



Framework for a National Strategy on Palliative and End-of-Life Care

Submitted by:

ALS Society
Canadian AIDS Society
Canadian Association for Pastoral Practice and
Education
Canadian Association of Community Care
Canadian Association of Occupational
Therapists
Canadian Association of the Deaf
Canadian Breast Cancer Network
Canadian Cancer Society
Canadian Home Care Association
Canadian Hospice Palliative Care Association

Canadian Lung Association
Canadian Medical Association
Canadian Nurses Association
Canadian Society of Palliative Care Physicians
Caregiver Network Inc.
Catholic Health Association of Canada
Childhood Cancer Foundation (Candlelighters)
The GlaxoSmithKline Foundation
Heart and Stroke Foundation of Canada
National Advisory Council on Aging
Pallium
VON Canada

September 2005

The Quality End-of-Life Care Coalition of Canada
Secretariat: Canadian Hospice Palliative Care Association
Annex B, Saint Vincent Hospital
60 Cambridge Street North
Ottawa, ON K1R 7A5

Framework for \$20 Million Long-Term, Sustainable, National Funded Strategy for Palliative and End-Of-Life Care

The Quality End-of-Life Care Coalition of Canada (QELCCC) attended a meeting with Minister Ujjal Dosanjh in June of 2005 with the goal of promoting the development and implementation of a long-term, sustainable and well-funded strategy on palliative and end-of-life care for Canada. During this meeting, Minister Dosanjh expressed an interest in this idea and asked the QELCCC to develop a brief document outlining what this strategy would entail. This resulting framework document highlights why a national strategy is needed, what it would encompass and who needs to be engaged to ensure a national strategy is meeting the end-of-life care needs of Canadians.

Why a long-term, sustainable, well-funded national strategy?

Since the publication of the Senate of Canada's 1995 report "Of Death and Dying" through to the latest report by Senator Sharon Carstairs released in June of 2005, "Still Not There: Quality End-of-Life Care - A Progress Report", hospice palliative care continues to be an area of health care that is not adequately addressed. A national strategy for palliative and end-of-life care will provide an opportunity for the federal government to show leadership in the development of best practices, provide evidence-based decision-making, increase knowledge transfer and knowledge translation, and disseminate the outcomes of palliative and end-of-life care research. A national strategy for palliative and end-of-life care will impact the health care system by reducing the overall cost of health care. Direct results will include a reduced number of patients in acute care settings, and staff and family and informal caregivers who are empowered with the resources they need to provide care. As well, lessons learned from a national strategy can be shared and disseminated widely among researchers, health care providers, policy makers, caregivers, governments and other interested groups working in palliative and end-of-life care.

The number of deaths in Canada is expected to increase 33% by the year 2020 and the current number of Canadians having access to hospice palliative care is estimated at 15%. These two statistics clearly show us that while hundreds of thousands of Canadians will experience the need for access to quality, coordinated, integrated, and comprehensive palliative care services, the system will not be prepared to undertake this challenge. An investment in a national strategy needs to be made now to ensure that our health care system can meet these forthcoming demands.

Minimal progress has been made since the initial 1995 Senate of Canada report. Today we see a patchwork of minor initiatives that do not address the larger issues that Canadians face when accessing hospice palliative care services. Health Canada currently has a national strategy for palliative and end-of-life care through the Secretariat on Palliative and End-of-Life Care, but it is woefully under-funded and is vulnerable to funding cuts or elimination as it is not an "A-based" program. In past years, the funding levels have been erratic and have jeopardized the national strategy's current initiatives and stalled future work. A long-term, sustainable, well-funded, national strategy would support a number of actions which include (as identified by the Coordinating Body of the current National Strategy on Palliative and End-of-Life Care):

- Providing access to coordinated, integrated, and comprehensive hospice palliative care services (including acute care, long-term care, residential hospice and home care settings)
- Raising public awareness of important issues that Canadians face regarding death and dying
- Enabling Canadians to make informed and educated decisions with regard to their end-of-life care

- Promoting interdisciplinary research that increases the base for evidence-based decision making and creates research networks
- Supporting the adaptation of norms of practice and standards for care providers across Canada

What needs to be included in a national strategy?

A national strategy should include several key areas that will ensure that Canadians have access to coordinated, integrated, and comprehensive end-of-life care services. These key areas include: Research, Policy Development and Best Practices, Knowledge Transfer, Knowledge Translation and Dissemination.

Research (Cost: \$5 million)

The Canadian Institutes of Health Research, among others, have begun to fund research in palliative and end-of-life care but a much broader and ambitious research agenda needs to be adopted. Current research initiatives tend to be disease specific but issues such as pain and symptom management vary greatly based on individual circumstances. It is important to understand how the unique progression of various diseases may influence the needs of patients at the end of life. For example, aged Canadians, whose bodies may be slowly losing functions due to age, have much different hospice palliative care needs than those who are dying from a specific disease such as ALS. The hospice palliative care needs of Canadians vary greatly depending on individual cases and disease progression and it is important that the research agenda be broadened to take these into account.

Research also needs to address the needs of family and informal caregivers. Family and informal caregivers incur significant physical, emotional, psychosocial, and financial costs. This area has a significant impact on hundreds of thousands of Canadians who care for a dying loved one every year. Research will assist in addressing these issues and supporting the needs of family and informal caregivers in Canada.

Policy Development (Cost: \$2 million)

It is important that policy is socially progressive and is responsive to the needs of Canadians. National organizations that support the development of public policy need to be supported financially to ensure this work is built on evidence, and is discussed and communicated to all levels of government, the voluntary health sector and most importantly – Canadians.

Best Practices, Knowledge Transfer, Knowledge Translation and Dissemination (Cost: \$10 million)

Best Practices

Canada needs to demonstrate leadership in the revision and development of current and future evidence-based norms and standards of practice in hospice palliative care. Engaging health care professionals, researchers, policy experts, consumers, and other key stakeholders in the development of best practices will improve the quality of care that Canadians receive, and reduce overall health care costs. The Canadian Hospice Palliative Care Association (CHPCA) has published “A Model to Guide to Hospice Palliative Care: Based on National Principles and Norms of Practice (2002)” which is widely endorsed as the model to influence the design and implementation of hospice palliative care programs and services. The norms and principles identified in the CHPCA Model can be further developed into best practices through more rigorous consultation using evidence-based research and

experience. A number of specialized fields within hospice palliative care that would benefit from the development of best practices include: home-based palliative care; pediatric palliative care; and respite for family and informal caregivers.

Best practices can also be identified as outcomes from demonstration projects. Information that is learned through these projects would be applicable and adaptable to other jurisdictions to reflect their models and systems of health care delivery. The resulting information can be used to influence best practices that are flexible enough to respond to the differences in delivery of services and design of programs, but are substantial enough to provide guidance in these areas.

Another way of ensuring that identified best practices are institutionalized within the system is accreditation. Accreditation assists health service organizations as they examine and improve the quality of care they are providing. Accreditation is important for hospice palliative care programs in various settings in which people die including acute-care facilities, long-term care facilities and free-standing or community hospices. Accreditation enables programs to adhere to a core set of standards against which they can be evaluated to ensure quality services are available to all Canadians.

Knowledge Transfer

Knowledge transfer is an important area to explore as various disciplines learn more about hospice palliative care. Currently the CHPCA and the Association of Faculties of Medicine of Canada (AFMC) are hosting a project that will see the incorporation of palliative and end-of-life care curriculum in medical schools across Canada. Evidence-based interdisciplinary education is key in ensuring quality care for all Canadians. Knowledge transfer is essential to ensure that disciplines such as nursing, social work, pharmacy, chaplains, and occupational therapy are able to incorporate hospice palliative care into their curriculum and share information among other disciplines.

Knowledge Translation

Knowledge that is gained through research and experience can be used in many milieus however this knowledge needs to be translated so that it is applicable to various audiences. It is essential that as the research community continue to develop hospice palliative care research initiatives, where results are utilized by a number of different audiences with an interest in end-of-life care research. Research findings also need to be readily available to ensure that health care providers, policy makers and key stakeholders have leading-edge information to ensure quality services for Canadians.

Dissemination

There is a great need to disseminate information about hospice palliative care to the hundreds of thousands of family and informal caregivers who are increasingly being asked to provide medical care that was traditionally performed by medical staff. To provide this advanced level of care family and informal caregivers must have access to the best resources possible.

Components of a National Strategy

A national strategy on palliative and end-of-life care needs to be long-term, sustainable, and adequately funded at \$20 million annually in order to ensure that Canadians have access to end-of-life care services that are integrated into the health system, coordinated with other health services, comprehensive in nature and make effective use of health care dollars. **The federal government has the moral authority to lead this initiative.**

The national strategy needs to involve three distinct models of working groups to ensure that it engages key end-of-life care stakeholders. Each of these working groups would be responsible for undertaking initiatives and projects within the scope of their mandate. These models are:

1. *Intra-Governmental Consultation & Engagement Working Group* - Health Canada identifies and engages other federal departments that impact on this issue. These departments include, but are not limited to, Social Development Canada, Human Resources and Skill Development Canada, Justice Canada, and Veterans Affairs. (Cost: \$.5 million)
2. *Inter-Governmental & Stakeholder Consultation and Engagement Working Group* - A working group that consists of federal, provincial, and territorial government representatives as well as leaders and experts in hospice palliative care. This innovative approach, differing from a traditional FPT working group or task force, would ensure engagement of the community and access to scientific knowledge. (Cost: \$2 million)
3. *Community-Based Working Groups* - A community sector working group that works with provincial, territorial and federal governments to provide leadership by raising awareness of hospice palliative care, engaging the research community, working on gathering support for policy directions and providing expert advice to influence the direction of the strategy. (Cost: \$.5 million)

National Strategy Timeline

The national strategy should be implemented using a staged approach. Leveraging the excellent work already accomplished through Health Canada's current National Strategy on Palliative and End-of-Life Care, the initial phase would confirm the Strategy's priorities and identify potential new areas. This should include input from the newly formed consultation and engagement working groups and the community working groups. Once a clear roadmap is developed and agreed upon, the working groups would begin the implementation of the strategy. An interim evaluation should be conducted by year three to ensure that the strategy is accomplishing its goals and that it is still relevant and meaningful to Canadians. This will set the stage for the longer ten-year process which will focus on front-line activities that engage the public and stakeholders across Canada through projects, awareness campaigns and research initiatives.

Conclusion

The Quality End-of-Life Care Coalition of Canada is pleased to provide this information to The Honourable Ujjal Dosanjh, Minister of Health, and it is our sincere hope that he will continue to engage the QELCCC in these discussions. National leadership is needed to ensure that all Canadians will be able to die with dignity, free of pain, surrounded by loved ones, in a setting of their choice. The QELCCC looks forward to a continued working relationship with Minister Dosanjh and his staff to advance this important issue.