



**The provision of relief, care and support:**  
**Choosing a compassionate society**

Submission made to the Parliamentary Committee on Palliative and Compassionate Care

by

**Palliative Care McGill**  
Department of Oncology, McGill University

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Editors:

**Dr. Bernard J. Lapointe**, MD, Eric M. Flanders Chair in Palliative Medicine and Director of Palliative Care McGill, Department of Oncology, McGill University

**Dawn Allen**, PhD, Associate Director of Palliative Care McGill, Department of Oncology, McGill University

In collaboration with members of the Executive Committee of Palliative Care McGill

**Members of the Executive Committee  
of Palliative Care McGill**

**Guylaine Arbour**, RN, Head Nurse, Cancer Care Program, Palliative Care Services, St. Mary's Hospital Center.

**Vasiliki Bitzas**, RN, CHCPN (C), PhD (c), Head Nurse, Palliative Care Services, Jewish General Hospital.

**Manuel Borod**, MD, Director, Division of Palliative Care, McGill University Health Centre.

**Robin Cohen**, PhD, Research Director, Palliative Care McGill; Associate Professor, Departments of Oncology and Medicine and School of Nursing, McGill University; Senior Investigator, Lady Davis Institute.

**Justine Farley**, MD, Director of Palliative Care Services, St. Mary's Hospital; Assistant Professor, Department of Oncology, McGill University.

**Kappy Flanders**, founder and co-chair of the McGill Council on Palliative Care.

**Bruno Gagnon**, MD, MSc., Assistant Professor and clinical researcher, Faculty of Medicine, McGill University.

**Tom Hutchinson**, MD, Division of Palliative Care, McGill University Health Centre; Professor and Director of Programs in Whole Person Care, Department of Oncology, McGill University.

**Elizabeth Kofron**, PhD, Associate Director, Montreal Neurological Institute.

**Stephen Liben**, MD, Director, Pediatric Palliative Care Program, Montreal Children's Hospital, Associate Professor, Departments of Pediatrics and Oncology, McGill University.

**Neil MacDonald** MD, Professor, Department of Oncology, McGill University.

**Judith Marchessault**, RN, MSc., specialist in home care nursing, Mount Sinai Hospital Centre.

**Sara Marcil-Johnson**, BA, Coordinator, Education and Student Affairs, Palliative Care McGill.

**Pedro Mejia**, PhD, Volunteer Coordinator, Hope & Cope, Division of Palliative Care, Jewish General Hospital.

**Rosemary O'Grady**, BSN, MSc. Nursing (in progress), Nurse Manager, Division of Palliative Care, McGill University Health Centre.

**Gayle A. Shinder**, PhD, Research Grants Coordinator, Department of Oncology, McGill University.

**Anna Towers**, MD, Division of Palliative Care, McGill University Health Centre; Associate Professor, Departments of Medicine, Family Medicine and Oncology, McGill University.

**Golda Tradounsky**, MD, Director of Palliative Care Services, Mount Sinai Hospital Centre; Education Director, Palliative Care McGill, Department of Oncology, McGill University.

## **Introduction**

The Palliative Care Program at McGill University is a place of excellence in the teaching, research and provision of palliative care in Quebec. McGill University and its affiliated hospitals are the cradle of modern palliative care in Quebec, Canada, and North America. Indeed it was in 1974, under the direction of Dr. Balfour Mount (Officer of the National Order of Quebec), that the first palliative care department was established in Quebec.

Over the past 36 years, the Palliative Care Program at McGill has distinguished itself nationally and internationally for the quality of its pre-doctoral and postdoctoral teaching, the quality of its research program on the development of novel agents for better symptom relief, on the quality of life for people at the end of life and that of their family, and finally on the models for providing effective and efficient end-of-life care. Our McGill-affiliated palliative care services draw on the expertise of professionals and volunteers working in the following sites: the McGill University Health Centre (the Montreal General Hospital, the Montreal Children's Hospital, Royal Victoria Hospital, the Montreal Chest Hospital, and the Montreal Neurological Institute -- which is about to develop the first neuro-palliative care unit in Canada), the Jewish General Hospital, St. Mary's Hospital and Mount Sinai Hospital Centre. In Quebec, our continuing care and palliative relief clinical teams treat, care for, and support annually more than 1,200 people suffering from cancer and other catastrophic diseases, as well as their families, up to the time of death and thereafter during the grieving period.

Our clinical services sites are staffed by truly interdisciplinary teams of health professionals and hundreds of volunteers who, together, strive to combine physical and psychological care, psychosocial support, art or music therapy, and spiritual support. The experience and expertise of our interdisciplinary palliative care teams continue to inspire hundreds of care teams in Quebec and elsewhere. By leveraging the expertise of its theoretical and clinical multidisciplinary teams, our palliative care program offers courses and practical training to undergraduate medical and nursing students, graduate students, medical residents, and fellows; continuing medical education to health care professionals; and, finally, training for volunteers working in our various sites.

It is as a team of multidisciplinary experts in palliative and end-of-life care that we bring to the Parliamentary Committee on Palliative and Compassionate Care the insights and concerns described in this brief.

The progress made over the past 10 years in palliative care, as articulated in the QELCCC *Blueprint for action (2010)*, is encouraging. Particularly encouraging to the members of Palliative Care McGill were the significant research funding from CIHR, the introduction of the Compassionate Care Benefit for all Canadians, and increased attention to improving access to palliative care for all those who need it. However, in light of our aging population and the increased prevalence of chronic illness, we remain very concerned about several aspects of palliative care that require urgent attention: equal and sufficient access to care, the development of an adequate number of palliative care experts, the quality and quantity of palliative care education and research, and support for family caregivers.

### **Access to palliative care: The nature and implications of its inadequacy**

That Statistics Canada is anticipating a 40% increase in deaths within the next 15 years is of particular concern in light of the current levels of access to palliative care. It is estimated that at least 70% of Canadians in need of palliative care cannot access it (Henteleff et al 2009; Carstairs 2010). In the Montreal region alone, the Agence de Santé et Services Sociaux (2009) has identified numerous reasons for inadequate access to palliative care:

- a) Insufficient interdisciplinary care teams to provide home care.
- b) Inadequate palliative care education of health care professionals working in long-term care facilities.
- c) Insufficient doctors with the palliative expertise necessary to support patients, families, and other health professionals in the homecare setting.
- d) Too few hospital beds dedicated to palliative care for patients with particularly complex pain and symptom control. (More beds would require more health professionals.).
- e) Poor or non-existent coordination of care across various care sites (e.g. home, various hospital units, long-term care facilities).

Fundamental to all other concerns addressed in this brief is that of access to palliative care. Lack of access to palliative care contributes to the current interest in the legalizing of euthanasia. Lack of access to palliative care is the result of a lack of palliative care specialists who support the many *non*-palliative care health professionals in their care for the dying. Lack of access is also the direct result of inadequate education of all health professionals in the basics of good palliative care: good pain and symptom management, skillful communication with patients and families, and effective collaboration with an interdisciplinary team.

Access to the most effective and efficient palliative care depends on excellent research. The development of palliative care expertise and top quality interdisciplinary educational programs relies on careful and pertinent research that provides us with the best knowledge about medications, care techniques, and various services to be translated into practice. Finally, insufficient access to palliative care is perhaps most obvious in recent statistics on the care challenges that are shouldered by family caregivers of palliative patients. Without access to the support that they need to sustain their invaluable contribution to palliative care, family caregivers suffer financially, emotionally, and physically in ways that may further strain our society's resources.

### **Recommendations:**

To address the serious lack of access to palliative care throughout Canada, we support the many recommendations made by the Quality End of Life Care Coalition of Canada in their *Blueprint for Action* (2010) with particular support for the following:

- a) Federal leadership in the area of palliative and end-of-life care through the development of national strategies that address the palliative care needs of Canadians living with chronic and terminal illnesses such as cancer, neurological diseases, heart disease, lung disease, kidney disease.
- b) A commitment from the government to fulfill its mandate to ensure good quality palliative care to all those who rely on the federal government for their health care: aboriginals, military personnel and their families, and inmates. Although some initiatives have been developed, more needs to be done to meet the palliative care needs of these populations across Canada.

- c) Increased support for the development of palliative care experts who educate and train current and future health professionals.
- d) Increased support for palliative care research that informs the best practices for palliative and end-of-life care.
- e) Increased support for family caregivers who are most immediately impacted by the lack of access to palliative care services.
- f) Commitment to no consideration/discussion of legalizing euthanasia until top-quality palliative and end-of-life care is available to all Canadians.

### **The threat of euthanasia: What is it telling us about quality end-of-life care?**

In response to a call from the Quebec government's Select Committee on Dying with Dignity, Palliative Care McGill shared with that Committee our serious concerns about the legalization of euthanasia and the impact such a law would likely have on the provision of palliative care. In our written brief and our oral presentation, we took a firm stance against the legalization of euthanasia for the following three key reasons:

- a) The arguments put forward during the debate reveal persistent misunderstandings about the medical terminology and practices that are at the heart of the debate.
- b) There would be little or no public interest in legalizing euthanasia if appropriate political will and funding ensured access to the quality end-of-life care currently enshrined in Canadian law.
- c) The risks associated with the legalization of euthanasia far outweigh the benefits.

The persistent misunderstanding by health professionals (including doctors) of key concepts in the euthanasia debate is an indication of how poorly palliative care is understood. Such limited understanding of care for the dying is not surprising given how little time is spent on this discipline at both the undergraduate and postgraduate levels of medical education alone. At McGill, undergraduate medical students receive a mere 20 hours (approximately one-half of a three-credit course) over 4 years in learning about palliative and end-of-life care. The educational programs for nursing, social work and other key disciplines that complete the interdisciplinary palliative care team offer equally limited attention to this area of health care.

That relatively little attention is paid to palliative care in the education of our health professionals, is perhaps not surprising in light of the Canadian Health Care Act's description of palliative care as a "supplementary service." However, according to Henteleff et al (2009), based on the Canadian Charter, it is quite possible to argue that palliative care should and soon could be reinterpreted as part of necessary or compulsory health services. According to the authors, in accordance with Section 7, which protects the security of a person, and Section 15, which guarantees provision of publicly-funded services without discrimination, palliative care may have the status of required services and should be provided to all Canadians through publicly-funded health care programs. While the right to quality end-of-life care may not yet be guaranteed by law, there is both potential for and interest in seeing this happen (Carstairs 1995, 2000, 2005, 2010). "Indeed, the federal Senate committee, in its 2000 report on end-of-life care, mentions the Bill of Rights to argue that human dignity and worth 'require' the provision of excellent care at the end of a person's life" (Henteleff et al, 2009 p. 9).

We expect that, despite the recent defeat of the proposed legalization of euthanasia by the Canadian Parliament in April of this year, this issue will not go away easily. At the recent International Congress on Palliative Care (hosted biennially at McGill), one of our Australian

colleagues presented news of the discouraging return to discussions of legalizing euthanasia in that country, despite a repeal of such a law in 1997. Boughey reported that the effects of Australia's brief and localized experience (1996-1997 in the Northern Territory) with euthanasia included an exodus of palliative care clinicians from the territory, the breakdown of patient-clinician trust, and subsequent challenges to pain management that occurs when patients distrust the clinicians who provide their care (Boughey et al, 2010; Gawlor, 2008).

Negative consequences for patients, health professionals, and the overall health care system have also been identified in places where euthanasia has been legalized for some time. For example, in the Netherlands, studies have shown a deterioration of medical standards in the care of patients with incurable illnesses (e.g. Hendin, 2004). In Belgium, a recent study found an alarming number of cases of unrequested euthanasia, particularly among the elderly and the demented (Chambaere et al., 2010).

#### Recommendation:

Deficiencies in our health care system should not become a motivation for legalizing euthanasia. We recommend that Parliament refuse to engage in discussions of legalized euthanasia until sufficient access to palliative care is established across Canada.

#### **The development of palliative care specialists: Building palliative care capacity**

Central to the challenge of providing adequate and equal access to palliative care is the lack of medical expertise available to meet the needs of the growing number of chronically ill people with complex symptoms. Because people are living longer with one or more chronic diseases, the holistic management of their symptoms for a good quality of life has become more complex and often requires specialist care. Palliative medicine provides such specialist care to people who are nearing the end of their life.

Because interest in and support for palliative care research and education have grown worldwide in the past 30 years, our discipline now has a solid body of knowledge, validated competencies, and a well developed curriculum. Palliative care experts (those who received specialist training elsewhere and those who have developed expertise over many years of practice) play an essential role in the health care system within and beyond the palliative care unit. In addition to their direct clinical work with patients and families, they are expert consultants and educators to health professionals in home care and hospital settings.

But as the statistics on access to palliative care suggest, there simply are not enough palliative care experts to provide the care and training needed to meet the needs of our aging population and the many health professionals who care for them across a broad range of care sites and medical disciplines. In order to improve access to palliative care, we need to attract physicians to palliative care and ensure that they have the necessary medical expertise to provide much needed specialized pain management, scholarship and leadership. Regrettably, tensions between the Royal College of Physicians and Surgeons of Canada (RCPSC) and the Canadian College of Family Physicians (CCFP) have prevented the recognition of a palliative medicine specialty / subspecialty.

Palliative Medicine is recognized as a specialty or subspecialty in many countries including the United States, the United Kingdom, Ireland, New Zealand, and Australia. In Canada, we have for 11 years been offering a year-long advanced training fellowship in palliative care to residents of

all disciplines and are well-prepared to train palliative care specialists. It is time to move forward in the development of recognized specialists in palliative medicine. It is unacceptable that conflicts between the RCPSC and the CCFP have hindered progress toward equal access to palliative care across Canada.

Recommendation:

We recommend that Parliament urge the RCPSC and the CCFP to establish palliative care as a medical subspecialty so that we can grow our discipline enough to meet the various care needs of terminally ill patients and their families regardless of where they are in the health care system.

**The quality and quantity of palliative care education and research: Ensuring best practices**

Currently in Quebec, most medical students receive only 20-25 hours of palliative care education over their 4 years of medical school. At McGill, nursing students can receive approximately twice as many hours as their counterparts in medicine, but attention to palliative care is not an official component in that curriculum and, as such, is at risk of being avoided or ignored by instructors who may lack the knowledge or comfort they feel they need to address this dimension of care.

Post-graduate residency programs do not fare much better. Aside from family medicine and some oncology programs that require a one-month rotation in palliative care, most specialist disciplines ignore the need for their residents to be trained in basic palliative care. Since 1999, most medical residents are eligible to complete a “year of added competency” in palliative care through which they develop expertise in palliative medicine and interdisciplinary care. However, through this program Quebec currently only trains approximately three such experts annually. A substantial increase in the number of palliative care experts would need to occur, in concert with other educational initiatives, in order to meet the growing needs of our aging population.

An additional concern is that physicians and nurses are but two of the many disciplines that provide the holistic, interdisciplinary care that is central to palliative care. Given the low priority of palliative care in both medicine and nursing school programs, one can safely assume that we are not doing much better in our preparation of the psychologists, social workers, pharmacists, dietitians and others who will one day be caring for those at the end of life.

Furthermore, since their inception, palliative care services have depended heavily on the support and mobilization of volunteers, financially and for the delivery of care. Palliative care is what it is today largely because of the essential contribution of countless volunteers. However, like the many paid disciplines that participate in palliative care, volunteers do not have standardized education and training guidelines that ensure best practices and protect against high turnover. The Parliamentary Committee on Palliative and Compassionate care has a rather unique opportunity to encourage the federal government, especially Health Canada, to support the volunteer sector’s participation in quality end-of-life care by investing in initiatives for volunteer education and training, volunteer recruitment and retention, and the development of palliative care volunteer services.

Finally, of great concern are the federal government’s radical cuts to funding for all research. Research is at the very core of building and maintaining the best quality health care for all Canadians. In palliative care, we rely on research to help us determine best practices, to create effective care programs, to train top quality health professionals, to refine and increase our knowledge of complex pain management, and to meet the needs of the many informal caregivers on whom the health system

so heavily relies. The 2004-2009 CIHR initiative for palliative care research was a much needed and very welcome contribution to the overall betterment of palliative medicine and palliative care services, and made Canada a leader in palliative care research support. Palliative care researchers made good use of those resources by doubling Canada's palliative and end-of-life care publications and by setting up palliative care research networks that are now emulated by the UK. However, despite the best intentions of CIHR to foster palliative care research, the advancement of palliative care has been grievously harmed by current government policies on research.

As a result of these restrictive policies, palliative care has been unable to build on the progress made with CIHR support. Furthermore, despite recent gains in research productivity, palliative care remains an emerging field and as a result it needs support through targeted research funding if it is to compete with older and more well-established disciplines such as cardiology and oncology. Finally, unlike most other medical research, palliative care cannot count on private industry for support. Our discipline is one for which lucrative drugs and medical technologies are not appropriate. Therefore, palliative care is especially dependent on the federal government to ensure that our care practices are based on sound research. The government's current policies on research are harming the advancement of palliative care, and these policies are especially disturbing in light of the growing end-of-life care needs across our country.

#### Recommendations:

- a) Invest in our future by investing in the evidence-based education and training of palliative care experts across the disciplines.
- b) Ensure that all future health care professionals receive a good basic education in palliative care, one which includes good communication skills, basic symptom management techniques, and an understanding of how to work collaboratively in an interdisciplinary team to provide the best possible support to patients and their families. In those situations where basic palliative care knowledge is not enough, all health professionals should know how and when to involve palliative care specialists to whom they should have easy access.
- c) Invest in all initiatives for volunteer education and training, volunteer recruitment and retention, as well as programs and services delivered by volunteers.
- d) Invest in qualitative and quantitative palliative care research which improves our understanding of best care practices and which facilitates the translation of research knowledge into practice.

#### **Support for family caregivers: An urgent need**

With the rising costs of health care, the rise in the median age of our population, and the increasing numbers of people living with one or more chronic illnesses, it is not surprising that family caregivers are facing a growing number of challenges in their provision of care. According to a 2007 national survey of health care in Canada (Health Care in Canada Survey, 2007), 41% of Canadians must use personal savings to support themselves when caring for their loved one and 22% miss one or more months of work. Family caregivers who provide palliative care at home undertake a wide range of tasks which include the complex administration of medications and other medical care; spiritual, social, and psychological care of their ill loved one; the abundant homemaking tasks involved in maintaining a healthy care environment (special cooking, extra cleaning, etc); and transportation and care-coordination (Voice in Health Policy Project, 2004). A recent study of middle-aged and older unpaid caregivers in Canada found that these caregivers incur \$80 billion in out-of-pocket expenses and provide the equivalent of over \$25 billion dollars in fiscal, psychological, and physical care for their ill loved one (Hollander et al 2009).

Despite the huge contributions made by informal, unpaid caregivers, the health care system fails to offer them the support they need: better information at the time of diagnosis, better training, more respite and counseling resources, and more financial support (Carstairs, 2010). Investment in this valuable resource will not only diminish health and financial problems within the caregiver population but it will increase the possibility of being able to die at home: the desire of 80% of Canadians.

#### Recommendation:

Family/informal caregivers are a vital part of quality home-care programs and they should be supported in ways that allow them to continue to provide quality care to their loved ones at home without damage to themselves economically, psychologically, or physically. We recommend that the federal government support informal and unpaid caregivers through fiscal initiatives and innovative programs that ease the financial, psychological, and physical burden of caring for the seriously ill and dying.

#### Conclusion

While we enthusiastically support the important strides that have been made over the past ten years by the Government of Canada to improve palliative care, we remain very concerned about certain inadequacies in palliative care access, expertise, education, research, and support for family caregivers.

To address those inadequacies, we have offered in this brief the following recommendations.

- 1) Develop national strategies that address the palliative care needs of Canadians living with chronic and terminal illnesses such as cancer, neurological diseases, heart disease, lung disease, and kidney disease.
- 2) Ensure good quality palliative care to all those who rely on the federal government for their health care: aboriginals, military personnel and their families, and inmates.
- 3) Commit to no consideration/discussion of legalizing euthanasia until top-quality palliative and end-of-life care is available to all Canadians.
- 4) Urge the RCPSC and the CCFP to establish palliative care as a medical subspecialty so that we can grow our discipline enough to meet the various care needs of terminally ill patients and their families regardless of where they are in the health care system.
- 5) Invest in our future by investing in the evidence-based education and training of palliative care experts across the disciplines.
- 6) Ensure that all future health care professionals receive a good basic education in palliative care (communication skills, symptom management techniques, interdisciplinary collaboration), and have access to palliative care specialists in those situations where basic palliative care knowledge is not enough.
- 7) Invest in all initiatives for volunteer education and training, volunteer recruitment and retention, as well as programs and services delivered by volunteers.
- 8) Invest in qualitative and quantitative palliative care research which improves our understanding of best care practices and which facilitates the translation of research knowledge into practice.
- 9) Support informal and unpaid caregivers through fiscal initiatives and innovative programs that ease the financial, psychological, and physical challenges of caring for the seriously ill and dying.

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