2015). *Advance Care Planning — Making choices*. Retrieved from <http://www.gundersenhealth.org/advance-care>.

Hinds, P. S., Meghani, S. (2014). The Institute of Medicine's 2014 Committee on Approaching Death Report: Recommendations and implications for nursing. *Journal of Hospice & Palliative Nursing*, 16(8), 543-548. doi:10.1097/NJH.0000000000000115.

Institute of Medicine (IOM). (2014). Dying in America: Improving quality and honoring individual preferences near the end of life. Retrieved from <http://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near>.

Kirchoff, K., Hammes, B., Kehl, K., Briggs, L., Brown, R. (2012). Effect of a disease-specific advance care planning intervention on end-of-life care. *Journal of the American Geriatrics Society*, 60(5), 946-950. doi:10.1111/j.1532-5415.2012.03917.

Mahon, M. M. (2010). Advanced care decision making: Asking the right people the right questions. *Journal of Psychosocial Nursing & Mental Health Services*, 48(7), 13-19. doi:10.3928/02793695-20100528-0.

Mahon, M. M. (2010). Clinical decision making in palliative care and end of life care. *Nursing Clinics of North America*, 45(3), 345-362. doi:10.1016/j.cnur.2010.03.002.

Mahon, M. M. (2010). US survey finds higher availability of palliative care programs, palliative physicians and consultation teams and palliative outpatient services in National Cancer Institute centers compared to non-NCI centers. *Evidence-Based Nursing*, 13, 105-106. doi:10.1136/ebn1087.

Mahon, M. M. (2011). An advance directive in two questions. *Journal of Pain & Symptom Management*, 41(4), 801-807. DOI: <http://dx.doi.org/10.1016/j.jpainsymman.2011.01.002>

Medicare Payment Advisory Commission (MedPAC). (2015). Hospice Services Payment System. Retrieved from <http://www.medpac.gov/docs/default-source/payment-basics/hospice-services-payment-system-15.pdf?sfvrsn=0>.

National Consensus Project for Quality Palliative Care. (2013). Clinical Practice Guidelines, 3rd Ed. Retrieved from https://www.hpna.org/multimedia/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf.

National Quality Forum. (2015). Palliative Care and End of Life Care. Retrieved from https://www.qualityforum.org/Topics/Palliative_Care_and_End-of-Life_Care.aspx

Nelson, J., Mathews, K., Weissman, D., Brasel, K., Campbell, M., Curtis, J., Lustbader, D. (2015). Integration of palliative care in the context of rapid response: Integration of palliative care in the context of rapid response: a report from the Improving Palliative Care in the ICU advisory board. *Chest*, 147(2), 560-569. doi:10.1378/chest.14-0993.

October, T., Fisher, K., Feudtner, C., Hinds, P. (2014). The parent perspective: "Being a good parent" when making critical decisions in the PICU. *Pediatric Critical Care Medicine*, 15(4), 291-298. doi:10.1097/PCC.0000000000000076.

Physician Orders for Life Sustaining Treatment (POLST) Paradigm. (2015). National POLST. Retrieved from <http://www.polst.org>.

Ramachandran, S., Mhyre, J., Kheterpal, S., Christensen, R., Tallman, K., Morris, M., Chan, P. (2013). Predictors of survival from perioperative cardiopulmonary arrests: A retrospective analysis of 2,524 events from the Get With The Guidelines-Resuscitation Registry. *Anesthesiology*, 119(6). 1322-39. doi:10.1097/ALN.0b013e318289baf6.

Sprung, C., Truog, R., Curtiss, R., Joynt, G., Baras, M., Michalsen, A., Avidan, A. (2014). Seeking worldwide professional consensus on the principles of end-of-life care for the critically ill. The consensus for worldwide end-of-life practice for patients in intensive care units (WELPICUS) study. *American Journal of Respiratory and Critical Care Medicine*, 190(8), 855-886. doi:10.1164/rccm.201403-0593CC.

Swetz, K., Ottenberg, A., Freeman, M., Mueller, S. (2011). Palliative care and end-of-life issues in patients treated with left ventricular assist devices as destination therapy. *Current Heart Failure Report*, 8(3), 212-218. doi:10.1007/s11897-011-0060-x.

Yang, T., Mahon, M. (2011). Considerations of quality adjusted life year in palliative care for the terminally ill.

Journal of Palliative Medicine, 14(11), 1197. doi:10.1089/jpm.2011.0158.

Yang, T., Mahon, M. (2012). Palliative care for the terminally ill in America: The consideration of QALYs, costs and ethical issues. *Medicine, Healthcare and Philosophy*. 15(4), 411-416. doi:10.1007/s11019-011-9364-6.

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 rather are meant to serve as an initial guide to some of the topics introduced in this position statement.

Caring Connections

Caring Connections is a resource of the National Hospice and Palliative Care Organization. This site includes a range of resources for providers, patients, and families related to palliative care and end-of-life care, including advance directives. <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3254&openpage=3254>.

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 fifty U.S. states plus eighty-eight international countries, have received ELNEC training through these national courses and are sharing this new expertise in educational and clinical settings. <http://www.aacn.nche.edu/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.” <http://www.growthhouse.org>.

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.” <http://www.nationalconsensusproject.org>.

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>.