



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

# **Advocacy Kit 2006-2007**

**Canadian Hospice Palliative Care Association  
Annex B  
Saint-Vincent Hospital  
60 Cambridge Street North  
Ottawa ON K1R 7A5**

**Telephone: 613-241-3663 or 1-800-668-2785**

**E-mail: [info@chpca.net](mailto:info@chpca.net)**

**Web Site: <http://www.chpca.net>**

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## **Advocacy Kit 2006-2007**

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## **Advocacy Kit 2006-2007**

**Time for Change: Still Gathering the Momentum**

## **Time for Change: Still Gathering the Momentum**

### **An Advocacy Strategy for Hospice Palliative and End-of-Life Care**

#### **Goal:**

Quality end-of-life care for all Canadians. Currently less than 15% of Canadians have access to hospice palliative care services.

#### **Vision:**

It should be the right of every Canadian to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice.

#### **Key Messages:**

##### *National*

1. We need a national hospice palliative and end-of-life care strategy that is committed, long-term and adequately funded (A-based) at \$20 million dollars per year. The national palliative and end-of-life care strategy should be socially responsive and work towards quality end-of-life care for all Canadians. This strategy will allow the federal government to show leadership and coordinate a national response to this issue.

##### *Provincial*

1. Canadians need hospice palliative care services that are integrated into the health care system, are coordinated with other services and are comprehensive in nature. Quality end-of-life care must be delivered with all the components available otherwise the burden on the family becomes overwhelming. The six main components include: home care; respite care; compassionate leave; pharmacare; access to non-prescribed therapies; and access 24/7 to hospice palliative care professionals including volunteers.
2. The provincial governments need to continue to invest in a palliative home care program, as stated in the 2004 Health Accord that meets the needs of their citizens and includes: nursing care; supportive care; pharmaceutical medications; case management; and other programs and services. Not all Canadians want to or can die at home. Hospice palliative care services and programs in other settings must not be reduced to offset these costs – programs and services in all settings are needed.
3. The provincial and territorial governments, as well as the federal government as a health care provider to Aboriginal people, prisoners and others, must develop strategies within their jurisdictions to meet the Pan-Canadian Gold Standards in Palliative Home Care as produced by the Canadian Hospice Palliative Care Association and other partners. This document will be released in December 2006.

### **Who Should Be Involved In This Strategy?**

Everyone who cares about end-of-life care and wants to see this care made available to all Canadians. This includes:

- Health care professionals working in hospice palliative care settings
- Health care professionals not working exclusively in hospice palliative care settings
- Volunteers
- Patients
- Families & Friends
- Caregivers

### **How The Journey Started?**

The Canadian Hospice Palliative Care Association (CHPCA) identified the need for a well-funded and sustainable national strategy as a result of gains made by the Canadian Strategy on Palliative and End-of-Life Care's Working Groups (Health Canada) over the last 24 months. Much has been leveraged however Canada still does not have a sustainable mechanism to ensure that hospice palliative and end-of-life care is a universal, equitable and available service.

The CHPCA Board of Directors has endorsed this Advocacy Strategy. CHPCA has also shared this Advocacy Strategy with the key stakeholders from the Coordinating Body of the Canadian Strategy on Palliative and End-of-Life Care (Health Canada), as well as the Executive Committee of the Quality End-of-Life Care Coalition of Canada (QELCCC). All of these stakeholders have endorsed this Advocacy Strategy. The next step is to engage provincial hospice palliative care associations and member organizations of the QELCCC to advocate for this action. It will take a concerted effort at both the federal and provincial levels to realize the goal of quality end-of-life care for all Canadians.

### **A Few Alarming Facts:**

- Approximately 245,000 Canadians die each year
- Each death affects approximately 5 family members and or caregivers
- With the advancement of treatment therapies Canadians are living longer in declining health for a longer time period than ever before
- Every Canadian will die with at least two chronic diseases
- By the year 2020 Canada will have more than 310,000 deaths per year
- If we have less than 15% of Canadians receiving adequate hospice palliative care services today, where will we be in the year 2020 without serious changes to the health care system?



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## **Advocacy Kit 2006-2007**

### **The 2006-2007 Advocacy Strategy**



**Long-Term, Sustainable National Strategy for  
Hospice Palliative and End-of-Life Care**

**Overarching goal:**

**It should be the right of every Canadian to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. Now ... how do we get there!**

**Key Messages:**

*National*

1. We need a national hospice palliative and end-of-life care strategy that is committed, long-term and adequately funded (A-based) at \$20 million dollars per year. The national palliative and end-of-life care strategy should be socially responsive and work towards quality end-of-life care for all Canadians. This strategy will allow the federal government to show leadership and coordinate a national response to this issue.

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1. Canadians need hospice palliative care services that are integrated into the health care system, are coordinated with other services and are comprehensive in nature. Quality end-of-life care must be delivered with all the components available otherwise the burden on the family becomes overwhelming. The six main components include: home care; respite care; compassionate leave; pharmacare; access to non-prescribed therapies; and access 24/7 to hospice palliative care professionals including volunteers.
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3. The provincial and territorial governments, as well as the federal government as a health care provider to Aboriginal people, prisoners and others, must develop strategies within their jurisdictions to meet the Pan-Canadian Gold Standards in Palliative Home Care as produced by the Canadian Hospice Palliative Care Association and other partners. This document will be released in December 2006.

Targets	Tactics/Activity	Who leads	Responsibility	Outcomes	Timelines
Political Level – Federal	Write letters to Prime Minister, Ministers of Health, Public Health, Human Resources	CHPCA QELCCC Coordinating body of Strategy Other key stakeholders (The Canadian Society for Palliative Care Physicians)	CHPCA QELCCC	Make the case for a national strategy and comprehensiveness of response.	November 2006 December 2006
	Face-to-face meetings with Prime Minister, Ministers of Health, Finance and HRDC and key Members of Parliament	Kits and instructions prepared by CHPCA	Same as above	Leverage commitment from political level	January 2007 - March 2007
	Seek out champions on this issue Meetings on Parliament Hill	CHPCA	CHPCA QELCCC	Same as above	November 2006 – March 2007
	Meet with staff at Prime Minister’s Office	CHPCA QELCCC Key Stakeholders	CHPCA		January 2007
Other National Bodies	Canadian Health Council	CHPCA	CHPCA	Update the Council on the Gold Standards project so they can track compliance to 2004 Health Accord commitments	November 2006

	National Public Policy Forum	CHPCA and other partners	CHPCA and Policy Committee	To hold a policy forum on end of life care with key stakeholders from the private, government and health care sectors	February 2007
General Public and Media	Media Campaign	CHPCA, CHCA and QELCCC	CHPCA	To solicit media attention to the need for a national strategy but also to launch the Gold Standards Project	December 2006 and Ongoing
Political Level – Provincial Level of Parliament	Write letters to Premiers and Provincial Ministers of Health and Social Services	Provincial Hospice Palliative Care Associations  Other provincial bodies of key stakeholders groups  Local Hospice Palliative Care Organizations	Provincial Hospice Palliative Care Associations	Leverage commitment from provincial political level	November 2006 - February 2007
Bureaucratic Level – Federally	Meet with key Health Canada staff regarding our goals and plan including the Secretariat staff and senior bureaucrats, including the Deputy Minister of Health	CHPCA QELCCC Key stakeholders	CHPCA		November 2006 – February 2007
Political Level – Provincially	Letter writing to Provincial Premiers and Ministers of Health	Provincial hospice palliative care associations	All	Provincial associations, their members and networks	November 2006 – January 2007

	Face-to-face meeting with the Premier and Minister of Health	Provincial associations, local groups and other key stakeholders		Same as above	November 2006 – March 2007
	Meet with your Member of Parliament from your Riding	Provincial associations, local groups and other key stakeholders		Same as above	November 2006 – March 2007
Political Level – Municipality	Write Letter to your Regional Health Board - stating the importance of coordinated, comprehensive and integrated end-of-life care services within the health care system	Local groups Canadians		Local networks and board of directors and key supporters including volunteers	Same as above

**Short-Term, Sustainable National Strategy for Hospice Palliative and End-of-Life Care**

**Goal: That the 2006-2007 budget for the Secretariat on Palliative and End-of-Life Care at Health Canada be funded at no less than \$1.7 million dollars.**

The budget for the National Strategy on Palliative and End-of-Life Care was funded to approximately \$1.7 million dollars in 2005. This Strategy is not an established program of Health Canada therefore its funding is based on funding levels within Health Canada as a whole on a year-by-year basis. This year (2006) Health Canada's overall budget was reduced due to a number of issues including SARS, resulting in the budget for the National Strategy on Palliative and End-of-Life Care being put in jeopardy since the Strategy is not an established A-based program within Health Canada.

For the 2006-2007 fiscal year the Strategy was substantially reduced to just \$470,000 with \$300,000 pending.

The National Strategy requires full funding to in the amount of \$1.7 million dollars to continue in the short term, while the hospice palliative care community in Canada engages in the political action necessary to achieve an appropriately funded, A-based, sustainable national strategy for the long-term.

<b>Targets</b>	<b>Tactics/Activity</b>	<b>Who leads</b>	<b>Outcomes</b>	<b>Timelines</b>
Bureaucratic Level - Federally	Face-to-face meetings with Minister of Health and Deputy Minister of Health	QELCCC CHPCA Coordinating body of the National Strategy	Leverage commitment from political level	November 2006 – January 2007
	Letter to Senior Bureaucrats at Health Canada regarding the need for additional funding for the Strategy and the opinion of the Coordinating Body regarding continuing this work in the short term	Same as above – all to provide feedback as it is developed	Same as above	November 2006 – January 2007
The Public and Media	Look at responses and plan next steps that could include a press conference and/or op-ed pieces in local and national media	Coordinating Body of Strategy – key stakeholders	Increase public awareness of the need to have a interim strategy	February 2007 – March 2007



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## **Advocacy Kit 2006-2007**

**What a National Strategy Can Do!**

## **What A National Strategy Can Do!**

### **An Advocacy Strategy for Hospice Palliative and End-of-Life Care**

#### **What A National Strategy Can Do!**

- A national strategy is a **STRONG CATALYST AND AN EFFECTIVE FORUM**
- A national strategy can be an **ASSURANCE OF QUALITY OF CARE ACROSS CANADA** – best care – verifiable quality and process support
- A national strategy assists in making hospice palliative care **AN ACCESSIBLE SERVICE OF CORE HEALTH CARE THAT IS RESOURCED, INTEGRATED, COORDINATED, COMPREHENSIVE IN NATURE AND ACCOUNTABLE**
- A national strategy can assist **CANADIANS TO MAKE EDUCATED AND INFORMED DECISIONS ON DEATH AND DYING**
- A national strategy can provide a strong **EVIDENCE BASE FOR DECISIONS AND PERFORMANCE**
- A national strategy can enable an **INTERDISCIPLINARY NETWORK OF RESEARCH IN PALLIATIVE CARE**

(As identified by the Coordinating Committee of the National Strategy on Palliative and End-of-Life Care during their strategic planning exercise, 2004)

#### **A National Strategy Can Assist In ....**

- Creating networks and partnerships
- Expanding the base and reach of hospice palliative care
- Generating momentum and awareness
- Expanding national interdisciplinary norms and collaborations
- Promoting the adoption of national norms of practice
- Serves as a focal point for hospice palliative and end-of-life care in the federal government



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### **Preparing Yourself for Your Face-to-Face Meeting With Your Premier, Minister or Deputy Minister**

## **Preparing Yourself for Your Face-to-Face Meeting with your Premier, Minister of Health or Deputy Ministers**

### **Before the Meeting**

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- Familiarize yourself with your province's current end-of-life care programs and services and be prepared to clearly discuss what you have outlined in your request for a meeting.
- Send a briefing note to the Premier/Minister/Deputy Minister that describes your organization, what it does, your concerns, and what you want to be addressed at a meeting.
- Arrive early (10-15 minutes) for the meeting and use this time to make contact with key bureaucrats in the Premier/Minister/Deputy Minister's office.
- Have extra copies of the Leave Behind Kit available to give copies to the key bureaucrats that you meet.
- If possible, meet in teams of two but no more than three. If you are planning on sharing the responsibility of presenting, be clear who is presenting each section before you go into the meeting.

### **The Meeting**

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- You may only have a few minutes (usually 15 to 30) to present your case. Make sure you have plenty of supporting materials to leave behind for the Premier/Minister/Deputy Minister and his/her staff.
- Be prepared to give background information; do not assume the Premier/Minister/Deputy Minister is knowledgeable about the issue.
- Be clear regarding what you are hoping to achieve from the meeting. Be clear and concise in asking the Premier/Minister/Deputy Minister to consider specific action (i.e. raising the issue in the Legislature, making a public statement about your concern, talking to the Premier/other Ministers/other Deputy Ministers on your behalf, etc.)
- Tell your story from the heart.
- Take charge of the meeting and stay on topic. You can easily get sidetracked or the politician may try to steer you away from a sensitive topic to avoid commitment or discussion.

- Encourage and entertain questions from the Premier/Minister/Deputy Minister. Try to engage them as much as possible.
- Find a personal connection, if possible.
- Do not prolong the meeting beyond the allotted time unless the Premier/Minister/Deputy Minister indicates they would like to continue.
- End the meeting by asking for a response by a certain date.

### **After the Meeting**

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- Debrief with your colleagues to talk about what went well; what could be done better and next steps.
- Send a thank-you letter to the politician highlighting your discussions and reminding them of the next steps that you would like achieved.
- Keep in touch with the Premier/Minister/Deputy Minister's office and keep them informed of what is happening when appropriate. Keep the links open!



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### **Resources**



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**Advocacy Kit  
2006-2007**

**Fact Sheet on Hospice Palliative Care in Canada  
(May 2006)**



## Hospice Palliative Care Fact Sheet

*At some time, in some way, we must all face the end of life. And most of us share a common hope – that when death comes to us or to a loved one, it will be peaceful and free of pain. We hope to face death surrounded by those we love, feeling safe, comfortable and cared for.<sup>1</sup>*

### The Growing Demand for Hospice Palliative Care in Canada

- Canada's population is aging: over the next 40 years demands for hospice palliative care (end-of-life care) will dramatically increase
- Each year more than 248,000 Canadians die.<sup>2</sup>
- CHPCA estimates that more than 160,000 of these annual deaths require access to hospice palliative care services.
- Statistics Canada projects that the rate of deaths in Canada will increase by 33% by the year 2020 to more than 330,000 deaths per year.<sup>3</sup>
- Each death potentially affects the immediate well being of an average of five other people, or more than one million Canadians each year
- Hospice palliative care programs allow patients to gain more control over their lives, manage pain and symptoms more effectively, and provides support to informal caregivers<sup>4</sup>

### Access to Hospice Palliative Care in Canada

- Between 5% - 15% of Canadians have access to hospice palliative care services<sup>5</sup>
- Canadians living in remote and rural areas, or those living with disabilities, have severely limited access to hospice palliative care services
- There is a growing trend for Canadians to want to die at home.
- As a result of health care restructuring, the number of institutionally-based palliative care beds has been cut and care has devolved to community-based agencies
- Government funding of community-based hospice palliative care has not increased proportionately, leaving a significant gap in the health care system
- Inadequate government support for hospice palliative care programs results in a significant additional burden on informal caregivers
- A 2004 Ipsos-Reid survey reported that on average, Canadians estimate that 54 hours per week would be needed to take care of a dying loved one in their homes.<sup>6</sup>
- Based on the estimate of 54 hours per week required to care for a dying loved one, 64% of those polled indicated that they could not devote the estimated number of hours per week given their current schedule.<sup>7</sup>
- 75% of deaths today still take place in hospitals and long-term care facilities<sup>8</sup>
- Only two provinces and one territory cover the cost of all medications for home-based care, leaving a significant gap in health care and increasing the financial cost to caregivers
- Billing schedules under provincial health plans focus on clinical procedures and discourage physicians from practicing palliative care.
- In June of 2005, the Quality End-of-Life Care Coalition of Canada (QELCCC) developed a "Framework for a National Strategy for Palliative and End-of-Life Care" for hospice palliative care needs in Canada.<sup>9</sup>
- This Framework developed by the QELCCC involves 3 distinct models or working groups identified as follows:
  - Intra-Governmental Consultation & Engagement Working Group
  - Inter Governmental & Stakeholder Consultation and Engagement Working Group
  - Community-Based Working Group
- The Framework also addresses the following key areas:
  - Research
  - Policy Development & Best Practices
  - Knowledge Transfer
  - Knowledge Translation & Dissemination

## Training and Education

- Canada has only 200 palliative care physicians, including those working full and part-time (Canadian Society of Palliative Care Physicians)<sup>10</sup>
- Not all of Canada's 17 medical colleges offer a palliative care certificate program.
- A very limited number of nursing schools offer formal palliative care as part of their curriculum.
- In April 2004 the Canadian Nurses Association began to offer Hospice Palliative Care Certification for nurses.
- Much of Canada's end-of-life care is provided by family physicians, many of whom lack adequate training in pain management and other required skills
- Training is equally under-funded for other disciplines involved in hospice palliative care, including nurses, social workers, psychologists, and spiritual counselors
- The CHPCA, in partnership with the Association of Faculties of Medicine of Canada (AFMC), co-hosts the Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) Project. [<http://www.efppec.ca/>]

## Research

- There is an acute need for research into more effective pain and symptom management, psychosocial aspects of palliative care, and effective methods of delivering hospice palliative care services and programs in the health care system
- Palliative care research has been poorly supported in the past. A sustained palliative care research strategy is required to ensure a coordinated approach to this issue
- The Canadian Hospice Palliative Care Association (CHPCA) has produced the *Canadian Agenda for Research in Palliative Care*. Recommendations include the need to build research capacity in Canada by establishing more fellowships in palliative care for researchers in the early stages of their careers<sup>11</sup>
- On September 21<sup>st</sup> 2004, CIHR announced 16.5 million dollars funding for research in Hospice Palliative Care.<sup>12</sup>
- The CIHR funding allows for a rich diversity of research topics in Palliative and End-of-Life Care:
  - Palliative and End-of-Life Transitions
  - Family Caregiving
  - Tackling Difficult Pain
  - Cancer-Associated Cachexia and Anorexia
  - Vulnerable Populations
  - Improving Communication and Decision-Making

## The Role of Informal and Family Caregivers

- With the devolution of care to the community and the home, families are facing an increased burden to care for loved ones with little formal support.
- As a leading-edge company, GlaxoSmithKline offers 13 weeks paid leave to their employees who require time off to take care of a relative
- 70% of informal caregivers acknowledge that providing care is stressful and 70% indicate that they need a break from this responsibility<sup>13</sup>
- Whether or not the informal caregiver has a choice in taking on this role is a significant factor in the degree of stress and disruption they experience
- Formal support is important, but does not seem to reduce stress
- Informal caregivers providing hospice palliative care at home undertake a wider range of tasks in an environment where they typically have less support from professionals. Tasks may include: psychological, social and spiritual care; personal care; medical care, including administration of medications and injections; homemaking services and advocacy and care-coordination<sup>14</sup>
- In January 2004 Human Resources Development Canada began offering 8 weeks leave (6 weeks paid leave) to eligible Canadians to care for a gravely ill or dying parent, spouse or child under the Compassionate Leave Benefit. In December 2005 the federal government announced the plan to broaden the current definition of "family" to broaden the list of those eligible to receive the benefit. No date has been set for the implementation of the new provisions.

## The Role of Home Care

- The delivery of formal home care generally relies on public funding. There has been an increase in demand for services without an increase in funding
- This affects the need for volunteer and informal caregivers
- There is a shortage of home care workers in rural and remote areas
- It is projected that by 2046 there will be twice as many people who require home care as in 1996

- The Canadian Home Care Human Resources Study indicates that 65% of informal caregivers are under 50 years of age and 64% were working full time, part-time or self-employed<sup>15</sup>
- Emerging trends indicate a shift from acute care to home care and the need for sustainability of public funding to home care

## Funding for Hospice Palliative Care Programs

- 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 of programs
- Currently only four provinces have designated palliative care as a core service under their provincial health plans. In other provinces, palliative care may be included in home care or other health service budgets, leaving it vulnerable to cutbacks
- The final report of the Commission on the Future of Health Care in Canada recommends the commitment of \$89.3 million annually to the Canadian health care system to address hospice palliative care needs<sup>16</sup>

## Raising Awareness

- Public awareness programs are critically important in helping Canadians face end-of-life issues and raising the awareness of the current gaps in service
- The CHPCA is the Secretariat of the Quality End-of-Life Care Coalition of Canada (QELCCC), a group of 31 national associations and organizations with an interest in end-of-life care issues.
- The CHPCA and the QELCCC support the full implementation of the June 2000 Senate report *Quality End-of-Life Care: the Right of Every Canadian*
- The GlaxoSmithKline Foundation in partnership with the CHPCA have created the **Living Lessons**<sup>®</sup> initiative, a public awareness campaign designed to provide resources to patients, caregivers, volunteers and medical professionals. You can visit the **Living Lessons**<sup>®</sup> website at: [www.living-lessons.org](http://www.living-lessons.org).<sup>17</sup>

## Canadian Strategy on Palliative and End-of-Life Care (Health Canada)

- Between \$1 and \$1.5 million dollars (per year) commitment from Health Canada since 2002.
- 3 Focus Areas;
  - Community
  - Inter-Department (at the Federal level)
  - Federal/Provincial/Territorial
- There are currently five working groups;
  - Research
  - Surveillance
  - Public Information and Awareness
  - Professional Education
  - Best Practices and Quality Care
- [http://www.hc-sc.gc.ca/hcs-sss/palliat/index\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/palliat/index_e.html)

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### Annex B

**Saint-Vincent Hospital  
60 Cambridge Street North  
Ottawa ON K1R 7A5**

**Telephone: 613-241-3663 or 1-800-668-2785**

**info@chpca.net    <http://www.chpca.net>**

## References

- <sup>1</sup> Living Lessons® - About quality of life for the last stages of life – The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association (2001)
- <sup>2</sup> Population Projections for Canada, Provinces and Territories – 2000-2026, Statistics Canada, Catalogue #91-520, p.124
- <sup>3</sup> Population Projections for Canada, Provinces and Territories – 2000-2026, Statistics Canada, Catalogue #91-520, p.124
- <sup>4</sup> Definition: *Informal Caregivers* are family members, loved ones, or friends and neighbours who provide support or care for the dying family member, loved one, or friend. The CHPCA's A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (2002) defines Informal Caregivers as, "not members of an organization. They have no formal training, and are not accountable to standards of conduct or practice. They may be family members or friends."
- <sup>5</sup> Website: <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm>
- <sup>6</sup> Ipsos-Reid Survey. Hospice Palliative Care Study: Final Report, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, January 2004 p.30
- <sup>7</sup> Ipsos-Reid Survey. Hospice Palliative Care Study: Final Report, The GlaxoSmithKline Foundation and the Canadian Hospice Palliative Care Association, January 2004 p.31
- <sup>8</sup> Quality End-of-Life Care: The Right of Every Canadian, Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology, FINAL REPORT, June 2000, <http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/upda-e/rep-e/repfinjun00-e.htm>
- <sup>9</sup> Website: [http://www.chpca.net/quality\\_end-of-life\\_care\\_coalition\\_of\\_canada.htm](http://www.chpca.net/quality_end-of-life_care_coalition_of_canada.htm)
- <sup>10</sup> Website: <http://www.cspep.ca/english/index.php>
- <sup>11</sup> Website: [www.chpca.net/initiatives/Canadian\\_Research\\_Agenda.PDF](http://www.chpca.net/initiatives/Canadian_Research_Agenda.PDF)
- <sup>12</sup> Website: <http://www.cihr-irsc.gc.ca>
- <sup>13</sup> Website: [http://www.hc-sc.gc.ca/hcs-sss/pubs/care-soins/2002-caregiv-interven/sum-som\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/pubs/care-soins/2002-caregiv-interven/sum-som_e.html)
- <sup>14</sup> Voice in Health Policy: The Role of Informal Caregivers in Hospice Palliative Care in Canada: A Discussion of the Legal, Ethical and Moral Challenges, CHPCA, August 2004, p. 9
- <sup>15</sup> Website: [www.cacc-acssc.com/english/pdf/homecareresources/highlights-final.pdf](http://www.cacc-acssc.com/english/pdf/homecareresources/highlights-final.pdf)
- <sup>16</sup> Website: [http://www.hc-sc.gc.ca/english/pdf/romanow/pdfs/HCC\\_Final\\_Report.pdf](http://www.hc-sc.gc.ca/english/pdf/romanow/pdfs/HCC_Final_Report.pdf)
- <sup>17</sup> Website: <http://www.living-lesons.org>

# **Influencing Change: A Patient and Caregiver Advocacy Guide**

*A Living Lessons<sup>®</sup> Resource*



The **GlaxoSmithKline**  
**Foundation**



**Canadian Hospice Palliative Care Association**  
**Association canadienne de soins palliatifs**

# **Influencing Change: A Patient and Caregiver Advocacy Guide**

## **A Living Lessons<sup>®</sup> Resource**

1-877-203-INFO (4636)  
[www.living-lessons.org](http://www.living-lessons.org)

Living Lessons<sup>®</sup> is an ongoing project of the Canadian Hospice Palliative Care Association (CHPCA) and hospice palliative care organizations across Canada, and is part of The GlaxoSmithKline Foundation's commitment to promoting quality of life during the end stage of life in Canada. The Living Lessons<sup>®</sup> campaign is focused on initiating public dialogue and promoting understanding, support and better access to quality care in the last stages of life.

### **Additional Copies of Influencing Change: A Patient and Caregiver Advocacy Guide**

Copies of *Influencing Change: A Patient and Caregiver Advocacy Guide* can be obtained from the Canadian Hospice Palliative Care Association national office or on-line at [www.chpca.net](http://www.chpca.net).

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## **Acknowledgements**

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### **National Advisory Committee**

We would like to thank the following individuals for their wisdom, insight and experience in the development of this guide:

**Tara Addis**, Director, Hospice Relations and Programs, Hospice Association of Ontario

**Sharon Baxter**, Executive Director, Canadian Hospice Palliative Care Association

**Karen Chow**, Vice President, The GlaxoSmithKline Foundation

**Bobbi Greenberg**, Director of Communications, ALS Society of Canada

**Catherine Hofstetter**, Patient Advocate

### **Project Co-Ordination**

**Ryan McCarthy**, Canadian Hospice Palliative Care Association

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## Introduction

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Welcome to *Influencing Change: A Patient and Caregiver Advocacy Guide – A Living Lessons® Resource*. This guide has been designed to provide patients and their caregivers with practical tools to help them advocate for better end-of-life care programs and services.

This guide provides you with information and tools to help you become a health-care champion for yourself and/or your loved one. It is designed to assist you in finding services and programs. As well, it will help you work with groups such as health-care professionals, government and media to raise awareness of issues related to end-of-life care.

The guide is divided into four sections:

1. **What is Advocacy** – Highlights what advocacy is and provides you with tips on how to take an active role in managing your loved one's care.
2. **Canada's Health-Care System** – Provides you with an overview of how the health-care system works and tips for navigating the system.
3. **Engaging the Political Level** – Provides you with an overview of how public policy is made as well as how you can get involved and make your case.
4. **Communicating Your Message** – Tips on how to engage the media so that your story can be told.

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## What is Advocacy?

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In general, advocacy can be defined as the effort to influence change through various forms of persuasive communication. This change could be in personal attitude or behaviour, political and public debate, public policy or legal issues.

Advocacy is about becoming knowledgeable and working with others to raise awareness of an issue or injustice and to effect change. We all act as an advocate at some time. Think of a time where you have worked with friends or colleagues to come up with a solution to a problem and then implemented that solution. That is advocacy.

As a patient or caregiver, advocacy is about the need for:

- Access to Knowledge – about your condition and care management (medical and non-medical)
- Access to Resources – finding the community services, programs and resources available to help you in your situation
- Support – asking for help or working with others to make change - you do not need to do this alone.

Being an advocate is being a champion - a champion for yourself or for someone you love. Each patient needs and deserves a champion, someone who will advocate on their behalf, who takes the opportunity to learn more and helps their loved one make informed decisions.

### ***Becoming a champion – The patients' and caregivers' rights and responsibilities***

Being a champion for you and your loved one is a rewarding experience. Part of being a champion is accepting personal responsibility for the care of yourself and/or your loved one. It is an important way in which to feel that you are managing end-of-life care in the best way possible. Personal responsibility is:

- Recognizing that you have the ability to learn and accept
- Using what you learn to make choices and ask questions
- Knowing that you are responsible for the choices that you make

Health-care professionals are your partners in care. Being as active as you can in how your care is managed is very important. Here are some tips on handling your care management:

1. Make sure that you collect as much information as you can about:
  - a. Your symptoms (nausea, fatigue, weight loss/gain)
  - b. Your medications
  - c. Medical tests you have had
  - d. What has worked/not worked with your treatments
2. Ask specific questions when you do not understand something that your health-care professional tells you.
3. Learn as much as you can about your condition.
4. Follow the treatment plans that are outlined by your health-care professional. Some examples of this are taking medicines at certain times, attending follow-up medical appointments or following a specific nutrition plan.
5. Understand the choices that are available to you by gathering as much information as possible. Do not be afraid to ask questions.

6. Inform health-care professionals of your wishes. If you have Advance Care Directives, let your health-care provider know. Advance Care Directives are a process by which you and your health-care professional develop and establish a valid expression of your wishes regarding future health care at end-of-life. More information is available later in this guide.
7. Follow through on what you are asked to do. You are the most important part of managing your care. Follow instructions carefully, ask lots of questions to make sure you understand and make choices that are best for you and your loved ones.
8. Remember that health-care professionals are under a great deal of stress as well. They are there to work with you.

More importantly, as a patient you have rights as well as responsibilities. Here are some rights and responsibilities you have as a patient.\*

As an individual dealing with an end-of-life care situation, you have the right to:

1. A timely and accurate diagnosis that you are living with a life-limiting illness.
2. Information about your specific illness as well as your end-of-life care needs.
3. Access to hospice, palliative and end-of-life care specialists.
4. Access to adequate pain and symptom management medications and therapies.
5. Access to research that may influence your end-of-life care.
6. To be fully engaged in your care management.
7. Representation in your care management.
8. Engage your loved one to work with you on Advanced Care Planning.

You also have the responsibility to:

1. Learn as much as you can about your condition and end of life.
2. Do everything you can to maintain your quality of life at end of life.
3. Actively participate in decisions about your care – this means you and your loved one.
4. Follow the care management plan that you and your health-care professional decide upon.  
Review and revise your care management plan as you and your caregiver see fit.

For more on the rights of caregivers, patients, and family members, please visit the Living Lessons Website at <http://www.living-lessons.org/cando/e.index.asp>.

### ***Gaining confidence***

Taking responsibility for your care or a loved one's care can be a rewarding experience. Here are some tips to help you along the way:

#### *Set small goals*

It is very satisfying to set a goal and achieve it. You can do this by focusing on small tasks, one by one. For example, one task might be starting a journal where you keep information about how you are feeling, what medications you are taking and what you achieved that day. Another task might be doing 20 minutes of light exercise as recommended by your health-care professional. Keep a running list of your achievements and see how fast they add up!

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\* Adapted from the Canadian Arthritis Bill of Rights.

### *Acknowledge your success*

Successes come in all shapes and sizes. Congratulate yourself for your wins and remember that even failures can be successes when you learn from them!

### *Know what you know*

Health-care professionals bring a wealth of expertise to their roles, but there is only one expert in your health which is you. There are many sources of information to learn about your condition and what may work best for you. Tell your health professional how you are feeling. Learn as much as you can about your illness, and do not let anyone dismiss what you know. No one knows how you feel better than you!

### *Visualize*

Have a goal in mind. Is there a part of your care that you are unhappy with and would like to see changed? As a caregiver, are you often left out of discussions that should involve you? Visualize the conversation that you would like to have with your health-care professional, think about the results that would make you happy.

### ***Making a plan***

How can you figure out where to start? Start by making a plan.

### *Define your goals*

What do you want the result of your efforts to be? Are you trying to have your medication changed? Is there a program or service you feel you should have access to? As a caregiver, do you need assistance? Do you have specific questions that you need answered? Set a realistic goal and make a plan to achieve it.

### *Know who you need to talk to*

Once you know what you want to achieve, figure out who you need to talk to. If you want to change your medication, you may want to talk to your doctor, but you can also talk to your nurse to get them to be a champion for you as well. You may need to talk to hospital or government administrators, to determine what programs and services are available and if you are eligible. Enlist others for help in identifying who needs to be involved and who you could talk to.

### *What you need them to hear*

Health-care professionals or administrators are there to help, so it is important to be clear about the results you want. Figure out exactly what you need them to hear and how they can help you. Be as specific as possible.

### *How will you communicate?*

Choose a way to communicate that works for you. Are you comfortable making a request or asking questions in person? Perhaps you would rather write a letter and request a response. There are many ways to communicate, find the way that works best for you. Make sure to follow-up with your health-care provider.

### *Setting timelines*

When you are making your plan, set deadlines that you can achieve. It is important to identify when you wish to accomplish something.

**Remember to recognize your successes!**

### ***Who can help***

You are not in this alone. Your loved ones are on this journey with you and are there to support you in whatever way they can. There are a number of people who may be able to help you throughout this journey including:

- Family
- Friends
- Other families who have been through similar circumstances
- Doctors
- Nurses
- Home Support Workers
- Pharmacists
- Dietitians
- Spiritual Care Professionals (Rabbi, Pastor, Chaplain, Priest, etc.)
- Naturopathic Doctors
- Occupational Therapists
- Counselors
- Homecare services
- Volunteers
- Hospice palliative care professionals and organizations
- Organizations that work with persons with specific diseases (ALS Society, Canadian Cancer Society, Heart and Stroke Foundation are some examples)
- Local and provincial government representatives who may be able to connect you to various programs

### ***Assessing information: is it credible?***

Learning about your illness and how you can best manage it, will help you in managing your care. There are several sources you can use to learn more about your disease or condition, end-of-life care and programs and services that you may be able to access.

There are numerous sources for health information including:

- Your local library
- Local, provincial, and federal government offices
- District Health Authorities, Local Integrated Health Networks, Community Health Boards, Centres des services de santé et de services sociaux
- Non-profit organizations such as Canadian Hospice Palliative Care Association, Heart and Stroke Foundation of Canada, The Arthritis Society, ALS Society of Canada and Canadian Cancer Society, etc. are groups which often have provincial branches with local programs and services.
- Medical or university libraries
- Nurses
- Doctors
- Pharmacists
- Counselors
- Internet

The Internet can provide a wealth of information, but do be careful as anyone is free to post information at anytime. People generally do not mean harm, but information regarding your care

should come from your health-care team or other reliable sources to ensure they are safe. Here are some tips that you can use to evaluate the information that you are reviewing online:

#### *Find out who runs the Website*

Check if the Website is managed by a branch of government, a private company, a non-profit organization, a hospital, a community health board or an individual. Professional organizations and companies post credible information that has been evaluated. You can often find this information by looking for a section on the Website called “About us.”

#### *How is information made available?*

Check how a Website posts its materials. Is there a committee of professionals who review the information? Websites that post credible medical information should have a process that is highlighted on their site.

#### *Be aware*

If something sounds too good to be true, it probably is. Use caution when a Website offers you a “cure,” a “breakthrough” or something else that does not seem likely. Also look at how a site is financially supported - advertisements should be clearly marked.

#### *Is the information new or old?*

There is a lot of great information on the Internet, everything from the latest research on diseases to tips for coping with the loss of a loved one. When you are looking at information, look for the date that it was published. Scientific information, such as research regarding a particular illness can become outdated quickly. Information on more general topics such as grief and coping with loss is often relevant for much longer periods of time.

#### *What do they want from me?*

Many Websites will track how you use the site, so they know what type of information people are looking for. If a site asks you to “subscribe” for more information, find out what kind of information they collect and how it will be used. They should have a privacy policy that clearly states how your information may be used.

### ***Connecting with others***

It often helps to connect with others who have been through similar circumstances. Building a network of people who can support you during a difficult time can be a positive experience. These networks can also work together to affect changes in programs and services, so that patients and their families do not need to do things alone.

You might want to look for support groups in your area. You can search the Internet, contact organizations that deal with specific diseases or conditions, to see if they have support groups or any kind of supportive care program. Ask your doctor, nurse or social worker if they know of any programs or services in your area that could be of assistance.

The Internet has also become a tool for people to develop their own support networks. A number of people write online journals about their experiences (“blogs”) where people can connect with

them and share experiences. Discussion boards, where people can post messages to ask questions regarding their experience and get answers from others who are experiencing the same thing, are a tool to connect with others. Finally, there are chat rooms where you can talk with people in real time. These are just some of the ways that people are connecting and building networks of support.

Remember the Internet is a wonderful tool to get connected, but make sure you discuss your health-care options with your health-care provider.

### ***For more information***

#### ***The following Websites can provide you with more information:***

For tips on searching the Internet, please visit the following Websites:

#### **Ten Tips for Searching the Internet More Effectively -**

<http://envision.ca/templates/resources.asp?ID=206>

**How to Search the Internet Effectively -** [http://www.media-awareness.ca/english/resources/special\\_initiatives/wa\\_resources/wa\\_teachers/tipsheets/search\\_internet\\_effectively.cfm](http://www.media-awareness.ca/english/resources/special_initiatives/wa_resources/wa_teachers/tipsheets/search_internet_effectively.cfm)

#### **The Canadian Hospice Palliative Care Association – [www.chpca.net](http://www.chpca.net)**

The Canadian Hospice Palliative Care Association (CHPCA) is the national association which provides leadership in hospice palliative care in Canada.

You will find contact information for the provincial hospice palliative care associations, fact sheets about end-of-life care in Canada as well as an order form for “A Guide for Caregivers” a resource with practical tips for caregivers. This guide is part of a national program called Living Lessons® designed to provide support resources for those dealing with end-of-life care; such resources are available at [www.living-lessons.org](http://www.living-lessons.org)

#### **The Canadian Virtual Hospice – [www.virtualhospice.ca](http://www.virtualhospice.ca)**

The Canadian Virtual Hospice is an interactive network for people dealing with life-threatening illness and loss.

The following Websites can provide you with more disease-specific information. Many of their provincial affiliates can be reached through these sites.

Alzheimer’s Society of Canada - [www.alzheimers.ca](http://www.alzheimers.ca)

ALS Society of Canada - [www.als.ca](http://www.als.ca)

Arthritis Society of Canada - [www.arthritis.ca](http://www.arthritis.ca)

Canadian AIDS Society - [www.cdn aids.ca](http://www.cdn aids.ca)

Canadian Breast Cancer Foundation – [www.cbcn.ca](http://www.cbcn.ca)

Canadian Breast Cancer Foundation – [www.cbcf.org](http://www.cbcf.org)

Canadian Cancer Society - [www.cancer.ca](http://www.cancer.ca)

Canadian Diabetes Association - [www.diabetes.ca](http://www.diabetes.ca)

Canadian Liver Foundation – [www.liver.ca](http://www.liver.ca)

Canadian Mental Health Association - [www.chma.ca](http://www.chma.ca)  
Heart and Stroke Foundation of Canada - [www.heartandstroke.ca](http://www.heartandstroke.ca)  
Kidney Foundation of Canada - [www.kidney.ca](http://www.kidney.ca)  
Lymphoma Foundation Canada – [www.lymphoma.ca](http://www.lymphoma.ca)  
Lung Association of Canada - [www.lung.ca](http://www.lung.ca)

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## Canada's Health-Care System

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Although the health-care system is complex and challenging at times, there are simple things you can do to navigate your way through the system. Get to know how things work in your province or territory.

### *How the system is set up*

The health-care system is a number of insurance plans that provide coverage to Canadians. It is publicly funded and administered, meaning that each system is managed by each province or territory within guidelines and principles set out by the federal government in the Canada Health Act.

The provinces and territories are responsible for the administration of health-care delivery. Many provinces and territories have established structures within their borders to deliver health-care services that are based on what their communities need. These are often referred to as district health authorities (DHAs), local integrated health networks (LIHNs), or centres de santé et de services sociaux (CLSCs) depending on the province or territory. Their purpose is to allow a community focus in the delivery of care.

As there are no government-directed standards, availability of programs and services may vary from area to area. This means that some programs and services may not be available in your community. It is important for you to contact your DHA, LIHN or CLSC to find the specific programs and services available to you.

If a service or program is not available in your area and you think it should be, you can advocate for this service. You will be making a difference for you and for other families who may experience the same challenges. This guide is a great starting place for more information on:

- Meeting with your elected official
- Working with other patients to raise awareness in your community
- Speaking with media to highlight challenges

### *You and the healthcare system*

The way health care is delivered can be explained in three different levels:

**Primary health care** – This is the first time that you make contact with the health-care system. Whether you visit your family doctor, talk to a pharmacist, or visit the emergency room – you are accessing this level of care. Primary health care is designed to treat acute (e.g. pneumonia) or chronic illnesses (e.g. diabetes), prevent illness or injury and understand what factors can make a person ill.

Primary health care can also be delivered in many settings. There are four settings for end-of-life care: hospital, long-term care, home or residential hospice. The services that are available in each of the settings vary greatly between each province and territory. For more specific information about hospice palliative care services in your community, please contact your local hospice palliative care organization. Contact information for these associations is located at the end of this section.

### *Trends in primary care*

As the health-care system has evolved, there has been a significant shift in the setting which care is provided. It was not uncommon twenty years ago to enter a hospital and either not leave or be placed in a long-term care facility. As health care has progressed, governments have realized the importance of patients being treated at home, as well as the significant economic savings of home care in addition to improving quality of care.

Patients are also leaving the hospital much sooner with intense medical needs. Caregivers are faced with providing a high level of care such as changing pain pumps, administering medications and assisting loved ones with tasks such as bathing and dressing. This is all in addition to coping with the illness and impending death of their loved one. Sometimes patients do not feel comfortable with their family providing that level of care.

Families also often find themselves in uncomfortable situations when asked to provide high levels of care for a loved one. There are a number of legal, moral and ethical challenges that face family and informal caregivers, including worrying about giving the wrong medications, managing their own daily living while providing a significant amount of care and coping with the impending loss of their loved one. For more information, please visit the Canadian Hospice Palliative Care Association's Website ([http://www.chpca.net/informal\\_caregivers/VOICE\\_PROJECT-DISCUSSION\\_DOCUMENT-August2004-2.pdf](http://www.chpca.net/informal_caregivers/VOICE_PROJECT-DISCUSSION_DOCUMENT-August2004-2.pdf)) to read more about the legal, moral and ethical challenges of family and informal caregivers at end-of-life.

### *What you can expect*

Patients and their loved ones have the right to tell their health-care provider if they are unhappy or not comfortable in this situation. Do not suffer in silence - if you do not want to provide care, or are not at ease with the care you are receiving, please let your physician, nurse, or personal support worker know.

**Secondary care** – Secondary care providers are specialists that focus on particular diseases (such as diabetes or cancer) or specialize in specific organs or functions of the body (such as kidneys, or ear, nose and throat.) Secondary care also involves areas such as diagnostic testing (X-rays) or rehabilitation (respiratory therapy). Usually, your primary care provider refers you to such services.

**Tertiary care** – The third level of services are those health-care professionals who have highly specialized skills. Hospice palliative care physicians and nurses are an example of tertiary care.

### ***How to find your way around the system***

Health professionals in Canada are under a great deal of pressure to keep current on the latest information regarding medical conditions, including end-of-life care. Knowing what is available to you will help you in being a partner in your and your loved one's care.

Here are some things to look for in your area:

**Patient Navigators/Case Managers** - Some provincial agencies have “patient navigators” or a patient navigator program. They also have case managers who will help you find what programs and services you need in all settings of care. These programs work with families to refer them to services they need at the right time, suggesting programs and services that may be difficult to find and assisting them throughout their entire illness. Organizations and health-care institutions that work with patients that have a life-threatening illness sometimes offer these programs. Ask your health-care provider if they are available in your area.

**Palliative Care Coordinators** - Some DHAs, CLSCs, and LIHNs have palliative care coordinators that can help you access services throughout your illness.

**Canadian Directory of Hospice Palliative Care Services** – The Canadian Hospice Palliative Care Association maintains a national directory of programs and services. This on-line directory provides information on hospice palliative care services across Canada. You can visit the directory at [http://www.chpca.net/canadian\\_directory\\_of\\_services.htm](http://www.chpca.net/canadian_directory_of_services.htm)

Make sure to:

- Contact your provincial hospice palliative care association to find out what services are available in your community.
- Contact organizations that specialize in a particular disease that will also be able to provide you with information.
- Visit Websites provide a wealth of information – get connected to Websites for your local DHA, LIHN, or CLSC.

### ***Working with your health- care provider/team***

Today people are more informed than ever and are taking a more active role in managing their care with their health-care professional. Traditionally, a doctor would make a diagnosis and advise the patient on next steps. Now patients are active partners in their own care.

The team that provides care is interdisciplinary and could include:

- You and your loved one
- Your family physician
- Nurse/Nurse Practitioner
- Specialists (oncologist, neurologist, cardiologist)
- Home support worker
- Dietitian
- Pharmacist
- Physiotherapist or occupational therapist
- Social Worker
- Counselor
- Naturopathic Doctor
- Spiritual Care professional
- Religious leader (Rabbi/pastor)
- Surgeons
- Palliative care physicians or nurses
- Volunteers

The most important member of this team is **you**. You are the best manager of your own care. You can best describe what level of pain you are experiencing, describe how your symptoms (such as fatigue) are affecting you and describe how certain medications or treatments are working. You and/or your caregiver can make the best decisions for you based on your needs.

Here are some tips for managing your care:

1. Prepare for your doctor visit. Make a list of questions that you need addressed. If your doctor cannot answer a question, then ask your doctor to refer you to someone who can.
2. Keep a journal. Make a list of:
  - a. the medications you are taking
  - b. medications that you tried and did/didn't work for you
  - c. any treatments you are receiving
  - d. any changes you have noticed in your symptoms (pain, fatigue, weight loss/gain); and
  - e. your entire test results to date (you can ask for copies)
3. Make sure you get contact information for everyone that you see along the way so you can contact him/her with any questions that you may have.
4. You and your caregiver need to be involved in all decisions that affect you. You are the captain of the team and you have the right to make the choices that are best for you. As a caregiver, if you are not comfortable with administering certain treatments in the home, tell your doctor. If you know about different medications that are available, ask your doctor which is the best and why s/he is recommending that particular medication.
5. Learn as much about your illness as you can. There are a lot of credible sources of information. Talk to your local librarian, use the Internet and contact local organizations that specialize in your illness or in end-of-life care. There are a number of ways to access this information. Let your doctor know that you are making an effort to manage your care.
6. Set goals for your care and tell your health-care provider what these goals are. You can set goals such as staying in your home as long as possible, managing your fatigue, or dealing with nausea. They can help you achieve these goals by developing a plan.
7. Try and understand the challenges your health-care provider faces. If you are frustrated with the system, chances are your provider is too. Try and anticipate questions that they are going to ask you or what your responses might be. Remember, you have the ability and the right to ask questions – it is your care!
8. Speak to your family physician regarding advanced care planning - a process by which you and your health-care professional develop and establish a valid expression of your wishes regarding future health-care at end-of-life.

There are three components to advanced care planning:

**Advance Directives** - Your oral and written instructions about your future medical care, in the event you become unable to communicate.

**Health-care Power of Attorney** - A document in which you appoint someone to make decisions about your medical care if you can't make those decisions yourself.

**Living Will** - A written form of advance directive in which your wishes regarding the administration of medical treatment are described, if you become unable to communicate at the end of life.

## ***Case management***

Case management is having someone who works with patients and their caregivers to identify, monitor and evaluate clients' needs on an ongoing basis. They help assess what type of programs and services you may need as well as determine what programs and services you are eligible for. They then coordinate these activities and check with the patients and caregivers to make sure that it is going well. They are a central point for referral to various programs and services that may be available to you.

For example, a case manager may assess a patient and determine the best settings of care, what support is needed to ensure the patient receives adequate care and also provides referrals to the programs and services needed. Along the way, the case manager works closely with patients and caregivers to ensure that patients and their caregivers are getting the required information, programs and services.

Talk to your health-care professional to see if case management is available in your area. If not, you may want to work with other families and patients to see how case management can be part of your care plan.

### ***For more information...***

#### **Provincial Hospice Palliative Care Associations:**

Alberta – <http://www.chpca.net/ahpca/index.htm>

British Columbia – [www.hospicebc.org](http://www.hospicebc.org)

Manitoba - <http://www.manitobahospice.mb.ca>

Quebec - <http://www.reseaupalliatif.org/>

Ontario:

Hospice Association of Ontario - <http://www.hospice.on.ca/>

Ontario Palliative Care Association - <http://www.ontariopalliativecare.org/>

Nova Scotia – <http://www.nshpca.ca/>

Newfoundland and Labrador - <http://www.nlpca.info/>

Prince Edward Island - <http://www.hospicepei.ca/>

Saskatchewan - [www.saskpalliativecare.ca](http://www.saskpalliativecare.ca)

#### **Federal Health Departments:**

Health Canada – [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

Public Health Agency of Canada – <http://www.phac-aspc.gc.ca/>

Primary Health-care Awareness Strategy - [http://www.phc-ssp.ca/home\\_eng.html](http://www.phc-ssp.ca/home_eng.html)

Ten Year Plan to Strengthen Health-care - [www.hc-sc.gc.ca/hcs-sss/delivery-prestation/fptcollab/2004-fmm-rpm/index\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/delivery-prestation/fptcollab/2004-fmm-rpm/index_e.html)

### **Provincial/Territorial Health Departments:**

Alberta – [www.health.gov.ab.ca](http://www.health.gov.ab.ca)  
British Columbia – [www.gov.bc.ca/healthservices](http://www.gov.bc.ca/healthservices)  
Manitoba - [www.gov.mb.ca/health/](http://www.gov.mb.ca/health/)  
Northwest Territories - <http://www.hlthss.gov.nt.ca/>  
Nunavut - [www.gov.nu.ca/hsssite/hssmain.shtml](http://www.gov.nu.ca/hsssite/hssmain.shtml)  
Quebec - [www.msss.gouv.qc.ca/en](http://www.msss.gouv.qc.ca/en)  
Ontario - [www.health.gov.on.ca](http://www.health.gov.on.ca)  
Nova Scotia – [www.gov.ns.ca/health](http://www.gov.ns.ca/health)  
New Brunswick - [www.gnb.ca/0051/index-e.asp](http://www.gnb.ca/0051/index-e.asp)  
Newfoundland and Labrador - [www.gov.nl.ca/health/](http://www.gov.nl.ca/health/)  
Prince Edward Island - [www.gov.pe.ca/hss/](http://www.gov.pe.ca/hss/)  
Saskatchewan - [www.health.gov.sk.ca](http://www.health.gov.sk.ca)  
Yukon – [www.hss.gov.yk.ca](http://www.hss.gov.yk.ca)

### **Provincial listing of District or Regional Health Authorities, Local Integrated Health Networks, and other provincial government health structures :**

Alberta – <http://www.health.gov.ab.ca/regions/RHA.html>  
British Columbia – <http://www.hlth.gov.bc.ca/socsec/index.html>  
Manitoba - <http://www.gov.mb.ca/health/rha/contact.html>  
Northwest Territories - [http://www.hlthss.gov.nt.ca/content/About\\_HSS/hss\\_authorities.asp](http://www.hlthss.gov.nt.ca/content/About_HSS/hss_authorities.asp)  
Nunavut - [www.gov.nu.ca/Nunavut/English/departments/HSS/](http://www.gov.nu.ca/Nunavut/English/departments/HSS/)  
Quebec - [www.msss.gouv.qc.ca/en](http://www.msss.gouv.qc.ca/en)  
Ontario - <http://www.lhins.on.ca/>  
Nova Scotia – [www.gov.ns.ca/health/dha\\_map.htm](http://www.gov.ns.ca/health/dha_map.htm)  
New Brunswick - [www.gnb.ca/hw-sm/hw/regions](http://www.gnb.ca/hw-sm/hw/regions)  
Newfoundland and Labrador - [www.nlchi.nf.ca/links.asp](http://www.nlchi.nf.ca/links.asp)  
Prince Edward Island - [www.gov.pe.ca/hss/index.php3](http://www.gov.pe.ca/hss/index.php3)  
Saskatchewan - [www.health.gov.sk.ca/ph\\_rha\\_map.html](http://www.health.gov.sk.ca/ph_rha_map.html)  
Yukon – [www.hss.gov.yk.ca](http://www.hss.gov.yk.ca)

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## Engaging the Political Level

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### *How policy is made*

When a government takes office, they establish priorities of what they want to accomplish. Policy helps guide the actions of government and meet their objectives. Programs that are delivered, such as home care at end-of-life, are based on policy.

Here is a quick overview of how policy is made:

1. **Someone identifies that a change is needed** – Citizens like you, health-care professionals, government, media, organizations that work with people living with certain diseases and conditions are all people that can identify that a change is needed.
2. **Figure out who needs to be involved** – If you are trying to make sure that people have access to hospice palliative care, you may need to talk to the provincial government or a district health authority. This is a good opportunity to talk to other families who have similar experiences, talk with community groups and chat with health professionals who might be able to support your cause.
3. **Getting your message to the right people** – There are a lot of policy issues that the government is trying to resolve. Who better to convince them of its importance than someone who is living or has lived through the experience. It is important that when you are working with the government, you make it easy to understand why they need to address this particular issue. Get as much information as you can and try to find others who are trying to work towards this particular issue to work with you. Every voice counts, and the more voices, the better!
4. **Getting a policy or program developed** – Once a policy is being considered a number of things might happen. The government will look at research to figure out how big the problem is; come up with some solutions/options that might work and get input from a number of different people. A program might be developed if a policy is in place, or the current policy may need to be changed.
5. **Keep involved** – When you have successes remember that it is important to keep involved. Policy and the programs that are implemented need to be evaluated and monitored to ensure a continued momentum.

One difference that must be noted is the difference between legislation and regulation. Legislation takes a significant investment of time as it involves changing laws. This means that it could take years to achieve. Regulations are developed based on legislation and are often done by senior levels of government. This means regulations can be changed within a shorter timeframe. Remember it takes patience to make change at a political level.

### *Engaging your elected official*

Whether you are working with elected officials at the federal level (MP) or a provincial level (MLA or MPP), you have an excellent opportunity to ensure that your voice is heard. Meeting with your elected official is a great way to have your concerns recognized. Here's a step-by-step guide.

1. **Write a letter** – Sending a letter is the first step in bringing your issue to the official’s attention. Your letter should:
  - a. **Be brief and concise** – Given the number of letters they receive, it is best to keep it brief.
  - b. **Tell them who you are** - Let them know you are a constituent with an issue that is relevant for your family and the other families in your community.
  - c. **Focus on no more than three key points** – Tell them what you want to see changed and why it is important to change it. Tell them how your end-of-life experience could be better and highlight three key areas that you think could be addressed.
  - d. **Personalize the letter** – Tell your story and why it is important that changes are made. Let them know what impact your end-of-life care experience has had for you and your loved ones.
  - e. **Have “an ask”**- Close your letter by asking for some type of action. For example, you could ask your elected official for a meeting to discuss your concerns.

An effective letter should:

- Present the issue
- Present possible solutions
- Provide the reader with a call-to-action. Tell them what you would like them to do.

### ***Meeting with politicians***

Remember, your elected official works for you. Your issue is just as important as everything else that they are trying to address. Your job is to help them understand why end-of-life care is an important issue!

Here are some pointers to help you with planning a meeting with your elected official.

- **Decide who will go** – It is helpful to have between two and four people attend the meeting. You could bring loved ones, someone from your community with a similar experience, maybe someone from an organization that addresses end-of-life care or focuses on a particular disease. Whoever goes to the meeting should be able to make a connection by using personal stories.
- **Call to arrange a meeting** – Call the official’s constituency office to ask for a meeting. Be sure to call the day before your meeting to confirm the time, as schedules change quickly.
- **Build relationships** – Be polite and courteous with elected officials and their staff. Their staff often manages the agenda as well as schedules and can be a great asset to you.
- **Be Prepared** – You will have a short time with your elected official and you want to get your points across.
  - Decide on two or three key points that you want to discuss and stay on topic. The meeting can go off track very fast and your time will be up before you have a chance to talk about your issue.
  - Try and know as much as you can. The elected official will try and present different opinions. Think of what they might say and come up with an answer that will keep to your point. Try to find out if your elected official has said anything publicly about your issue before you meet with him/her.
  - Decide who will speak to what points during the meeting and stick to the plan as much as possible to ensure all your points are heard.
  - Listen as well as talk. Your elected official might be trying to empathize or gain more insight into what you are trying to tell him/her.

- Be assertive, not aggressive. Be clear and concise.
- Thank the official for taking the time. Send a letter to him/her after the meeting highlighting a few points of your discussion.
- Leave information behind – You will have a lot of useful information to present at the meeting. Give brochures or a document that outlines your issue, the solutions and a call-to-action. This way when the elected official responds to your issue, they have all of the facts.

***For more information***

**Contact your Federal Member of Parliament: -**

<http://www.parl.gc.ca/information/about/people/house/PostalCode.asp?lang=E&source=sm>

**Find your provincial representative:**

Alberta – [http://www.assembly.ab.ca/net/index.aspx?p=mla\\_home](http://www.assembly.ab.ca/net/index.aspx?p=mla_home)

British Columbia – <http://www.legis.gov.bc.ca/mla/3-1-1.htm>

Manitoba - [http://www.electionsmanitoba.ca/mlasearch/mlasearch\\_link.htm](http://www.electionsmanitoba.ca/mlasearch/mlasearch_link.htm)

Northwest Territories - <http://www.gov.nt.ca/research/mla/index.html>

Nunavut - <http://www.assembly.nu.ca/english/members/index.html>

Quebec - [http://www.electionsquebec.qc.ca/en/find\\_electoral\\_division.asp](http://www.electionsquebec.qc.ca/en/find_electoral_division.asp)

Ontario - <http://www.electionsontario.on.ca/>

Nova Scotia – <http://electionsnovascotia.ns.ca/edf/edf.aspx>

New Brunswick - <http://app.infoaa.7700.gnb.ca/gnb/pub/ListMLA1.asp>

Newfoundland and Labrador - <http://www.hoa.gov.nl.ca/hoa/members/>

Prince Edward Island - <http://www.assembly.pe.ca/index.php?number=1012298&lang=E>

Saskatchewan - <http://www.legassembly.sk.ca/members/>

Yukon – <http://www.gov.yk.ca/leg-assembly/mlas/>

**An Accord Between the Government of Canada and the Voluntary Sector :**

[http://www.vsi-isbc.ca/eng/relationship/the\\_accord\\_doc/index.cfm](http://www.vsi-isbc.ca/eng/relationship/the_accord_doc/index.cfm)

Although this accord on policy collaboration is focused on organizations, there is some good information about how policy is made.

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## Communicating Your Message

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### *Persuasive communication*

Whether you are meeting with a politician, talking to a health-care professional about managing your care, or working with a media person to get your story told, being able to use persuasive communication to get your message across is a helpful skill. Persuasive communication is used to change, modify or reinforce responses from the person you are communicating with.

Here are some tips on how to persuade others:

#### *Focus on the other person*

What exactly is it that you want the other person to do for you? If you know what it is that you want and communicate it well, then the other person is more apt to be persuaded. Try and think of what it is that the person that you are trying to influence is going to want to know and any arguments he/she may make to refuse your request.

#### *Show them what you know*

You and your caregiver have a wealth of knowledge and are the best people to describe how you are feeling and what may not be working for you. When you are trying to persuade someone, use all of your knowledge and think of some of the points that they might counter with.

#### *Be confident*

You know what is best for you and your loved one and what your end-of-life care experience has been like. Be passionate and confident when you are trying to persuade someone to change his/her mind. No matter whom you are trying to persuade, confidence and passion about what you are talking about will help deliver your message.

#### *Make it easy to understand*

There are a lot of facts that you can present to make your case, but you want to be sure what you say is retained by the other party. Give them something to think about and peak their curiosity. Use clear examples that they can relate to and demonstrates the impact of the problem on people. Make it personal, so they can apply it to specific situations in their lives.

#### *Developing key messages*

- Keep it short. The average radio or television sound bite is 10 seconds long. The average print quote is one to three lines. Use everyday language and avoid jargon.
- Ensure your thoughts are honest and compelling, e.g.: “Let me put it this way. This issue will have a tremendous impact for all families.”
- Make your sentence a complete thought, so it stands on its own.

- Be passionate and energetic, e.g.: “Our population is aging. We have a responsibility to help people live as comfortably as possible with life-threatening illnesses.”
- Be colourful or metaphorical. “We have to bring death and dying out into the open.”

### ***Working with the media***

#### *What do reporters want?*

Reporters will want a story their audience can identify with - that people can see themselves being a part of. When you are approaching a reporter with a story that you think they should cover, try to outline:

- The personal aspect of the story, what kind of impact your experience has had on you and your family.
- Demonstrate how this story would be meaningful to the audience.
- Provide them with facts to support your position.

You can write a press release to try and garner media support for your issue. Here is how you can write an effective release.

Choose a headline that will get attention. It needs to summarize the article, but be interesting to stand out.

1. The opening paragraph should summarize what follows and should provide a quick overview of who, what, where, when, why and how. It needs to tell the reader why this is important and why they should keep reading.
2. The body of the press release should outline the personal story and the facts to present your issue. The first paragraph should contain the most important information and quotes - this will help editors if they need to cut down the press release for their article.
3. The final paragraph should present any conclusions highlighting the importance of telling this story.

An example is provided in Appendix B.

### ***Getting your message heard***

So now that you have your key messages, it’s time to get them out. The media are a great tool to help tell your story. There are several mediums that you can target including:

- Print Media (newspapers, magazines and community newspapers)
- Radio
- Television (local, provincial, and national)

## **Print Media**

### *Op-Ed*

One of the easiest ways to get your name in the paper is to write an op-ed piece. An op-ed piece is simply your opinion of a particular issue and can be written at any time. The trick to writing an op-ed piece is to include facts and personal experiences to sway the reader's opinion. Here's a quick list of tips to help you get started.

- Focus on one issue.
- Express your opinion and then use facts and personal experience to back it up.
- Be personal and conversational in tone which will engage your reader.
- Provide insight and demonstrate why people need to think differently.
- Be clear and concise.
- Clearly state your position and what you want to see happen at the end.
- Limit your op-ed piece to 600-800 words.

An example is provided in Appendix C.

### *Letter to the Editor*

Letters to the Editor are usually in response to something that you have read in a newspaper or magazine that you do not agree with and/or think was presented in a misleading way. These letters are often much shorter than an op-ed piece (100-200 words). When writing the letter, do not restate what was already said, start by telling why you disagree.

An example is provided in Appendix D.

### *Working with reporters*

Building relationships with reporters will help you to meet your goal of getting the message out. When communicating with a reporter, remember they are often juggling two or three deadlines and want to get facts that are quick and easy. You know why the issue is important, so who better to present the facts in a convincing manner!

## **Radio**

There are an increasing number of talk radio programs that often provide an opportunity for in-depth discussion on an issue. Interviews might happen individually or sometimes as part of a panel. Here's how to have a successful radio interview:

- You need to paint the picture for radio listeners, because there is no visual picture. It is an opportunity for you to provide detail and connect with the listener to demonstrate how important your point is.
- Try to answer each question in 15-20 seconds.
- Sound confident – you have a lot of information and personal experience to offer, listeners should hear your confidence.
- Make it personal – radio is a personal medium; stories and anecdotes connect with listeners.

## **Television**

Unlike radio, television is very emotional and uses visuals. Don't be nervous if a camera is around...follow these suggestions and you won't even notice it's there:

- When being interviewed, do not look at the camera. Focus on the interviewer just like you are having a conversation with someone.
- Try and speak with as few “umm’s” as possible. Try to rehearse what questions you think they will ask so you are prepared.
- Television news stories are short pieces that need to tell a story in a very compressed amount of time. Stick to your key messages and try and think of some quotes that will playback in 5 or 10 second segments.
- Body language is important. Do not fold your arms or put your hands in your pockets, this does not come across well on camera. Use your hands to gesture occasionally (shows your passionate about the issue), but generally keep them at your side. If you are uncomfortable with this, try holding a notebook or a file folder.
- If you are seated in a chair that moves, don't swivel.
- Wear solid, bright colors that are “TV-friendly”.

### ***For more information***

#### **Tips for working with media**

**Canadian Diabetes Association Media Guide** - [www.diabetes.ca/files/election\\_kit\\_2006/Module%206%20-%20News%20Release%20or%20Media%20Event%202005-06.doc](http://www.diabetes.ca/files/election_kit_2006/Module%206%20-%20News%20Release%20or%20Media%20Event%202005-06.doc)

**Preparing for a Media Interview** - <http://www.fullcirc.com/rlc/mediainterviewprep.htm>

**Media Advocacy Manual** - [http://www.apha.org/news/Media\\_Advocacy\\_Manual.pdf](http://www.apha.org/news/Media_Advocacy_Manual.pdf)

**World Health Communication Associates – Working with the Media Guide** - [http://www.whcaonline.org/assets/publications/wwtm\\_en.pdf](http://www.whcaonline.org/assets/publications/wwtm_en.pdf)

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## Appendix A – Canada Health Act

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### *The principles of the Canada Health Act:*

**Public Administration** –The health-care insurance plan of each province and territory must be carried out on a non-profit basis by a public authority that is responsible to the provincial/territorial government. For example, a district health authority (DHA) or local integrated health network (LIHN) is a public authority and they report directly to provincial or territorial governments on their accomplishments and challenges.

**Comprehensiveness** - All medically necessary health services must be insured including hospitals, doctors, and dental surgeons.

**Universality** – Every person in the province/territory is entitled to the same level of health-care.

**Portability** - Health insurance moves with you. Whether you move from one province or territory to another or leave the country for a brief period of time, you are insured.

**Accessibility** - Every person should have access regardless of their ability to pay, whether they are healthy or not, or regardless of their age.

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## Appendix B – Sample Press Release

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This sample press release was developed by the Hospice Association of Ontario to raise awareness of hospice services. You can use this sample as a base to write a press release that highlights what challenges you have encountered

### FOR IMMEDIATE RELEASE

Recognizing End-of-Life Care

Canadians Wish to Remain at Home during the Last Stages of Life

Hospice Awareness Week 2004 – October 10 - 17

*First paragraph highlights the problem.*

**Toronto, October 10, 2004** – According to a national poll conducted by Ipsos Reid and released September 2004, more than 90 percent of Canadians want to die at home, yet 75% still die in hospitals. Only 15% of Canadians receive quality end-of-life care. And only 6% of people who care for family members facing end of life believe they could care for their loved one at home without integrated practical and emotional support provided by hospices.

*The body of the release should highlight relevant facts and include quotes that will peak the reporter's interest.*

These numbers, as well as Canada's aging demographics and increasing incidence of cancer and other diseases, provide a stark picture of the growing need for the care and compassion provided by hospices such as Bayview Community Hospice in Toronto or Hospice Northwest in Thunder Bay.

October 10th to the 17th marks Hospice Awareness Week across the province, and it has never been more important to recognize the gift of time, care and humanity that hospices provide in more than 450 communities throughout Ontario.

"In 10 years," said Janet Napper Executive Director of the Hospice Association of Ontario "our membership has experienced a growth rate of 1000%. Across Ontario our member hospices have seen an explosion in need for compassionate end-of-life care services, our members now represent 13,300 volunteers who dedicate 630,000 hours of service each year in communities across Ontario. Helping more and more people live fully until the end of life is our goal." says Ms Napper.

Helping people means providing ongoing emotional, psychological and spiritual support to people who are dying. For family members, it means being able to have someone relieve them of their care-giving role, to provide respite support. It also means providing emotional and bereavement support, on average, to five family members.

This year marks the 15th Anniversary of the Hospice Association of Ontario and never before have we seen the kind of momentum that is building towards a societal movement for quality-of-life during the last stages of life. Adequate funding of community services is vital if we are to provide the type of home based compassionate care Canadians seek when living with a life-threatening illness such as cancer, ALS or AIDS.

*The final paragraph should include a “call to action.” It should tell the reader what you are wanting the end result to be.*

“As a society we often fear death more than we recognize the richness of life at end-of-life” says Hospice Association of Ontario Chairman, Bruce Peer. All citizens have the right to die with dignity, free of pain, surrounded by their loved ones in a setting of their choice. Hospice palliative care provides the practical, emotional, spiritual and bereavement care necessary to ensure quality of life through the final stages of life. Hospice Week 2004 marks a celebration of life, recognition of the many gifts caring for one another holds, noted Mr. Peer.

-30-

Contact:  
Put your contact information here

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## **Appendix C – Sample Op-ed Piece**

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This Op-ed piece is written by the Dr. Barbara Wylie, Chief Executive Officer of the Canadian Cancer Society. It presents the challenges, gives statistics to back up these challenges, provides potential solutions and then has a call to action.

By BARBARA WHYLIE  
Globe and Mail Update  
June 8, 2004

During the 37 days of this federal election campaign, almost 7,000 Canadians will die of cancer. Probably they will be strangers to you. Maybe, though, one of them will be someone you know a friend, a parent or a spouse.

Cancer wounds everyone in our society. It is the leading cause of premature death in Canada. In 2000, it eliminated an unimaginable 950,000 years of potential life and it's about to do much worse.

We are on the brink of a cancer epidemic. Between 1990 and 2010, the number of new cancer cases diagnosed in Canada each year will more than double. Why the increase? First, cancer is poised to strike the large baby-boom generation because as Canadians age, their risk of getting cancer increases. Second, the Canadian population is growing. The more people there are, the more cases of cancer will be diagnosed.

We must act now to prevent a national disgrace. Our new Parliament should heed the advice of the World Health Organization. In 2002, the WHO recommended that nations develop cancer control programs to reduce the number of new cancer cases and improve quality of life for people with cancer. This has not yet been done in Canada.

Just a few weeks ago, the WHO also endorsed a global strategy on diet, physical activity and health. This strategy stresses the need to prevent non-communicable diseases, including cancer, through diet and physical activity. The WHO strategy underlines the importance of cancer prevention and reminds us how much we need a Canadian strategy to control cancer - one that includes prevention.

Cancer-control strategies can save many thousands of lives. In the mid-1980s, targets for cancer control were set by the European Union's program known as Europe Against Cancer. Two members, Finland and Austria, reached their targets, reducing cancer by 15 per cent. Other countries such as the United Kingdom, Italy and Luxembourg achieved very significant reductions.

Canada is one of the few nations in the developed world that has failed to implement a strategy for cancer control. We are now paying for that failure with our very lives. Canadians are more likely to get some types of cancer than citizens of comparable nations such as the United Kingdom, Australia, Japan, Sweden or Singapore, and they are more likely to die of it.

Elements of cancer care in Canada are world-class, but the Canadian approach to cancer control is inconsistent, flawed and driven by political expediency rather than medical realities. Cancer prevention in Canada is pathetically underfunded and fragmented. Cancer patients experience uneven levels and quality of service. Cancer care is crippled by a growing lack of health-care providers and inconsistent support of research.

All this must change and soon. Every year, 68,000 Canadians die of cancer.

The groundwork for a national plan to fight cancer has already been laid. The Canadian Cancer Society and the National Cancer Institute of Canada have come together to advocate a comprehensive strategy. But agencies and individuals can only do so much. Health Canada, the Canadian Association of Provincial Cancer Agencies and more than 700 experts and cancer survivors have shared in this process. But, if a national strategy is to become a reality, at some point very soon, the federal government must provide leadership and funding.

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## Appendix D – Sample Letter to the Editor

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Dear Editor,

Currently in Canada, only 5 to 15% of Canadians have access to quality hospice palliative care. The number of Canadians that are expected to die will increase by 33% by the year 2020. Our health-care system resources are stretched. Even within the province I live in, the services and programs vary greatly depending on which jurisdiction the patient and their loved ones reside.

Access to quality hospice palliative end-of-life care is essential for every patient and their loved ones. Hospice palliative care aims to relieve the suffering at end-of-life. Even though Canadians should be able to access these specialized programs and services in acute care, long-term care, community and home settings, this is often not the case.

My experience has been...

(This is your opportunity to highlight your situation, present options for solutions and a call to action to move your challenge forward).

Everyone experiences death and most of us do not realize what challenges there are at end-of-life until we are living that situation. Every Canadian has the right to die with dignity, surrounded by their loved ones, free of pain, in a setting of their choice. We have a lot of work to do to make that happen and I for one am more than willing to ensure that other families will benefit from the experience of losing my loved ones.

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## Appendix E – Sample Letters to Elected Officials

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**John Doe**  
**555 Main Street**  
**Anywhere, Province H0H 0H0**  
Home Phone:(555) 5555

June 17, 2002

Honourable Jane Doe  
Minister of Health  
Government of Province

Dear Honourable Minister,

I have reached a point of desperation, and I need your assistance. Please help me.

I wrote to you on January 1, 2004 describing my plight in seeking approval for my medication. Although I applied at the end of November 2003, my application has been stalled in the system several times. Although my medical professional has supported the use of medication x, the provincial government still insists that I use medication y.

All this information was supplied to the appropriate person and yet this issue has yet to be resolved. My current supply of medication x is running low and I have had to resort to using the medication that is prescribed to another patient. It could take weeks or months for this drug to become effective again if I have to stop treatment.

Ms. Minister, I feel better now than I have in the almost 10 years since my diagnosis. I own and operate a small contracting business here in Anywhere, thus contributing to the financial prosperity of our province. Knowing what will happen if I have to go off medication x again, I will not be able to continue running my business. Don't let that happen. I need to receive an approval on my application for coverage and I need it within days to prevent a lapse in doses.

I know that my problem is not unique and that others are in the same situation. I would like to meet with you to discuss some solutions that would help people in this situation. I will contact your office in the next 14 days to request a time for a meeting. I look forward to working with you towards a positive outcome.

Respectfully yours,

Patient x



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

## **Advocacy Kit 2006-2007**

### **Key Public Awareness Messages and the Media**

## **Key Public Awareness Messages and the Media**

### **Messages and the Media**

Having determined what should be communicated—an overall messaging theme of “quality of life” and why it is important that care and genuine concern for the patient and family members is provided to the end—the focus gets shifted on how and where to say it. There are key messages and communications vehicle recommendations for each target audience and sub-segment of the population.

- *‘Care for the dying is care for the living’* speaks to health care providers as they have a special role to play in the management of hospice palliative care due to the relationships they share with patients and can help them make the transition with the continuing care of someone they trust and respect. This audience could be reached through advertising in specialized publications and web sites, brochures in association mail-outs and electronic newsletters through associations
- *‘Because everyone is touched by life-ending illness, hospice palliative care touches everyone’* speaks to 50-64 year-old Canadians as they have higher risk of dying from a long term, life-threatening illness, or are more likely to care for a close one, such as an elderly parent, who is dying. This audience could be reached through local newspaper advertising, direct mail letters or op-ed articles.
- *‘Make the most of living, right to the end’* speaks to 65+ year-old Canadians as the need for maintaining the best possible quality of life does not end when they or somebody close is diagnosed with a terminal or life-threatening disease. There remains the need to ensure the best possible quality of dying. This audience could be reached through local newspaper advertising, direct mail letters or op-ed articles.
- *‘There are many people who can help and many ways to provide comfort and support.’* speaks to 35-49 year-old Canadians who may be untouched by illness but should talk about death as facing it without adequate planning will make the inevitable worse. They can learn about the options and how to plan for the best possible quality of life for them and their loved ones. This audience could be reached through magazine and radio advertising and direct mail letters.

(Adapted from Hospice Palliative Care Public Awareness Raising Framework  
Secretariat on Palliative and End-of-Life Care)



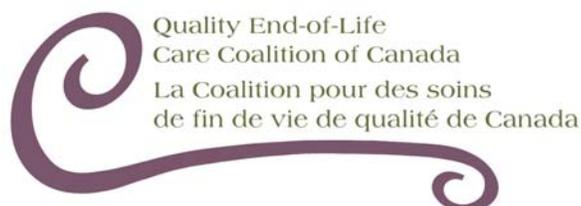
**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

**Advocacy Kit  
2006-2007**

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

**Updated May 2006**



## 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 Social Workers
- Canadian Association of the Deaf
- Canadian Breast Cancer Network
- Canadian Caregiver Coalition
- Canadian Cancer Society
- Canadian Home Care Association
- Canadian Hospice Palliative Care Association
- Canadian Lung Association
- Canadian Medical Association
- Canadian Nurses Association
- Canadian Pharmacists 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 Project
- VON Canada

***Updated May 2006***

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) is promoting the development and implementation of a long-term, sustainable and well-funded strategy on palliative and end-of-life care for Canada. To move this issue forward the QELCCC has developed a national Framework to outline what this strategy would entail. This Framework 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. National leadership is needed to ensure that all Canadians will be able to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice.



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

**Advocacy Kit  
2006-2007**

**Federal Template Letter (to be personalized by you)**

***2006-2007 Advocacy Strategy: Federal Template Letter***  
***Please customize this letter for your own situation.***

*Prime Minister, Minister of Health, or Deputy Minister of Health*  
*Insert Address*  
*Fax Number*

*Date*

Dear *(insert name)*,

All Canadians deserve the right to quality end-of-life care. Yet in the 2000 Senate Report entitled “*Quality End-of-Life Care: The Right of Every Canadian*”, it was estimated that less than 15% of Canadians currently have access to these kinds of services. Since the release of the Senate Report there have been some improvements in the availability of hospice palliative care services in Canada but there is still much to be done to ensure that all Canadians have equal access to these services when needed.

*(Insert your name, the name of your program, organization or association here)* is calling upon you in your role as *(insert their title here: PM / Minister of Health / Deputy Minister of Health)* to create a well funded and sustainable Canadian Strategy for Palliative and End-of-Life Care. To be effective, this national strategy needs to be committed, long-term and funded to an appropriate level (\$20 million per year). The Secretariat on Palliative and End-of-Life Care (Health Canada) has begun the initial work towards the development of a national strategy however current funding for the Secretariat is inadequate and unprotected under Treasury Board guidelines. Protection and adequate funding of the Secretariat is key to the creation of a Canadian Strategy for Palliative and End-of-Life Care.

All Canadians have the right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. More and more Canadians are saying that at the end-of-life they want to be cared for at home or in the community, yet community services have not been increased to assist them in achieving this goal. The health system cannot expect Canadians to provide end-of-life care at home to their loved ones without providing them with the support they need. If access to these services is not available in the community, the result will be an increase in admissions to more expensive acute care beds within our institutions. A continuum of community services must be put into place to ensure that services are comprehensive. A Canadian Strategy for Palliative and End-of-Life Care that is integrated within the Canadian health care system, coordinated with other services, and comprehensive in nature will ensure that Canadians are treated with respect and dignity at the end of life.

Quality end-of-life care must include access to:

- Access 24 hours a day, 7 days a week to hospice palliative care professionals including volunteers
- Home Care (hospice palliative care expertise by professional and support staff, volunteers and coordination)

- Pharmacare
- Non-prescribed Therapies
- Respite Care or care for the informal caregiver
- Compassionate Leave

Both the federal and provincial governments have made progress on some of the items listed above, and for that we are grateful. However, we risk losing all of the progress that has been made over the past few years without the continued and long-term support of a Canadian Strategy for Palliative and End-of-Life Care.

*(I/We)* have enclosed a copy of a hospice palliative care Fact Sheet prepared by the Canadian Hospice Palliative Care Association for your information and look forward to hearing from you on your government's plan to ensure quality end-of-life care for all Canadians through the creation of a Canadian Strategy for Palliative and End-of-Life Care.

Yours sincerely,

*Name*

*Title*

*Organization*

Enclosed: Hospice Palliative Care Fact Sheet



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

**Advocacy Kit  
2006-2007**

**Provincial Template Letter (to be personalized by you)**

**2006-2007 Advocacy Strategy: Provincial Template Letter**  
**Please customize this letter for your own situation.**

*Premier, Minister of Health, or Deputy Minister of Health*

*Insert Address*

*Fax Number*

*Date*

Dear *(insert name)*,

All Canadians deserve the right to quality end-of-life care. Yet in the 2000 Senate Report entitled “*Quality End-of-Life Care: The Right of Every Canadian*”, it was estimated that less than 15% of Canadians currently have access to these kinds of services. Since the release of the Senate Report there have been some improvements in the availability of hospice palliative care services in *(insert Province Name)* but there is still much to be done to ensure that all residents of *(insert Province Name)*, and indeed all Canadians, have equal access to these services when needed.

*(Insert your name, the name of your program, organization or association here)* is calling upon you in your role as *(insert their title here: Premier / Minister of Health / Deputy Minister of Health)* to support the creation of a well funded and sustainable Canadian Strategy for Palliative and End-of-Life Care. The Secretariat on Palliative and End-of-Life Care (Health Canada) has begun the initial work towards the development of a national strategy however current funding for the Secretariat is inadequate and unprotected under Treasury Board guidelines. Protection and adequate funding of the Secretariat is key to the creation of a Canadian Strategy for Palliative and End-of-Life Care.

All Canadians have the right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. Currently hospice palliative care services are not funded as a core service in the province of *(insert province name \*\* confirm your provincial/local situation!)*. More and more Canadians are saying that at the end-of-life they want to be cared for at home or in the community, yet community services have not been increased to assist them in achieving this goal. The health system cannot expect Canadians to provide end-of-life care at home to their loved ones without providing them with the support they need. If access to these services is not available in the community, the result will be an increase in admissions to more expensive acute care beds within our institutions. A continuum of community services must be put into place to ensure that services are comprehensive. A Canadian Strategy for Palliative and End-of-Life Care that is integrated within the Canadian health care system, coordinated with other services, and comprehensive in nature will ensure that Canadians are treated with respect and dignity at the end of life.

Quality end-of-life care must include access to:

- Access 24 hours a day, 7 days a week to hospice palliative care professionals including volunteers
- Home Care (hospice palliative care expertise by professional and support staff, volunteers and coordination)

- Pharmacare
- Non-prescribed Therapies
- Respite Care or care for the informal caregiver
- Compassionate Leave

The provincial government has made progress on some of the items listed above, and for that we are grateful. *(Add any specific provincial initiatives or programs here.)* The residents of *(insert your Province Name)* are counting on you do all in your power to support the creation of a Canadian Strategy for Palliative and End-of-Life Care. *(I/We)* have enclosed a copy of a hospice palliative care Fact Sheet prepared by the Canadian Hospice Palliative Care Association for your information and look forward to hearing from you on your government's plan to support the creation of a Canadian Strategy for Palliative and End-of-Life Care, thereby ensuring quality end-of-life care for the residents of *(insert your Province Name)*.

*(Optional) I / Someone from the (name of organization) will be in contact with your office in the next few weeks to answer any questions you might have or to arrange a possible meeting to discuss this issue in more detail.*

Yours sincerely,

Name  
Title  
Organization

Enclosed: Hospice Palliative Care Fact Sheet

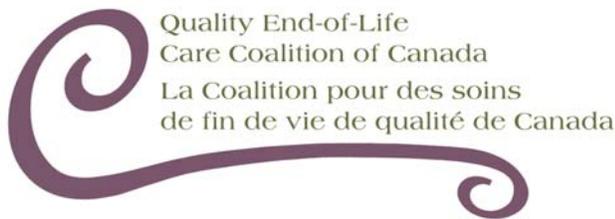


**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

**Advocacy Kit  
2006-2007**

**QELCCC Media Release – September 14, 2006**



# Press Release

## **Harper Government Cuts Funding for a National Strategy for Dying Canadians and their Caregivers**

*For immediate release – September 14, 2006*

Ottawa – In the May 2006 Federal Budget, The Honourable James M. Flaherty, Minister of Finance announced that “the President of the Treasury Board will identify savings of \$1 billion in 2006-2007 and 2007-2008.” While not specific about where these savings will take place, it is clear that all federal departments will be affected by this reduction in spending. With regard to the ongoing development of a national strategy for end-of-life care, it is expected that the Secretariat on Palliative and End-of-Life Care (Health Canada) will see substantial budget reductions for the 2006-2007 fiscal year. In 2005-2006 the Secretariat was funded at the level of \$1.7 million dollars. The continued national coordination and leadership provided by the Secretariat on Palliative and End-of-Life Care is essential as Canada moves forward to address the end-of-life care needs of all Canadians.

Since 2001 the Secretariat on Palliative and End-of-Life Care has been actively involved in the development of a National Strategy for Palliative and End-of-Life Care. This important initiative includes five priority areas for quality end of life care: Best Practices and Quality Care, Education for Formal Caregivers, Public Information and Awareness, Research, and Surveillance. A substantial cut in funding to the Secretariat will mean that many of the ongoing initiatives are at risk of being severely cut back or even eliminated.

The Canadian population is aging. Statistics Canada has reported that at present, 75% of the 225,000 Canadians who die each year are age 65 or over. In addition, Statistics Canada estimates that by the year 2020 there will be a 33% increase in the annual number of deaths in Canada. Currently only 15% of Canadians have access to high quality hospice palliative care. The federal government must take a leadership role in ensuring a long-term, adequately funded, comprehensive and sustainable National Strategy for Palliative and End-of-Life Care that will address the issues of services, resources, education, research, and support for patients and families.

“It now seems clear that the federal government is not as committed as it once was to providing national leadership and coordination for a national strategy for palliative and end of life care.”, says Diana Rasmussen, Quality End-of-Life Care Coalition of Canada

representative on the Coordinating Body of the National Strategy for Palliative and End-of-Life Care. She goes on to say, “The National Strategy Working Groups have accomplished so much in the past few years, I am disappointed that the work may not continue and we will slide backwards with regard to the provision of end of life care services in Canada. Canadians deserve better from their federal government.”

The Quality End-of-Life Care Coalition of Canada calls upon the federal government to maintain the current \$1.7 million level of funding to the Secretariat on Palliative and End-of-Life Care, and to commit to a long-term sustainable funding solution for the future.

The Quality End-of-Life Care Coalition of Canada believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. The Coalition believes that to achieve quality end-of-life care for all Canadians there must be a well funded, sustainable national strategy for palliative and end-of-life care. It is the mission of the Quality End-of-Life Care Coalition of Canada to work together in partnership to achieve this goal.

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Members of the Quality End-of-Life Care Coalition of Canada:

ALS Society of Canada  
Canadian AIDS Society  
Canadian Arthritis Patients Alliance  
Canadian Association for Community Care  
Canadian Association for Pastoral Practice and Education  
Canadian Association of Occupational Therapists  
Canadian Association of Social Workers  
Canadian Association of the Deaf  
Canadian Breast Cancer Network  
Canadian Cancer Society  
Canadian Healthcare Association  
Canadian Hospice Palliative Care Association  
Canadian Nurses Association  
Canadian Society of Palliative Care Physicians  
Caregiver Network Inc.  
CARP: Canada’s Association for the Fifty Plus  
Catholic Health Association of Canada  
Heart and Stroke Foundation of Canada

More information:

Sharon Baxter

Secretariat – Quality End-of-Life Care Coalition of Canada

613-241-3663 ext.227



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

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2006-2007**

**CHPCA Media Advisory – September 26, 2006**



**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**

# Media Advisory

## Canadians are Dying for Care – Federal Government Cuts Funding for End-of-Life Care in Canada

### REVISED

For Immediate Release  
September 26, 2006

Montreal - The Canadian Hospice Palliative Care Association (CHPCA) at their Annual General Meeting held in Montreal on Monday, September 25, 2006 passed the following Resolution to focus attention on the recent decision of the Federal Government to cut the budget of the Secretariat on Palliative and End-of-Life Care (Health Canada). Health Canada confirmed on Monday, September 25, 2006 that the budget for 2006-2007 will be \$470,000 with \$300,000 in funding still pending. This amount is significantly lower than the \$1.7 Million the Secretariat on Palliative and End-of-Life Care received in 2005-2006.

### Background

Dying and death affects every Canadian, and how we treat our dying citizens reflects who we are as a society. The 2000 Senate Report entitled “*Quality End-of-Life Care: The Right of Every Canadian*” stated that less than 15% of Canadians have access to hospice palliative care. The situation has improved only slightly over the intervening 5 years as evidenced by the follow-up report published by Senator Sharon Carstairs in June 2005 entitled “*Still Not There Yet - Quality End-of-Life Care: A Progress Report*”.

Approximately 245,000 Canadians die each year, many with multiple chronic diseases. It is estimated that more than 1 million Canadians are caring for a dying loved one at any given time. This has profound impacts on Canadian families, their employment and on the health and social fabric of this country.

Statistics Canada estimates that by 2020 there will be a 33% increase in the number of deaths in Canada. The need for quality end-of-life care will necessarily increase.

### **Resolution #1**

*Whereas the Canadian Hospice Palliative Care Association (CHPCA) has been advocating for a fully funded, sustainable and long term national strategy for hospice palliative care for a number of years; the CHPCA has worked with its partners and stakeholders including both the Quality End-of-Life Care Coalition of Canada and each of the eleven provincial hospice palliative care associations to direct the government to make this strategy a reality;*

*And whereas the federal government has in the past shown leadership in developing strategies and supporting the hospice palliative care community to better educate health care providers including volunteers, the general public and patients and their caregivers on the end of life care issues;*

*And whereas the current situation of allocating small amounts of money within the Health Canada budget on an annual basis does not allow for the federal government to engage stakeholders on this issue in a sustainable and meaningful way;*

*And whereas expected budget reductions to the inadequately funded 2006-2007 budget for the Secretariat on Palliative and End-of-Life Care will put in jeopardy the accomplishments of the work of the National Strategy Working Groups for the past four years;*

***Be it resolved that:***

- 1. Funding from the Health Canada budget to the Secretariat on Palliative and End-of-Life Care be immediately funded to the 2005-2006 funding level of \$1.7 Million dollars to continue to meet the goals and finish the work of the current Working Groups.*
- 2. The federal government immediately starts work towards the implementation of a \$20 million dollar, fully funded, sustainable, long term national strategy for hospice palliative care.*
- 3. The Secretariat on Palliative and End-of-Life Care, with sufficient funding is transformed into a permanent office within Health Canada's structure.*
- 4. In order to achieve the above resolution the federal government engage provincial and territorial governments as well as stakeholders from the hospice palliative care community including stakeholders who work in acute care hospitals, complex continuing care, long term care facilities, residential hospices, the home and on the street (for those unstably housed), in a national consultation process to direct the development of the above mentioned national strategy for hospice palliative care.*

The Canadian Hospice Palliative Care Association and its members will be pursuing the above resolution in the coming weeks.

The Canadian Hospice Palliative Care Association is the national voice for hospice palliative care and end-of-life care in Canada. The Association represents in excess of 480 hospice palliative care programs and services that provide end-of-life care for Canadians.

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For more information:

Sharon Baxter           613-447-3906  
Executive Director