

Achieving quality palliative care in Canada

by DEREK MIEDEMA

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INSTITUT
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EXECUTIVE SUMMARY

Canada's population is aging as the Baby Boomer generation reaches retirement. Statistics Canada estimates that, for the first time in history, the number of Canadians over 65 will outnumber those 14 and under.¹ The sheer numbers of ageing Baby Boomers means something must be done to change—and seriously improve—end of life care.

The medical community at large views death as a failure of medicine, in the sense that they, understandably, are trained to treat and heal. This can lead to nightmares of unwanted tubes and machines as well as the desire to prepare living wills and “do not resuscitate orders.” However, there is another medical option when death is approaching, and that is palliative care.

Palliative care addresses death as the normal part of life that it is; not a problem to be solved but a process to be lived. Where this care is available for all who need it, fear of heroic measures at the end of life is unnecessary. The problem is that more than half of Canadians who need palliative care can't get it.²



DR. BALFOUR MOUNT



SENATOR CARSTAIRS

This paper tells the story of the beginnings of palliative care in Canada through the eyes of two palliative care pioneers, Dr. Balfour Mount and Senator Sharon Carstairs (retired). It will show the roots of palliative care in order to discover how such care may grow in Canada into the future.

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EXECUTIVE SUMMARY - CONTINUED

Recommendations:

- Increase palliative care training in medical schools for general practitioners, both to know more about palliative care practice as well as to know when to consult palliative care specialists or refer patients for palliative care
- Expand the ability of a GP to consult a palliative care specialist– in person, over the phone or via an internet-based video conversation – so that every GP in every community has such access
- Officially recognize palliative care as a necessary aspect of Canadian healthcare in every province, resulting in consistent and strong funding
- Solidify funding and consensus in support of local hospice houses and organizations which allow patients to receive quality care without leaving their communities
- Increase government resources for local palliative care efforts

1. Statistics Canada. (2011). Annual demographic estimates: Canada, provinces and territories. Cat. No. 91-215-X, Chart 2.2. Retrieved October 20, 2011 from <http://www.statcan.gc.ca/pub/91-215-x/91-215-x2011000-eng.htm>
2. The Canadian Institute of Health Information estimates, based on estimates from the four western Canadian provinces, that roughly 16 per cent of Canadians have access to quality palliative care services. See http://secure.cihi.ca/cihiweb/products/end_of_life_report_aug07_e.pdf, table 8.

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WHAT IS PALLIATIVE CARE?



DR. BALFOUR MOUNT

Dr. Balfour Mount is a founder of palliative care. He brought it over from England to Montreal in 1975 when he applied the English hospice movement to a hospital setting at the Royal Victoria Hospital there.³ He defines palliative care this way: “The goal of palliative care is to enhance

the quality of life. It really attempts to be sensitive to the multi-dimensions of the human experience, starting with physical suffering that are modifiers of quality of life. It therefore involves the whole person and the response to a whole person’s needs.”⁴



SENATOR CARSTAIRS

Senator Sharon Carstairs (retired) was the Minister with Special Responsibility for Palliative Care from March 2001 to December 2003 directing the federal government’s efforts on this topic.⁵ She has been a tireless worker for palliative care since her appointment to the Senate

in 1994. Senator Carstairs echoes Dr. Mount: “I define quality palliative care as being total person care at the end of life involving the physical, mental, spiritual and mental needs of the individual who is facing a prognosis that death is near. Furthermore, you can’t support the patient without supporting the members of the family. Bereavement care, which goes on after the person has died, should be an integral part of palliative care.”⁶

The Canadian Hospice Palliative Care Association, a national organization dedicated to advancing the cause of palliative care based in Ottawa, Ontario adds the following:

“Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.”⁷

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3. Personal communication with Dr. Balfour Mount, July 22, 2011.

4. *Ibid.*

5. Carstairs, Senator S. Curriculum Vitae. Retrieved August 18, 2011 from http://sen.parl.gc.ca/scarstairs/SenCarstairs/Cv_e.asp

6. Personal communication with Senator Sharon Carstairs, July 21, 2011.

7. Canadian Hospice Palliative Care Association. (2010). What is hospice palliative care? Accessed October 5, 2011 from <http://www.chpca.net/Home>

Two examples of good palliative care

Temmy Latner Centre for Palliative Care, Toronto, Ontario

- Offers homecare palliative care so that patients can remain in their home as long as possible
- Offers in-hospital care when in-home care is no longer possible
- Offers care for children whose parents are dying. “Our Dr. Jay Grief Program educates and supports children who have a loved one who is dying or who has died. We use creative approaches to help children learn about dying and death, and to encourage them to ask questions and explore their feelings. Our counselors also help adults learn to speak with children about dying and death.”⁸

The Temmy Latner Centre for Palliative Care at Mount Sinai Hospital in Toronto is a fine example of professional and caring work now being done in palliative care across the country. Through programs serving people of all ages, this centre cares for over 2,500 adults and children each year.⁹ All these services are available to patients as part of regular medical care.¹⁰

Hospice Simcoe, Barrie Ontario

Hospice Simcoe, based in Barrie, Ontario, is an example of a residential palliative care service. Here, trained volunteers visit patients in their homes to offer care and support.¹¹ Individuals are available to walk with family members through their grief, in groups or one-on-one.¹² Hospice Simcoe also operates a 10-bed residential home for individuals in the last three months of life.¹³ Patients are supported by registered nurses with 24-hour care, chaplains, personal support workers, trained volunteers and others.¹⁴ Hospice Simcoe operates on a budget comprised of funding from the provincial government combined with generous financial and volunteer support from the community.

These two examples show that palliative care service delivery is adaptable, from a hospital in downtown Toronto to a residence in Barrie.

8. Temmy Latner Centre for Palliative Care. (2011). Helping people who are living with and dying from a terminal illness. Retrieved October 6, 2011 from www.tlpc.org
9. *Ibid.*
10. *Ibid.*
11. Hospice Simcoe. Supporting you in your home. Retrieved October 27, 2011 from <http://www.hospicesimcoe.ca/index.php/programs-services/community-client-care.html>
12. Hospice Simcoe. Grieving a loved one is hard. Retrieved October 27, 2011 from <http://www.hospicesimcoe.ca/index.php/programs-services/bereavement-support.html>
13. Hospice Simcoe. Residential hospice care. Retrieved October 27, 2011 from <http://www.hospicesimcoe.ca/index.php/programs-services/residential-care.html>
14. *Ibid.*

continued from page 3

In short, palliative care is a rigorous medical discipline which seeks to help individuals and their families walk toward a natural and good death. In palliative care death is not an enemy to be overcome, but a part of life to be experienced as comfortably as possible.

WHY DOES PALLIATIVE CARE EXIST?

Palliative care operates in an area of medicine that often differs from the model used in hospitals. Other medical disciplines, such as oncology, see sickness and death as something to be cured; a patient who has died is, in a sense, a failure of medicine to keep them alive. Palliative care sees allowing life and death to take their course at the end of life as paramount for those who are dying. All physical and spiritual disciplines are then brought to bear to ensure a peaceful passage for the dying person and their family. Death is not something to be overcome as much as it is something to be experienced with support and caring people surrounding you.

The question that palliative care providers still face today in hospitals, in light of the drive to cure, is this: Why take time, funds and staff away from the care of the living when palliative care patients are just going to die anyway?

To answer this question, let us turn to the stories of Dr. Mount and Senator Sharon Carstairs.

Dr. Balfour Mount was trained as a surgical oncologist, working at the Royal Victoria Hospital, a teaching hospital at McGill university. Along with colleagues, he engaged in a study of patient care there and found two things: “First

of all, the initial study we did demonstrated two sobering facts. One is that patients at the end of life in our health care system get sub-optimal care.” This was surprising to him, “because the Royal Vic was then—and still is—an outstanding teaching hospital. Yet there was poor control of pain and other symptoms and that was a great surprise to us. Once one realizes that there is a significant health care problem within our institutions there’s a moral obligation, I would say, to address that deficiency. So that’s what we tried to do.”¹⁵

He continues: “I’d seen at St. Christopher’s in London, excellence of care beyond anything I’d ever seen before. I’m a surgeon, a surgical oncologist originally, and I was very impressed with the quality of care that the patients at St. Christopher’s were receiving. And so our initial experiment was to see whether that could be transposed into a teaching hospital setting and also into a program linked to a homecare program, the bereavement follow up program and the consult service.”¹⁶

Dr. Mount became engaged in end of life care because he saw a failing in then-current care which needed to be addressed.

Senator Sharon Carstairs became a passionate advocate of palliative care after witnessing the death of her mother. The Senator states: “I didn’t like the way my mother died, quite frankly. Both of my parents died in 1980. My father died in May and my mother in December. She had been his caregiver for 10 years after he had suffered a massive stroke. She brought him home from hospital and cared for him in our home but at great personal sacrifice to her own health. When she finally came to live with me in Winnipeg, she knew that she was very close to dying and asked to go to the hospital. We put her there. At her request she signed a Do Not Resuscitate order but they

15. Personal communication with Dr. Balfour Mount.

16. *Ibid.*

resuscitated her anyway. She then went into a coma and they did not resuscitate her again. I've always felt I let her down. She had asked for the DNR order and she asked me to make sure that it was followed. Those are things that live with you for a lifetime.”¹⁷

Too many Canadians have had an experience similar to that of Senator Carstairs. Yet the experience of painful deaths inspired both Senator Carstairs and Dr. Mount to spearhead an effort to improve end of life care in Canada. Palliative care shares compassion and support and stems from a common desire to allow every patient to have a good death, whether in the context of illness or simply as the end of life draws near.

HOW HAS PALLIATIVE CARE IMPROVED SINCE IT WAS INTRODUCED IN CANADA?

The quality of care which existed in Montreal in 1975 was very high, modeled as it was after St. Christopher's hospice in the UK. Since then, the quality of care has increased as has the number of Canadians who have access to quality palliative care.

With respect to improvements in palliative care since its inception, Dr. Mount makes this observation: “Like any other aspect of healthcare or science in general, once you turn your attention to a neglected area, new observations and discoveries lead to improvements. For example, I've just come from seeing a person with nerve injury pain. When we started in 1975 we were *extremely* limited in the medications available and in our understanding of neuropathic pain. Now it is just a totally different place, because we understand the pathophysiology of it and we know more about what's going on. We're also fortunate that we have a wide range of painkillers that are effective.

So, yes, there have been a lot of advancements.”

On the Canada's west coast, Dr. Margaret Cottle of the University of British Columbia is an active and dedicated palliative care practitioner and professor. She notes the amazing progress made in palliative care in the last 20 years: “When I first started, the only long acting medication we had was a long acting morphine. And now we have long acting hydromorphone and long acting oxycodone and others. We have a much better understanding of nausea and anti-nausea medication. We're better at dealing with breathlessness. We also have much better anti-depressants, which have much fewer side effects and are faster acting.”¹⁸

As much as the capacity for pain and other treatments has increased, such abilities are less comforting if doctors don't know how to use them or even that they exist. In this respect, there has been much progress, while further improvements are still needed.

Great strides have been made in training doctors in palliative care since the 1995 Senate report, *Of Life and Death*. Senator Carstairs explains: “In our committee report in 1995, we identified that the average amount of pain relief training that the average medical student was receiving was one hour. I decided that had to be our number one priority to ensure that every single graduating doctor ... knew how to provide a good death. Because you're not going have enough palliative care physicians to do this, it's going to have to happen with the family care physicians.”

“What is very interesting is that I'm now being told by the acute care teaching hospitals that they used to get requests from maybe two residents to do a rotation in palliative medicine; now they're getting 60 to 70 a year asking to do that rotation. So, by introducing it to them

17. Personal communication with Senator Sharon Carstairs.

18. Personal communication with Dr. Margaret Cottle, July 21, 2011.

at the undergraduate level, what we now have is doctors saying ‘this is something I want to know more about, this is something that I want to be better trained in.’ And as the senior palliative care physicians will tell you, that won’t make these people experts in palliative care, what it will do is tell them what they don’t know so that they will reach out to people that they know have the training and expertise when they run into a problem.”¹⁹

Senator Carstairs clarifies a key need for the future of palliative care in Canada. As Canada’s population ages, it will be virtually impossible to have a palliative care ward in every Canadian hospital or a community hospice in every village, town and city. What is urgently necessary is that family physicians and hospital nursing staff need to learn the basics of end of life care. They need to be able to contact an expert in this field when they have questions of care they can’t answer on their own. The medical community is building that capacity, but there are still many miles to go before we have universal access to quality palliative care across Canada.

CHALLENGES GOING FORWARD

Out of the progress that has already been made in Canada, we can see further challenges going forward. If we are to live in a country where no one need fear a horrible death full of untreated pain and suffering, we must both grow the number of doctors and nurses able to provide quality end of life care and make such care applicable to a wider range of illnesses.

- **Ability to care for more than patients with cancer:**

Senator Carstairs notes some of the challenges with respect to applicability: “It’s better for those who

suffer from cancer than it is for those who suffer from other chronic diseases. And that’s the real conundrum that’s facing palliative care right now, is that palliative care in Canada really began as cancer care both in Montreal under Dr. Balfour Mount and in Winnipeg under Dr. Paul Henteleff because cancer had such excruciating pain symptoms associated with it. Parkinson’s disease, Huntington’s disease, Amyotrophic Lateral Sclerosis (better known as ALS), COPD (Chronic Obstructive Pulmonary Disease) are diseases that also should be on the trajectory of quality end of life care and unfortunately are not.”²⁰

- **Improve access to care**

One of the main needs that Dr. Mount sees in terms of the future of palliative care in Canada is to expand its application across the country. “The issue and the area of concern is to make that high standard of end of life care available across the board. And that still *clearly* has a long way to go. We know how to give good and excellent care, but now we have to see that it happens and see it as an ethical responsibility to provide that kind of care.”²¹

Governments cannot impose ethical responsibility, but they can provide the funding and space for such responsibility to develop. If palliative care is to continue growing in Canada, all levels of government must allow local services and expertise to develop and thrive from coast to coast.

This is a pressing need now because Baby Boomers today are growing older and moving toward death. As they have reshaped other aspects of life (education and the workforce, for example), some Baby Boomers are creating pressure to

19. Personal communication with Senator Sharon Carstairs.

20. *Ibid.*

21. Personal communication with Dr. Balfour Mount.

reshape how people die by legalizing assisted suicide and euthanasia. Senator Carstairs responds to such pressure this way: “When 100% of people have access to palliative care then maybe, but not until then, because this is about choices. And if you don’t have palliative care as a choice, then you have no choice.”²²

WHY WE MUST GROW PALLIATIVE CARE

On the surface asking for government funding in an era of deficits and economic downturn may appear to be difficult. Unfortunately, palliative care is not yet considered a fundamental and permanent facet of our healthcare system. However, increasing palliative care is also fiscally wise because palliative care services are more cost effective than acute care in a hospital setting. The Parliamentary Committee on Palliative and Compassionate Care found that “it costs \$600-\$800 per day to have a palliative care bed in the hospital. It costs \$200 a day to have a palliative care bed at home. It costs \$300 a day to maintain a hospice bed [in a residential hospice program]. In many provinces people are dying in acute care beds at \$1200 per day or more.”²³ In other words, by providing higher quality end of life care to dying patients governments could in fact save money.

Since palliative care is not yet included as part of the Canada Health Act, governments are not required to fund it in their jurisdictions. The Canadian Hospice Palliative Care Association (CHPCA) notes that the majority of funding for hospice palliative care initiatives comes instead from private sources: “Generally hospice palliative care programs rely disproportionately on charitable giving; a majority of the cost of programs is provided by

private donors, restricting the size, scope and access to programs.”²⁴ Private donations can fluctuate from year to year depending on the financial wellbeing of donors. Transferring at least a large portion of this funding to core funding by the public purse would allow a stability that does not now exist.

The CHPCA notes how the current situation affects service delivery on the ground: “Currently only a small number of provinces have designated hospice palliative care as a core service under their provincial health plans. In the remaining provinces, hospice palliative care may be included in provincial home care budgets or other health service budgets, leaving the funding vulnerable to budget reductions.”²⁵

But Canada’s population is aging. Our population will soon cross the threshold where there are more people over 65 in Canada than there are 14 and under.²⁶ This is uncharted territory; Canada’s population is growing older fast. As we age, we will require more, not less, palliative care at the end of life. For services to expand in Canada, we need a solid foundation on which to build today. That foundation cannot exist without core funding from governments to offset (but not replace) the need for private donations.

Senator Carstairs illustrates the difficulty with hard numbers: “We know that each death in Canada affects the immediate wellbeing of, on average, five other people. If projections of a rate of 480,000 deaths per year by 2056 are realized, that means potentially 2.4 million people affected by death in their family or social circle in any given year. The number of caregivers experiencing

22. Personal communication with Senator Sharon Carstairs.

23. Parliamentary Committee for Palliative and Compassionate Care. (2011, November 17). Not to be forgotten: Care of vulnerable Canadians. p. 28. Retrieved November 21, 2011 from <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

24. Canadian Hospice Palliative Care Association, GlaxoSmithKline Foundation. Hospice palliative care fact sheet. Retrieved October 27, 2011 from <http://www.living-lessons.org/main/hospice.asp>

25. *Ibid.*

26. Statistics Canada. (2011). Annual Demographic Estimates: Canada, Provinces and Territories. Cat. No. 91-215-X, Chart 2.2. Retrieved September 28, 2011 from <http://www.statcan.gc.ca/pub/91-215-x/91-215-x2011000-eng.htm>

loss of work for a month or more could rise to 25,000 each year.”²⁷

As Canadian demographics change, with more citizens growing older and fewer younger people, our working age population will shrink. Statistics Canada notes that “As a result of the baby boom cohort gradually leaving the labour force, the share of the working-age population in the total population is expected to decrease in the coming years.”²⁸ With a smaller workforce, the loss of 25,000 months or more of work could have serious consequences for those organizations affected.

Yet before the economy feels the pain of these deaths, family members will feel it more powerfully and personally. Senator Carstairs shows the great impact of death on loved ones: “This is truly a family issue. Our stats show that the single death of a Canadian has an immediate impact on an average of five people. In our aging society, the number of deaths is actually going to increase. If you have more people dying and you don’t grow palliative care, then you’re going to have a situation in which, in percentage terms, you are able to deliver less palliative care than we deliver now.”²⁹

Across Canada, many people have worked long and hard to improve palliative care services in their community. The advances which have been realized are the result of countless hours of dedication and practice. But, by even the most positive estimate, those receiving palliative care represent 25 to 30 per cent of those who need such services. This means that, at best, 70 per cent of those in need do not currently have access.

Death is one thing that we have in common. Many people across this country have worked to ensure that quality palliative care is available to as many people as possible.

In order to maintain their gains, we must continue to expand palliative care services. As the Canadian population ages, simply maintaining current levels of service means that availability will decrease across the country.

Too many people today are dying painful, horrible deaths. If palliative care were considered a necessary part of healthcare delivery in Canada, those numbers would shrink dramatically. We owe it to our grandparents, our parents and to ourselves to make these changes. For a better life for those left behind and a better death for those leaving, we must expand the geographical scope and improve the quality of care in palliative care.

To that end, we make the following recommendations:

- Increase palliative care training in medical schools for general practitioners, both to know more about palliative care practice as well as to know when to consult palliative care specialists or refer patients for palliative care
- Expand the ability of a GP to consult a palliative care specialist— in person, over the phone or via an internet-based video conversation – so that every GP in every community has such access
- Officially recognize palliative care as a necessary aspect of Canadian healthcare in every province, resulting in consistent and strong funding
- Solidify funding and consensus in support of local hospice houses and organizations which allow patients to receive quality care without leaving their communities
- Increase government resources for local palliative care efforts ■

27. Carstairs, Hon. Senator S. (2010). Raising the bar: A roadmap for the future of palliative care in Canada. Ottawa: Senate of Canada, p. 12. Retrieved August 22, 2011 from <http://sen.parl.gc.ca/scarstairs/PalliativeCare/Raising%20the%20Bar%20June%202010%20%282%29.pdf>

28. Statistics Canada. (2011). Annual demographic estimates: Canada, provinces and territories, p. 37.

29. Personal communication with Senator Sharon Carstairs.

