End-of-life issues came to the forefront once again earlier this year with the Supreme Court of Canada decision in *Carter v. Canada (Attorney General)* (2015) that removed the prohibition against physician-assisted death for competent adults within specific parameters. However, end-of-life issues cover a broad area and assisted death is just one component.

This is the first of a three-part series that explores a variety of end-of-life issues from an ethical perspective for nurses. This series 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.

### 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

There was nothing controversial about Amalia’s dying — no hastening of death or prolonging of life. At the core of Amalia’s situation is the wish for a dignified death with relief from suffering. This desire is also present in individuals facing more complex end-of-life situations. Amalia’s death speaks to the concept of individual autonomy and the right of self-determination.

A capable person’s entitlement to refuse unwanted medical treatment flows from the principle of self-determination and is the basis of individual decision-making rights. This right, which is protected by law, is a key element in CNA’s *Code of Ethics for Registered Nurses*: “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” (2008, p. 11).

The code of ethics also provides important guidance for nurses caring for individuals who are going through a death experience similar to Amalia’s: “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” (CNA, 2008, p. 14) and “When a person receiving care is terminally ill or dying, nurses foster comfort, alleviate suffering, advocate for adequate relief of 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” (CNA, 2008, p. 14).

Nurses should also become familiar with palliative care resources. For example, a joint...
A capable person's entitlement to refuse unwanted medical treatment flows from the principle of self-determination.

Position statement (in press) developed by CNA, the Canadian Hospice Palliative Care Association and the Canadian Hospice Palliative Care Nurses Group outlines the many ways nurses’ efforts need to be directed. These efforts include advocating for and supporting individuals in their experience of living and dying, and honouring their values and healthcare wishes and supporting their families.

Research over the past decade shows 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 failed 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). Often too, nurses find themselves caught between the differing wishes and stated desires of patients and the requirements or orders of families, physicians, administrators and laws or regulations.

**ACTIONS FOR NURSES**

Nurses and other health-care professionals need to be clear about the law and ethics of death and dying, as well as practice standards developed by their provincial and territorial regulatory body and any workplace policies, to prevent potential errors. They also need to discuss their practice with colleagues and other health-care professionals, which will enable them to practise with a higher degree of confidence in their own knowledge and with support from their team. They can open communication channels on a topic that still causes discomfort, act as teachers and instigate discussions with the public. This role is important, especially in countering any misinformation the public may receive from various sources.

It has been suggested that the approach to death and dying in health care has been excessively rationalistic and that end-of-life decision-making has been excessively individualistic (Murray & Jennings, 2005). 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. Nurses can play an important role in this shift from what Gawande (2014) called a culture that has accepted death as a medical event to a culture that sees death as part of life. Nurses have a unique therapeutic relationship with patients and their families; people often turn to them to talk to and answer their questions. Nurses are intimately involved in end-of-life care processes and, in many cases, play an important role in their development (Gastmans, 2012, p. 603).

The scenarios explored in Part 2 of this series (in the October 2015 issue) will highlight the complex and sometimes distressing situations nurses might face when a patient is incapable of decision-making.

**ACKNOWLEDGMENT**

The author thanks Laurie Sourani, BA, LLB, policy analyst at CNA, for her assistance in the preparation of this article.

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This is the second article in a three-part series exploring end-of-life issues from an ethical perspective and what they mean for nurses. The first article focused on a capable person experiencing a natural death (September 2015 issue). In Part 2, I present two distinct scenarios in which the person is clearly incapable. It is important to note that the Carter decision on physician-assisted dying, which focuses on competent adults, does not have any impact on either scenario. In the first, the family wants care for their loved one to continue, through life support measures. In the second, the family wants certain care measures to be discontinued.

Abdul, in his late 50s, unexpectedly became comatose following brain surgery and is on life support. His doctors eventually came to the conclusion that he would never recover and advised that the ventilator and feeding tube keeping him alive be removed. Propelled by her religious beliefs, his wife sought an injunction to stop the doctors from ending life support. Abdul has no advance directive; there is no written indication of his wishes.

Abdul’s physicians considered his continuing treatment to be inappropriate because there was no hope he would recover from his persistent vegetative state. The treating physicians also 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. They argued that the treatment was akin to torture because a prolonged life on artificial supports leads to great suffering, all medically induced (Schafer, 2013). Abdul’s nurses, too, who provided his care in 8- to 12-hour shifts, were placed in a compromising position.

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in ending life support and that future similar cases in that province would best be decided by the Consent and Capacity Board (CCB). 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.

The Rasouli case reminds us that family members are an important consideration in patient care. The code of ethics provides guidance 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, 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 those in their care if they believe that the health of those persons is being compromised by the decision-making of others (CNA, 2008, p. 11).

**ACTIONS FOR NURSES**

Talking about complex end-of-life issues can cause discomfort for patients and families. Nurses can facilitate positive dialogue by using neutral language. For example, some words are emotionally charged and detract from a rational discussion. Rather than referring to Abdul’s continued treatment as being *futile* — a word that implies Abdul himself is no longer useful — nurses can speak about the *appropriateness of his care*, which is more objective and considers what is in his best interest.

Nurses have a duty to be advocates “for resources that support persons and families in choosing their preferred environment for a peaceful and dignified death” (CNA, Canadian Hospice Palliative Care Association, Canadian Hospice Palliative Care Nurses Group, 2015). In addition, nurses can choose to 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.

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**At issue: Administering food and fluids**

Monika, 82, is in a nursing home, where she exists in a near-vegetative state. She had previously worked as a nurse for many years, caring for patients with Alzheimer’s disease. Before 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, 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 rejected the notion that this could be a reflex action. Monika’s daughter filed a lawsuit arguing that this continued feeding constituted battery.

**SUMMARY OF LEGAL AND ETHICAL ASPECTS**

This scenario is based, in part, on the B.C. Supreme Court case *Bentley v. Maplewood Seniors Care Society* but does not reflect all of its complexities and complicating factors. One of the many problematic issues in this case is that Mrs. Bentley’s instructions about her care were muddled by different statements that used unclear and ambiguous language, and were found not to comply with the formal requirements of an advance directive in British Columbia (Rule, 2014).

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, p. 22), 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, capacity assessment and substitute decision-making in their jurisdiction. Furthermore, they must be aware of any related workplace policies and practice standards developed by their provincial/territorial regulatory body.

**ACTIONS FOR NURSES**

Although advance directives are important, it has been observed that too much focus has been placed on creating documents instead of improving communication between patients, their families and friends, and care providers (Piemonte &
Acknowledgment

The author thanks Laurie Sourani, BA, LLB, policy analyst at CNA, for her assistance in the preparation of this article.

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References


Nurses can play a key role in encouraging patients at the end of life to be clear about what they want. Along with advance directives, equally important are open discussion and sensitive listening, which can lead to greater clarity for all.

The scenarios explored in the last part of this series (in the November 2015 issue) will highlight the issue of physician-assisted death and what it may mean for nurses.

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Ethics in Practice: At End of Life — Part 3

Challenges and opportunities for professional growth when providing end-of-life care

BY JANET STORCH

This is the last article in a three-part series exploring end-of-life issues from an ethical perspective. The first article focused on a capable person experiencing a natural death (September 2015 issue). The second examined situations in which the people receiving care were clearly incapable and the family wanted care to be continued in one case and stopped in the other (October 2015 issue). In this third article, I present two scenarios in which a capable individual’s wish is for assisted death.

SUMMARY OF LEGAL AND ETHICAL ASPECTS

The scenario is a poignant illustration of the agony that can be associated with losing one’s sense of self-determination during the course of a terminal illness. The concept of self-determination was discussed in the first article in this series (September 2015 issue); it featured Amalia, who, like Maurice, wished for a dignified death with relief from suffering. Although palliative care was the answer for her, it was not sufficient for Maurice, whose deteriorating condition was causing him unbearable pain.

This scenario is based, in part, on the case of Dr. Donald Low, a physician who captured national attention for his management of the 2003 SARS epidemic in Toronto. Low died in 2013, prior to the 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.

ACTIONS FOR NURSES

CNA’s Code of Ethics for Registered Nurses (2008) provides guidance to nurses to support patients “in maintaining their dignity and integrity” (p. 13). This support is particularly relevant at end of life. When a patient is terminally ill or dying, “nurses foster comfort, alleviate suffering, advocate for adequate relief of discomfort and pain and support a dignified and peaceful death” (2008, p. 14).

SUMMARY OF LEGAL AND ETHICAL ASPECTS

The next scenario incorporates some elements of the Carter case, which involved two women who had intractable and progressive diseases. Gloria Taylor, who had ALS, and Kay Carter, who had advanced spinal stenosis, challenged the constitutionality of subsection 241(b) of the Criminal Code. The Court’s decision provided the change in law Rashida (next page) was hoping for: to allow physician-assisted death for “a competent adult person who (1) clearly consents to the

At issue: Challenging the status quo

Maurice, a physician, had terminal brain cancer. In his final weeks, Maurice had become paralyzed, was struggling to breathe, had failing vision and hearing, and had lost control of his bodily functions. He was completely dependent on his family and attending nurses. A few days before his death, he was videotaped making a public plea for the legalization of assisted death in Canada. In the video, he called on physicians who did not support assisted death to understand his suffering and to consider that they might feel quite differently if they lived in his body for 24 hours. He lamented having lost control over his life and having no legal option to end it.
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 her wish that someone help her end her life at the point she perceives it to be unbearable. She followed the Carter case with great interest, hoping the Supreme Court’s decision would help her with her own situation. Her home care nurse, Rolf, feels uncertain about what he should say to Rashida and how to support her. He knows he must be careful not to shut down communication but also understands that any changes to the Criminal Code, as a result of the Carter decision, will take time to come into effect.

physician-assisted death; the latter should be assessed with a critical eye, however.

Quebec has passed legislation to allow for medically assisted dying in special cases, and other provinces and territories may follow a similar path in the near future. The timing is right for nurses like Rolf to lend their voices to discussions with public officials and in public forums and consultations about any such legislation.

Nurses can contribute their knowledge and experience to this area by becoming involved in professional initiatives to help prepare the nursing profession for its role in physician-assisted death. One way to do this is to reach out to their provincial/territorial regulatory body to see how they can assist in shaping professional standards. They may also think about approaching their employer to see if there is a committee they might join or start up that focuses on policy and guideline development on this issue. Certainly, spearheading discussions with peers and other health-care providers is important, as is modelling neutral language in discussion and debate, as noted in Part 2 of this series. For example, using the term physician-assisted death (as communicated in the Carter decision) rather than euthanasia or assisted suicide will facilitate rational dialogue.

As this issue of Canadian Nurse goes to print, government consultations are occurring at federal and provincial/territorial levels to prepare for the implementation of the Carter decision, which is due to come into effect February 2016. As new information and guidance emerge, nurses are encouraged to continue to refer to the code of ethics for its valuable teachings.

The case scenarios in this three-part series illustrate the unique situations of patients at end of life and the associated ethical and legal aspects to consider. It is hoped that these articles will encourage helpful discussion and foster insight and understanding.

ACTIONS FOR NURSES

Nurses need to reflect upon and thoughtfully consider how to listen and appropriately respond to competent patients who express a desire for help to die. In this scenario, Rolf could explore Rashida’s reasons for making the request. Is her request motivated by fear of pain or abandonment, or does she have other concerns? Rolf might then explore with Rashida how each of her expressed concerns could be addressed. Rolf needs to 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.

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 he protect Rashida’s privacy and maintain confidentiality (CNA, 2008, p. 15). Rolf needs to understand the law, the practice standards developed by his provincial or territorial regulatory body, and any workplace policies relating to end-of-life care, as they are at present and as they may evolve. Professional journals and media reports will assist Rolf in keeping abreast of emerging issues surrounding 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).

REFERENCE

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