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Time to fix Canada's palliative care system

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CALGARY, AB, Nov. 22, 2010/ Troy Media/ – When 72-year-old Alice was diagnosed with breast cancer, she bravely faced a mastectomy and chemotherapy treatment in Calgary. Although she had been declared cancer free at the end of five years, she began to experience heart problems, and received a pacemaker.

By the time she reached age 88, Alice's pacemaker was starting to fail, and her cardiologist recommended a new one. Just six weeks after receiving her new pacemaker, Alice was hospitalized for what the doctors initially believed was pneumonia. In fact, the cancer had returned and had metastasized in her lungs. Her decline was swift, and she instructed the doctors and family members that she didn't want any more interventions to extend her life.

Excellent palliative care

Alice, whose name has been changed to protect her family's privacy, received excellent palliative care, had a loving family, and was made comfortable with painkillers. As her family gathered around her to maintain a prayerful all-night vigil with the singing of hymns, they were all prepared for her to be eased into the next life. But the pacemaker kept her body alive for another two weeks. Finally, after the doctor suggested they might need to move her to a cardiac facility to have the pacemaker deprogrammed, the exhausted family began to ask, against their own moral consciences, "What about euthanasia?" To their relief, Alice finally died peacefully the next day.

Alice's story was a particularly memorable one for the Calgary palliative care nurse who cared for her because it touches on so many of the issues that confront dying patients today.

Thanks to medical advances, Canadians are living longer. At the same time many are experiencing longer periods of declining health. As in Alice's case, there are those whose end-of-life experience is extended, perhaps too long, by the capabilities of technology. This is just one of the issues that is part of a new debate in Canada around end-of-life care.

In fact, a perfect storm is brewing on the horizon in Canada. Three factors are coming together that will create an unprecedented scenario in our society in a decade or so. At its centre swirl questions around how, when, where and at what cost Canadians will die. At the eye of the storm is physician-assisted suicide and euthanasia, a thorny issue that raises controversy and passion wherever it is broached, and is currently being debated in Quebec.

Other factors compound the issue. Many palliative care advocates say before we even consider physician-assisted suicide (PAS), Canadians have a long way to go to perfect our palliative care system.

And Canada is a death-denying culture, in which discussions around death are avoided, and the natural effects of aging are fended off with Botox and a host of other strategies, so few Canadians, and fewer politicians, are interested in preparing for this storm.

A demographic bulge

The first storm factor is the demographic bulge of the aging boomer cohort that will push the death statistics in Canada to approximately 450,000 per year by the year 2036, up from the current rate of about 235,000. Less than 10 per cent of those deaths are sudden, through accidents or heart attacks. The other 90 per cent are deaths from disease, chronic illness, organ failure, or cancer. This means that 90 per cent of Canadians could benefit from some degree of palliative care. But the tsunami of boomers heading into their final years simply cannot be warehoused in Canada's already strained hospitals to spend their final months, weeks, or days.

Hospices are being built, and well-developed palliative care services are enabling Canadians to choose palliative home care, but this is not the case in every province.

The second storm factor is the absence of a national palliative care strategy with federal guidelines, standards and best practices, nationally funded research, and a public education campaign to let Canadians know of the range of choices they have for end-of-life care.

Manitoba Liberal Senator Sharon Carstairs has been pushing for a national palliative care strategy since 1995 when she was involved in the Special Senate Committee on Euthanasia and Assisted Suicide, which was prompted by the case of Sue Rodriguez, a Canadian suffering from Lou Gehrig's disease who, in 1993, requested a physician-assisted suicide, but was turned down by a decision of the Supreme Court of Canada. In 1994, she had an anonymous physician give her a lethal injection, sparking a national debate on euthanasia.

The Senate committee's report, *Of Life and Death: Final Report*, found that Canada would not be prepared for euthanasia and physician-assisted suicide until it developed a national strategy for palliative care. The committee defined euthanasia as the act of taking a person's life without their consent by administering lethal medications, or withdrawing a person's life support systems before they are in the final stage of dying. Physician-assisted suicide occurs when a physician administers a lethal dose of medication to terminate life, at the patient's request, or makes the drug available to a patient to administer to themselves. Both were rejected and both remain illegal in Canada.

The report sparked the creation of a federal secretariat on end-of-life care after 2000, and work began on a national strategy. But when the Conservative government came into power in 2006, it viewed palliative care as a provincial issue, and the secretariat and

its initiatives were scrapped. Without federal standards, palliative care varies dramatically from province to province, and between rural and urban areas.

Palliative care comes first

In June, the Senate tabled yet another report, *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*, which contains 17 recommendations for governments to work together to provide funds for research, public education and a national strategy. Carstairs can see the storm of physician-assisted suicide coming.

“We shouldn’t have the PAS-euthanasia debate in Canada until we’ve got great palliative care in place,” says Carstairs.

The third factor is Canadians’ attitudes toward death and health care. Baby boomers have been the most rights-conscious, autonomy seeking, self-directed generation in history. Many boomers heading into their final years will want as much control over their deaths as they have sought to have over their lives.

An example of this is evident in Quebec where the province has undertaken a consultation to examine the concept of introducing euthanasia as a medical procedure. If it is deemed a “medical procedure,” it would cease to be a criminal act, and would come under the jurisdiction of provincial health authorities. A commission examining the issue will table its recommendations to the Quebec government next year.

“Dying with dignity” advocates say that Canadians should be allowed to die on their own terms. They insist that people with degenerative diseases in particular might want to end their lives before they reach the point of intolerable suffering and the loss of dignity. Or they might not want to become a burden to their families.

But critics say that view has two flaws. First, it is predicated on a belief that dignity is dependent upon the circumstances of death. Many professionals and family members who care for those with serious physical or mental handicaps, dementia or Alzheimer’s disease would disagree. They argue that each human being has intrinsic value and dignity.

Second, Canadians already have access to a range of choices in end-of-life care, including hospitals, hospices and palliative care at home. In addition, Canadians can already make decisions about the limits to care at the end of life. When the best palliative care options are available, there is no need for suffering.

So the three storm factors, that is, the surge of boomers and a strained health system, the lack of a federal strategy, and the control-seeking nature of boomers, have led to the perfect storm of formal discussions of physician-assisted suicide in Canada.

But the practice of euthanasia in other countries indicates that it opens a Pandora’s Box of complex, ethical, moral, social and legal ramifications.

Open door to abuse

Seven jurisdictions in the world have legalized the practice of physician-assisted suicide and/or voluntary euthanasia: Switzerland and Oregon in 1997, followed by the Netherlands and Belgium in 2002, and then Washington, Montana and

Luxembourg. In every jurisdiction, so-called safeguards have been established to prevent patients from being euthanized against their wishes. But the safeguards have not been maintained, which has opened the door to abuses.

Dr. Jose Pereira practises palliative care medicine at the Elizabeth Bruyere Hospital in Ottawa. Pereira worked on a palliative care team in a hospital in Geneva, Switzerland, for three years where he saw how physician-assisted suicide was implemented.

“What I observed is that it is very difficult to put safeguards in place,” says Pereira. “Once the law allows PAS, the notion that there are safeguards that will reduce abuse is an illusion.”

In Belgium, of more than 200 cases that received euthanasia, for a third of them, there was no written consent. In Holland, there are about 500 deaths a year without written consent.

“Only a very few people who receive PAS die with intolerable suffering at the end of their lives, yet that was the premise for the law,” says Pereira.

In Belgium, patients with dementia are being euthanized with consent from families as they are unable to give consent. In the Netherlands, within two years of passage, the law was changed to allow children born with severe disabilities to be euthanized. According to Pereira, the equivalent of the College of Physicians in the Netherlands has said that anyone over the age of 70 who is “tired of living” should be given the opportunity to be euthanized.

“This is the perspective eight years after the law was introduced,” says Pereira. “That is a very short window of time to go from only relieving intolerable suffering to suggesting anyone who is ‘tired of living’ be given the opportunity to be euthanized.”

Oregon now experiences a suicide rate 35 per cent higher than the national average in the U.S. Some experts speculate that legalizing physician-assisted suicide has lifted the social stigma of suicide.

Pereira says that most Canadians are unaware of what good palliative care is, and that the fear of dying in severe pain or “without dignity” is based on ignorance. Painkillers and sedation can make dying comfortable and pain-free.

Good palliative care obviates need for euthanasia

Removal of life support systems, which include feeding tubes, respirators and cardiac machines, is not euthanasia, nor is it physician-assisted suicide. It is simply good palliative care when it occurs at a point when the dying individual is only being sustained by these measures.

“Palliative care physicians would say that good palliative care obviates the need for euthanasia or physician assisted suicide,” says Dr. Martin LaBrie, a palliative care consulting physician and a clinical assistant professor in the division of palliative medicine at University of Calgary. “Life matters to the last breath.”

In Calgary, there are 13 full-time palliative care physicians in addition to specialized nurses. Calgary currently has six hospices with a total of about 85 beds, and a seventh hospice is being added to the Peter Lougheed Centre. Some hospice care is covered by Alberta Health Services, while other hospices are privately run and must fundraise to operate. There are home-care programs to help families care for dying loved ones who choose to die at home.