ETHICS IN PRACTICE

RESPECTING CHOICES IN END-OF-LIFE CARE: CHALLENGES AND OPPORTUNITIES FOR RNs

INTRODUCTION

This paper will explore a variety of end-of-life issues from an ethical perspective. This paper is designed to provide clarification about the many concepts and terms used in public discussion about death and dying, and how law and ethics are applied, understood and sometimes misunderstood by nurses and others. This paper will also consider the recent Supreme Court of Canada ruling that struck down the prohibition on physician-assisted death for competent adults within specific parameters.

This paper focuses on five scenarios, based, in part, on real situations. The unique circumstances and ethical and legal aspects of each scenario call for different responses from nurses and other health-care professionals, families and society. Understanding these differences can assist nurses in ethical analysis of what measures might be taken to enable these patients to live with dignity to the end and also die with the dignity they deserve.

Interspersed throughout the discussion is guidance for nurses to assist them with the diverse issues they may encounter when providing end-of-life care.
FIVE SCENARIOS

1. **Amalia** was a 95-year-old woman who spoke about wanting God to take her home. She was not afraid of death and was ready to “let nature take its course.” Nurses listened to her wishes and attended to her needs by providing care to support her dying. She died a *natural death*.

2. **Abdul** was a man in his late 50s who unexpectedly became comatose following brain surgery and was sustained on life support. His doctors wished to remove life supports, as they could see no possibility that he would recover. The family demanded that all life supports be continued. The nurses caring for Abdul experienced *moral distress* and a conflict of conscience knowing continued medical care was considered inappropriate (or *futile*) and the cause of increased *suffering*.

3. **Monika** had worked as a nurse for many years, caring for people with advanced dementia. Prior to being diagnosed with Alzheimer’s disease herself she had stated in a written *advance directive* that she be allowed to die if she was ever in a state of advanced dementia. In spite of this, nurses and care aides were instructed to continue to give her food and fluids.

4. **Maurice** was a physician diagnosed with terminal brain cancer who, in his final days, made an impassioned plea that he receive help to die because his suffering was so great. Nurses on the *palliative care* team felt in conflict with their professional ethics (Canadian Nurses Association [CNA], 2008), that required them to promote health and well-being, foster comfort and “work to relieve pain and suffering, including appropriate and effective symptom and pain management, to allow persons to live with dignity” (p. 14), and Maurice’s wishes, particularly because the team was unable to relieve his suffering.

5. **Rashida** wishes to be able to make a choice to die when her amyotrophic lateral sclerosis (ALS) prevents her from taking her own life through medically assisted means. Rolf, her home care nurse, feels uncertain about what he can say to Rashida and how to support her but knows he must take care to keep communication lines open.
BACKGROUND

The situations outlined in the five scenarios centre on a wish for a dignified death with relief from suffering. This long-standing wish was expressed well by a prominent medical ethicist (Fletcher, 1954) who wrote:

This issue is not one of life or death. The issue is what kind of death, an agonized or peaceful one. Shall we meet death in personal integrity or in personal disintegration? Should there be a moral or demoralized end to mortal life? (p. 754)

During the past few years in Canada there have been particularly poignant situations described in the media and in health-care professional journals about choices concerning dying many individual people wish could be theirs, but they have been restricted from having their wishes honoured. In February 2015 that restriction was declared unconstitutional in Carter v. Canada (Attorney General) (2015) by the Supreme Court of Canada for competent adults only. The two sections of the Criminal Code involved in this ruling were Section 14 and Section 241(b). Section 14 states that “no person is entitled to consent to have death inflicted upon him” and Section 241(b) states that anyone who “aids or abets a person to commit suicide” commits a crime (Picard, 2015a, p. A11). These sections were and are designed “to protect vulnerable persons from being induced to commit suicide at a time of weakness” (Carter v. Canada, 2015). In making this ruling, the Court made provision for a 12-month period in which these two sections will still apply to competent adults, to allow time for processes to be put in place to effect the changed law. This means that until February 2016 the old law applies, creating opportunities for nurses and other health-care professionals to provide input into new processes to fulfil this legal change.

Nurses are intimately involved in end-of-life care processes and in many cases “they play an important role in the development of these processes” (Gastmans, 2012, p. 603). Nurses are the health-care professionals who people talk to and question most often, as they are the most constant care providers attending to people at home or in hospital. Nurses often hear people ask that they be allowed to die and may be seeking advice about how they can end their suffering. Frequently nurses witness life-prolonging treatment that seems inherently wrong but which they feel powerless to change and often perceive that their voices are not heard in discussions about these situations. Sometimes nurses do not understand what is permissible and they can be challenged by their colleagues as well. These situations leave nurses in a particularly untenable position, as they often find themselves caught between the differing wishes

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1 During the final preparations of this paper, the federal government had requested a six-month extension of time from the Supreme Court of Canada to consider its response to the Carter decision.
and stated desires of patients and the requirements or orders of families, physicians, administrators and laws or regulations.

In most cases, health-care professionals understand end-of-life care and legal restrictions, but they may have difficulty knowing how to apply that knowledge in particular situations. In many other instances their understanding is lacking or misinformed, and they may be misinterpreting the law. It is critical that nurses understand the ethics and laws relative to death and dying. This understanding will enable them to open communications channels on a topic that still causes discomfort, act as teachers and instigate important discussions with the public. This role is important, especially in countering any misinformation the public may receive from various sources.

**Main Objectives of this Paper**

1. To illustrate how the five case scenarios described are the same or different in terms of the law and ethics, including clarifying concepts and terms (see glossary);

2. To use each case or situation to examine related issues such as advance directives, futile care and nurses’ care of persons who are dying (see Appendix A, Background on Advance Directives);

3. To promote an understanding of the change in legislation on assistance in dying so that nurses will not be party to misinformation, and to refer to the legal provisions of other countries to see how this issue is being addressed elsewhere;

4. To review measures being taken by Canadian provinces, such as Quebec, that have developed structures to deal with a person’s request for choosing the timing of their death;

5. To review the guidance that is available to nurses though particular sections of the CNA Code of Ethics, *Ethics in Practice* papers and other professional documents; and

6. To stimulate greater awareness and advocacy for people involved in end-of-life care.
FROM HAVING A RIGHT TO REFUSE MEDICAL TREATMENT TO REQUESTING CONTROL OVER DEATH

Legal cases can become a landmark in ethics since the judge’s reasoning about a case can often lay a conceptual foundation for an ethical principle. For example, in 1914 U.S. Judge Cardozo eloquently spoke to the concept of individual autonomy and the right of self-determination in the *Schloendorff* decision, when he articulated that “every human being of adult years and sound mind has a right to determine what shall be done with his own body” (Picard & Robertson, 1996, p. 41).²

More recently, Supreme Court of Canada Justice Cory expressed the right of self-determination in *Ciarlariello v. Schacter* (1993) as follows: “It should not be forgotten that every patient has a right to bodily integrity. This encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. Everyone has the right to decide what is to be done with one’s own body.”

Picard and Robertson point out that these principles have been endorsed by the Supreme Court of Canada on several occasions, and that the right to refuse unwanted medical treatment is so fundamental that it is protected by common law and the Canadian Constitution under the Charter of Rights and Freedoms.

In Canada there has been a growing cry for clarity and for change in the law surrounding assisted dying to make room for choice in determining the timing of death. This is, for many, a very critical element of a dignified death, particularly since medical science has advanced to such a degree that people’s lives can be prolonged despite severe disability or unalleviated suffering.

The generations alive today are the first to live in an era of advanced medical technology, like ventilators, cardiopulmonary resuscitation (CPR), and tube feedings that can prolong life and delay death. Patients and families face difficult choices and nurses are often at the center of these difficult situations. (Norlander, 2014, p. 156)

At the same time, it is important to remember that there are many ways to die with dignity. These include living out the slow decline of a progressive illness, as long as a person’s symptoms are managed so that he or she has a chance for quality of life within the context of dying with supportive care.

In an attempt to address the needs of the dying, the Law Reform Commission of Canada undertook studies in the late 1970s and 1980s related to “euthanasia, aiding suicide and cessation of treatment” (Law Reform Commission, 1982; Senate of Canada, 1995, p. A27; Storch, 1983, pp. 72-73). In preparing their report, this Commission invited a group of nurses to Ottawa to discuss situations nurses faced in dealing with these matters. Despite careful consideration of the legislation prohibiting interventions that would hasten death, no actions were taken by the federal government at that time regarding recommendations to change the Criminal Code.

Although many advances have been made in end-of-life care, several research studies over the past decade still show that one of the greatest ethical problems for nurses is poor care of the dying, particularly in acute care. In many cases a nurse’s angst was about lack of adequate pain relief and attempts of dying patients to refuse further treatment (Fenton, 1988; Rodney et al., 2002; Storch, Rodney, Pauly, Brown, & Starzomski, 2002; Varcoe, Pauly, Storch, Newton, & Makaroff, 2012; Wilkinson, 1987).

In 2004, Downie published a book called Dying Justice to present her reasons for why the legal status of assisted death in Canada needed clarification and how it needed to be reformed. She stated that the law relative to “withholding and withdrawing potentially life-sustaining treatment and providing potentially life-shortening palliative treatment” (p. 3) was not clear and was causing at least six serious harms. She argued that:

- due to misunderstandings about what the law means, some people are getting unwanted treatment;
- across the country patients will get very different treatment or non-treatment;
- some people are not getting adequate pain control;
- health-care providers practise defensively rather than attending to their patient’s best interest or wishes;
- law is being made on the backs of individuals, compelling them to expend precious financial, emotional and physical resources going to court to challenge the system; and
- law is being made on a narrow case-by-case basis.

Downie concluded by stating that “clarification of the legal status of assisted death would contribute significantly to ending these six harms” (pp. 3-4).

Over the years in Canada, practices surrounding death and dying have evolved but, apart from more standardized practices in many palliative care units, there is a tendency towards localized approaches and agreements. These divergences can leave
room for misunderstanding. As an example, in one Canadian province a young registered nurse who was new to the province, the hospital and its neonatal intensive care unit, gave a fatal dose of morphine to an infant who was severely brain damaged at birth and had been removed from life support (Senate of Canada, 1995). The nurse was following the orders of the resident pediatrician who had written an order for a very high dose of morphine for the newborn. The nurse, knowing the dose was too high, checked with her nurse supervisor, who took the infant’s chart to the resident to ask him to change the order. He confirmed his original order, following which the nurse gave the morphine and the child died shortly thereafter. This nurse was subject to professional discipline by the nursing regulatory body in her province and was suspended for her action. Her supervisor was also disciplined but the resident pediatrician escaped disciplinary action by leaving Canada.

Nurses and other health-care professionals need to be very clear about the law and ethics of death and dying, as well as practice standards developed by their provincial and territorial nursing regulatory body and any workplace policies, in order to prevent potential errors in judgment they may feel persuaded to make. They also need to discuss their practice with colleagues and other health-care professionals if an order or action appears to be inappropriate. This will enable nurses to practise with a higher degree of confidence in their own knowledge and with the support of their team.

WHAT CAN WE LEARN FROM THE FIVE SITUATIONS OR CASES?

Scenario 1: Amalia

At Issue: A Natural but Supported Death

Amalia was an elderly person ready to let nature take its course. She was not afraid of death and she was not asking that death be hastened by medical intervention. She was provided with palliative care in the nursing home where she had lived for several decades. During her final three weeks she required support and help for pain relief, breathing distress and general anxiety, which were eased with oxygen and medication. The administrators of the facility and the nurses were clear about Amalia’s wishes. A residential care aide was with her 24/7 in those final weeks, with nurses overseeing all care and a physician visiting every other day. Her loved ones agreed with this course of action and she died peacefully surrounded by her family.

Summary of legal and ethical aspects

Amalia received comfort care and symptom management. There was nothing controversial about her dying — no hastening of death or prolonging of life. Up until her final days, Amalia was a competent person who was in charge of her care and ready
to meet death, and the nursing staff and physician accepted her refusal of any life-saving treatment, allowing her to die a dignified death. Callahan (2005) noted, “almost all of us know old people who, while still enjoying life, profess themselves ready to die and seem to mean it. It is hard to see indignity in a death marked by that acceptance” (p. S8).

The CNA code of ethics (2008) provides important guidance for nurses caring for individuals who are going through a similar death experience to Amalia:

- “Nurses ensure that nursing care is provided with the person’s informed consent. Nurses recognize and support a capable person’s right to refuse or withdraw consent for care or treatment at any time” (C4, p. 11).
- “In all practice settings, nurses work to relieve pain and suffering including appropriate and effective symptom and pain management, to allow persons to live with dignity” (D8, p. 14).
- “When a person receiving care is terminally ill or dying, nurses foster comfort, alleviate suffering, advocate for adequate relief or discomfort and pain and support a dignified and peaceful death. This includes support of the family during and following the death, and care of the person’s body after death” (D9, p. 14).

Another helpful resource that nurses may wish to consult is the joint CNA, Canadian Hospice Palliative Care Association (CHPCA) and Canadian Hospice Palliative Care Nurses Group (CHPC-NG) position statement entitled The Palliative Approach to Care and the Role of the Nurse (2015).

When a natural death occurs, the 2015 Supreme Court of Canada ruling in Carter has no effect on the dying process. Palliative care was the answer for Amalia; however, the point has been made that effective palliative care resources or having more of it, is not the answer for every case. This consideration will be discussed in more detail later in the paper.

**Scenario 2: Abdul**

**At Issue: Providing Life-Support Measures**

Abdul was a retired engineer in his late 50s with a wife and two adult children. He entered hospital as a relatively healthy man for the removal of a benign brain tumor, contracted a brain infection following surgery and became comatose, requiring intubation and mechanical ventilation. Two of his treating doctors eventually came to the conclusion that Abdul would never regain consciousness and advised that the ventilator and feeding tube keeping him alive and requiring around-the-clock care be removed. Propelled by her religious beliefs, his wife sought an injunction to stop the
doctors from ending life support. Abdul had no advance directive; there was no written indication of his wishes.

Abdul’s physicians contended that if the court granted the family’s request, they would be forced to act against their professional and ethical obligations to “do no harm” by maintaining a biologically alive man in a state of living death. The physicians maintained that the treatment being provided to Abdul was akin to torture. Abdul’s nurses, too, who provided his care in 8- to 12-hour shifts, were placed in a compromising position. This case raises particular ethical issues about appropriateness of care (futility), conflict of conscience, causing harm to a patient without subsequent benefit, and the cost of health care that is considered futile.

Summary of legal and ethical aspects
Abdul’s physicians considered his continuing treatment to be inappropriate because there was no hope he would recover from his persistent vegetative state (Sharpe, 1997). Normally the situations that highlight the issue of appropriateness of care (problem of futility) are those in which there is a difference of opinion between health-care professionals and families about continuing treatment, as reflected in the differing opinions of Abdul’s wife and his physicians. As noted in CNA’s Ethics in Practice series paper, titled “Futility Presents Many Challenges for Nurses” (2001), “the resulting tension can create difficult ethical situations for nurses” (p. 1). This paper suggests that to deal with the tension, nurses are encouraged to keep lines of communication open and find ways and means, such as calling a patient conference or involving a clinical ethics committee, to have a rational dialogue.

In situations that involve these types of disagreements nurses often suffer moral distress. Moral distress occurs “when constraints interfere with acting in the way one believes to be right” (CNA, 2001, p. 2). Nurses experience moral distress because they perceive their inability to provide appropriate care for the person and for his or her family. They perceive that they are causing harm because they know that a prolonged life on artificial supports leads to great suffering, all medically induced by being forced to live (Schafer, 2013). Nurses’ moral distress, therefore, is far more than their concern about treatments that will not help. The moral distress they experience is knowing that they are part of the team prolonging suffering and treating the person as a body, not a sentient being. This leads to a deep sense of anguish and despair. The harm done, in its fullest extent, is not only to the comatose patient but also to the health-care professionals locked into prolonging death. Helpful guidance concerning moral distress is available from the CNA code of ethics (2008), a CNA Ethics in Practice paper on this subject and research studies (e.g., Storch et al., 2009).
Such situations may also cause nurses to feel a conflict of conscience. This realization may lead them to declare their conscientious objection, requesting permission from their employer “to refrain from providing care because a practice or procedure conflicts with the nurse’s moral or religious beliefs” (CNA, 2008, p. 23). The CNA code of ethics (2008) provides guidelines for making such a request (pp. 33-46). Further, the code points out that the objection should not be based on prejudice, fear or convenience (p.45).

Conflict of conscience was acknowledged by the Supreme Court of Canada in the Carter case on physician-assisted death. In its decision, the Court noted that nothing in the change in law “would compel physicians to provide assistance in dying,” and that their participation in assisted death is a matter of conscience and in some cases religious beliefs (Carter v. Canada, 2015, para. 132). This recognition is important to all health-care providers and their right to follow their conscience. Other than this aspect, the Carter case would not have any bearing on Abdul’s situation since it pertains to a competent individual consenting to terminate his or her own life. The Abdul scenario, in contrast, is about a family who wants continued access to life-support measures for a loved one who does not have the capacity to be involved in any decision about himself.

Abdul’s situation also sparked discussion on the cost of health care that is deemed futile. Concerns about the expenses associated with his health care were raised by the media, with a caution that intensive care unit (ICU) beds are limited, and that maintaining a patient in an ICU bed is roughly $1 million dollars per patient per year (Schafer, 2013). Several voices echoed alarm at this figure and the need to calculate “the spiralling costs of dying” was written about in the press (Priest, 2011, p. A3). While rising costs of health care are widely discussed in the press, professional journals and professional forums, in ethics discussions linking costs to specific patients use of health-care resources is relatively rare.

In addition to highlighting the excessive cost of Abdul’s care, physicians and journalists also remarked on the need for criteria regarding the use of costly ICU beds. It was noted that in current practice, when in doubt, emergency room doctors and ICU intensivists may admit a person to ICU to evaluate his or her need for intensive care. However, it was suggested that if they are then unable (based on their assessment) to move a person out of ICU due to family demands that all treatments proceed, even when they are considered inappropriate, these doctors may be less inclined to admit other persons on a trial basis for such an assessment (Schafer, 2013). This decision could impact the greater good for many others. Consequently, there is a great need for clear and supportive policies for admission and discharge from ICUs to mitigate situations such as the one involving Abdul. Such preventive policies could minimize the
difficult decisions individual physicians are caught in and avoid harms to patients, nurses and other staff.

The Abdul scenario is based on the Ontario case of Cuthbertson v. Rasouli (Editorial, *Globe and Mail*, 2013), in which the Supreme Court of Canada determined that when patients are not capable, substitute decision-makers must have a say in ending life support and that future similar cases in that province would best be decided by the Consent and Capacity Board (CCB), which acts as a tribunal, largely for people who have lost capacity to make an informed decision about their care, including the mentally ill. The Supreme Court emphasized that its decision specifically addressed what the Ontario *Health Care Consent Act* allows. Because such boards do not exist in other parts of the country, conflicts must go to the courts for resolution. Consequently, a different ending might result if the Rasouli situation were determined in another jurisdiction.

In another case, a two-year old comatose child in Alberta was the focus of a similar struggle between health-care providers and the child’s parents, who refused to allow life-sustaining measures to be discontinued. This case, with its own complexities (the parents had allegedly abused the child), was heard in the Alberta Appeal Court, with one reporter noting that “every hour there is a delay in acting to remove life support, they put this child at risk of more dehumanizing medical interventions” (Simons, 2012). This case concluded with the Supreme Court of Canada clearing the way for doctors to take the child off life support, as this action was deemed to be in the best interests of the child.

These two cases point to how nurses and other health-care professionals need to carefully consider whether the courts are the best avenue for decisions when health-care professionals and substitute decision-makers are in conflict. Early and highly public legal cases in the U.S. led to recommendations that these sorts of matters should be considered by mediating bodies and other out-of-court options (see Poland, 1997, and Storch, 1998, for a description and reference to cases such as Quinlan, Saikewicz, Brother Fox, Cruzan, etc.). As noted, Ontario has the CCB. A similar board or committee with a broader mandate and with a sufficient number of physicians and nurses on the committee, would likely be a preferred option in each province (see http://www.cleo.on.ca).

These cases also highlight the fact that family members are an important consideration in patient care. The CNA code of ethics (2008) acknowledges this importance, affirming that a nurse’s care is to also include the health and well-being of a patient’s family. The code provides the guidance that nurses need to work with families “to take into account their unique values, customs and spiritual beliefs, as well as their social and
economic circumstances” (CNA, 2008, D3, p. 13). It is through recognizing the intrinsic worth of each person that nurses can support and communicate with families, even when disagreeing with them. At the same time, nurses must “advocate for persons in their care if they believe that the health of those persons is being compromised by . . . the decision-making of others” (CNA, 2008, C6, p. 11).

Scenario 3: Monika

At Issue: Administering Food and Fluids

Monika was an 82-year-old woman who resided in a nursing home, where she existed in a near vegetative state. She had previously worked as a nurse for many years, caring for Alzheimer patients. Prior to being diagnosed with the disease herself, she had stipulated in a written advance directive that she be allowed to die if she was ever in a state of advanced dementia. In spite of this, the facility’s nurses and care aides were instructed to continue to give her food and fluids, using teaspoons, as doing otherwise would constitute neglect. When challenged by Monika’s daughter, the facility argued that Monika opened her mouth when being fed, which they saw as a sign that she wanted food. They did not seem to consider the possibility that this could be due to a reflex action. Monika’s daughter filed a lawsuit in a provincial court against the nursing home, the health region and the provincial government. In that lawsuit she argued that this continued feeding, constituted battery (a tort committed by intentionally bringing about harmful or offensive contact with another person) (Picard & Robertson, 1996).

Summary of legal and ethical aspects

Monika had been a fully competent person when she completed her advance directive. Advance directives, written statements about how and what decisions should be made if the person becomes incapable of making decisions for himself/herself (CNA, 2008), fall under provincial/territorial jurisdiction, and there are differences in how these documents are viewed and used (Godkin, 2008). Nurses need to be aware of the laws governing advance directives in their jurisdictions. Furthermore, they must be aware of any related workplace policies and practice standards developed by their provincial/territorial nursing regulatory body.

Once an advance directive is completed, it is very important that family and/or friends know what the individual person making the directive wants at the end of his or her life. Note that it is also important that a competent individual completing the directive continue to review and update this document so the health-care professionals involved in his or her care have confidence that the advance directive is current. In the past, the completed advance directive was often treated as a legal document, like a property will, and promptly filed in a safe place (a safety deposit box or some secure place in the
home) without conveying its contents to family, friends or physicians. However, family or friends who might accompany a person with an advance directive to a hospital or other health agency where they might receive treatment, need to know the essence of the directive. That way they can advocate for the person who might otherwise be treated against his or her wishes if unable to express what he or she wants.

In this particular scenario, Monica knew the disease and its pattern well. Knowing that people with severe Alzheimer’s reach a stage where they do not recognize their loved ones and they lose contact with reality, Monika did not wish to end her life in what she considered to be an undignified and uncertain end. Her own nursing background helped her choose the way of her death and her daughter could confirm her directives.

CNA’s code (2008) reminds nurses to be aware of the laws governing substitute decision-making in their jurisdiction. For example, in B.C., a person cannot appoint a substitute decision-maker under an advance directive (this is instead done under a different document: the representation agreement). This becomes important as we will see later on.

Some nurses and care workers may have difficulty with the idea of allowing a person to die of starvation or dehydration. While some health-care professionals recommend this as a simple way to die (requiring no intervention) to hasten the time of death, it is clear that this choice has the problem of unpredictability (i.e., how long a person may live while foregoing nourishment and liquids). Some who argue that this should not be allowed base their dissent on religious reasons. For example, people “who believe in the sanctity of life object in principle to decisions that may hasten death (and especially to the discontinuation of artificial nutrition and hydration)” (Murray & Jennings, 2005, p. S53). Others argue that providing food is not a treatment and still others refer to specific sections in the Criminal Code of Canada, Section 197 or Section 202, and other provincial legislation that prescribes a duty to provide the necessities of life for someone in their charge. Some agencies have local policies about the permissibility of withdrawal of food and fluids; others tend to operate on case-by-case basis.

In situations such as Monika’s, health-care professionals need to engage in dialogue with each other and with the family. In addition, nurses involved in caring for patients need to be knowledgeable about their disease and significant symptoms. A patient’s wishes and directions need to be taken seriously and should be investigated and honoured unless there is reasonable doubt as to their finality. Otherwise continued treatment (resuscitation, ventilation or artificial nutrition and hydration) by nurses and others could be regarded as an illegal action and certainly a questionable ethical action.
A person’s choice to stop eating or drinking can become an emotionally charged issue for nurses. This was not the experience of the nurses in the Monika scenario — as Monika opened her mouth and ate when presented with food — but it is an important issue to consider. Indeed, it is very important that nurses recognize their own values, as well as the values of those for whom they care, and reflect on and question who is suffering as a result of a decision to not feed nor provide fluids to an individual. Again, nurses need to familiarize themselves with the laws, the practice standards of their provincial/territorial nursing regulatory body, workplace policies and the CNA code of ethics, to guide their care in such complex situations.

Monika’s scenario is based in part on the B.C. Supreme Court case of Bentley v. Maplewood Seniors Care Society, but it does not reflect all of its complexities and complications. One of the many problematic issues in this case is that Mrs. Bentley’s instructions about her care were muddled by different statements, which used unclear and ambiguous language and were found not to comply with the formal requirements of an advance directive in B.C. (Rule, 2014). Furthermore, legislative requirements for a representation agreement (the means by which people can appoint someone to act on their behalf in case of illness, injury or disability in B.C.) had not been complied with. As a result, Mrs. Bentley’s family members were not authorized to act on her behalf (Sultan, 2014). In addition, the judge noted that assisting with food and drink was considered to be personal care rather than health care, and that by opening her mouth during feedings, Mrs. Bentley was consenting to being fed (Fayerman, 2015). On these bases, the initial court response in this case was to deny the family’s request to cease feeding Mrs. Bentley, and that judgment was reinforced by the appeal court.

Like the scenario with Abdul, the Carter decision is not relevant to Monika’s situation, since she is no longer competent.

Scenario 4: Maurice

At Issue: Challenging the Status Quo

Maurice was a physician who was diagnosed with terminal brain cancer. A few days before his death in 2013, he requested that he be videotaped to broadcast a public plea for the legalization of assisted death in Canada. He challenged other physicians who did not support assisted dying to understand his suffering and to consider that they might feel quite differently if they lived in his body for 24 hours. Maurice was paralyzed, struggled to breathe, had failing vision and hearing and had lost control of his bodily functions in his final weeks. He was completely dependent on his family and

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3 For more information on representation agreements, see http://www.nidus.ca/?page_id=50
attending nurses. In the video he lamented having lost control over his life and having no legal option to end it. Some who saw the video were saddened to see Maurice’s personal disintegration in his plea.

In many instances when people beg for help as Maurice did, those who oppose assisted death are quick to suggest that more and better palliative care services would lead to fewer requests of this nature because quality palliative care can relieve physical and existential suffering (often described as “spiritual suffering or a search for meaning, for hope, for connections with oneself, others or with a higher power” [Norlander, 2014, p. 90]). Pain control may well be possible but other symptoms, such as incessant vomiting and shortness of breath, can be far more troublesome and cannot always be alleviated (Downie, 2004). Those who support assisted dying point out that pain management may not be sufficient for some patients. They emphasize that palliative care is therefore not the solution for all, and that assisted death is a needed option for situations such as Maurice expressed.

In certain cases, however, some may regard end-of-life suffering as both expected and important. Serious tension and problems can arise when the person’s values and beliefs about suffering do not correspond with views held by family, the physician or other health-care professionals (Victoria Hospice Society, 2006). Where there is a strong religious belief that there is value in suffering and patients refuse pain and other symptom control, their wishes need to be respected because suffering for them may be restorative and offer personal reintegration. This view of suffering as valuable can be traced to the Judeo-Christian tradition, but that tradition “should not be imposed on non-believers” (Downie, 2004, p. 101). Sometimes it is those who witness the suffering who urge relief. In these cases, it is important to ask the question: “relief for whom?” (Victoria Hospice Society, 2006, pp. 108-109). Also not to be overlooked are the potential benefits to family and friends of being at the bedside of their dying loved one, in terms of the bonding and nurturing experience.

In palliative care units, sedation is often used to relieve pain and, more commonly, to control symptoms. Such sedation can “vary in degree from light to full unconsciousness” (Berger, 2010, p. 32-33), with the intention being symptom management and not the intention to cause death. Continued palliative sedation to unconsciousness may be used as a last resort for terminally ill patients with severe symptoms. Even then, there is disagreement about how close to death the person needs to be for this course of action (e.g., within hours of death or several weeks of death). There also does not appear to be consensus that it is a medical treatment subject to restrictions, and not euthanasia.
The justification for terminal sedation — equivalent to palliative sedation to unconsciousness — is often based upon the principle of double effect. This principle, commonly cited by the Roman Catholic Church (Catholic Health Alliance of Canada, 2012), sanctions medical treatments that can bring benefit to a person but that also may have a harmful result. In the case of palliative care, the argument is accepted that increasing the level of palliative sedation could have the effect of shortening a life (conversely, there is evidence to indicate that sedation may also prolong life) even though it is given to relieve severe pain and the intention of the health-care professional administering the sedation is not to kill the person.

Summary of legal and ethical aspects
The Maurice scenario is based, in part, on the real life case of Dr. Donald Low, a Canadian physician who captured national attention for his management of the 2003 SARS epidemic in Toronto. Dr. Low died in 2013, prior to the 2015 Supreme Court of Canada decision in Carter v. Canada (Attorney General) on physician-assisted death. Low’s suffering and plea for help to die with dignity were hard to dismiss and served as a wake-up call to all who have limited experience with the challenges of death and dying. He gave voice to those who have experienced pain, severe discomfort and suffering while dying. His situation also illustrates the fragility that patients feel. The Supreme Court of Canada’s ruling in Carter would have been welcomed by Dr. Low, since his request was essentially for an assisted death.

Nurses providing end-of-life care play an important role in supporting their patients “in maintaining their dignity and integrity” as per guidance in CNA’s code of ethics (2008, D2, p. 13). Nurses need to keep in mind that “when illness or other factors reduce a person’s capacity for making choices, nurses assist or support that person’s participation in making choices appropriate to their capability” (C9, p. 12). Furthermore, if a patient becomes incapable, “the nurse respects the law on capacity assessment and substitute decision-making in his or her jurisdiction” (C10, p. 12).

Scenario 5: Rashida
At Issue: Inquiring about Assisted Death
Rashida is in agony, knowing that in a matter of months she will experience the locked-in syndrome typical for patients with amyotrophic lateral sclerosis (ALS). She has often expressed the wish to have someone help her end her life at the point she perceives it to be unbearable. She has been following the Carter case about physician-assisted death with great interest, hoping the Supreme Court’s decision would help her with her own situation. Rolf, her home care nurse, feels uncertain about what he can say to Rashida and how to support her. He knows he must take care not to shut down
communication but also understands that any changes to the Criminal Code following as a result of the Carter decision will take time to come into effect.

Summary of legal and ethical aspects
The Rashida scenario incorporates some elements of the Carter case, which involved two B.C. women, Kay Carter and Gloria Taylor, who had intractable and progressive diseases. Like Rashida, Gloria suffered from ALS, while Kay had advanced spinal stenosis. They challenged the constitutionality of subsection 241(b) of the Criminal Code that made assisted dying a criminal offence. The Court’s decision to remove this prohibition provided the change in law Rashida was hoping for: to allow physician-assisted death for “a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition” (Carter v. Canada, 2015).

While Carter is a monumental case for Canada, one cannot forget the Sue Rodriguez case that paved its way. Sue was a young woman living in B.C. who suffered from ALS. In 1993 she challenged the constitutionality of section 241 of the Criminal Code of Canada, making a request to the courts that she be allowed to have an assisted death. Sue’s challenge moved up to the Supreme Court of Canada, where it was defeated by a majority opinion (a five to four decision) that upheld the legality of section 241. She subsequently died as a result of an assisted death, but the identity of the person(s) who assisted her could not be established (Downie, 2004; Moorhouse, Yeo, & Rodney, 2010; Senate of Canada, 1995). Another significant legal case in Canada is Nancy B. v. Hotel-Dieu de Quebec (1992), in which “a young woman sought an injunction to compel the hospital and her physician to respect her request to discontinue the use of the respirator” (Downie, 2004, p. 17; Moorhouse et al., 2010, pp. 174-175). Nancy had contracted Guillain-Barre syndrome, leading to irreversible paralysis from the neck down. With respirator support she could live for some time; without it, she would die quickly. The judge ruled that the action of a physician stopping the respirator should not attract liability because the directive was given by a competent person. Nancy died within hours of her respirator being disconnected. Nancy died by refusing treatment, while Sue, Kay and Gloria were requesting help to die.

With the Carter ruling coming into effect, nurses need to reflect upon and thoughtfully consider how to listen and appropriately respond to competent patients, like Rashida, who express a desire for help to die. As a start, Rolf and his nursing colleagues might explore Rashida’s reasons for making the request. Is her request motivated by fear of pain or abandonment, or some other concern? Rolf might then explore with Rashida how each of her expressed concerns might be addressed. In doing so Rashida can
learn that there are strategies to address many, if not all, symptoms and concerns. This is a way to reassure her, build hope and dispel fears. Rolf should also maintain an open dialogue to ensure Rashida has someone to talk to, calling on others on her care team — such as a psychologist, social worker or chaplain — to be there for her as well (Dickens, Boyle, & Ganzini, 2008; Health Canada, 2000).

Rolf should carefully document any discussions he has with Rashida, her family members and other members of the health-care team about end-of-life questions and concerns. At the same time, it is paramount that Rolf have regard for Rashida’s privacy and maintain confidentiality (CNA, 2008). Rolf needs to understand the law, professional standards from his provincial/territorial regulatory body and any workplace policies relating to end-of-life care as they are at present and as they may evolve.

**Practices in Other Countries**

Several countries have legislation to allow physician-assisted death, and other countries are exploring these laws and practices. Switzerland has had permissive legislation since 1942, the Netherlands since 2002. Belgium and Luxembourg are relative newcomers to these laws. At least four U.S. states have also made provisions for physician-assisted death, including Oregon in 1997, Washington in 2008, Montana in 2009, Vermont in 2013 and California is 2015. Evidence from Oregon and the Netherlands considered in the courts "showed that a system can be designed to protect the socially vulnerable" (Carter v. Canada, 2015, para25).

At least two other countries contemplating legislation to permit medically assisted dying are Spain and Norway. In Spain nurses have been active in studying the proposed legislation. To their dismay they found that one regional parliament in Spain had created a document outlining duties of health-care professionals involved in caring for terminally ill individuals but had not recognized the responsibility of nurses. These nurse researchers expressed their grave concern about legislation that excludes nurses and argued that “it is the nurse who, from the patient’s bedside, is the communicator among all those involved and acquires a comprehensive understanding of the process, preferences and directives” (Fernandez-Sola et al., 2012, pp. 619, 625). In another study conducted in Spain, nurse researchers found there was a “lack of consensus among nurses on euthanasia in general and their involvement in particular” (Tamayo-Velazquez, Simon-Lorda, & Cruz-Piqueras, 2012, p. 678).

In Norway (Lind, Lorem, Nortvedt, & Hevray, 2012), nurse researchers studied the perspectives of relatives of patients in intensive care regarding the process of end of life. Although these relatives reported experiencing compassionate care and comfort from the ICU nurses, communication from these nurses about end-of-life processes was
vague and evasive. The relatives found it was “a big effort to search for information” about end-of-life care, which the nurses did not or could not give them (p. 671). This may also be typical of nurses in Canada who experience the effects of communication difficulties when uncertainties about the medical prognosis and risk can make it difficult to speak openly with patients and families.

In a Swiss study of nurses working with people in end-of-life care, nurses found that people’s narratives held more meaning about their preferences for end-of-life care than written preferences and that patients may make contradictory statements about their wishes. Further, they reported a difference between what nurses are told and what physicians are told (Ohnsorge, Gudat Keller, Widdershoven, & Rehmann-Sutter, 2012). Situations like these researchers describe are commonly experienced by nurses looking after people who are very ill and dying. The nurses hear and know what the patient has told them over long hours of caring for them, which is often different than what the physician is told or hears. The different, often conflicting information, is distressing for nurses if the physician is not willing to hear their voices.

In the U.S., the nurse’s role in assisted death was somewhat permissive until 2013, when the American Nurses Association (ANA) issued a position statement declaring that “the nurse may not administer the medication that will lead to the end of the patient’s life. Also, the nurse may not subject patients, families, or colleagues to judgmental comments about the patient’s choice” (ANA, 2013). The ANA reinforced their position in their most recent code of ethics, stating that a nurse “may not act with the sole intent to end a life” (ANA, 2015, p. 3).

The Canadian Context

Even before the Carter decision, we know that Canadians accessed assisted death and that only a very few cases have been brought forward to court (Downie, 2004). When Gloria Taylor’s situation became public, several other end-of-life stories appeared in major newspapers about others who had either fled the country for an assisted death or were living in another country where assisted dying was legal. Two stories stand out in this regard: a young man writing about his father’s legally assisted death in the Netherlands and a mother’s trip to Switzerland to have a legally assisted death. In the first instance the young man wrote about travelling to see his father in his home in the Netherlands. He knew his father was dying of an illness that caused such severe pain that his father could no longer live with it, and that his quality of life had changed drastically. He wrote about his father sitting with his wife and children to drink to life — the father with a glass of poison and others with a glass of red wine. He noted how peaceful an end it was (Landsmeer, 2013). In the second story, a mother (Kay Carter)
who had been diagnosed with a severe degenerative spinal cord condition requested that her family accompany her to Switzerland so that she might end her life legally, surrounded by her loved ones. This plan was known only to close family members and the act not revealed until three years after she died. Her daughter and son-in-law joined legal action initiated by Gloria Taylor to promote a change in Canadian law so that people will not have to travel elsewhere for physician-assisted dying, which has now become known as Carter v. Canada (Attorney General).

Many opinion editorials and letters to the editor in the press that have expressed opposition to physician-assisted death have argued that physicians should be in the business of saving lives, not ending them, and that if legislation was passed to allow for assisted dying, too many people would end up dying without their knowledge or consent. These writers often reference drastic figures from Holland and Belgium to support their views. Another writer pointed to the need for caution and clear restrictions if such a law was enacted but also stated that “when the disease is untreatable and terminal and the needs of the patient are most profound, physicians (and many medical ethicists) hide behind the ‘do no harm’ edict. In doing so, they deny their patients the only and ultimate relief they request because, perversely, death is considered a harm” (Fine, 2013).

As noted, the implementation of the Carter case will take time to come into effect, and it remains to be seen how Parliament will respond.

The province of Quebec has taken the lead in this area, where terminal palliative care and medically assisted death in special circumstances and under strict conditions was first proposed in 2013 (Quebec National Assembly Bill 52, 2013) and approved June 5, 2014. Prior to circulation of the proposed legislation, the Quebec government provided a consultation document titled Dying with Dignity in May 2010. It featured information and definitions about types of end-of-life care including palliative care, terminal sedation, euthanasia and assisted death, and requested that interested citizens respond to suggested changes in legislation that would permit some of these procedures to be legalized in Quebec. This law was subsequently passed, but its proclamation is not expected until December 2015. Its main purpose is to allow doctors, in exceptional circumstances, to help competent terminally ill patients die, if that is what the individual wants.
DEATH, DYING AND NURSING ETHICS

We sometimes seem to act as though dying were solely the concern of the dying person. The fact is, we die, as we live, in a web of vital and complex relationships. (Murray & Jennings, 2005, S54)

Murray and Jennings (2005) suggested that our approach to death and dying in health care has been excessively rationalistic and that end-of-life decision-making has been excessively individualistic, with too much emphasis on autonomy instead of caring, family solidarity, love, mutual respect and attentiveness. The “law, ethics and policy must come to grips with the fundamental communal public — not private — issues of mortality and meaning” (pp. S52-S53).

Callahan (2005) suggested that perhaps focusing on palliative techniques and strategies to improve care of the dying may inadvertently have led to evading dealing with death itself “since how people died and the meaning of death were (previously) inextricably blended” (p. S5). In several articles, books and newspaper stories about end-of-life care and people’s freedom to choose the timing of their death, questions are raised about the meaning of life and death. Because society has focused to such an extent on clinical issues, the larger issues of death and dying have been sidelined by this medical focus.

In large part, major changes to legislation are not required to achieve the goals of dealing with death and attending to the meaning of death itself. Instead, reaching these goals will likely involve a change from a culture that has accepted death as a medical event to a culture that sees death as part of life (Gawande, 2014). Therefore the goals of one’s living should be reflected in one’s dying.

Issues related to end-of-life care are not new for nurses, but they have become more complex and intense with advances in life-saving technology and less easy to avoid altogether. Nurses have a “professional responsibility to be reliably informed about the ethical, legal, cultural and clinical implications of euthanasia and assisted suicide, recognizing and supporting the appropriateness of nurses taking a conscientious position on the matter” (Johnstone, 2009, p. 255).

CHALLENGES AND OPPORTUNITIES FOR NURSES

The issue of physician-assisted death offers important opportunities for nurses to take greater responsibility, such as those provided in “Update: The Supreme Court ruling on physician-assisted death” (CNPS, 2015b). These responsibilities include documenting discussions with patients and families seeking assisted death, respecting
the privacy of their decisions and becoming involved in professional initiatives to help prepare the nursing profession for its role in this area. Additional actions are proposed below.

1. As noted, nurses need to understand the law and professional standards from their provincial/territorial nursing regulatory body and any workplace policies relating to end-of-life care as they currently exist and as they may evolve. “From a legal perspective, it is important that assisted suicide be distinguished from the withholding or withdrawal of futile or unwanted medical treatment, or the provision of palliative care, even when their practices shorten life. These practices have been lawful, and important components of end-of-life care currently being delivered by nurses across Canada” (CNPS, 2015a, p. 31). The Supreme Court of Canada judgment in *Carter* needs to be understood with a keen ongoing awareness of its implementation.

2. Nurses need to reflect upon and thoughtfully consider how to *listen* and appropriately respond to patients who express a desire for help to die in step with current laws and guidance from professional standards. It is hoped that this paper will lead to informed ethical discussions about nurses’ responsibilities to their patients since vague responses and lack of information for patients means that a key item of the CNA code of ethics (2008) — i.e., recognition, respect and promotion of “a person’s right to be informed and make decisions” (p. 11) — is being breached. Further, building trusting relationships is critical “to understanding people’s needs and concerns [and] involves a conscious effort” (p. 8). Trusting relationships with others are difficult if only vague communication occurs.

3. Nurses can encourage patients to reflect upon their life story and meaning and their goals and needs in dying. Recognizing that providing end-of-life care is an interprofessional endeavor (CNA, CHPCA, & CHPC-NG, 2015) nurses should communicate with team members and engage in problem solving to provide optimal care for patients.

4. Nurses can be instrumental in changing the language in daily discussion and debates about end-of-life care so that it will be more neutral. Many terms are emotionally charged and detract from a rational debate. Rather than using the words *assisted suicide*, for example, altering the term to *assisted death* (as has been stated in the Supreme Court of Canada decision) is less emotionally charged. Abdul’s continued treatment was considered *futile*, a word that also conveys a sense that Abdul was no longer useful to society. Rather, speaking about the *appropriateness of his care* states his situation more neutrally and
allows one to consider what care is appropriate. Nurses could be very effective in helping all those involved map out a way to discuss this matter without any trappings of futility, but rather by considering what goal is in Abdul’s best interest.

5. Nurses can play a key role in encouraging patients at the end of life to be clear about what they want. Whether they meet individuals through home care, community clinics, in hospital or hospice, listening to their stories can lead to greater clarity about goals and wishes. Along with advance directives, equally important are open discussion and sensitive listening. Robinson (2011) found that shifting advance care planning from the traditional notion of patient autonomy to an in-depth discussion with family allowed for a “deeply relational process where meaning, values, and preferences were negotiated in conversation” (p. 19). Such dialogue can evoke recognition of cultural sensitivity; for example, appreciating that emphasis on personal autonomy in decision-making is a stronger value in Western culture and other cultures may have different values relative to decision-making. The important goal in any such discussion is that people are treated as they wish to be treated rather than how nurses wish them to be treated.

6. Nurses can promote the involvement of all types of people in public education and dialogue about death and dying, including those with disabilities, strong religious beliefs and those who have felt left out by mainstream medicine. It is particularly important to appreciate the different views that might be held by individuals who feel less powerful in making health decisions and how threatened they may feel in health-care encounters. It is essential to provide accurate information to counter any misinformation obtained from media reports that often sensationalize this already emotional and complex subject. Furthermore, it is important to remember that fearful feelings can increase when health-care professionals begin to discuss advance directives before forming a relationship with the person being admitted to care.

7. Nurses can contribute their knowledge and experience by becoming involved in different initiatives that would support the nursing profession and its role in physician-assisted death. For example, nurses can be integrally involved in discussion and dialogue with public officials and in public forums and consultations.

8. Nurses should keep abreast of emerging issues about assisted death and can become actively involved in policy and guideline development. Emerging issues and questions include some of the following: The extension of population groups to whom assisted death may apply: How does assisted dying fit with suicide prevention? Could failure to immunize elderly people against seasonal flu be
considered assisted death? Finally, how might we consider instances of extreme weather and euthanasia? (a matter drawn to public attention by health-care professionals’ decisions to euthanize patients when they could not evacuate them from hospital during Hurricane Katrina) (Fink, 2013; Johnstone, 2009; Shea, 2010).

9. As outlined in the CNA, CHPCA and CHPC-NG (2015) position statement titled *The Palliative Approach to Care and the Role of the Nurse* (2015), there are many areas of end-of-life care where nurses’ efforts need to be directed. These include advocacy for persons in their experience of living and dying, honouring their values and health-care wishes, and advocating for resources that support persons and families in their choice of supportive environments for a peaceful and dignified death at the end of life.

10. Nurses, and particularly nurse practitioners, need to consider their role in assisted dying: “nurses will have to determine whether their own ethical or religious values are consistent with providing care to a patient who has made the choice to end his or her life” (CNPS, 2015b). As noted, guidance on conscientious objection is included in the CNA code of ethics, including the process for declaring a conscientious objection.

11. Collectively, nurses can actively participate in policy and guideline development, including law reform as needed, to allow them to practice ethically. “How and when you die, like how we live, should be a person’s choice with very few exceptions” (Picard, 2013). Yet, fulfilling this seemingly reasonable goal has become a major public policy issue during the past decade. Nursing research findings on end-of-life care, examples of which are noted in this paper, can help nurses to better appreciate the context and the perspectives of colleagues in other countries and in Canada, including views about palliative sedation (Gielen, Van den Branden, Van Iersel, & Broeckaert, 2012). In addition, nurses can advocate for better decision-making mechanisms, similar to Ontario’s CCB, in other jurisdictions or promote the role of ethics committees in their own facilities.
SUMMARY AND CONCLUSION

In this *Ethics in Practice* series paper, five scenarios were presented for consideration and discussion. They reflect to some extent real cases given significant media attention during the past several years. Each case indicates unique circumstances about end-of-life care and circumstances that give rise to different themes such as needs for palliative care, attention to advance directives, appropriateness of continued treatment, challenges for nurses in discussing assisted death with patients, dealing with suffering and other related challenges.

Throughout, the paper has emphasized learning, dialogue with other nurses and the health-care team, and particularly, listening to people’s wishes for their end-of-life care. References are made in the paper to resources available through the CNA, for example the *Code of Ethics for Registered Nurses* (2008) and several ethics in practice papers, with many additional resources in the reference list.

Nurses are in a key position to initiate discussion about end-of-life care, remembering that every case will be unique regardless of similarities in disease and conditions. That means providing comfort care, pain relief and support is critical for all who are dying, and that these matters need to be carefully considered and responded to as a team. Until the *Carter* decision takes effect, the current lack of guidance in Canadian law regarding assisted death makes it essential that nurses and other health-care professionals be active in debates and information-sharing to promote the development of clear standards and guidelines. Provincial/territorial nursing regulatory bodies will in turn need to consider how best to provide guidance and support for nurses, as well as engage in advocacy to create helpful guidelines and proper monitoring of practitioners.

Some attention has been directed to the *Carter* case because of its recentness. Keep in mind that while the changes it sparked to the Criminal Code of Canada are significant, physician-assisted death is likely only to be used by a small percentage of the Canadian population. However, knowing that the law has changed will bring comfort to a number of Canadians who know they will not have to choose to end their life prematurely to experience a peaceful death.
REFERENCES


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Criminal Code, RSC 1985, c C-46, s 241.


GLOSSARY

**Advance care planning** is an ongoing process of reflection communication and documentation of a person’s values and wishes for future health and personal care in the event that they become incapable of consenting to or refusing treatment or other care. Conversations to inform health care providers, family and friends — and (especially) a substitute decision-maker — should be regularly reviewed and updated. Such conversations often clarify the wishes for future care and options at the end of life. Attention must also be paid to provincial/territorial legal and health guidelines

**Advance directives (AD)** are a person’s written wishes about how and what decisions should be made (about medical treatment and the supportive care the individual wishes to receive) if they become incapable of making decisions for themselves. In decisions about life-sustaining treatment, advance directives are meant to assist with decisions about withholding or withdrawing treatment. (Canadian Nurses Association [CNA], 2008).

**Assisted suicide** is “intentionally killing oneself with the assistance of another who deliberately provides the knowledge, means, or both” (Dickens, Boyle, & Ganzini, 2008).

**Best interests** is a term used to describe the basis for a decision made on behalf of an incapable person in the absence of knowing what that person would have wanted.

**Conscientious objection** occurs when a nurse experiences a conflict of conscience leading to the nurse requesting permission from his or her employer to refrain from providing care because a practice or procedure conflicts with the nurse’s moral obligation or religious beliefs (CNA, 2008, p. 23).

**Decisional capacity** means the ability of an adult to give valid consent, meaning that he or she must be able to understand the information provided about his or her health condition as well as alternatives and options or treatment, and be able to deliberate on the particular choices in terms of his or her own personal values and preferences, make a decision and communicate that decision to others (Molloy, 2004).

**Double effect** is a principle that means that “some human actions have both a beneficial and harmful result”; for example, some pain treatment for the terminally ill person might carry a possibility of shortening life, even though it is given to relieve pain and is not intended to kill the person (Catholic Health Alliance Canada 2012, p. 115).

**Euthanasia** is a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person’s suffering (Dickens et al., 2008, p. 72). **Voluntary euthanasia** means that the person has asked or agreed to be mercifully killed.
Involuntary euthanasia means that the person administering the lethal injection has acted to release the person from suffering from an incurable condition considered to be unbearable without the person’s consent (Johnstone, 2009).

“The literal meaning of the term ‘euthanasia’ is a ‘good death’ but in contemporary parlance the term evokes considerably more than that. Euthanasia tends to mean knowingly and intentionally preforming an act that is explicitly intended to end another person’s life” (Moorhouse, Yeo, Khan, & Rodney, 2010, p. 170).

Futility refers to a medical treatment that is seen to be non-beneficial because it is believed to offer no reasonable hope of recovery or improvement of the patient’s condition (CNA, 2001). Since this term was considered to be too value-laden (e.g., futility meaning utility of life), dialogue about care decisions when the continued treatment of a person is in doubt moved to use the language of goal setting and appropriate and inappropriate care (Sharpe, 1997, p. 342).

Informed consent is the process of giving permission or making choices about care. It is based on both a legal doctrine and an ethical principle of respect for an individual’s right to sufficient information to make decisions about care, treatment and involvement in research.

Letting die often implies “letting nature take its course.” However, one can argue that not acting is an act in itself. Withholding or withdrawing treatment is a decision/action.

Moral distress is “the experience of being seriously compromised as a moral agent in practising in accordance with accepted professional values and standards. It is a relational experience shaped by multiple contexts, including the sociopolitical and cultural context of the workplace environment” (Varcoe, Pauly, Webster, & Storch, 2012, p. 59). It arises “when constraints interfere with acting in the way one believes to be right” (CNA, 2003).

Natural death is often described as “letting nature take its course.” It is a concept legalized by the California Natural Death Act (1977) that paved the way for people to choose to die from natural causes without medical intervention to sustain their life. Such interventions would include, for example, withholding antibiotics, food or fluids. Their physician/caregivers would not be held liable for their death. It has been noted that such withdrawal of treatment is not considered to be suicide and does not invalidate life insurance (Storch, 1983, pp. 15-16).

Palliative care is care given to improve quality of life for people facing challenges associated with chronic, life-threatening illnesses. Palliative care is provided in all care settings including homes, communities, institutions (e.g., hospitals, hospices, long-term
care facilities). It is care that starts at diagnosis of a chronic, life-threatening condition, carries through until death and continues on into bereavement and care of the body (Carstairs, 2010, p. 6). According to people’s specific and individualized needs, palliative care can be delivered at three levels:

1. a “palliative care approach” to care adopted by all health-care professionals;

2. “general palliative care” provided for people with life-threatening diseases, provided by health-care professionals and others who have knowledge of the palliative approach;

3. “specialist palliative care” for people with complex conditions (complex care) provided by specialized individuals or teams of professionals.

Palliative sedation is the sedation of a terminally ill patient to relieve pain and suffering.

Person/Persons receiving care means an individual, family, group, community or population that accesses the services of the registered nurse; may also be referred to as client(s) or patient(s) (CNA, 2008, p. 27).

Physician-assisted death refers to a patient’s wilful and intentional ending of his or her own life with the assistance of a physician.

Sanctity of life is a principle based on either religious or secular beliefs. The religious argument is based on the view that life is sacred and on divine commandments; the secular argument is based the Kantian view that there is a rule that killing is wrong (Downie, 2004, p. 100).

Substitute decision-maker is a capable person with the legal authority to make health-care treatment decisions on behalf of an incapable person. Since provincial and territorial legislation is not uniform across Canada, each jurisdiction has its own guidelines related to substitute decision-making and instructional directives for treatment and care.

Suffering is a state of real or perceived distress (i.e., physical or emotional pain) that occurs when the person’s quality of life is threatened. It may be accompanied by a real or perceived lack of options for coping, which may create great anxiety.

Terminal sedation is sedation provided to those patients where suffering is deemed uncontrollable. It is a means of keeping a patient asleep and pain-free until he or she passes on peacefully (Wilke, 2013). This would be equivalent to palliative sedation to unconsciousness.
GLOSSARY REFERENCES


Canadian Nurses Association, Canadian Hospice Palliative Care Association, Canadian Hospice Palliative Care Nurses Group. (2015). *The palliative approach to care and the role of the nurse* [Joint position statement]. Ottawa: Authors.


APPENDIX

Background on Advance Directives

An advance directive is nothing more or less than a statement by a person about how and what decisions should be made about medical treatment and the supportive care he or she wishes to receive at the end of life should he or she become incapable of making decisions and should choices be available (e.g., assuming the individual’s life does not end in immediate death as a result of an accident or other sudden medical condition) (Canadian Nurses Association [CNA], 2008).

The advance directive is developed from the concept of a living will. Originally the living will was a simple statement, like a letter to family and friends, to express the wishes of a person near the end of life. Gradually, it became more formalized by stating these wishes in a quasi-legal form that expressed the person’s intent to refuse or decline treatment or request particular treatments, and to name someone to be his or her substitute decision-maker. This was followed by the name and signature of the person executing the directive.

This letter or document was, however, not legally binding and in the late 1970s and into the 1980s it was clear that neither physicians nor health-care facilities were willing to be bound by such a written statement. Thus, in the years that followed, considerable effort was directed to developing documentation that would have greater authority. Many such documents were developed but health-care professionals and administrators were still reluctant to accept the moral authority of these written statements not sanctioned by the law. Thus, several U.S. states moved to create laws that would allow people a right to die with their wishes being met, California being the most notable.

In 1979 the status of Canadian law was summarized by Rozovsky (a prominent health-care lawyer) as follows: (1) the patient has no legal right to heroics and the physician has no legal obligation to prolong life beyond reasonable care; (2) the general rule of consent to treatment applies; (3) if the patient is unable to either consent or refuse treatment, the law assumes consent, and (4) relatives should not have authority to consent to withdrawal of treatment for a patient (Rozovsky, 1972).

Gradually case law in the U.S. began to influence thinking and action in Canada. Attention was focused on two young women, Karen Ann Quinlan and Nancy Cruzan, who were both in comas. Although their parents’ made repeated requests for

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discontinuation of life-prolonging treatment their requests were denied by the courts because these young women had given no advance directive. The Law Reform Commission of Canada (LRC) actively pursued the identification of obstacles to discontinuation of treatment that had to be overcome if advance directive documents were to be honoured. Although the LRC made many recommendations for change, none were adopted. An action consequential to acceptance of refusal of treatment was hospital policy development in various regions of Canada. A pivotal event, initiated by nurses and approved by the Board of Trustees of the Chedoke-McMaster Hospital in Hamilton, Ontario, regarding refusal of resuscitation of patients resulted in accepted directives called Do Not Resuscitate Orders (MacPhail, Moore, O’Connor, & Woodward, 1981). This policy confirmed a competent patient/person’s right to refuse cardiac resuscitation and established a process to be taken if the person was not competent. The role of the family was confirmed as critical to any action taken.

Time has moved on and there have been many attempts by the provinces to legalize advance directives, not always with full support from the health-care facilities or physicians. A major failure cited by many authors is that too much time has been spent creating documents when the focus should be on “improving communication between patients, their loved ones, and providers” (Piemonte & Hermer, 2013). Exploring the person’s goals, values, and expectations in a way that naturally leads to decisions about specific ends of treatment is a way to capture the mural of a person’s life, rather than a snapshot taken in final stages of life. Some provinces (e.g., B.C. [B.C. Ministry of Health, 2012]) have begun to focus on advanced care planning to reflect that mural.

A formal advance directive should be only part of the communication and planning to help people prepare for death. If the people the dying person cares most about have been engaged in this communication, problems of interpretation are less likely to arise and the passage to death is eased, the level of comfort rises and the burden of care is lightened for the substitute decision-maker (Carstairs & Beaudoin, 2000).
APPENDIX REFERENCES


