

The Nurse's Role When a Patient Requests Aid in Dying

DRAFT ANA Position Statement

Purpose: The purpose of this position statement is to provide nurses with ethical guidance in response to a patient's request for aid in dying (AID). This statement offers assistance with understanding nurses' ethical obligations and responsibilities amidst social and legislative shifts which make this option legal in an increasing number of U.S. jurisdictions.

Statement of ANA Position: The delivery of high-quality, compassionate care for patients at the end-of-life is central to nursing practice. Hallmarks of end-of-life care include respect for patient self-determination, non-judgmental support for patients' end-of-life preferences and values, and prevention and alleviation of suffering. In states where aid in dying is legal, patient self-determination extends to include a patient's autonomous, voluntary choice and informed request to self-administer medication to hasten death. The term *aid in dying* can be confused with the term *euthanasia*. There is a key distinction between the two terms. Laws that allow aid in dying permit the adult patient with terminal illness and capacity for medical decision making to self-administer oral or enteral medication to end suffering when certain criteria are met. Euthanasia, which is not legal in the United States, occurs when someone other than the patient administers medication in any form, with the intention to hasten the patient's death. Euthanasia is inconsistent with the core commitments of the nursing profession and profoundly violates public trust. The term *aid in dying* (AID) will be used in this document. This position statement clarifies the scope of the nursing role in the care of patients who request aid in dying, with a particular focus on the *Code of Ethics for Nurses with Interpretive Statements*' elucidation of nurses' ethical obligations and responsibilities regarding this end-of-life option (ANA, 2015a).

Nurses are ethically prohibited from administering aid-in-dying medication. Yet nurses must be comfortable supporting patients with end-of-life conversations, with assessing the context of an aid in dying request, advocating for optimized palliative and hospice care services, and knowing about aid-in-dying laws and how those affect practice. Nurses should reflect on personal values related to aid in dying and be aware of how those inform one's ability to provide nonjudgmental information in response to a patient's request. ANA recognizes that AID is a controversial topic that encompasses a plurality of views. Arguments for AID are based in respect for patients' self-

ANA Position Statement

The Nurse's Role When a Patient Requests Aid in Dying

THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION

30 determination, a desire to prevent unnecessary suffering, assurance that patients have access to
31 the full range of care options at the end of life, and consideration that AID is a last resort.
32 Arguments against AID include the sacredness of life, the potential conflict with professional
33 core values, and fears of a “slippery slope,” where the increased acceptability of AID may
34 impact perceptions of a “life worth living” (Olsen, Chan & Lehto, 2017; Sulmasy et al., 2018).

35 **History/Previous Position Statements:** The position statement entitled *Euthanasia, Assisted*
36 *Suicide and Aid in Dying* (2013) was a revised, combined position statement, which originated
37 from The Center for Ethics and Human Rights Task Force on the Nurse’s Role in End-of-Life
38 Decisions, Center for Ethics and Human Rights. Previously, there were two separate position
39 statements; Assisted Suicide (12/08/94) and Active Euthanasia (12/08/94). The position
40 statement on Active Euthanasia was then retired. This position statement supersedes these
41 previous statements.

42 **Other Nursing Organization Positions.** The International Council of Nurses (ICN) position
43 statement *Nurses’ Role in Providing Care to Dying Patients and their Families* (2012) focuses
44 on the right to die with dignity as a basic human right. They also recognize the impact of cultural
45 values and the necessity for ongoing advocacy that nurses have knowledge and awareness of
46 how these inform end-of-life discussions and decisions. The ICN highlights the role of the
47 patient in making informed choices and having the right to be free from pain. The Hospice &
48 Palliative Nurses Association recognizes that nurses employed in states where AID is legal may
49 experience significant moral and ethical conflict (HPNA, 2017). Nurses unable to provide care
50 on moral grounds should ensure the ongoing care of the patient by identifying nurse colleagues
51 willing to do so.

52 **Background and Supporting Material:**

53 **Natural Continuum of Life:** Nurses recognize that death is part of the natural continuum of life,
54 and respect that end-of-life decision making is multifactorial and deeply personal. The *Nursing:*
55 *Scope and Standards of Practice* (2015b) informs the discussion on aid in dying, noting that
56 “nursing occurs whenever there is a need for nursing knowledge, wisdom, caring, leadership,
57 practice, or education. The term “whenever” encompasses anytime, anywhere, with anyone” (p.

ANA Position Statement

The Nurse’s Role When a Patient Requests Aid in Dying

THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION

58 16). Nurses provide expert care throughout life’s continuum, managing the biopsychosocial and
59 spiritual needs of patients and families, both independently and in collaboration with the
60 interprofessional healthcare team. The *Code of Ethics for Nurses* Interpretive Statement 5.3
61 underscores that in patient care at every stage of life, including at the end of life, “nurses assist
62 others to clarify values in reaching informed decisions, always avoiding coercion, manipulation,
63 and unintended influence. When nurses care for those whose health condition, attributes,
64 lifestyles, or situations are stigmatized, or encounter a conflict with their own personal beliefs,
65 nurses must render compassionate, respectful and competent care” (ANA, 2015a, p. 20).
66 Interpretive Statement 1.2 of the *Code* supports this as well, stating that “nurses establish
67 relationships of trust and provide nursing services according to need, setting aside any bias or
68 prejudice.... Such considerations must promote health and wellness, address problems, and
69 respect patients’ or clients’ decisions,” (ANA, 2015a, p. 1).

70 **Participation:** The *Code* is clear in Interpretive Statement 1.4 that nurses “should provide
71 interventions to relieve pain and other symptoms in the dying patient consistent with palliative
72 care practice standards and may not act with the sole intent to end life” (ANA, 2015, p. 3). A
73 nurse’s ethical response to patient inquiry about AID is not based in the intention to end life, it is
74 a response to the patient’s quality of life complaint, whether based in loss of independence,
75 inability to enjoy meaningful activities, loss of dignity or unmanaged pain and suffering. Nurses
76 understand that aid-in-dying legislation consistently requires that the patient, never a healthcare
77 professional, self-administers the aid-in-dying medication. This is a strict legal and ethical
78 prohibition on active participation in aid in dying. An important distinction is that a nurse who
79 supports dialogue, assesses the context for the request for AID, as well as decisional capacity and
80 patient understanding; and provides factual information in a neutral manner is not actively
81 participating in aid in dying. These nursing actions are aligned with the ethical commitment to
82 support patients in clarifying their goals of care and making fully informed decisions (Scanlon &
83 Rushton, 1996).

84 **Suffering:** The ANA’s Social Policy Statement (2010) includes *alleviation of suffering* as part
85 of the core definition of nursing, a nursing action fundamental to patient and family centered
86 care. Requests for AID often originate from fear of unmanaged physical pain and suffering and

ANA Position Statement

The Nurse’s Role When a Patient Requests Aid in Dying

THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION

87 loss of control (Hamric, Schwarz, Cohen & Mahon, 2018; Sulmasy et al., 2018). States with
88 longstanding statutes which allow aid in dying provide perspectives about the reasons patients
89 request this option. The most frequent reasons in Oregon, which have remained stable since
90 1997, include loss of autonomy (89.5%), decreasing ability to participate in activities that made
91 life enjoyable (89.5%), and loss of dignity (65.4%) (State of Oregon Health Authority, 2016).
92 Fear of intractable pain and suffering associated with dying are very real concerns for people at
93 the end of life. Some healthcare professionals might argue that palliative and hospice care are
94 designed to address symptoms, pain and suffering, thus, aid in dying is not necessary. Indeed,
95 since legalizing aid in dying in Oregon, there has been significant growth in the use of palliative
96 and hospice care resources and support (Oregon Health Authority Death with Dignity Annual
97 Reports, 1998-2017). A central feature to ethical nursing practice in the care of patients
98 requesting AID is assuring exploration of all alternatives to AID, including high quality
99 palliative care and aggressive management of pain and suffering. Further research is needed to
100 better understand the AID process and variables impacting patient decisions and the nurse's role.

101 **Conscience-based Refusals:** Interpretive Statement 1.2 of the *Code* notes that “respect for
102 patient decisions does not require that the nurse agree with or support all patient choices” (p. 1),
103 thus the nurse is not required to compromise his or her integrity in the provision of such
104 care. “When a particular decision or action is morally objectionable to the nurse, whether
105 intrinsically so or because it may jeopardize a specific patient, family, community, or population,
106 or when it may jeopardize nursing practice, the nurse is justified in refusing to participate on
107 moral grounds. Conscience-based refusals to participate exclude personal preference, prejudice,
108 bias, convenience, or arbitrariness” (ANA, 2015a, p. 21). A well-established ethical
109 commitment when declining to provide care on moral grounds is the primacy of patient care.
110 “Nurses are obliged to provide for patient safety, to avoid patient abandonment, and to withdraw
111 only when assured that nursing care is available to the patient,” (ANA, 2015a, p.21).

112 **Presence:** A patient may request that a nurse be present when the patient ingests the aid-in-
113 dying medication. Presence that is consistent with the *Code of Ethics for Nurses* includes
114 sensitivity to the patient's vulnerability, demonstration of care and compassion, and promotion of
115 comfort to sustain trust in an established nurse-patient relationship (Numminen, Repo & Leino-

ANA Position Statement

The Nurse's Role When a Patient Requests Aid in Dying

THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION

116 Kilpi, 2017). When making the decision on whether to be present, the nurse should consider the
117 nurse’s personal values, organizational policy as well as the professional relationship that exists
118 with the patient and family. At no time should the nurse advocate for or against the patient’s
119 decision. If present during AID, the nurse promotes patient dignity as well as provides for
120 symptom relief, comfort, and emotional support to the patient and family. The nurse must
121 maintain patient confidentiality and privacy in the AID process. The nurse’s decision to be
122 present should not be negatively evaluated (Ersek, 2004; Johnson & Weiler, 1990; Orentlicher et
123 al., 2016).

124 **Social Justice:** “Nurses must continually emphasize the values of respect, fairness, and caring,”
125 (ANA, 2015a, p.35). Statutes that allow AID are not present in every state, which presents
126 geographic inequity in terms of access. Additionally, AID medication is expensive, which
127 presents an additional barrier to access for those who cannot afford it, even if they live in a
128 jurisdiction or state where this option is legal. Nurses act to reduce or eliminate disparities.
129 While this is most commonly associated with health promotion and disease prevention, the
130 current AID landscape raises questions of fairness which require ethical reflection.

131 **Regional and Organizational Alignment:** *The Nursing: Scope and Standards of Practice*
132 (2015b) underscores the importance of knowing state statutes and organizational policies which
133 guide practice. “To function effectively, nurses must be knowledgeable about ANA’s *Code of*
134 *Ethics for Nurses with Interpretive Statements*; standards of practice for the profession; relevant
135 federal, state, and local laws and regulations; and the employing organization’s policies and
136 procedures” (ANA, 2015b, p. 12). This is crucial in the context of AID, whether a nurse works
137 in a jurisdiction where this option is legal or not.

138 **Summary:** Patients expect nurses to be able to discuss all end of life options (Monteverde, 2017;
139 Vogelstein, 2017). An understanding of the ethical issues surrounding AID is essential to support
140 patients in making informed end-of-life decisions. Nurses should be aware of ethical arguments
141 which support and challenge AID. It is especially important that nurses are clear about the
142 ethical foundations of their own views on AID. Knowledge of one’s own stance helps clarify the
143 boundary between non-judgment and respect for patients’ decisions, and imposition of personal
144 values. Clarity about personal and professional values related to end-of-life options and care can

ANA Position Statement

The Nurse’s Role When a Patient Requests Aid in Dying

THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION

145 also help nurses recognize the conditions in which they may wish to conscientiously object.
146 Nurse understand the distinction between aid in dying and euthanasia, and refrain from acting
147 with the sole intent to end life.

148 **Recommendations:**

149 “It is the shared responsibility of professional nursing organizations to speak for nurses
150 collectively in shaping health care and to promulgate change for the improvement of health and
151 health care” (ANA, 2015a, p. 36). Therefore, the ANA supports that:

- 152 1. The nurse should remain non-judgmental when discussing end of life options with
153 patients, who are exploring AID.
- 154 2. The nurse must have self-awareness of his/her personal values regarding AID and how
155 these values might affect the patient/nurse relationship.
- 156 3. The nurse has the right to conscientiously object to being involved in the AID process.
- 157 4. The nurse must never “abandon or refuse to provide comfort and safety measures to the
158 patient” who has chosen AID (Ersek, 2004, p. 55). Nurses should ensure the ongoing
159 care of the patient considering AID by identifying nurse colleagues willing to provide
160 care.
- 161 5. The nurse must protect the confidentiality of the patient who chooses AID.
- 162 6. The nurse must remain non-judgmental about and protect the confidentiality of health
163 care professionals who are present during the AID process as well as those who choose
164 not to be present.
- 165 7. Nursing research is needed to provide an evidence base for AID.
- 166 8. Nurses should be involved in issues of social justice, end-of-life policy discussions and
167 development (Ersek, 2004) on local, state and national levels, including palliative and
168 hospice care services.

169

170

171

172

ANA Position Statement

The Nurse’s Role When a Patient Requests Aid in Dying

THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION

173

References

- 174 American Nurses Association. (ANA). (2010). *Nursing's social policy statement: The essence of the profession*
175 (3rd ed.). Silver Spring, Maryland: Author.
- 176 American Nurses Association. (2013). *Euthanasia, assisted suicide, and aid in dying* [Position statement].
177 Washington, DC: ANA.
- 178 American Nurses Association (2015a). *Code of ethics for nurses with Interpretive statements*. Silver Spring,
179 MD: Nursesbooks.org.
- 180 American Nurses Association. (2015b). *Nursing: Scope and standards of practice (3rd ed.)*. Silver Spring,
181 MD: Author.
- 182 Ersek, M. (2004). The continuing challenge of assisted death. *Journal of Hospice and Palliative Nursing*, 6(1),
183 46-59.
- 184 Hamric, A. B., Schwarz, J. K., Cohen, L. & Mahon, M. (2018). Assisted suicide/aid in dying: What is the
185 nurse's role? *American Journal of Nursing*, 118(5), 50-59.
- 186 Hospice & Palliative Nurses Association. (2017). *HPNA position statement: Physician assisted*
187 *death/physician assisted suicide*. Retrieved from <https://advancingexpertcare.org/position-statements/>
- 188 International Council of Nurses. (2012). *Nurses' role in providing care to dying patients and their families*.
189 Retrieved from <https://www.icn.ch/nursing-policy/position-statements>
- 190 Johnson, R. A., & Weiler, K. (1990). Aid-in-dying: Issues and implications for nursing. *Journal of*
191 *Professional Nursing*, 6(5), 258-264.
- 192 Monteverde, S. (2017). Nursing and assisted dying: Understanding the sounds of silence. *Nursing Ethics*,
193 24(1), 3-8. doi: 10.1177/0969733016684967
- 194 Numminen, O., Repo, H., & Leino-Kilpi, H. (2017). Moral courage in nursing: A concept analysis. *Nursing*
195 *Ethics*, 24(8): 878-91.
- 196 Olsen, D. P., Chan, R. & Lehto, R. (2017). Ethical nursing care when the terminally ill patient seeks death.
197 *American Journal of Nursing*, 117(7), 50-55.
- 198 Oregon Health Authority Death with Dignity Annual Reports. Retrieved from
199 [https://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/a](https://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx)
200 [r-index.aspx](https://www.oregon.gov/oha/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx)
- 201 Orentlicher, D., Pope, T. M., & Rich, B. A. (2016). Clinical criteria for physician aid in dying. *Journal of*
202 *Palliative Medicine*, 19(3), 259-262.
- 203 Russell, J.A., Epstein, L.G., Bonnie, R.J., Conwit, R. Graf, W.D., Kirschen, M., ... Williams, M.A. (2018).
204 Lawful physician-hastened death: AAN position statement. *Neurology*, 90, 420-422. doi:
205 10.1212/WNL.0000000000005012
- 206 Scanlon, C. & Rushton, C.H. (1996). Assisted suicide: Clinical realities and ethical challenges. *American*
207 *Journal of Critical Care*, 5(6) 397-403.

ANA Position Statement**The Nurse's Role When a Patient Requests Aid in Dying*****THIS DOCUMENT IS FOR PUBLIC COMMENT USE ONLY AND NOT INTENDED FOR CITATION***

208 Sulmasy, D. P., Finlay, I., Fitzgerald, F., Foley, K., Payne, R. & Siegler, M. (2018). Physician-assisted suicide:
209 Why neutrality by organized medicine is neither neutral nor appropriate. *Journal of General Internal*
210 *Medicine*, 33(8), 1394-1399.

211 Vogelstein, E. (2017). Evaluating the American Nurses Association's arguments against nurse participation in
212 assisted suicide. *Nursing Ethics*. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/28532236>
213

214

215