British Columbia
HOSPICE
PALLIATIVE CARE
Association

Our Vision

Quality end-of-life care for all people in BC and the Yukon

Our Mission

Building capacity in communities

A Call to Action to the Candidates for the 2009 BC Election

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The Time to ACT is NOW!

Dear BCHPCA Members:

BCHPCA has developed this kit to assist you in creating an advocacy strategy leading up to the next provincial election. We hope you will find it a helpful addition to any local actions you may be planning in your community.

The election is scheduled for this May. Individually and collectively, our input is essential and our voice must be heard. The next four years depend on it! This kit contains everything you need to get started.

BCHPCA has chosen three keys issues that are the focus of this kit. These issues are summarized on page 4 of this kit and are included in the form letter provided in Appendix A. They include: elimination of per diems for hospice services, 24/7 access to care, and ongoing support and funding of a provincial end of life strategy based on the provincial framework.

This call to action is just the first step. BCHPCA is already writing and calling provincial political parties and their leaders to make them aware of the issues. We will continue to follow up with you, but we need your voice to strengthen the message.

Acting locally is important! Get to know the issues – build a relationship with your politicians – educate friends and neighbours. The important thing is to reach out.

Any questions? If you need more information contact your Regional BCHPCA Director or the folks working within your local hospice palliative care.

Backup information contained in this kit:

Appendix A: Form letter to assist you when contacting candidates and others

Appendix B: Contact information

Appendix C: BCHPCA 2005 Report: *Still Not There: A Call to Action in BC*

Appendix D: CHPCA Fact Sheet

As members of BCHPCA, we know you are passionate about hospice palliative and end of life care in our province.

We're asking you to join us in turning that passion into action now!

Wendy Pratt, President

What Can I Do To Help?

Become informed – identify the key messages.
We don't expect you to do everything but we encourage you to act on at least one of the items suggested below:

a. **Identify local candidates and get their contact information. Keep an eye out for scheduled all-candidates meetings and other political events.**
Ask questions! Find out as much information as possible about each candidate. Politicians use this technique all the time – use it to your own advantage.

b. **Write/e-mail letters to each candidate.**
Don't delay – write today using the enclosed form letter (Appendix A). Us this as a guide – try to personalize it to your area. **Remember to keep it simple.** Back the letter up with other information (Appendix C & D).

c. **Follow up with a phone call or visit.**
Whenever possible, deliver your letter by hand. If you email it, call to make sure they got it. Get to know the staff at your candidate's office. While you are there, make an appointment to come in and follow up. Call two days before the appointment to remind the candidate about your letter. If you can't go in, make a phone call and say, "*You may recall I wrote you concerning issues surrounding hospice palliative care. I was wondering if you had had a chance to look at the information and if we could have a quick chat."* If they say now is not a good time, don't be deterred. Ask when you can call back.

d. **Attend the candidates' events and the all-candidates meetings.**
Bring along your written key messages and questions – by speaking up you are educating both the candidates and everyone else in the room.

e. **Write letters to the editor in your local newspapers.**
Candidates are sensitive to media attention. A letter to the editor is a great opportunity to educate the community. Your chances of being published are greater if you stay within the guidelines set out by the newspaper for "word count" – keep it simple!

f. **Monitor the local radio call-in shows and call in to express your views.**
This is another chance to educate everyone concerned. Every contribution will help the cause both locally and provincially.

g. **Organize your own local community town hall candidates meeting.**
Invite the candidates, the media and the general public, and start with your hospice palliative care questions of the candidates.

h. **When candidates call, be ready to make your point on the phone or on your doorstep.**
Talk about a captive audience! They are there to talk to you and to get your vote. Make sure you take advantage of it and get your message out.

The BCHPCA 2009 Provincial Election Messages

We are asking the Provincial Government to:

1. **Eliminate per diem user fees charged according to provincial policies for hospice services.** Patients should not have to pay to die. End of life care must become a fully funded core service**.**

2. **Ensure 24/7 hospice palliative care is available with adequate community supports** such as primary care physicians, nurses, home support workers, and hospice staff and volunteers.

3. **Actively develop and fund a Provincial Strategy on End of Life Care** to ensure access to a core set of end of life care services for all those living and dying in BC.

BCHPCA and its membership fully endorse the *Provincial Framework on End of Life Care in BC* as a foundational document for end of life care, and as the basis for moving forward with a provincial strategy and action plan. We are counting on our government to move forward with a funded and coordinated set of services for all British Columbians facing dying, caregiving, and bereavement.

For more information visit www.hospicebc.org.

Local Hospice Palliative Care Messages

(Please use this space to identify your own local Hospice Palliative Care issues)

Hospice Palliative & End of Life Care Background Information

We know you are already familiar with the philosophy of hospice palliative care, but it's important to keep your thoughts focused. Here are some keys points to remember.

Hospice palliative and end of life care aims to relieve suffering and improve the quality of living and dying for patients and families. It is best delivered by an interdisciplinary team consisting of professional and volunteer caregivers and managers, all knowledgeable and skilled in this area of health care delivery.

Hospice palliative care strives to help patients and families:

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

Progress here in BC:

In 2002 BCHPCA was a key stakeholder in the development of the Ministry of Health Services' *Discussion Paper on A Provincial Strategy for End of Life Care in British Columbia.* The paper identified the need for a provincial strategy, estimating that only 5 to 10% of people in BC had access to hospice palliative care.

By mid 2005 no strategy had been released. BCHPCA released their own report *Still Not There: A Call to Action in BC.* Issues #1 and #2 in Appendix A are from this report.

In 2006, as a result of pressure from BCHPCA, the *Provincial Framework on End-of-Life Care in BC* was launched at the BCHPCA Conference. We continued to urge the Ministry to create a strategy.

In 2008 the Ministry of Health Services hired consultants to develop a strategy and action plan to move the Provincial Framework forward.

In 2009 BCHPCA visited the Minister of Health in person and asked him to commit to moving a provincial strategy and action plan forward. Issue #3 in Appendix A relates to this initiative and is crucial in moving our agenda forward over the next four years.

We hope the contents of this kit inspire you to action. If you have any questions contact our office, your Regional BCHPCA Director, or those involved in your local programs. See Appendix B for contact information.

APPENDIX A
Form Letter

Date

Candidate's Name & Address

Dear _____________,

As a member of the BC Hospice Palliative Care Association (BCHPCA), and as a citizen of this community (or program operating in this community) I (we) would like to bring the following issues to your attention concerning access to, and delivery of, hospice palliative and end of life care both locally and provincially.

We are asking the Provincial Government to:

1. **Eliminate per diem user fees charged according to provincial policies for hospice services.** Patients should not have to pay to die. End of life care must become a fully funded core service**.**

2. **Ensure 24/7 hospice palliative care is available with adequate community supports** such as primary care physicians, nurses, home support workers, and hospice staff and volunteers.

3. **Actively develop and fund a Provincial Strategy on End of Life Care** to ensure access to a core set of end of life care services for all those living and dying in BC.

BCHPCA and its membership fully endorse the *Provincial Framework on End of Life Care in BC* as a foundational document for end of life care, and as the basis for moving forward with a provincial strategy and action plan. We are counting on our government to move forward with a funded and coordinated set of services for all British Columbians facing dying, caregiving, and bereavement. For more information visit the BCHPCA website at www.hospicebc.org.

If you are elected, or if your party forms the next government, where will you stand on these issues? Will you help us move them forward? I will be following up with you within the next two weeks and look forward to speaking with you at that time. If you have any questions, please contact me.

Sincerely,

(insert your name and contact information here)

APPENDIX B
Contact Information

Wendy Pratt, BCHPCA President, Nanaimo, 250-758-8857, wendyp@nanaimohospice.com

Nancy Kilpatrick, President-elect, Westbank, 250-862-0537, nancykilpatrick@shaw.ca

Carolyn Taylor, Past President, Surrey, 604-587-4683, carolyn.taylor@fraserhealth.ca

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Terri Odeneal, Director: Vancouver Island, Comox, 250-339-5533, cvhs1@telus.net

Sandra Castle, Director: Fraser, Surrey, 604-530-1115, sandracastle@langleyhospice.com

Carol Weremy, Director: North, Quesnel, 250-747-1841, jcweremy@shaw.ca

Marjorie Griffin, Director: Vancouver Coastal, Vancouver, 604-736-4593, mgriffin@telus.net

Meg Milner, Director: Interior, Nelson, 250-352-2600, themilners@shaw.ca

Rob Appleton, Director: Provincial, Vancouver, 604-738-7827, rappleton@spacecentre.ca

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APPENDIX C

STILL NOT THERE:

A CALL TO ACTION IN

BRITISH COLUMBIA

Prepared by:

BCHPCA Board

December 2005

Table of Contents

Page

1. **Executive Summary ………………………………………… 3**
2. **Introduction …………………………………………… 4**
3. **Background……………………………………………….. 4**
   National Recommendations
4. **Call to Action…………………………………………… 6**
   Regional Integrated Programs and Services
   Structures and Accountabilities of HPC Programs
   Specific Action Steps 2006 to 2008:
5. **Conclusion……………………………………………. 8**
6. **References ………………………………………….. 9**

EXECUTIVE SUMMARY
December 2005

In 2002 the British Columbia Ministry of Health Services released a Discussion Paper on A Provincial Strategy for End of Life Care in British Columbia. The paper identified the need for a Provincial Strategy and noted that of all persons who died in hospital in 2000, it was estimated that only 5 to 10 per cent received palliative care as part of their care in hospital.

The majority of deaths in British Columbia take place in hospital yet research indicates that patients and their families are best supported by a system that offers choices for location of care and an integrated system based on strong community supports that involve volunteers and professional services.

Three years after the release of the Discussion Paper, British Columbia still has no provincial strategy for end of life care. The British Columbia Hospice Palliative Care Association (BCHPCA) is the provincial voice for hospice palliative care in BC and supports the need for regional integrated programs aligned with the norms of the Canadian Hospice Palliative Care Association.

The BCHPCA urges the provincial government to release an end of life strategy for BC and over the next two years to begin implementing the following specific strategies:

1. Changing physician billing schedules in order to support family physicians in providing palliative care in the home.
2. Investing in the education of caregivers at all levels including professionals and community health workers, students, volunteers, family caregivers and the public
3. Eliminating per diem user fees charged according to provincial policies for residential hospice services and providing additional funding to replace the resulting lost income.
4. Establishing policy/legislation/funding supports for care outside of acute care that will allow patients and families to receive care in their homes or in a hospice residence.
5. Developing strategies which are inclusive ofther patient populations not just cancer, in terms of services and supports.
6. Providing supports such as additional staffing, specialized equipment, medications and supplies to palliative patients living in residential facilities so they do not have to be transferred to acute care to die.
7. Ensuring job security for those who must take leave time from their employment to care for someone who is dying.
8. Including non prescribed therapies and services such as home oxygen, counseling, bereavement support, nutritional supplements, etc.
9. Review the BC PC Benefits program and make the information available publicly.

The Provincial Ministry of Health must recognize that improvements in end of life care in BC require an investment in the resource infrastructure, education and recruitment of knowledgeable health professionals and support for volunteer associations, if the needs of British Columbians and their families who are facing life limiting illness and bereavement are to be met.

INTRODUCTION

The British Columbia Hospice Palliative Care Association (BCHPCA) is an umbrella organization whose purpose is to ensure the quality of life for all British Columbians affected by life limiting illness, death, and bereavement. BCHPCA serves 300 individual members and 100 member programs in BC and the Yukon by building and supporting the capacity of the hospice and palliative care community and providing leadership and advocacy at all levels as the collective voice of hospice palliative care in BC.

Our members provide a broad range of services that include both professional and volunteer components such as medical symptom management, spiritual care, volunteer and bereavement support, psychological counseling, pharmacy and nursing care. A BCHPCA Board member sits on the Board of the Canadian Hospice Palliative Care Association (CHPCA), which is the national association for hospice palliative care in Canada. CHPCA offers leadership in the pursuit of excellence in care for persons approaching death so that the burden of suffering, loneliness and grief is lessened.

The purpose of this briefing paper is to identify a number of key areas for action that are required to achieve the goal of ensuring quality end of life care for British Columbians.

BACKGROUND

The nationally accepted definition of hospice palliative care cited in the document developed by the CHPCA (2002), *A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice:* states that:

Hospice Palliative Care (HPC) aims to relieve suffering and improve the quality of living and dying. It strives to help patients and families to: address physical, psychological, social, spiritual and practical issues, prepare for and manage self – determined life closure and the dying process and cope with loss and grief during the illness and bereavement. HPC is appropriate for any patient/family with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet needs, and are prepared to accept care.

End of Life Care (EOL) (Institute of Medicine, 1997) is a term which refers to the reliable, skillful and supportive care of people with advanced potentially fatal illnesses and those close to them.

Numerous reports have been written in Canada over the last few years identifying the need for improvements in care for the dying. These include the Senate of Canada reports, ***Of Life and Death (1995)*** and ***Quality End of Life Care: The Right of Every Canadian (2000).*** Five years later, Senator Sharon Carstairs released an assessment which decried the lack of progress in the earlier documents aptly titled: ***Still Not There (2005).***

The BC Ministry of Health Services (BC MOHS, 2002) developed a ***Discussion Paper on a Provincial Strategy for End of Life Care in British Columbia.*** The paper noted that the majority of people in BC were dying in hospital often without appropriate care and support. Key challenges identified were the rise in demand for end of life care, the use of inappropriate settings for end of life care, a need for coordination of services, meeting the needs of distinct populations, lack of integration in end of life care and a scarcity of research and public awareness of care options. Yet three years later a provincial strategy has not been publicly released!

Last year approximately 22,000 people died in British Columbia (BC). The CHPCA (2004) assumes that about 65% of persons who die could benefit from Hospice Palliative Care Services. Based on self report by British Columbians in the Ipsos- Reid poll (2004), if we assume that 22% of these persons had access to hospice palliative a service that means that over 11,000 patients and families in BC will have been without the standard of care that is increasingly recognized as necessary to support a quality death.

As noted in the Romanow Commission Report (2002) , the overwhelming majority of people who die are the elderly. Yet at this time, 90% of HPC services are largely provided to cancer patients. It is known that only 1 in 5 people will die with

a recognized and terminal illness that has a predicable course. Two thirds of us will die of a more serious chronic illness that gradually restricts our activities, often requiring hospital care.

Recent economic studies point to a common picture of costly acute care utilization during the last year of life often linked to inappropriate and often overly aggressive treatment. We remain a death defying culture with deep seated beliefs in the limitless possibilities of medical technologies. In Canada and BC, our services for end of life are largely geared towards those, whom Dr. Joanne Lynn (2004), a clinician and researcher in geriatric medicine, describes in her book: ***Sick to Death and Not Going to Take It Anymore,*** as "sure to die" rather than the majority of elderly patients who are "sick enough to die".

Unfortunately in Canada today, many of our hospice palliative care services and programs are by definition set up to disqualify those "sick enough to die". An example of this would be the BC Palliative Care Benefits program, which supplies medications, medical equipment and supplies to home care patients but is restricted to the last six months of life.

The following facts will paint a picture of the challenges we face in Canada (CHPCA, 2004):

- Rates of death in Canada will increase by 33% to the year 2020.
- Each death in Canada affects the immediate well being of an average of five other people or more than one million each year.
- 75% of deaths in Canada take place in acute and long term care facilities.
- 2004 Ipsos Reid study reported Canadians estimate 54 hours per week would be required to take care of a dying loved one, but 64% of those polled said they could NOT devote this much time.
- For the 248,000 Canadians who died in 2004, we have only 200 palliative care physicians (full and part time).
- Canadians living in remote and rural areas or those living with disabilities have severely limited access to HPC.

National Recommendations

In order to meet these challenges the following recommendations have been put forward by the CHPCA and the Quality End of Life Care Coalition of Canada (QELCCC) (March 2005) :

1. The federal government, in collaboration with the provinces, must develop a national strategy on end of life care. Currently one million dollars has been allocated by Health Canada for this work. The QELCC estimates that 20 million dollars per year is needed to ensure that a sustainable long term strategy is in place. This amount would allow the engagement of all levels of government as well as health care and community stakeholders to participate. A national strategy that has long term funding linked to provincial governments can be a strong catalyst for educating Canadians to make informed decisions about death and dying, build an interdisciplinary network of research and education in palliative care to occur and provide a strong evidence base for decisions and performance measurement.

2. All provincial/territorial governments fund a comprehensive, coordinated integrated set of end of life services that would include access to:

- HPC professionals and volunteers 24 hours per day, 7 days a week in all four settings including acute care hospitals, and long term care facilities, residential hospices or the home.
- Home care services including home support.
- Care for the caregiver often referred to as respite care
- Compassionate leave for the caregiver(financial assistance).
- Prescription medications
- Access to non-prescribed therapies

3. There is a need at <u>both</u> the federal and provincial level for clarification of the legislation around end of life issues, such as terminal sedation, withdrawal of treatment, medical futility and advance care planning. Many of these end

of life issues remain undefined in law and poorly understood by the public. As a result, they are deeply challenging to physicians, nurses and the judicial system.

A CALL TO ACTION FOR BRITISH COLUMBIA

In British Columbia we currently have a strong base of committed volunteers, community groups and professionals who are developing innovative quality programs. The BCHPCA supports the need for regional integrated programs and services as the foundation for achieving the goals of quality end of life care. These programs need to be developed under sound principles which align with the Norms and Practices of CHPCA. BC can become a leader in end of life care in Canada. This paper outlines the principles and attributes under which such programs should develop as well as the specific actions that could occur in the next two to three years.

Regional Integrated Programs and Services

Important components of integrated services include:

- A primary care model (family physician and home health nurse with basic EOL /HPC skills) supported by community based interdisciplinary teams of professional, volunteer and community care providers with EOL/HPC skills..
- Designated individuals in communities responsible for implementation and maintenance of the local community program and services.
- Development of grief and bereavement services
- 24/7 care available with adequate community supports such as family physician, home nursing care, home support and volunteers.
- Care coordinated throughout the continuum i.e., residential care, acute care, primary care office, home and residential hospice care.
- Access to adequate acute/tertiary services.
- Development of alternatives to acute care which allow for a wide range of options to be available and adequately resourced i.e., hospice/respite beds.
- Priority admission to acute care/respite when needed so that patients are not admitted through the emergency department.
- Palliative care physician support through service contracts or sessional support.
- Support for specialized education and ongoing training at all levels including volunteers and informal caregivers
- Dedicated resources that ensure adequate social work, counseling and spiritual care professional services are integral to all HCP programs
- For Residential Hospices, the province should begin to address the lack of Canadian and provincial standards for human resources, design, licensing or standards of care under which hospice facilities should operate.

Structures and Accountabilities of HPC Programs

In order to be effective, the following attributes of integrated programs must be recognized and adhered to:

- Application of the Norms of practice and program elements as described by the CHPCA (2002) in particular, the location of patients and families at the centre of care, the need for an interdisciplinary team (including volunteers), and the necessity for care that moves across all settings, diseases and illness trajectories including bereavement.
- Planning and coordination, standard setting, quality indicators and best practices should be at the central level in each region, while care delivery should be driven by local/community based teams who have the flexibility to implement services based on the unique needs and characteristics of the community
- Care must be cost effective i.e., shift from an acute care focused model of delivery to a community based one that improves access and quality, while avoiding unnecessary diagnostic and interventional costs.

- Equitable resources exist amongst communities which reflect the realities of rural or hard to reach communities.
- Health Authorities be required to provide an integrated network of hospice palliative service to patients and families in all sectors (acute care, home and community care) as a defined core service.
- Health Authorities be directed through the provincial strategy to consider EOL/HPC a strategic priority activity.
- Health Authorities be required to measure their progress towards specific goals and provincial benchmarks around access, cost and quality.
- The EOL/HPC services should have both clinical and administrative leadership and encompass all sectors of care.
- EOL/HPC services would be represented by a dedicated leadership position at the senior administrative level with responsibility and accountability for such services.
- Relationships exist between Health Authorities, Hospice Societies and other related community providers in order to ensure provision of consistent, seamless care to patients and families. These partnerships should be formalized through contracts that acknowledge the contribution of each partner and ensure ongoing relationships and viability of the services.

Specific Action Steps 2006 to 2008:

The BCHPCA urges the provincial government to move quickly in implementing the following strategies:

- Changing physician billing schedules in order to support family physicians in providing palliative care in the home.
- Investing in the education of caregivers at all levels including professionals and community health workers, students, volunteers, family caregivers and the public
- Establishing policy/legislation/funding supports for care outside of acute care that will allow patients and families to receive care in their homes, in a hospice residence
- Eliminating per diem user fees charged according to provincial policies for residential hospice services and providing additional funding to replace the resulting lost income..
- Developing strategies which are inclusive of other patient populations' not just cancer in terms of services and supports.
- Providing supports such as additional staff, specialized equipment, medications and supplies to palliative patients living in residential facilities so they do not have to be transferred to acute care to die.
- Ensuring job security for those who must take leave time from their employment to care for someone who is dying.
- Including non prescribed therapies and services such as home oxygen, counselling, bereavement support, nutritional supplements, etc.
- Reviewing the BC PC Benefits program and make the information available to the public.

CONCLUSION

BCHPCA was involved with and supported the strategies described within the provincial discussion paper of 2002. They represent substantial improvements and enhancements to our current system of care. BCHPCA is particularly pleased to see the support for community/voluntary sector as a key element of the proposed strategic direction. We support the strategy outlined to formalize partnerships with Hospice Societies. Tremendous capacity can be achieved through partnership with communities that are unachievable through the public health care system.

However, it is critical the Provincial Ministry of Health recognizes that further resources are required to implement strategies for quality EOL/HPC and that implementation for such plans must begin immediately. Investments now, in less costly options for care, for the ever increasing numbers of patients and families who will be requiring care, not only makes better use of public resources but increases safety and quality by providing the right kind of care.

BCHPCA is planning early in 2006 to provide leadership in the bringing together of the many professional and community groups in British Columbia who share a passion for quality end of life care such as was done at the national

level with the QELCC. If all such groups with a stake in improving end of life care form such a coalition, together we can develop a clear vision and devote our energy and talents to addressing the enormous task before us.

Those involved in the provision of health care as well as volunteer and community groups look forward to further defining and enabling "real" improvements in end of life care in BC and building on the work and passion of those caring for the dying and bereaved.

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APPENDIX D
Canadian Hospice Palliative Care
FACT SHEET

Canadian Hospice Palliative Care Association

Association canadienne de soins palliatifs

Fact Sheet: Hospice Palliative Care in Canada

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.[1]

The Demand for Hospice Palliative Care in Canada

- Canada's population is aging. As a result, the Canadian Hospice Palliative Care Association (CHPCA) estimates that over the next 40 years demand for hospice palliative care services will continue to increase.
- Each year more than 259,000 Canadians die.[2]
- The leading causes of death in Canada are: diseases of the circulatory system (about 35%), neoplasms (tumours or cancers) (about 28%) and diseases of the respiratory system (about 10%).[3] Hospice palliative care programs and services are beneficial for all of these groups, which total 73% of all Canadian deaths.
- In 2004, Statistics Canada projected that the rate of deaths in Canada will increase by 33% by the year 2020 to more than 330,000 deaths per year.[4]
- In 2007, 37% of Canadians reported that they have been diagnosed by a physician as having a chronic condition or illness.[5]
- 1 in 3 Ontarians lives with one or more chronic diseases. Of those, almost 4 of 5 over the age of 65 have one chronic disease, and of those, about 70% suffer from two or more.[6]
- Chronic diseases account for 70% of all deaths.[7]
- The CHPCA estimates that each death in Canada affects the immediate well being of an average of five other people, or more than 1.25M 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 family and informal caregivers.[8]

Access to Hospice Palliative Care in Canada

- The 2000 Senate Report *Quality End-of-Life Care: The Right of Every Canadian* reported that approximately 15% of Canadians who require hospice palliative care services have access to these specialized services.[9]
- Canadians living in remote and rural areas, or those living with disabilities, have severely limited access to hospice palliative care services.
- When asked, most people have indicated that they would prefer to die at home in the presence of loved ones[10], yet almost 60% of Canadian deaths occur in a hospital[11]
- 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.

CHPCA Fact Sheet – Hospice Palliative Care in Canada
April 2008

Page 1 of 6

- Inadequate government support for hospice palliative care programs results in a significant additional burden on family and 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.[12]
- 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.[13]
- 75% of deaths today still take place in hospitals and long-term care facilities.[14]
- Billing schedules under provincial health plans focus on clinical procedures and discourage physicians from practicing palliative care in the community.
- 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.[15]
- The QELCCC Framework includes three distinct models or working groups:[16]
    - Intra-Governmental Consultation & Engagement Working Group
    - Inter Governmental & Stakeholder Consultation and Engagement Working Group
    - Community-Based Working Group
- The QELCCC Framework also addresses the following key areas:[17]
    - Research
    - Policy Development & Best Practices
    - Knowledge Transfer
    - Knowledge Translation & Dissemination
- In December 2006, the Canadian Hospice Palliative Care Association and the Canadian Home Care Association published *The Pan-Canadian Gold Standards for Palliative Home Care: Toward Equitable Access to High Quality Palliative and End-of-Life Care at Home.* This document identifies the gold standard level of care and a consistent approach across the country for hospice palliative care services at home in the following areas: Case Management, Personal Care, Nursing Care and Palliative-Specific Pharmaceuticals.[18]

Training and Education

- Canada currently has just over 200 palliative care physicians who work either full-time or part-time.[19]
- Canada's schools of nursing are moving forward with plans to offer formal hospice palliative care training and education as part of their curriculum.
- In April 2004, the Canadian Nurses Association (CNA) began to offer Hospice Palliative Care Nursing Certification to Canadian nurses.[20]
- 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.
- Hospice palliative care training and education is equally under-funded for other disciplines engaged 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-hosted a project, entitled Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC), which worked with all 17 medical schools in Canada. Its purpose was

to integrate hospice palliative care education into the core medical curriculum by its completion in March 2008.[21]

Research

- There is an acute need for research into more effective pain and symptom management, psychosocial aspects of hospice palliative care, and effective methods of delivering hospice palliative care services and programs within the health care system
- Traditionally hospice palliative care research has been poorly funded. A sustained hospice palliative care research strategy is required to ensure a coordinated approach to this issue.[22]
- In 1999, the Canadian Hospice Palliative Care Association (CHPCA) produced the *Canadian Agenda for Research in Palliative Care*. Recommendations included the need to build research capacity in Canada by establishing more fellowships in hospice palliative care for researchers in the early stages of their careers.[23]
- On September 21st 2004, the Canadian Institutes for Health Research (CIHR) announced 16.5M dollars to fund research in hospice palliative care.[24] The CIHR funding allows for a rich diversity of research topics in hospice palliative care including:
  - 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

- In 2007, 23% of Canadians said that they had cared for a family member or close friend with a serious health problem in the last 12 months. Adverse effects on this group of people included: using personal savings to survive (41%) and missing one or more month of work (22%).[25] In 2006, of the 26% of Canadians who said that they had cared for a family member or close friend with a serious health problem in the previous 12 months, other adverse effects reported were: negative effect on mental health (41%) and negative effect on physical health (38%).[26]
- 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.[27]
- As a leading-edge global company, GlaxoSmithKline has included in their employee benefit package the option of up to 13 weeks paid leave to employees who require time away from work to care for a dying family member.[28]
- 70% of family and informal caregivers acknowledge that providing care to a loved one is stressful.[29]
- 70% of family and informal caregivers indicate that they require time away from the responsibility of caring for a loved one.[30]
- Whether or not the family or informal caregiver has a choice in taking on the role of caregiver is a significant factor in the degree of stress and disruption they experience[31]
- Formal support is important, but does not seem to reduce stress.[32]
- Family and informal caregivers providing hospice palliative care at home are undertaking a wider range of tasks in an environment where they typically have less support from

professional caregivers. Tasks assigned to family and informal caregivers may include: psychological, social and spiritual care; personal care; medical care, including administration of medications and injections; homemaking services; and advocacy and care-coordination.[33]

- In January 2004 Human Resources and Skills Development Canada (HRSDC) began offering the Compassionate Care Benefit through the Employment Insurance program. The benefit provides 8 weeks leave (6 weeks paid) to eligible Canadians to care for a dying loved one.[34]

The Role of Home Care

- The delivery of formal home care generally relies on public funding. Unfortunately there has been an increase in the demand for home care services without an increase in funding of these programs.
- A lack of funding of home care programs affects the need for trained volunteers and family and informal caregivers.
- There is a shortage of home care workers in urban, rural and remote areas.
- In 2003 the Home Care Sector Study Corporation published a report entitled Canadian Home Care Human Resources Study that has projected that if all variables remain the same, in 2046 Canada can expect to have more that 750,000 Canadians receiving home care. When factoring in changes in the age distribution of the population, by 2046 Canada may have an additional 700,000 people using home care. This means that if we had the population distribution today which we will have in 2046 we may need to care for twice as many people with home care as we do today.[35]
- The Canadian Home Care Human Resources Study indicates that 65% of family and informal caregivers are under 50 years of age with 64% of them working full time, part-time or self-employed.[36]
- Emerging pan-Canadian health trends indicate that effective home care can contribute to lower long-term costs for the health care system, therefore these costs should fall under the parameters of the *Canada Health Act*.[37]

Funding for Hospice Palliative Care Programs

- Generally hospice palliative care programs rely disproportionately on charitable giving; a majority of the cost of programs is provided by private donors, restricting the size, scope and access to programs.
- Currently only a small number of provinces have designated hospice palliative care as a core service under their provincial health plans. In the remaining provinces, hospice palliative care may be included in provincial home care budgets or other health service budgets, leaving the funding vulnerable to budget reductions.
- 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.[38]

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 30 national associations and organizations with an interest in end-of-life care issues.[39]
- The QELCCC supports the full implementation of the recommendations identified in the June 2000 Senate report entitled *Quality End-of-Life Care: the Right of Every Canadian.*[40]
- The GlaxoSmithKline Foundation in partnership with the CHPCA have created the ***Living Lessons®*** initiative, a public awareness and social marketing campaign designed to provide tools and resources to patients, family members, caregivers, volunteers and health care providers.[41]

Secretariat on Palliative and End-of-Life Care (Health Canada)[42]

- From 2001 to 2006 the federal government funded the Secretariat on Palliative and End-of-Life Care (Health Canada) with an annual budget between $1M and $1.5M dollars.
- The Secretariat was charged with the development and implementation of a National Strategy for Palliative and End-of-Life Care in Canada.
- The Secretariat focused on the following three areas:
    - Community
    - Inter-Departmental (at the Federal level)
    - Federal/Provincial/Territorial
- The Secretariat created five Working Groups and a Coordinating Committee to oversee the development and implementation of the National Strategy.
- The five Working Groups included:
    - Research
    - Surveillance
    - Public Information and Awareness
    - Professional Education
    - Best Practices and Quality Care
- The 2006-2007 budget for the Secretariat on Palliative and End-of-Life Care (Health Canada) was $470,000, down from almost 1.2M in 2005-2006.
- In March 2007, the Secretariat disbanded the Working Groups and the Coordinating Committee.
- In April 2007, the Secretariat entered into an evaluation and analysis phase and will report to the Minister of Health when their analysis is complete.

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