

Impact of Legal Physician-Assisted Dying on Palliative Care

[Excerpted from: [Carter v Canada \(Attorney General\), 2012 BCSC 886 \(CanLII\)](#)]

[686] A number of the defendants' experts express their concern that legalization of physician-assisted dying will impede the further development of palliative care. Dr. Pereira, for instance, deposes that legalization would jeopardize attempts to train more professionals in palliative care and to increase palliative care resources. Dr. Sheldon and Dr. Bereza both advert to the pressures on resources in the health system. Dr. Bereza questions whether those pressures might lead to an irresistible temptation to view physician-assisted death as a more cost-effective and efficient way of dealing with frail, vulnerable or disenfranchised people, a concern that is also reflected in Dr. Sheldon's evidence. Dr. Chochinov refers to the fact that only a minority of Canadians have access to comprehensive quality end-of-life care, and opines that "[d]esigning a system that will accommodate a request for hastened death but does not assure attentiveness to the various sources of suffering that can undermine patients' will to live makes little sense". Baroness Finlay expresses her concern that patients may choose a physician-assisted death without ever becoming aware of the complex, holistic aspects of palliative care and the improved experience, reality and support that palliative care may provide.

[687] The evidence, the defendants say, supports concerns that if physician-assisted death is legal, physicians' attention will be diverted from providing therapeutic counselling, comfort and care to their patients, confusion about palliative care (that it includes killing patients) will be generated, and our society's will to invest money and resources in palliative care will be weakened.

[688] In response, the plaintiffs say that the evidence does not bear out these concerns. In particular, they say that the evidence shows that physicians' care for terminally ill patients in permissive jurisdictions improved following legalization. They also say that there is no evidence that permitting physician-assisted dying would exacerbate misconceptions about palliative care, and may in fact provide a needed opportunity for education. They submit that physician-assisted dying and palliative care are complementary.

[689] The Province placed extensive evidence before the Court regarding the palliative care system in British Columbia.

[690] According to Heather Davidson, British Columbia's Assistant Deputy Minister of Health, this province's framework for end-of-life care is based on an integrated approach of providing care to individuals that takes into account their fluctuating and changing needs as they approach the end of life. This integrated approach is designed to provide a range of options to individuals, in terms of settings and caregivers, that will support their quality of living and assist in facilitating a meaningful, comfortable death in the most appropriate setting.

[691] Dr. McGregor, a palliative care specialist and Regional Medical Director, Palliative Care for Vancouver Coastal Health, estimates that 15% of British Columbians die at home, 24% in residential care facilities, 12% in hospices and 47% in hospital. There is no charge for most hospice palliative care services, although there is a daily fee for in-hospice care. The BC

Palliative Care Benefits Program will also cover most pharmaceutical prescriptions at home or in a hospice setting if a patient is deemed by his attending physician to have a life expectancy of six months or less.

[692] While the province exercises a superintending and policy role, actual health services are provided by five regional health care authorities. Dr. McGregor explains that each of the five health authorities in the province has developed, and is further developing, primary care and specialized services to meet the needs of the end-of-life population.

[693] According to Dr. McGregor, the Vancouver Coastal Health Authority delivers hospice palliative care services to patients in their homes, hospital, hospice and residential care facilities.

[694] Dr. McGregor explains that most ill patients who are expected to die within six to 12 months receive the majority of their care through primary care and community services. Home and community care teams (which are provided and structured by the Health Authority) are able to provide a range of health care and support services in patients' homes. In addition to care from their family physicians, patients eligible for home and community care may receive home visits from nurses, occupational therapists and physiotherapists, nutritional consultants, and community health workers.

[695] Included in primary care and community services are residential care facilities and hospices. There are approximately 6,000 residential care facility beds in the Vancouver Coastal Health region, and approximately 50 hospice beds in the province. Dr. McGregor testified that the waiting list for a residential care bed is usually three or four days. In Vancouver, 99% of patients are admitted to their first choice of hospice.

[696] Specialized palliative care services are provided in four dedicated acute hospital palliative care units, as well as through outreach consulting to any other unit in the hospital where patients require such care. There is an emphasis on interdisciplinary teamwork.

[697] Dr. McGregor explains that at any given time, the needs of approximately 65% of individuals requiring end-of-life care and support can be met in primary care services in the community; 20% can have their needs met in the community but require some input from specialist palliative care services; and 15% need specialist, often in-patient, services beyond the scope of practitioners with standard training.

[698] Carolyn Tayler, the Director, Clinical Programs End of Life Care at the Fraser Health Authority, describes the Fraser Health Authority's End of Life Program. In brief, that program builds on community-based models, and has shifted the focus of service delivery away from stand-alone acute palliative care units to an integrated continuum of care that includes the home, residential care, hospice and acute/tertiary care.

[699] Vancouver Island Health Authority's Victoria Hospice is an internationally recognized centre for expertise in palliative pain and symptom management, education and research in palliative care. Dr. Downing, a palliative care physician and Research Director at Victoria Hospice, describes the facilities and services that facility offers and delivers by interdisciplinary

teams of palliative care physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers and volunteers. The Hospice provides palliative care services within its 17-bed unit in the Royal Jubilee Hospital, in patients' homes and as specific medical consultation to patients in other health care facilities.

[700] Dr. Downing describes what palliative care services may entail, and the Australian Palliative Approach model, which has three levels: primary, intermediate and complex care. He deposes that serious deficiencies can occur at any of the three levels due to limited funding, training or expertise. He further states that:

Thus, while the field of palliative medicine as a specialty is growing, and there are an increasing number of clinicians interested in this as an area of practice, there are still, in Canada and British Columbia, an insufficient number of professionals in all disciplines to provide optimal palliative care to all individuals who need it. Also, the range of palliative care services in Canada remains highly variable, both in terms of the availability of services and access to the comprehensive expertise of palliative care providers. Cost pressures for palliative care services do exist and will only increase with the aging population and increasing numbers of people who require end of life services. Good palliative care is complex, holistic and time-consuming. However, public funding of palliative care services is increasing and models of palliative care are being researched and developed in order to ascertain better ways for high quality palliative care to be integrated into the health system, efficiently and economically.

[701] Various Senate and Parliamentary committees have examined the challenges facing the delivery of palliative care in Canada. The Senate Subcommittee established to examine progress in implementing the recommendations made in the Special Senate Committee Report, tabled its report in June 2000: Standing Senate Committee on Social Affairs, Science and Technology, *Quality End-of-Life Care: the right of every Canadian* (Chair: Sharon Carstairs) [the Senate Subcommittee Report]. As its title makes clear, the Subcommittee concluded that quality end-of-life care, including adequate pain and symptom control, appropriate use of life-sustaining treatments, and support for patients and their families, is an entitlement of all Canadians:

Quality end-of-life care must become an entrenched core value of Canada's health care system. Each person is entitled to die in relative comfort, as free as possible from physical, emotional, psychological, and spiritual distress. Each Canadian is entitled to access skilled, compassionate, and respectful care at the end of life. This Subcommittee sees care for the dying as an entitlement for all.

[702] While concluding there had been some movement on the issue, the Subcommittee found that overall there had not been sufficient progress in implementing the palliative care recommendations from the Special Senate Committee Report, and recommended that the federal government, in collaboration with the provinces, develop a national strategy for end-of-life care and a five-year plan for its implementation.

[703] Senator Carstairs tabled two further reports on palliative care in Canada, in June 2005 and June 2010 respectively. *Still Not There: Quality End-of-Life Care: A Progress Report* (Ottawa: Senate Canada, 2005) (Tabled in Senate, *Journals of the Senate*, 38th Parl., 1st Sess.,

No. 66 (2 June 2005)) highlighted the progress that had been made since the Senate Subcommittee Report, but also called attention to the significant disparities in access to quality of end-of-life care across the country resulting from the relative newness of palliative care, and the number of health care jurisdictions. The report urged the federal government to renew its commitment to a national strategy on palliative and end-of-life care.

[704] *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada* (Ottawa: Senate Canada, 2010) (Tabled in Senate, *Journals of Senate*, 40th Parl., 3rd Sess., No. 35 (8 June 2010)) recognizes that there have been significant improvements in public policy regarding end-of-life care and the delivery of palliative care services in Canada over the years, but urges that it remains necessary to “raise the bar”.

[705] *Raising the Bar* states that only 10% of people die suddenly; the remaining 90% potentially benefit from palliative care. In 1995, only 5% of Canadians had access to quality palliative care. In 2008, a best estimate suggested that between 16-30% of Canadians had some level of access, depending on their location. According to the report, it follows that upwards of 70% of Canadians lack access to even minimal forms of palliative care. The report cautions that the health care system will be further stretched and access to palliative care will be at risk of erosion given the increase in the number of deaths expected over the next generation, together with the prevalence of chronic disease (a result of our ability to manage these conditions longer and more effectively than ever before).

[706] Palliative care was also the subject of recent all-party study in the House of Commons, resulting in the Canadian Parliament Committee Report. The report focused on three areas relating to compassionate care: palliative care, suicide prevention, and elder abuse.

[707] The Committee observed that the current health care system is geared toward short-term acute care and is less effective at dealing with individuals with chronic conditions, serious pain or mental health concerns, or with the psycho-social and spiritual needs of patients and their families throughout the dying process.

[708] The various Senate and Parliamentary reports consistently note that even where palliative care is available, its quality and accessibility vary according to place of residence – a consequence, in significant measure, of provincial jurisdiction over the delivery of health care. This “patchwork” of services is more pronounced in less populated regions. Many parts of Canada have no palliative care services at all.

[709] Returning to the question of impact of legalized physician-assisted death on the development of palliative care, I turn to the situation in Oregon and Washington.

[710] Dr. Ganzini co-authored E.R. Goy et al., “Oregon hospice nurses and social workers’ assessment of physician progress in palliative care over the past 5 years” (2003) 1 *Palliat Support Care* 215. Dr. Ganzini provides the following summary of the study and its findings in her affidavit:

I co-authored a study to obtain hospice nurse and social workers' assessments of efforts made by Oregon physicians to improve their palliative care skills over the previous 5 years since the enactment of the ODDA. A survey was sent to nurses and social workers from all 50 Oregon outpatient hospice agencies. Oregon hospice nurse (185) and social worker (52) respondents, who had worked in hospice for at least 5 years, rated changes they observed over the past 5 years in physicians' approach to caring for their hospice clients. Seventy-seven percent of hospice workers rated physicians as more willing to refer patients to hospice whereas only 3% rated them as less willing, 83% rated them as more willing to prescribe sufficient pain medications whereas 3% rated them as less willing, 76% rated physicians as more knowledgeable about using pain medications in hospice patients whereas 6% rated them as less knowledgeable, 67% rated physicians as more interested in caring for hospice patients whereas 5% rated them as less interested, 66% rated them as more competent in caring for hospice patients whereas 4% rated them as less competent, and 26% rated Oregon physicians as more fearful of prescribing sufficient opiate medications whereas 47% rated them as less fearful. We concluded that most respondents rated Oregon physicians as showing improvements in knowledge and willingness to refer and care for hospice patients. The major limitation of the study is that physician knowledge and competence in end-of-life care was not actually measured.

[711] Dr. Ganzini was involved in an earlier study which looked at the views of physicians themselves: Ganzini et al., "Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death With Dignity Act" (May 9, 2001) 285:18 JAMA – J Am Med Assoc 2363. That study indicated that most Oregon physicians who care for terminally ill patients reported that since 1994 (the year the ballot initiative establishing the ODDA was passed), they had made efforts to improve their ability to care for these patients. As Dr. Ganzini summarizes in her affidavit, 30% of the 2,461 physicians who responded to the self-administered questionnaire reported that they had increased referrals to hospice, whereas 3% reported they had decreased their hospice referrals since passage of the ballot initiative five years earlier. Of the 2,094 respondents who cared for terminally ill patients, 76% reported that they had made efforts to improve their knowledge of the use of pain medications in the terminally ill.

[712] Dr. Ganzini cautions, with respect to both of these studies, that the improvements cannot necessarily be attributed to the ODDA; they do, however, counter concerns that legalization of physician-assisted dying will undermine attempts to improve access to palliative care.

[713] Dr. Ganzini deposes that contrary to the concerns expressed by some, such as Dr. Pereira, the legalization of physician-assisted dying in Oregon has not jeopardized palliative care training. The Oregon Health & Science University, where she holds a number of positions, has a highly sought after palliative medicine fellowship. Further, she says, hospice resources and palliative care consultation groups have grown since passage of the ODDA.

[714] Mr. Eighmey deposes that, based on his experience in counselling terminally ill individuals and their physicians with Compassion & Choices Oregon, he believes that patients' ability to obtain the services of a physician who was able to provide adequate end-of-life care increased following enactment of the ODDA. Accordingly to Mr. Eighmey, there has been a significant increase in physicians' knowledge of palliative care, as well as an increase in

physicians' willingness to refer patients to hospice and to care for hospice patients. More than 82% of the patients of Compassion & Choices who obtained lethal prescriptions under the *ODDA* were enrolled in hospice care.

[715] Mr. Miller gives similar evidence based on his personal experience with Compassion & Choices Washington. He deposes that since the enactment of the Washington Act, there has been an increase in physicians' knowledge of palliative care, and an increase in the number of individuals he has dealt with who have been referred as patients to palliative care specialists and to hospice care. More than 85% of the patients who work with Compassion & Choices Washington and who obtain medications for aid-in-dying are enrolled in hospice care.

[716] In response to the evidence concerning the experience in Oregon, Canada says that Dr. Ganzini's evidence does not establish that any improvements in palliative care can be definitively attributed to the legalization of physician assisted death. It says that palliative care improved everywhere, not just in Oregon.

[717] Dr. van Delden and Dr. Kimsma give evidence about the situation in the Netherlands.

[718] Dr. van Delden deposes that a wide range of palliative care services is available in the Netherlands. Palliative care can be received at home or in nursing homes, care homes, hospitals, and both professional and volunteer hospices. He says that it is striking that special facilities for terminally ill patients, such as hospices, only began to appear in the Netherlands in the early 1990s; these sorts of facilities existed earlier in neighbouring countries. The probable explanation, he writes, is that medical practitioners in the Netherlands have always given high priority to care for the dying. (He cites *The Netherlands, Ministry of VWS [Health], "Palliative care for terminally ill patients in the Netherlands"*, by A.L. Francke (The Hague: NIVEL Netherlands Institute for Health Services Research, 2003), for this evidence).

[719] Citing the same article, Dr. van Delden further deposes as follows:

It is also worthwhile to comment on the relation between society's commitment to (palliative) care and euthanasia. It is sometimes argued that euthanasia cannot be made available to people in vulnerable groups because that would lessen pressures for improvement of their background circumstances. What is particularly disturbing about this argument is the usually tacit assumption that the suffering of those who are in vulnerable circumstances where euthanasia cannot be allowed, will serve as leverage for improving the provision of such things as adequate terminal care, adequate pain control, and the like. The evidence appears to be the other way around. Pain management was improving in the Netherlands before euthanasia was fully legalized, but has continued to do so at an increasingly rapid rate since legalization. It is legalization, or the prospect of immediate legalization, which appears to contribute to the improvement of terminal care and pain control.

[720] Dr. Kimsma also refers to the "steep rise" in programs aimed at improving palliative care access and expertise in the Netherlands, again beginning in the early 1990s. Dr. Kimsma states that by all comparisons, including the latest European Community-initiated overviews, the Dutch level and practice of palliative care stand well in comparison to other European states.

[721] The plaintiffs' experts also provided evidence on the experience with palliative care in Belgium. Both Dr. Bernheim and Professor Deliëns opine that the legalization of physician-assisted dying in Belgium has not impeded the development of palliative care in that country. Professor Deliëns states that, to the contrary, legalization has enhanced and is an integral component of palliative care. Dr. Bernheim describes the situation as one of "reciprocity and synergistic evolution".

[722] Dr. Bernheim was lead author of "Development of palliative care and legalisation of euthanasia: antagonism or synergy?" (April 19, 2008) 336 *Brit Med J* 864. Of note, two of his co-authors, Arsene Mullie and Wilm Distelmans, are the current and past presidents of the Federation Palliative Care Flanders, a professional organization for palliative care practitioners with more than 1,000 members. The article looks at "the effect of the process of legalisation of euthanasia on palliative care and vice versa by reviewing the published historical, regulatory, and epidemiological evidence in Belgium" (at 864). The authors conclude from this evidence that the movements to develop palliative care and regulate euthanasia in Belgium have been mutually reinforcing.

[723] As Bernheim et al. describe in some detail, the development of palliative care in Belgium began in the early 1980s, at the same time as the drive for the legalisation of euthanasia. These movements were simultaneous and pioneered to a significant degree by the same caregivers. For example, two of the founders of Belgium's first palliative care organization – Continuing Care Community – were advocates of the legalization of euthanasia. (One of these two individuals was Dr. Bernheim.) Several early palliative care workers were also active in Belgian right to die societies.

[724] With respect to palliative care, in an update to this article in the *Belgian Medical Journal* (Bernheim et al., "The Belgian model of integral end-of-life care: palliative care and legal euthanasia as complementary developments" *Tijdschr Geneeskd* (forthcoming)), Dr. Bernheim and his co-authors conclude (at 23):

The concern of some that euthanasia would be performed for lack of access to PC [palliative care] was not verified. All epidemiological data suggest that the more PC, the more life-abbreviating medical decisions at the end of life. We found no data supporting the second concern of the EAPC [European Association for Palliative Care] that the movement for legalisation of euthanasia would hinder development of PC. On the contrary, there were numerous indications of reciprocity and mutually stimulating enhancement.

[725] I referred to a number of studies co-authored by Professor Deliëns earlier during my review of some of the empirical evidence regarding the effectiveness of safeguards in Belgium. Some of those studies include data relevant to palliative care.

[726] The Smets et al. Characteristics Study looked at various trends in the characteristics of reported cases between 2002 and 2007. I refer to two trends that relate to palliative care.

[727] First, a physician who receives a euthanasia request is required to consult with an independent physician. In 2002/2003, the speciality of that second physician was palliative care

19.3% of the time. That number decreased to 14.7 in 2004, 10.9% in 2005, 10.0% in 2006 and 8.7% in 2007.

[728] Second, although the Belgian Act does not mandate that a palliative team be consulted, such consultations occurred in 33.9% of cases in 2002/2003; 33.7% in 2004; 31.4% in 2005; 32.5% in 2006 and 39.4% in 2007.

[729] The Chambaere et al. Trends Study found that the rate of euthanasia and assisted suicide rose in all patient groups between 1998 and 2007. Of relevance for present purposes, intensified alleviation of pain and symptoms occurred more often in 2007 than in 1998 and 2001 in all patient groups, except in patients with higher education and in cancer patients. The authors also acknowledge that other factors may have affected this increase in pain and symptom alleviation, such as improved knowledge of opioids abating physicians' fears of providing adequate pain relief at the cost of possible life shortening.

[730] Canada takes issue with the idea that palliative care in Belgium has improved since the legalization of euthanasia, pointing to Dr. Bernheim's evidence on cross-examination that only half of Belgian physician-assisted deaths took place at the end of a palliative care pathway, even though he agreed that adequate palliative care can reduce requests for euthanasia, and to Professor Bernheim's agreement that Belgium has seen a decrease in its ranking in various measures of the quality of palliative care. I take into account, however, Dr. Bernheim's explanation that since Belgium ranked at the top of palliative care providers, there was little room for Belgium to improve and inevitably a change in Belgium's ranking would be in a negative direction as other countries improved. He maintains that palliative care in Belgium continues to rank extremely high.

[731] My review of the evidence regarding Oregon, the Netherlands and Belgium suggests that in those jurisdictions, legalization of assisted death has not undermined palliative care; on the contrary, palliative care provision has improved since legalization by some measures.

[732] Few conclusions, however, can be reached about the possible impact on palliative care from a change in Canadian law regarding physician-assisted death.

[733] First, as Canada points out, palliative care is a developing field; it may be assumed that it is improving not only in permissive jurisdictions but also in jurisdictions that continue to prohibit physician-assisted death.

[734] Second, there are differences in the history, culture and modes of medical practice among the jurisdictions.

[735] Third, further improvements in palliative care in Canada would require commitment of public resources, since health care in Canada is largely delivered through a public system. Some of the debate in the United States has raised the question whether health insurers would refuse to fund palliative care when assisted death was available; no evidence was provided to show that that fear has become reality in Oregon or Washington. It is difficult to imagine that Canadian

politicians, public officials or health care providers, if physician-assisted death were legal, would reduce resources for palliative care services for that reason.

[736] In summary, having reviewed the evidence and the submissions on this point, I conclude that while a change in the law to permit physician-assisted death could affect the palliative care system, predictions as to how would be speculative. I find that the evidence establishes that the effects would not necessarily be negative.