

Guiding Decisions About End-of-Life Care, 2009

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Guiding Decisions About End-of-Life Care, 2009 Pub. No. 43001

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Practice guidelines are documents that help nurses understand their responsibilities and legal obligations to enable them to make safe, effective and ethical decisions when practising. They provide an outline of professional accountabilities and relevant legislation. As self-regulating professionals, nurses are responsible for practising in accordance with the College's practice documents and relevant legislation.

– College of Nurses of Ontario

Introduction

End-of-life care¹ is grounded in the ethical values of nursing, which include respecting a client's² choice, well-being and life, maintaining commitments, and valuing privacy, confidentiality, truthfulness and fairness. The *Guiding Decisions About End-of-Life Care, 2009* practice guideline aims to help nurses³ understand their roles and responsibilities when providing end-of-life care. The document includes key concepts to help nurses assist clients in making choices and articulating their **wishes** about **treatment** such as resuscitation and end-of-life care.

Nurses must keep in mind that euthanasia and assisted suicide are illegal; there is no role for nurses in facilitating these activities.⁴

This guideline helps nurses apply the following principles:

- providing clients with support at the end of their lives or in making decisions about end-of-life care in any practice setting (such as pediatrics, research and the community);
- supporting informed discussion about care goals and treatment options by facilitating communication with clients and members of the **interprofessional team**;
- contributing to client well-being and acting

in the best interest of the client by facilitating the implementation of the client's wishes about treatment and end-of-life care; and

- knowing and understanding current legislation relevant to treatment and end-of-life care.

This practice guideline replaces the *Resuscitation, 1999* practice standard. Nurses should use this guideline in conjunction with other College documents including the *Consent, Ethics* and *Therapeutic Nurse-Client Relationship, Revised 2006* practice documents, as well as the policies and procedures in place in their work settings.

Glossary

Advance directive. The means used to document and communicate to a substitute decision-maker a client's preferences regarding treatment in the event that the client becomes incapable of expressing those wishes.^{5,6} A client may provide an advance directive for decisions such as organ donation and resuscitation. Nurses should be familiar with legislation and their organization's policies about the use of advance directives.

Capable. A client is capable when he or she can understand the information that is relevant to making a decision about treatment, and appreciate the reasonably predictable consequences of a decision or lack of decision.

End-of-life care. For the purpose of this practice document, the term *end-of-life care* refers to the care that is provided to a client at the end of his or her life⁷. The goal of end-of-life care is to improve the quality of living and dying, and minimize unnecessary suffering. It encompasses the physical, spiritual, social, psychosocial, cultural

¹ Bolded words are defined in the glossary that begins on this page.

² In this document, *client* refers to an individual, family, group or community.

³ In this document, *nurse* refers to a Registered Practical Nurse (RPN), Registered Nurse (RN) and Nurse Practitioner (NP).

⁴ For more information, refer to the College's *Ethics* practice document at www.cno.org/publications.

⁵ (Canadian Nurses Association, 2008)

⁶ (Dunbrack, 2006)

⁷ The definition may vary across organizational and practice environments. There is no legal definition for end-of-life.

and emotional dimensions of client care. While palliative care can be a component of end-of-life care,⁸ end-of-life care also includes aspects that are beyond the scope of palliative care, such as advance care planning.^{9,10}

Emergency (treatment without consent).

According to the *Health Care Consent Act, 1996*, an emergency occurs when the person for whom the treatment is proposed is apparently experiencing severe suffering or is at risk of sustaining serious bodily harm if the treatment is not administered promptly. In an emergency situation, treatment can be given without consent.

Expected death. For the purpose of this practice document, the term *expected death* refers to when, in the opinion of the health care team, the client is irreversibly and irreparably terminally ill; that is, there is no available treatment to restore health or the client refuses the treatment that is available.¹¹

Informed consent. A consent to treatment given by a client only after the client has received information about the treatment (including the nature of the treatment, the expected benefits, material risks, material side effects, alternative courses of action and likely consequence of not having the treatment), which a reasonable person in the same circumstances would require to make a decision about the treatment. The person making the decision must also receive responses to his or her requests for additional information about the treatment. Consent to treatment may be expressed or implied.

Consent must:

- relate to the treatment;
- be informed;

- be given voluntarily; and
- not be obtained through misrepresentation or fraud.¹²

Except for emergency treatment as defined in the *Health Care Consent Act, 1996*, no treatment can proceed without informed consent.

Interprofessional team. Multiple health care providers with education in different fields who work collaboratively to deliver quality care within and across settings.

Palliative care. Care that aims to relieve client suffering and improve the quality of living and dying. It strives to help clients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears. Palliative care prepares the client and others for managing self-determined life closure and the dying process. Palliative care is appropriate for any client and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, and whenever they have unmet expectations and/or needs and are prepared to accept care, regardless of age.¹³

Plan of treatment. A plan that:

- is developed by the client or substitute decision-maker, and one or more health practitioners;
- deals with one or more health problems that a client has. It may also deal with one or more health problems that the client is likely to have in the future as a result of the client's current health condition;
- provides for the administration to the client of various treatments or courses of treatment; and
- may provide for the withholding or withdrawal of treatment in light of the client's current health condition.¹⁴

⁸ (Health Canada, 2007) There is no consensus in the literature on the definition of end-of-life care.

⁹ (Health Canada, 2002)

¹⁰ (Canadian Nurses Association, 2008)

¹¹ The definition may vary across organizational and practice environments. There is no legal definition of expected death.

¹² Refer to the *Health Care Consent Act, 1996*, at www.e-laws.gov.on.ca.

¹³ (Canadian Hospice Palliative Care Association, 2002)

¹⁴ Refer to the *Health Care Consent Act, 1996*, at www.e-laws.gov.on.ca.

Power of attorney for personal care. A legal document that gives another person the right to act on the client's behalf with regards to the client's personal decisions, such as housing and health care. Making a power of attorney is voluntary; no one can be forced to make one.

Resuscitation. An invasive and immediate life-saving treatment that is administered to a client who has a sudden unexpected cardiac or respiratory arrest. It may include basic cardiac life support involving the application of artificial ventilation (such as mouth-to-mouth resuscitation and bagging) and chest compression. It may also include advanced cardiac life support, such as intubation and the application of a defibrillator.

Substitute decision-maker. The person who is authorized to give or refuse consent on behalf of an incapable client. The substitute decision-maker may be a relative or a specially appointed person, such as someone with power of attorney for personal care.¹⁵

Treatment. For the purpose of this practice document, treatment relates to options a client may have available at or near end of life. The *Health Care Consent Act, 1996* defines a treatment as any act that is performed for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course or plan of treatment. Resuscitation is categorized as a treatment under this Act.

Wishes. What a capable person expresses about treatment, admission to a care facility or a personal assistance service. Wishes may be expressed in a power of attorney, in any written form, orally or in any other manner. The most recent wishes a client expresses while he or she is capable prevail over any earlier wishes the client may have given.¹⁶

Guiding Decisions

When assisting clients in making choices and articulating their wishes about end-of-life care, nurses are guided by two core themes: communication and implementation. Clear and ongoing communication between the nurse, client and interprofessional team facilitates the implementation of client wishes about treatment and end-of-life care.

Communication

Nurses communicate with clients and members of the interprofessional team to guide informed discussion about the goals of care and treatment.

Nurses communicate the goals of care and treatment by:

- a) using professional judgment to determine how the interprofessional team needs to be involved in discussions about the client's end-of-life care wishes;
- b) assessing whether the client has sufficient and relevant information to make an informed decision¹⁷ about treatment and end-of-life care, including **resuscitation**;
- c) providing an opportunity to discuss, identify and review the client's end-of-life care wishes;
- d) identifying the client's wishes about preferred treatment and/or end-of-life care as early as possible, while considering the client's condition and the degree to which the therapeutic nurse-client relationship has been established;
- e) identifying and using appropriate communication techniques when discussing treatment and end-of-life issues with the client;
- f) helping and being involved in client and family discussions about treatment and/or end-of-life care;^{18,19}
- g) consulting with other health care team members as required, to identify and resolve treatment

¹⁵ Refer to the *Substitute Decisions Act, 1992*, at www.e-laws.gov.on.ca.

¹⁶ Refer to the *Health Care Consent Act, 1996*, at www.e-laws.gov.on.ca.

¹⁷ For more information, refer to the College's *Consent* practice document at www.cno.org/publications.

¹⁸ For more information, refer to the College's *Conflict Prevention and Management* practice document at www.cno.org/publications.

¹⁹ For more information, refer to the College's *Therapeutic Nurse-Client Relationship, Revised 2006* practice document at www.cno.org/publications.

and/or end-of-life care issues. (For example, a nurse could present a client situation during a team meeting or rounds or include an ethicist on the care team, if it is appropriate);

- h) knowing the end-of-life care wishes of the client or obtaining that knowledge from:
 - the client's direct instructions (which include non-verbal means);
 - the client's **advance directive** (such as a living will or **power of attorney for personal care**);
 - the **substitute decision-maker's** instructions, if the client is incapable; or
 - documented instructions from another member of the health care team;
- i) explaining the client's wishes to all members of the interprofessional care team;
- j) maintaining records²⁰ of client and interprofessional team communications about treatment and end-of-life care decisions according to organizational policies and procedures as well as the College's *Documentation* practice document;
- k) contributing to ongoing communication about end-of-life care wishes and implementing the client's wishes by:
 - reviewing the client's **plan of treatment** including resuscitation wishes as needed or when required by organizational policy. (For example, in long-term care settings, the review could be part of the regular client health review);
 - documenting the relevant information; and
 - communicating any changes in client's wishes to the interprofessional team and ensuring the wishes are included in the plan of treatment; and
- l) advocating for the creation or modification of practice-setting policies and procedures to support client choices during treatment and end-of-life care, based on College documents.

Implementation

Nurses advocate for the client and help implement the client's treatment and end-of-life care wishes.

Nurses implement a client's treatment and end-of-life care wishes by:

- a) ensuring that the creation of the plan of treatment has involved both the interprofessional team and the client, and that the client has given **informed consent** for the plan of treatment before implementation;
- b) acting on behalf of the client to help clarify the plans for treatment when:
 - the client's condition has changed and it may be necessary to modify a previous decision;
 - the nurse is concerned the client may not have been informed of all elements in the plan of treatment, including the provision or withholding of treatment;²¹
 - the nurse disagrees with the physician's plan of treatment;²² and
 - the client's family disagrees with the client's expressed treatment wishes;²³
- c) initiating treatment when:
 - the client's wish for treatment is known through a plan of treatment and informed consent;
 - the client's wish is not known, but a substitute decision-maker has provided informed consent for treatment; or
 - it is an **emergency** situation, there is no information about the client's wish, and a substitute decision-maker is not immediately available;
- d) not initiating treatment that is not in the plan of treatment, except in emergency situations, when:
 - the client has not given informed consent, and/or the plan of treatment does not address receiving the treatment;
 - the incapable client's wish is not known, and the substitute decision-maker has indicated

²⁰ For more information, refer to the College's *Documentation, Revised 2008* practice document at www.cno.org/publications.

²¹ For more information, refer to the College's *Consent* practice document at www.cno.org/publications.

²² For more information, refer to the College's *Disagreeing with the Plan of Care* practice document at www.cno.org/publications.

²³ For more information, refer to the College's *Conflict Prevention and Management* practice document at www.cno.org/publications.

- that he or she does not want the client to receive the treatment;
- the attending physician has informed the client that the treatment will be of no benefit and is not part of the plan of treatment that the client has agreed to. In this situation, the nurse is not expected to perform life-sustaining treatment (for example, resuscitation), even if the client or substitute decision-maker requests it; or
 - the client exhibits obvious signs of death, such as the absence of vital signs plus rigor mortis and tissue decay;
- e) documenting in a written plan of treatment all information that is relevant to the implementation of the client's wishes for treatment at end of life;
- f) following the client's wish for no resuscitation even in the absence of a physician's written do-not-resuscitate (DNR) order;
- g) engaging in the following when a client's death is expected or unexpected:
- identifying whom to notify when the client dies;
 - identifying the most appropriate category of health care provider to notify the family;
 - identifying the client's and family's cultural and religious beliefs and values about death, and management of the body after death;²⁴
 - identifying whether the family wants to see the body after death; and
 - documenting according to policies and procedures;
- h) possessing the knowledge, skill and judgment to determine that death has occurred;
- i) deciding, if necessary, the category of health care provider that will pronounce the death;
- j) recognizing that all nurses have the authority to pronounce death when clients are expected to die and their plan of treatment does not include resuscitation. While RNs and RPNs do not have

- the authority to certify death in any situation, Nurse Practitioners do have the authority to certify an **expected death**, except in specific circumstances;²⁵ and
- k) advocating for the creation or modification of practice-setting policies and procedures on the implementation of clients' treatment and end-of-life care wishes that are consistent with College documents.

²⁴ For more information, refer to the College's *Culturally Sensitive Care* practice document at www.cno.org/publications.

²⁵ For more information about Nurse Practitioners and medical certificates of death, refer to the *Nurse Practitioners* practice resources web page at www.cno.org/np_pr.

Appendix A: Supporting Nursing Practice

All nurses, including employers, researchers and educators, must demonstrate the knowledge, skill, judgment and attitude²⁶ required of regulated health professionals. Nurses must also reflect and understand their roles in improving their practice settings and advocating for quality nursing care practices. Nurses, nurse employers and organizations have a shared responsibility to create safe practice environments in which to deliver optimal health care.

To support safe and effective treatment and end-of-life care practices, nurses in all roles as well as their employers, educators and related organizations can:

- facilitate nursing staff involvement in developing, implementing and evaluating policies and procedures, such as helping nurses advocate on behalf of clients;
- provide access to evidence-based information;
- ensure that staff orientation includes information about end-of-life care issues relevant to the practice setting;
- help other nurses meet the College's practice expectations as well as their organization's policies;
- support nurses in the development of relevant competencies;
- initiate continual quality improvement activities;
- recognize the need for, and facilitate, debriefing as appropriate;
- identify and acknowledge nursing excellence in providing care to clients; and
- advocate for ways to implement evidence-informed practices.

Appendix B: Legislation Relevant to Nursing Practice and End-of-Life Care

Nurses are expected to practise in accordance with the College's practice documents as well as relevant legislation. To make safe and ethical decisions when providing end-of-life care, it is important for nurses to know and understand current legislation that is relevant to treatment(s) and end-of-life care such as the *Health Care Consent Act, 1996* and *Substitute Decisions Act, 1992*.

The following are some of the major features of the legislation:

- a) Under the *Health Care Consent Act, 1996*, resuscitation is considered to be a treatment. There is no legal requirement to obtain a physician's written, telephone or verbal DNR order.²⁷
- b) The *Health Care Consent Act, 1996* and *Substitute Decisions Act, 1992* enable a **capable** person to create an advance directive. Through an advance directive, the person can indicate the kinds of treatment he or she would like to be accepted or rejected in the event that the person becomes incapable. If the person becomes incapable, these directives would be interpreted by the person's substitute decision-maker;
- c) Under the *Health Care Consent Act, 1996*, a client's wishes about treatment may be expressed in:
 - a power of attorney for personal care;
 - any written form;
 - a verbal form; or
 - any other manner (such as sign language).
 In addition, a client's wishes about treatment:
 - can be changed at any time (nurses must respect the most current wishes and ensure the client has given informed consent for the treatment choice); and
 - are to be interpreted by the client's substitute decision-maker if the client is found to be incapable; and the wishes do not constitute consent or refusal of consent.²⁸

²⁶ For more information, refer to the College's *Professional Standards, Revised 2002* practice document at www.cno.org/publications.

²⁷ Although there is no legal requirement for a DNR order, organizations may have policies and procedures in place to direct nursing practice.

²⁸ Refer to the *Health Care Consent Act, 1996*, at www.e-laws.gov.on.ca.

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Notes:



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