

## PROVIDING NURSING CARE AT THE END OF LIFE

### CNA POSITION

Nurses<sup>1</sup> have an important and integral contribution to make in the provision and enhancement of end-of-life<sup>2</sup> care through their varied roles in practice, research, education, administration and policy.

The Canadian Nurses Association (CNA) believes that nursing care at the end of life should be rooted in the values outlined in CNA's *Code of Ethics for Registered Nurses*.<sup>3</sup> These include providing safe, compassionate, competent and ethical care; promoting health and well-being; promoting and respecting informed decision-making; preserving dignity; maintaining and respecting privacy and confidentiality; and being accountable. The code states that when people in their care are dying, nurses “foster comfort, alleviate suffering, advocate for adequate relief of discomfort and pain and support a dignified and peaceful death. This includes support for the family<sup>4</sup> during and following the death.”

CNA believes in the essential value of providing appropriate and compassionate care to individuals facing life-threatening illness, and to their loved ones. Important considerations for providing quality end-of-life care are discussed below.

### *Interprofessional teams*

Quality end-of life care is “best provided through the collaborative practice of an interdisciplinary team to meet the physical, emotional, social and spiritual needs of the person and their family.”<sup>5</sup> Nurses, as members of the interprofessional team, collaborate with the person, the person's family and all those involved in providing care (such as physicians, other health-care professionals and volunteers) to support a holistic approach; incorporate the person's priorities, values and choices in all aspects of care; and address any specific concerns that may arise.

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<sup>1</sup> *Nurses* refers to registered nurses throughout.

<sup>2</sup> There is no definitive definition for the term *end of life*. It is generally understood to describe a period during which an individual is experiencing a decline in health that is ultimately expected to lead to death over a period of days, weeks, months or years. This can include serious acute or chronic illnesses or frailties associated with advanced age. The end of life may occur at any age (Lunney, Foley, Smith & Gelband, 2003).

<sup>3</sup> (CNA, 2008)

<sup>4</sup> “In matters of caregiving, family is recognized to be those people identified by the person receiving care or in need of care as providing familial support, whether or not there is a biologic relationship. However, in matters of legal decision-making it must be noted that provincial legislation is not uniform across Canada and may include an obligation to recognize family members in priority according to their biologic relationship” (CNA, 2008, as paraphrased from CNA, 1994).

<sup>5</sup> (Canadian Hospice Palliative Care Association [CHPCA], 2002. See also King & Jordan-Welch, 2003; Mitty, 2004; Price, 2003)



### ***Informed choice and advance care planning***

CNA recognizes a person's right to make informed choices<sup>6</sup> about his or her plan of care for the end of life that reflect his or her personal, cultural and religious values. When assisting an individual in this planning, nurses should consider the individual as a person in relationship with others, including his or her family.

CNA believes that nurses have an important role to play in encouraging all individuals, whether healthy or ill, to express their goals and wishes related to end-of-life care (such as preferred location of death, choices about organ donation, and whether or not they would like life-sustaining treatments such as cardiopulmonary resuscitation,<sup>7</sup> artificial nutrition and hydration, dialysis and mechanical ventilation). The plan of care should include current and future treatment options, as well as the right to refuse treatment.<sup>8</sup> Refusal of treatment may involve a request that life-sustaining treatment, including artificial nutrition and hydration, be withdrawn or withheld. Treatment options in the plan may include alternative and complementary therapies.<sup>9</sup>

CNA believes that nurses, when helping a person identify their wishes for their end-of-life care plan, have a responsibility to provide education and impartial interpretation of medical information in a way that individuals and their families can understand.<sup>10</sup>

Making and documenting decisions about future treatment options, including life-sustaining treatments such as cardiopulmonary resuscitation, is often referred to as *advance care planning*.<sup>11</sup> Advance care planning, although often initiated to provide direction regarding end-of-life care, can be undertaken at any point in life. Nurses should encourage all individuals to document their wishes regarding care options, which may also include appointing someone to make decisions on an individual's behalf should he or she become incapable. Capable individuals may change their mind about their goals and wishes at any time.

### ***Providing end-of-life care***

Developing and delivering a care plan for the end of life requires ongoing, open and honest communication; the timing and delivery of information should be tailored to the needs, developmental stage and readiness of the person and/or their family. When caring for children, nurses must be knowledgeable about the levels of understanding of death and dying related to developmental stages, and they must incorporate this knowledge into their care.

CNA believes that nurses, other health-care providers, and substitute decision-makers have an ethical and legal duty to respect any wishes that an individual previously expressed when capable. If a person is incapable of making decisions for him or herself, nurses must comply with specific legislation related to substitute decision-making in

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<sup>6</sup> To make an informed choice, an individual must receive accurate and sufficient information about their diagnosis and prognosis, as well as the nature, potential risks, side effects and benefits of proposed treatment(s), alternatives to proposed treatment(s), and the consequences of refusing proposed treatment(s).

<sup>7</sup> Cardiopulmonary resuscitation (CPR) is a treatment intervention for cases of sudden unexpected cardiac or respiratory arrest. CPR is understood to include mouth-to-mouth resuscitation, chest compression, ventilation, intubation and defibrillation. For further information, please refer to the 2006 InfoLAW Bulletin of the Canadian Nurses Protective Society *Consent for CPR*.

<sup>8</sup> (Price, 2003)

<sup>9</sup> (CNA, 1999)

<sup>10</sup> (Engström, Bruno, Holm & Hellzén, 2006; Hohenleitner, 2002; Robichaux & Clark, 2006)

<sup>11</sup> *Advance care planning* is an ongoing process that encourages individuals to engage in conversations about potential future treatment options with their health-care providers and family or community. It may include completing a written document, often referred to as an advance directive or living will. In an advance directive, individuals may appoint one or more people to make decisions on their behalf (proxy directive) and/or outline what decisions should be made if they become incapable of making decisions for themselves (treatment or instructional directive) (Dunbrack, 2006).

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their jurisdiction.<sup>12</sup> Persons who are deemed incapable, which may include young children, should be involved in decision-making to the extent that they are able. Jurisdictional legislation determines the legal right of parents to make decisions on their child's care, and the focus in these instances is on the family as a unit of decision-making. Nurses must be familiar with specific legislation related to choices and decision-making in their jurisdiction. Decisions around the withdrawing or withholding of treatments may involve the individual, the family, the health-care team and, if necessary, ethicists and ethics committees. Regardless of the outcome of decision-making around the withdrawing or withholding of treatments, nurses continue to provide quality end-of-life care and comfort measures.

Nurses should advocate for the communication of and respect for individuals' goals and wishes across health-care settings as well as for the development of appropriate processes and documentation that will facilitate this.<sup>13</sup> Nurses should also advocate for opportunities for revisiting, revising and documenting end-of-life care plans that can be clearly communicated across the continuum of health-care settings.

### ***Pain and symptom management***

Nurses, in all practice settings, “work to relieve pain and suffering, including appropriate and effective symptom and pain management, to allow persons to live with dignity.”<sup>14</sup> Appropriate pain and symptom management is a key component of end-of-life care and addresses one of the common concerns expressed by dying individuals: a fear that they will experience pain and suffering.<sup>15</sup> Although increasing doses of pain medication may, in very limited instances, have a secondary and unintended effect of hastening death, this action is ethically justifiable if the dosage of pain medication is adjusted appropriately and the primary intent is to relieve pain. However, there is evidence that under-treatment of pain is a far more pressing concern.<sup>16</sup>

### ***Providing palliative care***

Palliative care is the provision of care aimed at relieving suffering and improving the quality of living and dying. This model of care is appropriate for any person at any stage of a life-threatening illness, regardless of age. The Canadian Hospice Palliative Care Association defines palliative care as “the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved.”<sup>17</sup> Individuals and families living with life-threatening illness benefit from palliative care with its focus on pain and symptom management; social, psychological, emotional and spiritual support; and caregiver support.<sup>18</sup> CNA believes that nurses should advocate for health-care systems that provide for access to safe, compassionate, competent and ethical end-of-life care, including access to hospice palliative care services.

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<sup>12</sup> For further information, please refer to the 2004 InfoLAW Bulletin of the Canadian Nurses Protective Society *Consent for the Incapable Adult*.

<sup>13</sup> (Blatt, 1999; Breier-Mackie, 2001; Briggs & Colvin, 2002; Hohenleitner, 2002; Jezewski, Meeker & Schrader, 2003; Robichaux & Clark, 2006; Storch & Dossetor, 1998)

<sup>14</sup> (CNA, 2008)

<sup>15</sup> (Price, 2003; Schroepfer, 2006; Volker, Kahn & Penticuff, 2004)

<sup>16</sup> (Portenoy et al., 2006)

<sup>17</sup> (CHPCA, 2002)

<sup>18</sup> (CHPCA, 1997)



### ***Professional competencies and support***

To provide quality end-of-life care, nurses must seek an understanding of the cultural, religious and other values and beliefs around death and dying that an individual and/or their family and/or their community may hold.<sup>19</sup> To engage in conversations about death and dying with individuals in their care, nurses need to explore their own knowledge of, attitudes toward and beliefs around death and dying.<sup>20</sup> Caring for individuals at the end of life is often emotionally and physically difficult,<sup>21</sup> and caring for infants and children who are dying may be especially challenging.

If nurses identify gaps in their knowledge and skills, they should seek education or support.<sup>22</sup> Continuing education, adequate staffing and psychological support are needed to ensure that nurses are able to provide quality end-of-life care. It is important that nurses have access to support from colleagues and employers and the opportunity to engage in reflective self-care practices.

### ***Education, research and advocacy***

Nurses have a role to play in facilitating positive experiences for nursing students and novice nurses in end-of-life care by modeling and teaching appropriate skills and behaviours.<sup>23</sup> CNA believes that palliative care education<sup>24</sup> should be included in basic and post-basic nursing curricula.

CNA recognizes and supports the involvement of nurses in research,<sup>25</sup> policy development, quality education, the identification and adoption of evidence-based best practices and the evaluation of outcomes related to the provision of end-of-life nursing care.<sup>26</sup> Nurses have a duty to provide and advocate for quality end-of-life care.

## **BACKGROUND**

Most individuals desire an end-of-life experience that is peaceful and dignified and in which they are able to exercise their own autonomy<sup>27</sup> and remain in control to the greatest extent possible.<sup>28</sup> Many individuals are concerned that if they become incapable, they might receive treatments they would not have chosen when capable. There is considerable research that suggests there is significant room for improvement to be made in

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<sup>19</sup> (Ferris et al., 2002, p. 19)

<sup>20</sup> (Engler et al., 2004)

<sup>21</sup> Ibid.

<sup>22</sup> (Engler et al., 2004; Mallory & Allen, 2006)

<sup>23</sup> (Mallory & Allen, 2006)

<sup>24</sup> Palliative care “refers to the comprehensive management of the physical, psychological, social, spiritual and existential needs of patients. It is especially suited to the care of people with incurable, progressive illnesses” (Price, 2003). The World Health Organization (n.d.) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

<sup>25</sup> (Arraf, Cox & Oberle, 2004)

<sup>26</sup> (Bottrell, O’Sullivan, Robbins, Mitty & Mezey, 2001)

<sup>27</sup> Within a health-care context, *autonomy* refers to an individual’s right to consent or to refuse to consent to a proposed treatment or plan of care (Beauchamp & Childress, 1994).

<sup>28</sup> (Breier-Mackie, 2001; Volker, Kahn & Penticuff, 2004)

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the provision of end-of-life care to all age groups in Canada.<sup>29</sup> Indicators of inadequate end-of-life care include admissions to intensive care units, emergency department visits, insufficient symptom relief (particularly of dyspnea and pain), limited availability of home health services, limited access to palliative care services and lack of continuity of care.<sup>30</sup>

As the number of elderly people increases and medical interventions become more advanced, more people are experiencing lengthier periods of chronic illness. Improvements in neonatal care have also resulted in altered survival rates for infants. Seventy per cent of people are likely to face a decision around withholding and/or withdrawing life-sustaining treatment at some point in their lives.<sup>31</sup> These decisions must be supported by impartial, informative discussions with the health-care team.

End-of-life situations are not limited to elderly people or to people with cancer. These situations can be encountered by individuals of all ages, including infants and children, and in relation to a broad spectrum of medical conditions. Nor are these situations confined to palliative care units: people at the end of life can be found throughout the health-care system, in acute and long-term care facilities, emergency departments and intensive care units, as well as in their homes, in residential hospices, in shelters or on the street.

Nurses are uniquely situated to develop therapeutic relationships with dying people and their families.<sup>32</sup> Nurses who provide care at the end of life are witness to, and part of, a complex process that is physically, psychologically, emotionally and spiritually intimate and profound for most individuals, their families and their health-care providers.<sup>33</sup> Because of the nature and complexity of end-of-life experiences, a number of ethical, legal and practical issues may arise. Uncertainty or conflict may come up related to conveying the diagnosis and/or prognosis, goals of care, withholding and/or withdrawing life-sustaining treatment, refusal of treatment, management of pain and other symptoms, organ donation, palliative sedation<sup>34</sup> and requests for euthanasia or assisted suicide. Euthanasia<sup>35</sup> and assisted suicide<sup>36</sup> are practised in some countries but are illegal in Canada. Holistic, quality end-of-life care is believed to be linked to decreased requests for euthanasia and assisted suicide,<sup>37</sup> although this has not yet been validated empirically.

Nursing care at the end of life must continue to improve, evolve and respond to societal and technological changes and challenges through ongoing research, education, policy development and advocacy.

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<sup>29</sup> (Barbera, Paszat & Chartier, 2006; Goodridge, Bond, Cameron & McKean, 2005; Heyland et al., 2005; Widger et al., 2007)

<sup>30</sup> Ibid.

<sup>31</sup> (Kelley, 1995; Matzo, 1997)

<sup>32</sup> (Engler et al., 2004; Hohenleitner, 2002)

<sup>33</sup> (King & Jordan-Welch, 2003)

<sup>34</sup> *Palliative sedation*, also referred to as *terminal sedation*, refers to the administration of medications in sufficiently high dosages to induce an ongoing state of sleep for people experiencing intractable pain and suffering (Lo & Rubinfeld, 2005; Muller-Busch, Andres & Jehser, 2003).

<sup>35</sup> *Euthanasia* is “a deliberate and intentional act which causes the death (often by the administration of a lethal injection) at the voluntary request of an adult who is incapable of causing his or her own death” (Schwarz, 1999).

<sup>36</sup> *Assisted suicide* is “the provision of the means to end life, for example, a prescription for a lethal amount of drug, the lethal drug itself, or other measures, to an adult who is capable of ending life, with knowledge of that person’s intentions” (Schwarz, 1999).

<sup>37</sup> (Schroepfer, 2006; Schwarz, 1999)

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