



AN INTEGRATED PALLIATIVE APPROACH TO CARE • DES SOINS QUI INTÈGRENT L'APPROCHE PALLIATIVE



SYNTHESIS OF RECOMMENDATIONS FROM NATIONAL  
REPORTS ON HOSPICE PALLIATIVE CARE:  
A DISCUSSION PAPER - MAY 2012

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## PREAMBLE

This discussion paper has been developed as part of a series of scoping reviews and discussion papers which will form part of the foundational documents for the Quality End-of-Life Care Coalition of Canada's initiative **The Way Forward: Towards Community-Integrated Hospice Palliative Care in Canada**. The goal of the initiative is to engage critical stakeholders in dialogue and action to move forward a community-integrated system of hospice palliative care. In particular, the two key objectives will be: to change the understanding and approaches to aging among key stakeholders as they relate to chronic, serious and life-limiting illness and dying, and hospice palliative and end-of-life care and advance care planning; and to enable stakeholders to move towards community-integration of hospice palliative care across all care settings. By engaging in collaborative partnerships which influence real change, the initiative will develop a framework to achieve transformative change.

The purpose of this discussion paper is to summarize the recommendations from the relevant national reports on hospice palliative care over the last two decades. This paper will form part of the background work necessary to articulate the issues, landscape, challenges and opportunities which need to be considered in order to achieve the objectives of the initiative.



## BACKGROUND

Since 1995, there have been nine major national consultations with Canadians dealing in whole or in part with hospice palliative and end-of-life care. The nine final reports from these studies contain a total of 85 recommendations for improving care for the dying and their families. The 85 recommendations can be grouped into five broad policy categories:

- 1. ACCESS TO CARE;**
- 2. SUPPORTS FOR FAMILY CAREGIVERS;**
- 3. QUALITY OF CARE;**
- 4. ADVANCE CARE PLANNING AND PUBLIC AWARENESS; AND**
- 5. FEDERAL RESPONSIBILITY.<sup>1</sup>**

This discussion paper will summarize the 85 recommendations from the nine national reports, examine the continued relevance of these recommendations and identify recommendations which are still important to implement as potential priority areas for the Integration Initiative (the initiative).

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<sup>1</sup> These policy categories closely reflect the Quality End-of-Life Care Coalition's policy priorities as set out in the Blueprint for Action 2010 to 2020:

1. Ensure all Canadians have access to high quality hospice palliative end-of-life care.
2. Provide more support for family caregivers.
3. Improve the quality and consistency of hospice palliative end-of-life care in Canada
4. Encourage Canadians to discuss and plan for end-of-life.

## OVERVIEW OF THE REPORTS

The following table summarizes the nine national reports since 1995 which are reviewed in this paper. Each of these reports either specifically addressed palliative and end-of-life care in Canada, or contained significant recommendations regarding end-of-life care. Also, each of these reports included significant national public consultations with stakeholders and ordinary Canadians.

DATE	REPORT	DESCRIPTION
June 1995	<p><i>Of Life and Death</i></p> <p>Final Report of the Special Senate Committee on Euthanasia and Assisted Suicide. Senate of Canada.</p> <p>The Honourable Senator Joan Neiman, Chair.</p>	<p>Although the report primarily examines the issues of assisted suicide and euthanasia, it contains chapters on palliative care, pain control and sedation practices, and advance directives. Although not specifically part of the study at the outset, these issues were raised repeatedly during the public hearings, and the Committee included these chapters in its final report. The Committee was unanimous in the 12 recommendations made in these three chapters.</p>
June 2000	<p><i>Quality End-of-Life Care: The Right of Every Canadian</i></p> <p>Final Report of the Subcommittee to Update Of Life and Death of the Standing Senate Committee on Social Affairs, Science and Technology. Senate of Canada.</p> <p>The Honourable Senator Sharon Carstairs, Chair.</p>	<p>In the fall of 1999 a Subcommittee of the Senate was struck to examine the developments in palliative and end-of-life care in the five years since the tabling of the 1995 report, <i>Of Life and Death</i>, and the progress made in implementing the unanimous 1995 recommendations.</p> <p>The report found little had been done to implement the 1995 recommendations. It contained two recommendations which reiterated support for the 1995 recommendations and made an additional 12 new recommendations concerning palliative and end-of-life care.</p>
October 2002	<p><i>The Health of Canadians – The Federal Role</i></p> <p>Volume Six: Recommendations for Reform.</p> <p>Final Report of the Standing Senate Committee on Social Affairs, Science and Technology. Senate of Canada.</p> <p>The Honourable Senator Michael J.L. Kirby, Chair.</p>	<p>This report was the culmination of a two year study by a Senate Committee on the state of the Canadian health care system and the federal role in that system. Although more generally about Canada's health care system, five of the 106 recommendations were specifically on palliative home care and caregivers.</p>
November 2002	<p><i>Building on Values: The Future of Health Care in Canada</i></p> <p>Final Report of the Royal Commission on the Future of Health Care in Canada. Government of Canada.</p> <p>Roy J. Romanow, QC, Commissioner.</p>	<p>Known as the Romanow Commission, this Royal Commission was struck by the federal government to report on the future of Canada's public health care system, and to recommend policies and measures required to ensure the long term sustainability of a universally accessible, publicly funded health system. Two of the 47 recommendations specifically relate to palliative care.</p>

DATE	REPORT	DESCRIPTION
June 2005	<b><i>Still Not There. Quality End-of-Life Care: A Progress Report</i></b> Senate of Canada. The Honourable Sharon Carstairs, P.C., Author	This report by Senator Sharon Carstairs examines developments in end-of-life care in the five years since the tabling of the 2000 Senate report <i>Quality End-of-Life Care: The Right of Every Canadian</i> . It was tabled in the Senate and contained ten recommendations.
April 2009	<b><i>Canada's Aging Population: Seizing the Opportunity</i></b> Final Report of the Special Senate Committee on Aging. Senate of Canada. The Honourable Sharon Carstairs, P.C., Chair	This report is the culmination of a two and a half year study of a Special Senate Committee on Canada's aging population. Eight of its 32 recommendations are specifically related to palliative and end-of-life care and caregivers.
June 2010	<b><i>Raising the Bar: A Roadmap for the Future of Palliative Care in Canada</i></b> Senate of Canada. The Honourable Sharon Carstairs, P.C., Author	This report by Senator Carstairs examines developments in end-of-life care in the ten years since the tabling of the 2000 Senate report <i>Quality End-of-Life Care: The Right of Every Canadian</i> and the five years since the tabling of <i>Still Not There: Quality End-of-Life Care: A Progress Report</i> . Tabled in the Senate, it contained 17 recommendations.
November 2011	<b><i>Not to Be Forgotten: Care of Vulnerable Canadians</i></b> Final Report of the ad hoc Parliamentary Committee on Palliative and Compassionate Care House of Commons. Harold Albrecht MP, Co-Chair Joseph Comartin MP, Co-Chair Frank Valeriote MP, Co-Chair	This report is by an ad hoc, all party committee of Members of the House of Commons and addresses palliative care, suicide prevention, elder abuse and disability issues. Eleven of the 14 recommendations concern palliative care and support for caregivers.
March 2012	<b><i>Time for Transformative Change: A Review of the 2004 Health Accord</i></b> Final Report of the Standing Senate Committee on Social Affairs, Science and Technology The Honourable Kelvin Kenneth Ogilvie, Chair	In January of 2011, The Standing Senate Committee on Social Affairs, Science and Technology was charged with examining and reporting on the progress in implementing the 2004, <i>10-Year Plan to Strengthen Health Care</i> . This report was more generally about the reform of the 2004 Health Accord and tabled 46 recommendations based on 13 hearings and one roundtable discussion. Six of the recommendations focused on hospice palliative care.



## SYNTHESIS OF RECOMMENDATIONS

The recommendations have been grouped into five policy areas. Each section will include a summary of the recommendations, examine the continued relevance of these recommendations and identify recommendations which are still important to implement as potential priority areas for this initiative.

For a list of the complete recommendations from the nine national reports grouped by policy area, please see Appendix A (pg. 21).

### Excluded Recommendations

Two recommendations do not appear anywhere in the policy groupings which follow as they are of a different nature. In 2000, the report reiterated support for the unanimous recommendations found in the 1995 report and made two recommendations about them.<sup>2</sup>

Recommendation 13 reads:

*That the federal government, in collaboration with the provinces, develop a five-year plan for implementing the 1995 unanimous recommendations.*

Recommendation 14 reads:

*That the federal government prepare an annual progress report on the implementation of the unanimous recommendations.*

These recommendations were addressed partially through the Canadian Strategy on Palliative and End-of-Life Care from 2002 to 2007 and by the annual progress.

<sup>2</sup> Carstairs, The Honourable Sharon, Chair. *Quality End-of-Life Care: The Right of Every Canadian*. Final report of the Subcommittee to Update of Life and Death of the Standing Senate Committee on Social Affairs, Science and Technology. June 2000. Senate of Canada. p.38.



## A. ACCESS TO CARE

The issue of access to palliative care has been raised in all nine reports with a total of 24 recommendations covering the establishment of a national strategy, the need for integrated care, and funding and support for homecare and pharmacare.

### SUMMARY OF RECOMMENDATIONS

**1995 NEIMAN** - The recommendations were for governments to make palliative care programs a top priority in the restructuring of the health care system and for there to be an integrated approach to palliative care coordinated across care settings.

**2000 CARSTAIRS** - This report contained seven recommendations around improving access to palliative care. Three recommendations noted the development of a national strategy for end-of-life care, a five year implementation plan for implementing the strategy, and an annual progress report on the implementation of the strategy. A fourth recommendation concerned assessing the need for homecare and pharmacare and appropriate funding. A fifth recommendation highlighted the establishment of a federal interdepartmental strategy on end-of-life care. The final two recommendations on access to care were for the federal minister to discuss at the next First Ministers' meeting regarding both the strategy on end-of-life care and appropriate measures for funding end-of-life initiatives.

**2002 KIRBY** - The report recommended the federal government contribute \$250 million per year towards a National Palliative Home Care Program to be shared 50/50 with the provinces.

**2002 ROMANOW** - The report recommended a new Home Care Transfer to support the expansion of the *Canada Health Act* to include medically necessary services in several areas, including palliative home care services.

**2005 CARSTAIRS** - The report recommended long-term sustainable funding for the further development of a cross departmental, cross jurisdictional Canadian Strategy on Palliative and End-of-Life Care. It also recommended that federal, provincial and territorial governments

make palliative care a top priority in the restructuring of the health care system through implementing norms of practice across jurisdictions, integrating services to make transitions between health care settings seamless and enhancing homecare and pharmacare, including respite care.

**2009 CARSTAIRS** - The report recommended a federal initiative to provide funding support to provinces and territories to facilitate the move towards integrated models of care and that the federal government fund a national partnership with provinces, territories and community organizations to provide leadership and vision to support the provision of integrated quality end-of-life care for all Canadians.

**2010 CARSTAIRS** - There were five recommendations in the report pertaining to improving access to palliative care. First, the report recommended the re-establishment of the Canadian Strategy on Palliative Care as a partnership between the federal, provincial and territorial governments and the community. Second, it recommended a Health and Social Care Transition Fund to assist in the realignment of the health care system, including support for transitioning to alternate settings of care such as residential hospice or home care. Third, it recommended the establishment of common data definitions, technologies and policies within health care regions to facilitate smoother transition between care settings. A fourth recommendation was that palliative care services be covered under all provincial and territorial health plans. A fifth recommendation was for reciprocal agreements among provincial and territorial jurisdictions to create national standards of palliative care services and improve portability of service between jurisdictions.

### 2011 ALBRECHT, COMARTIN & VALERIOTE -

The report contained four recommendations. It recommended the re-establishment of the Palliative Care Secretariat to develop a National Palliative and End-of-Life Care Strategy to collaborate on developing and implementing national standards, coordinate the dissemination of research and information and provide ongoing support and coordination to the Strategy. It also recommended the development of a flexible integrated model of palliative health care delivery, including funding to the provinces and territories for implementation; the development of rural palliative care delivery within the primary health care system utilizing home care services and long term care homes; and the

implementation of a right to homecare, long term care and palliative care for all residents of Canada, equal to the current rights in the *Canada Health Act* for insured health services.

**2012 OGILVIE** – The report contained three recommendations. It recommended that jurisdictions expand public pharmaceutical coverage to drugs and supplies used by home care recipients. The report also recommended that the federal government work with the provinces and territories to increase access to palliative care as part of end-of-life health services in a broad range of settings, including residential hospices, and that the governments develop and implement a strategy for integrated hospice palliative care systems.

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## CONTINUED RELEVANCE

Although there have been some initiatives since 1995 in the areas of establishment of a national strategy, the need to move to an integrated model of care, and funding for homecare and pharmacare, access to palliative care services continues to vary significantly from province to province, and often even within a province. Rural and remote areas have even less access to services.

There have been a number of recommendations for the federal government to take on a leadership role to support standards, best practices, public awareness, research and capacity building through the creation of a national strategy. The federal government created the Secretariat on Palliative Care at Health Canada in 2001 to support the Minister with Special Responsibility for Palliative Care and funded the Canadian Strategy on Palliative and End-of-Life Care from 2002-2007. Although there were many successes under the Canadian Strategy, it ended in 2007. The Secretariat at Health Canada has also been discontinued and now a Palliative and End-of-Life Care Unit within Health Canada's Strategic Policy Branch is the federal focal point for issues faced by Canadians who are dying or dealing with life-threatening illnesses. Canada does currently have eight

national health strategies. Palliative care is one of four pillars in the National Cancer Strategy and is identified as a priority in the National Heart Health and HIV/AIDS strategies.

Recommendations in 2009, 2010, 2011 and 2012 have reiterated the need for a national partnership between the federal, provincial, and territorial governments and community organizations to provide leadership and coordination to ensure the provision of integrated quality end-of-life care for Canadians. In particular, the reports note the need for common standards, best practices, coordination and capacity building to ensure equitable access for all Canadians across all settings of care. These recommendations for coordination and leadership are still relevant.

The 2009 recommendation of the Special Senate Committee on Aging regarding a move towards integrated models of care is also still relevant. An integrated model of care would: integrate a broad domain of services, including health care, home and community services and residential care services; improve access to comprehensive care; increase emphasis on health promotion, disease prevention and chronic disease management; expand multi-disciplinary teams; improve portability between provinces; and provide access

to the appropriate services needed by patients and families when and where they need them.

In 2001, the issue of palliative care was on the agenda of a federal, provincial and territorial meeting of Ministers of Health. It was also included in the 2003 and 2004 Health Accords. In particular, in the 2004 Health Accord, there was an agreement to provide first dollar coverage by the end of 2006, based on assessed need, for a base level of home palliative care services, including: case management; nursing; palliative care specific pharmaceuticals; and personal care at end-of-life. These services have been implemented to varying degrees across the provinces and territories. For example, in February 2012 the Nova Scotia government

became the last jurisdiction to agree to cover pharmaceuticals for palliative care. However, not all jurisdictions have 24/7 access to hospice palliative care professionals and access to palliative home care services vary greatly across the country. In the March 2012 report, a recommendation detailed the need for improved pharmaceutical drug coverage for home care recipients.

Three of the reports, 2010, 2011 and 2012, also called for palliative care to become a core service, covered by provincial and territorial health insurance plans, similar to the way hospital services, physician services and surgical dental services are defined as “insured health services” under the *Canada Health Act*.

### POTENTIAL PRIORITY ACTION AREAS

- Foster a national partnership between all jurisdictions and community organizations to provide the leadership and coordination necessary to ensure equitable access to quality integrated hospice palliative and end-of-life care to all Canadians. This should include encouraging the other national health strategies to incorporate end-of-life care into their strategies.
- Support the move towards an integrated model of care; beginning with community-integration of hospice palliative care across all health care settings.
- Foster interprovincial/territorial cooperation to establish common data definition, technologies, and policies within health care regions to facilitate smoother transitions between care settings, and to eliminate wait times. Also create a national standard of care to improve portability of services between provinces.
- Ensure palliative care services are covered under all federal, provincial, and territorial health insurance plans, perhaps by including them as an insured service under the *Canada Health Act*, thereby recognizing a right to home care, long term care and palliative care for all Canadians.
- Focus on rural palliative home care delivery.

### B. SUPPORTS FOR FAMILY CAREGIVERS

Improving support for family caregivers was not raised in the 1995 report; however, it has been raised in the other eight reports, with a total of 20 recommendations on the issue.

#### SUMMARY OF RECOMMENDATIONS

**2000 CARSTAIRS** - The report recommended income security and job protection for family caregivers.

**2002 KIRBY** - In this report there were four recommendations for family caregiver support. In particular, the report recommended: that Employment Insurance (EI) benefits be extended to Canadians who must take time off to care for a dying relative; that tax measures be expanded to support caregivers; that the federal, provincial and territorial Labour Codes be amended to extend job protection for employees who take leave to care for a dying family member; and that the federal government show leadership by amending Treasury Board legislation to provide job protection for its own employees.

**2002 ROMANOW** - This report contained one recommendation calling for the federal government to develop proposals to provide direct support to informal caregivers.

**2005 CARSTAIRS** - There were two recommendations for family caregiver support. The first was that the new Compassionate Care Leave Benefit under Employment Insurance be amended to improve access and eligibility for the benefit by lengthening the benefit from six to 16 weeks, to allow the patient to determine the best person to be their caregiver, to not limit the benefit to the last six months of life and to mount a public awareness program. The second recommendation was that the federal, provincial and territorial Labour Codes be amended to reflect these changes to the Compassionate Care Leave Benefit.

**2009 CARSTAIRS** - There were three recommendations in the report pertaining to supports for family caregivers: the creation of a National Caregiving Strategy; changes to the

Canada Pension Plan to provide a drop-out provision for caregivers; and a recommendation that the Compassionate Care Leave Benefit under Employment Insurance be amended to improve access and eligibility by eliminating the two week waiting period, increasing the benefit to 75% of earnings, increasing the length from six to 13 weeks and not limiting it to the last six months of life.

**2010 CARSTAIRS** - There were six recommendations in the 2010 report: establishing a Canada Pension Plan drop-out provision; revamping the Compassionate Care Benefit to improve access and eligibility<sup>3</sup>; establishing a Caregiver Benefit similar to the Child Tax Benefit; establishing a National Strategy for Family Caregivers; establishing a program similar to the Nova Scotia Caregiver Allowance to provide income assistance for those not eligible for the EI Compassionate Care benefit; and establishing system navigators to assist caregivers and patients in accessing the supports and services they need.

**2011 ALBRECHT, COMARTIN & VALERIOTE** - The report had three recommendations pertaining to support for family caregivers. It recommended: an expansion of the EI Compassionate Care Benefit to 26 weeks; flexibility for partial weeks to be covered to deal with episodic care needs; an increase in the amount of the benefit; and a change in the qualifying criteria to "gravely ill" instead of "significant risk of death". It also recommended establishing a refundable tax credit for family caregivers and setting up a Canada Pension Plan credit for family caregivers.

**2012 OGILVIE** - This report contained a recommendation that the federal government develop a pan-Canadian Homecare Strategy, which would include a focus on reducing the burdens faced by family and informal caregivers.

<sup>3</sup> This recommendation was similar to the one in 2009 and specified: an awareness campaign; improving the application process; lengthening benefit from six to 26 weeks; increasing the amount of financial assistance; and changing the criteria from "significant risk of death" to "high need of care due to a life-threatening illness". See Appendix A for full recommendation.

## CONTINUED RELEVANCE

The Compassionate Care Benefit under the federal Employment Insurance (EI) program was established in 2004 as a direct result of the recommendations in the 2000 report and both the Kirby and Romanow reports in 2002. The benefit was extended to self-employed persons on an opt-in basis in 2009. The benefit offers six weeks EI benefits to people who have to be away from work temporarily to provide care or support to a family member, or person designated as like family, who is gravely ill and who has a significant risk of death within 26 weeks (six months). As recommended, amendments were made to the Canada Labour Code and Treasury Board regulations to provide job protection for federal employees. All provinces and territories have amended their Labour Codes, with the exception of Alberta.

The Compassionate Care Benefit was amended in 2007 to expand the criteria for the caregiver so that the patient can designate who they wish as caregiver, as was recommended in 2005. However, the other recommendations made in 2005, 2009, 2010 and 2011 regarding improving access and eligibility for the benefit have yet to be implemented.

Since 2002 there have been several improvements to tax measures as well. For example, in 2003 the list of eligible medical expenses was expanded for the medical expense tax credit, and in 2011 the federal government introduced a new 15-per-cent non-refundable Family Caregiver Tax Credit.

However, as noted in several of the reports, not everyone is eligible for the EI Benefit and tax credits are only helpful for those with an income. The economic stresses placed on family caregivers remain high and recommendations for additional income support remain valid.

Apart from income and job protection, the reports have recommended other supports for family caregivers, including: respite care; system navigation; information and education; home care supports; and bereavement care. CHPCA has created some materials to support caregivers, in particular the Living Lessons handbook and training material for family caregivers. However, caregivers are critical components of the health care system and a basket of services is necessary to support family caregivers and safeguard their health and well-being.

### POTENTIAL PRIORITY ACTION AREAS

- Amend Compassionate Care Benefit to improve access and eligibility, by increasing the amount of the benefit, increasing the length of the benefit, simplifying the application process, and amending the criteria regarding “significant risk of death.”
- Establish a refundable tax credit for family caregivers.
- Amendments to the Canada Pension Plan to allow for a caregiver drop-out provision or a Canada Pension credit for family caregivers.
- Creation of a National Strategy for Family Caregivers which addresses not just the financial burden, but also grief and bereavement services, respite care, home care, information and education, system navigation, and promotes research and the dissemination of best practices.



## C. QUALITY OF CARE

Recommendations for improving the quality of palliative care encompass a broad range of strategies including research and dissemination of best practices, education and training for health care providers, and national standards and guidelines. There have been 25 recommendations in seven reports concerning improving the quality of hospice palliative and end-of-life care in Canada.

### SUMMARY OF RECOMMENDATIONS

**1995 NEIMAN** - This report contained eight recommendations concerning improving the quality of palliative care, including recommendations on: developing national guidelines and standards; increased training for health care professionals; additional research; and research, education, training and practice guidelines for pain control and total sedation.

**2000 CARSTAIRS** - The report contained four recommendations aimed at improving quality of care, including: increasing multidisciplinary training and education for health care professionals; creating a Canadian Institute of Health Research (CIHR) institute focussed on end-of-life issues; calling for the Canadian Institute for Health Information (CIHI) to develop and report on indicators for quality end-of-life care; and implementing a multi-dimensional agenda for end-of-life research.

**2005 CARSTAIRS** - The recommendation that CIHI develop indicators for quality end-of-life care was made again in this report along with a second recommendation for CIHR to undertake research on the socio-economic impact of palliative care, including the impact on caregivers. There was a third recommendation on the need for federal support of multi-disciplinary education and training and an integrated and coordinated approach to palliative care across care settings. A fourth recommendation called for education of health care providers on providing treatment for the purpose of alleviating suffering that may have the unintended effect of shortening life.

**2009 CARSTAIRS** - The report contained a recommendation that the federal government apply the palliative homecare gold standards to those populations for which they have direct service delivery. It contained a second

recommendation that CIHR funding for palliative care research be renewed.

**2010 CARSTAIRS** - The report had four recommendations in this area. It recommended that palliative care be recognized as a specialty; that all disciplines adopt nationally standardized core competencies in palliative care; and that professional organizations work in partnership with the CHPCA to promote an early referral system designed to educate and support physicians in referring patients to palliative care services at the time of diagnosis of a life threatening illness. A fourth recommendation was for the creation of a Capacity Building Fund to support the establishment of a health human resources workforce plan, a nationally standardized volunteer training package, research and knowledge translation, dissemination of best practices and the development and implementation of culturally sensitive, interdisciplinary education and training materials for all health care providers.

**2011 ALBRECHT, COMARTIN & VALERIOTE** - The report recommended the federal government provide stable funding to the Pallium Project and the Canadian Virtual Hospice, which it identified as two important examples of innovation, and develop a venue for funding other innovative programs. It also recommended the development and implementation of a National Pain Strategy to provide a unified approach in the delivery of pain control methods.

**2012 OGILVIE** - The report recommended that the federal government develop indicators to measure the quality and consistency of home care, end-of-life care and other continuing care services across the country.

## CONTINUED RELEVANCE

Although there have been some initiatives since 1995 in the areas of research, education and training and the development of national standards, the quality and consistency of palliative care services continues to vary significantly from province to province, and often even within a province.

With respect to research, although a specific CIHR institute on Palliative and End-of-Life Care was not created, in 2003 the CIHR's Institute on Cancer Research led a Palliative and End-of-Life Care Research Initiative in collaboration with 18 partners, including several other CIHR institutes. The objectives of the Initiative were to support infrastructure development, enhance interdisciplinary research collaboration, encourage the development of early career researchers and attract trainees to this emerging area. With a total investment of \$16.5 million over six years, the Initiative was the largest research investment in palliative and end-of-life care research in Canada. CIHR also allocated \$25 000 per year to create a peer review committee to set research priorities. Since 2009, CIHR funding for palliative care research has decreased substantially. CIHR has several current projects and a new Network Centre of Excellence, known as TECH VALUE NET, will be established this year with a focus on research evaluating technologies for the critically ill elderly, including palliative care.

However, the 2010 report found a need for additional research in the socio-economic impacts of palliative care, common definitions, quality indicators, common data collection methods, models of care, caregiver support and use of technology. Furthermore, the 2010 report noted the need for knowledge translation and dissemination of best practices so that research knowledge can be translated into practice. These findings are still valid.

Education and training of health care providers has improved since 1995. The Educating Future Physicians in End-of-Life Care project resulted in all 17 medical schools in Canada now educating new physicians in palliative care. Palliative care is also now part of the core curriculum for nursing, social work, pharmacy and pastoral care students.

Projects like Pallium's LEAP (Learning Essential Approaches to Palliative and End-of-Life) have also provided multi-professional educational opportunities for health care providers. The Canadian Virtual Hospice's online resources also provide information and advice for providers. CHPCA initiatives such as the manual and training program for home support workers, training material for volunteers and the Living Lessons® handbook and training material for family caregivers have also been significant improvements in the area of training and education since 1995.

However, despite these advances, the recommendations of the 2010 and 2011 reports have not been implemented. Only nursing provides a specialty certification in hospice palliative care. Furthermore, the 2010 report found that there was a continued need for multidisciplinary education, continuing education and dissemination of best practices, particularly cross-cultural awareness training for health care providers to meet the varied social and cultural needs of patients.

Regarding national standards and guidelines, with funding from Health Canada, the CHPCA led the development of the Palliative and End-of-Life Care Norms of Practice released in 2002. From 2002-2007, one of the Working Groups under the Canadian Strategy on Palliative and End-of-Life Care collaborated with Accreditation Canada to develop hospice palliative and end-of-life care accreditation standards. CHPCA in partnership with the Canadian Home Care Association released the *Pan-Canadian Gold Standard for Palliative Home Care* in 2006. Unfortunately, these gold standards have not been widely adopted. There are also paediatric norms, palliative care nursing standards and national norms for volunteers.

The Canadian Institute of Health Information has not created general quality end-of-life indicators; although indicators have been created in certain areas such as for breast cancer.

The 2010 report also addressed the need for building capacity through research, education and training and a health human resources workforce plan. There is still a need to address health human resource workforce needs.

### POTENTIAL PRIORITY ACTION AREAS

- Support research into the socio-economic impacts of palliative care, common definitions, quality indicators, common data collection methods, models of care, caregiver support and use of technology.
- Support the development of multi-disciplinary education and training with respect to palliative and end-of-life care and support an integrated and coordinated approach to palliative and end-of-life care across care settings.
- Build capacity by establishing a health human resources workforce plan, implementing nationally standardized volunteer training package; pursuing knowledge translation and dissemination of best practices and developing and implementing culturally sensitive, multi-disciplinary education and training.
- Develop indicators for quality end-of-life care.
- Recognize palliative care as a specialty.
- Adopt nationally standardized core competencies in all disciplines.
- Work towards full adoption by all jurisdictions of the gold standards for palliative home care.



## D. ADVANCE CARE PLANNING & PUBLIC AWARENESS

There have been a total of seven recommendations made over five reports regarding advance care planning and public awareness on end-of-life issues.

### SUMMARY OF RECOMMENDATIONS

**1995 NEIMAN** - There were two recommendations concerning advance directives: that those provinces and territories that do not have advance directive legislation adopt such legislation; and that the provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

**2005 CARSTAIRS** - Of the two recommendations in this report concerning advance care planning, one recommendation called for advance care directive legislation in all provinces and protocols to recognize advance directives executed in other provinces and territories. A second recommendation called for a national campaign designed to inform the public about end-of-life care, including information on: palliative and end-of-life care services; advance directives; the compassionate care leave benefit; their legal

rights with respect to the withdrawal and withholding of life sustaining treatment; and caring for the dying as an informal caregiver.

**2010 CARSTAIRS** - The report contained one recommendation for a national public awareness campaign on advance care planning and palliative care.

**2011 ALBRECHT, COMARTIN & VALERIOTE** - The report contained one recommendation for a national public awareness campaign on palliative and end-of-life care which would include discussions about end-of-life and advance care planning.

**2012 OGILVIE** - The report contained one recommendation for the implementation of an awareness campaign for Canadians about the importance of planning end-of-life care.

### CONTINUED RELEVANCE

All provinces and territories now have some version of advance care directive legislation, except for Nunavut<sup>4</sup>. Most provinces and territories also have a protocol for recognizing advance care directives drawn up in other provinces<sup>5</sup>. However, research has shown the most important aspect of an advance care plan is the conversation between family members that goes into the planning process.

Under the Canadian Strategy for Palliative and End-of-Life Care there was a Public Information and Awareness Working Group which undertook several initiatives around public awareness for end-of-life care. Since the wrap up of the Canadian Strategy in 2007, the CHPCA has

continued the public education piece around advance care directives with the Advance Care Planning Project and the Speak Up campaign, which is designed to start conversations around advance care planning. The tools and information on the Speak Up website and on the CHPCA Advance Care Planning Resource Commons are important to disseminate to health care professionals so they can start the conversation with patients and families. These tools and resources are also important to disseminate to the general public. Ongoing partnership and research with TECH VALUE NET will also be important in fine tuning resources and tools for advance care planning and measuring outcomes.

<sup>4</sup> New Brunswick's legislation is limited to "power of attorney for personal care". In 2009, a committee sought input for advance health care directives legislation, but new legislation has not been adopted.

<sup>5</sup> Quebec, Nova Scotia and Newfoundland and Labrador have advance care legislation, but have no reciprocity in recognizing advance care directives drawn up in other provinces.

The 2010, 2011 and 2012 reports all recommended a need for a broader public awareness campaign around palliative care to inform Canadians about palliative care services, with advance care planning being one component. Part of the reason for this recommendation in 2010 was the recognition of a need for a societal change to accept death as a natural part of living and to help Canadians

understand what palliative care is and what they should expect from it<sup>6</sup>. Expanding the discussion about advance care planning to include information on the role of palliative care across care settings and throughout the course of a life limiting illness would improve patient and family understanding of end-of-life care options, particularly for those with chronic and life-limiting illnesses.

### POTENTIAL PRIORITY ACTION AREAS

- Continue to raise awareness on end-of-life care issues through the expansion of the Advance Care Planning website and use of social media platforms.
- Support ongoing research, development and measurement of advance care planning tools and resources.
- Expand the discussion around advance care planning to include the role of palliative care across care settings and throughout the course of a life-limiting illness to raise awareness about end-of-life care more generally.

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<sup>6</sup> Carstairs, The Honourable Sharon. *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. June 2010. Senate of Canada. p. 19-21.

## E. FEDERAL RESPONSIBILITY

Although health care delivery is primarily a provincial responsibility, all reports since 2000 outline the federal responsibility for direct service delivery for certain population groups, for leadership and coordination and for funding research and disseminating best practices. There have been three recommendations over three reports specifically concerning the federal government's direct responsibility for health care delivery for specific population groups.

### SUMMARY OF RECOMMENDATIONS

**2009 CARSTAIRS** - The report recommended that the federal government address the needs of First Nations and Inuit peoples, including providing more support for caregivers and increased home care and hospice palliative care services.

**2010 CARSTAIRS** - The report recommended the federal government recognize and accept its role as a direct service provider to certain populations and ensure appropriate programs and funding, especially for the First Nations and Inuit peoples.

**2011 ALBRECHT, COMARTIN & VALERIOTE** - The report recommended that the federal government: strengthen homecare delivery programs for First Nations, Métis and Inuit communities; develop home-delivered palliative care resources sensitive to cultural needs; and support research, training and capacity building to ensure First Nations, Métis and Inuit peoples receive high quality palliative and end-of-life care.

### CONTINUED RELEVANCE

Although there have been some efforts since 1995 to address the needs of population groups under federal responsibility, such as the development of palliative care standards for federal inmates, pilot projects for tele-homecare for veterans, and research projects addressing the needs of our aboriginal peoples, these efforts have been insufficient. The findings in the 2009, 2010 and 2011 reports remain valid. These populations, particularly the First Nations, Métis and Inuit peoples need special attention.

The federal government should be engaged as a direct health care service provider as it has

responsibility for direct health care delivery for inmates in federal institutions, members of the RCMP, military and veterans, refugees, and First Nations on reserve and the Inuit peoples.

Particularly in the case of First Nations on reserve, jurisdictional disputes and funding envelopes result in poor outcomes for these patients and their families. Lack of palliative care services in all care settings in the north mean aboriginal peoples must often leave their home and community at end-of-life.

#### POTENTIAL PRIORITY ACTION AREA

- Encourage appropriate programs and funding for populations who receive direct health care service delivery from the federal government.



## OTHER REPORTS TO NOTE

### QELCCC REPORTS

There have also been four reports by the Quality End-of-Life Care Coalition of Canada (2004, 2006, 2007 and 2008) which have made recommendations regarding improved care for hospice palliative and end-of-life care. These reports were more limited in scope than the nine national reports reviewed above, but should be noted. See Appendix B (pg. 29) for the list of specific recommendations for all four reports.

The 2004 report, *Dying for Care*, was based on a survey of provinces and territories on the delivery of palliative care. It contained four recommendations to the provinces and territories, including recommending the provision of quality, integrated, comprehensive palliative care services, including home care, care for the caregiver and medications.

The 2006 report, *The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-life Care at Home*, was commissioned by the Canadian Hospice Palliative Care Association in conjunction with the Canadian Home Care Association. The report tabled five recommendations aimed at all jurisdictions, created to provide the benchmarks for high quality hospice palliative care at home.

The 2007 report was fundamentally a policy statement aimed at the new federal government. Titled *A Pan-Canadian Partnership for Palliative and End-of-Life Care*, the report made three recommendations to the federal government: the development of an action plan based on a pan-Canadian comprehensive consultation; the creation of an advisory committee to offer guidance and direction on new policies and strategies; and continued support and funding for research in multi-level partnerships.

The 2008 report, *Hospice Palliative Home Care in Canada: A Progress Report*, was based on a survey of federal, provincial and territorial governments based on the *Pan-Canadian Gold Standard for Palliative Home Care*. The report contains ten recommendations to the provinces and territories aimed at enhancing hospice palliative homecare and aligning their programs with the Gold Standard. The report included recommendations on case management, nursing care/personal care and pharmaceuticals.

## THE CANADIAN MEDICAL ASSOCIATION

In 2010 the Canadian Medical Association launched a discussion of the future of health care and the Medicare system. They produced a discussion document on health care transformation and then launched a national public dialogue through their website and six town halls across the country.

The Report on the National Dialogue on Health Care Transformation 2011 is the summary of that national consultation. It does not contain any specific recommendations; but there were several themes relevant to this discussion paper that were repeated throughout the consultations.

- Strong support for broadening the scope of the existing *Canada Health Act* to include services such as long term care, home care and hospice care as insured services.
- The need for integrated, person-centred care was raised at most of the six town halls across the country.
- Recognition of the importance of the social determinants of health.
- Need to provide better services to vulnerable groups such as children, the elderly, Aboriginal Peoples, people in rural settings and those with mental illness.
- Urgent need for home-based care with the aging of the population.

In July 2011, the Canadian Medical Association and the Canadian Nurses Association<sup>7</sup> released *Principles to Guide Health Care Transformation in Canada*. These principles are based in the aim of better care, better health, and lower costs. Specifically the six principles are:

- Patient centred
- Quality
- Health promotion and illness prevention
- Equitable
- Sustainable
- Accountable

<sup>7</sup> The Canadian Nurses Association has undertaken its own review of the health care system in Canada, but has not yet released its final report.



## CONCLUSION

Since 1995, there have been 85 recommendations concerning hospice palliative care made in nine national reports. Although progress has been made on implementing many of the recommendations from the 1995 and 2000 reports, there are still recommendations from all the reports which remain relevant. These recommendations can help inform the work of **The Way Forward** initiative and assist to position Canada to move towards better access to community-integrated hospice palliative care.



## Appendix A – Full List of Recommendations by Issue

### A. ACCESS TO CARE

#### 1995 NEIMAN

- The Committee recommends governments make palliative care programs a top priority in the restructuring of the health care system.
- The Committee recommends there be an integrated approach to palliative care. The delivery of care, whether in the home, in hospices or in institutions, with the support of volunteers, must be coordinated to maximize effectiveness. The provision of respite services is an essential component.

#### 2000 CARSTAIRS

- That the federal government, in collaboration with the provinces and territories, develop a national strategy for end-of-life care. (Rec. #1)
- That the federal government, in collaboration with the provinces and territories, establish a five-year plan for implementing this national strategy. (Rec. #2)
- That the federal government prepare an annual progress report on implementing this national strategy. (Rec. #3)
- That the federal government immediately assess the need for home care and pharmacare for the dying and establish, in collaboration with the provinces and territories, the funding required for these programs. (Rec. #4)
- That the federal Minister of Health work with other relevant federal ministers to develop an interdepartmental strategy on end-of-life care. (Rec. #7)
- That the federal Minister of Health discuss the establishment of a federal, provincial, and territorial strategy on end-of-life care with provincial and territorial counterparts at the next meeting of the Ministers of Health. (Rec. #8)
- That the federal Minister of Health discuss with provincial and territorial counterparts appropriate measures for funding of end-of-life initiatives. (Rec. #9)

#### 2002 KIRBY

- The federal government agree to contribute \$250 million per year towards a National Palliative Home Care Program to be designed with the provinces and territories and co-funded by them on a 50:50 basis. (Chapter 9)

#### 2002 ROMANOW

- The proposed new Home Care Transfer should be used to support expansion of the *Canada Health Act* to include medically necessary home care services in the following areas:
  - Home mental health case management and intervention services should immediately be included in the scope of medically necessary services covered under the *Canada Health Act*.
  - Home care services for post-acute patients, including coverage for medication management and rehabilitation services, should be included under the *Canada Health Act*.
  - Palliative home care services to support people in their last six months of life should also be included under the *Canada Health Act*. (Rec. #34)



## 2005 CARSTAIRS

- Health Canada provide long-term, sustainable funding for the further development of a Canadian Strategy on Palliative and End-of-Life Care which is cross-departmental and cross-jurisdictional, and meets the needs of Canadians. (Rec. #1)
- Federal, provincial and territorial governments make palliative and end-of-life care programs a top priority in the restructuring of the health care system through:
  - implementing consistent norms of practice to eliminate disparities between different jurisdictions;
  - integrating services to make the transitions between all health care settings (including hospital, long-term care, home and hospice) seamless; and
  - enhancing homecare and pharmacare, including the provision of respite care. (Rec. #2)

## 2009 CARSTAIRS

- That the federal government develop a federal initiative which would provide financial support to the provinces to facilitate the move toward integrated models of care for the elderly as a model for quality care for all ages. The objectives of the program should be designed to ensure:
  - Integration of a broad domain of services, including, but not limited to, health care, case management, home and community services, and residential care services;
  - Improved access to comprehensive care;
  - Increased emphasis on health promotion, disease prevention and chronic disease management;
  - Expanded multi-disciplinary teams so the most appropriate care is provided by the most appropriate provider;
  - Increased emphasis on one-stop-shopping for seniors and their families; and
  - Improved portability of services between provinces, including reciprocal agreements to eliminate waiting periods for services. (Rec. #7)
- That the federal government fund a national partnership with provinces, territories and community organizations to provide the leadership and vision, standards, best practices, awareness, and support for capacity building necessary to ensure the provision of integrated quality end-of-life care for all Canadians. (Rec. #11)

## 2010 CARSTAIRS

- Re-establish a Canadian Strategy on Palliative Care as a partnership between the federal, provincial and territorial governments and the community. With federal leadership, financial support and coordination, this Strategy would: Pave the way for consistent minimum standards and benchmarks of nationally available palliative care services; Support the integration of comprehensive palliative care services into the system; and Provide the leadership, vision, best practices, coordination and awareness necessary to ensure the provision of quality palliative care services for all Canadians. (Rec. #1)
- Establish a Health and Social Care Transition Fund to assist provinces and territories in continuing to realign the health care system to meet the needs of the aging population and increase in incidences of chronic disease. This would include support for communities to transition to alternative settings of care, such as a residential hospice and home care services. (Rec. #7)
- Using the Canadian Association of Provincial Cancer Agencies as a model, foster interprovincial/ territorial cooperation to establish common data definitions, technologies, and policies within health care regions to facilitate smoother transitions between care settings. (Rec. #9)
- Ensure palliative care services are covered under all provincial and territorial health insurance plans. (Rec. #13)
- Create reciprocal agreements among the provincial and territorial governments to eliminate waiting periods and create a national standard of care for palliative care services for all Canadians to improve the portability of services between provinces and territories. (Rec. #14)



## 2011 ALBRECHT, COMARTIN & VALERIOTE

- We strongly urge that the federal government re-establish a Palliative Care Secretariat, provided with adequate funding to conduct and support research, and to facilitate communication and collaboration between the various levels of government, and community stakeholders, for the sake of: a) Developing and implementing a National Palliative and End-of-Life Care Strategy . b) Collaborative development and implementation of national standards as a benchmark of quality palliative care. c) Coordination and dissemination of palliative and end-of-life research and information resources. d) Ongoing coordination and support as the Strategy is implemented in jurisdictions across Canada. (Rec. #1)
- We recommend the development of a flexible integrated model of palliative health care delivery, able to take into account the geographic, regional and cultural diversity of Canada; while providing a funding mechanism to help the provinces and territories with implementation. (Rec.#2)
- We recommend the development of rural palliative care delivery within the primary health care system, utilizing home care services, and local long-term care homes; allowing care to be delivered in or close to a person's home community. (Rec. #6)
- We recommend that the federal government in collaboration with the provinces and territories implement a right to home care, long-term care and palliative care, for all residents of Canada, equal to the current rights in the *Canada Health Act*, to those services defined as "insured health services", including hospital services, physician services and surgical dental services. (Rec. #8)

## 2012 OGILVIE

- That where necessary, jurisdictions expand their public pharmaceutical coverage to drugs and supplies utilized by home care recipients. (Rec. #14)
- That the federal government work with the provinces and territories to increase access to palliative care as part of end-of-life health services in a broad range of settings, including residential hospices. (Rec. #18)
- That the federal, provincial, and territorial governments develop and implement a strategy for continuing care in Canada, which would integrate home-, facility-based long-term, respite and palliative-care services fully within health care systems. The strategy would establish clear targets and indicators in relation to access, quality and integration of these services and would require governments to report regularly to Canadians on results. (Rec. #19)

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## B. SUPPORTS FOR FAMILY CAREGIVERS

### 2000 CARSTAIRS

- That the federal government immediately implement income security and job protection for family members who care for the dying. (Rec. #5)

### 2002 KIRBY

- The federal government examine the feasibility of allowing Employment Insurance benefits to be provided for a period of six weeks to employed Canadians who choose to take leave to provide palliative care services to a dying relative at home. (Chapter 9)
- The federal government examine the feasibility of expanding the tax measures already available to people providing care to dying family members or to those who purchase such services on their behalf.(Chapter 9)
- The federal government amend the Canada Labour Code to allow employee leave for family crisis situations, such as care of a dying family member, and that the federal government work with the provinces to encourage similar changes to provincial labour codes. (Chapter 9)
- The federal government take a leadership role as an employer and enact changes to Treasury Board legislation to ensure job protection for its own employees caring for a dying family member. (Chapter 9)

## 2002 ROMANOW

- Human Resources Development Canada, in conjunction with Health Canada should be directed to develop proposals to provide direct support to informal caregivers to allow them to spend time away from work to provide necessary home care assistance at critical times. (Rec. #35)

## 2005 CARSTAIRS

- The federal government amend the Compassionate Care Leave Benefit under the Employment Insurance Program to improve Canadians' access and eligibility under the Benefit by: extending the leave from 8 weeks to 16 weeks, including a two week waiting period; allowing the patient to determine the best person to be their caregiver, be it a family member or a friend; not limiting the benefit to the last six months of life, especially for children; and mounting a public education campaign designed to inform Canadians about the benefit. (Rec. #3)
- The federal government and the Provinces and Territories amend their respective Labour Code provisions to reflect these changes to the compassionate care leave benefit. (Rec. #4)

## 2009 CARSTAIRS

- That in their next triennial review of the CPP, the Ministers of Finance consider:
  - Increasing the income replacement rate for the CPP (currently 25 percent of allowable income);
  - Increasing the maximum pensionable earnings above the average wage;
  - Investigating actuarial adjustments to the Canada Pension Plan to increase the incentive to delay uptake;
  - Examining mechanisms to allow older workers who begin to collect CPP before age 65, but who are not receiving the maximum benefit, to continue to contribute to the CPP;
  - Eliminating the requirement in the CPP that individuals between the ages of 60 and 65 who apply for CPP must quit work or earn up to the maximum of CPP in the months prior to the application; and
  - Introducing a drop-out provision for caregivers. (Rec. #19)
- That the Employment Insurance Act be amended to:
  - Eliminate the two-week waiting period before receipt of the compassionate care benefit;
  - Increase the compassionate care benefit to 75 (seventy-five) percent of the earnings of workers;
  - Increase the length of the benefit from 6 to 13 weeks; and
  - Provide access to the benefit during times of medical crisis, and not only during the palliative stages of illness.

Furthermore, the federal government must promote awareness of the compassionate care benefit among all Canadians. (Rec. #23)
- That the federal government work collaboratively with the provinces and territories, policy-makers, stakeholders and family caregivers to establish a National Caregiving Strategy. The Strategy should form a part of a larger federal integrated care initiative. (Rec. #24)

## 2010 CARSTAIRS

- Establish a Canada Pension Plan drop-out provision for caregivers, similar to that for parents who stay home with new babies. (Rec.#3)
- Revamp the Compassionate Care Benefit Program under Employment Insurance to include the following elements:
  - Implement a CCB awareness campaign that targets all stakeholder groups and the public simultaneously through a range of formats; Improve the application process to be quicker, simpler, and more sensitive to the stressful and emotional realities of CCB applicants;
  - Lengthen the period of support from 6 to 26 weeks to allow for flexibility because of the challenges in prognosticating death, a more reflective and not rushed process, and to allow caregivers to extend the paid leave after death to include time for bereavement;

- Increase the financial assistance to more adequately reflect the real costs endured by family caregivers when taking time off to work to provide end-of-life care; and
- Change the eligibility criteria from “significant risk of death” to “high need of care giving due to a life threatening illness”. (Rec. #4)
- Establish a Caregiver Benefit, similar to the Child Tax Benefit, to cover expenses such as nursing, bookkeeping help and transportation. (Rec. #5)
- Establish a National Strategy for Family Caregivers which safeguards health and wellbeing with respite care; recognizes the importance of grief and bereavement services; minimizes excessive financial burden; provides information and education for caregivers; provides adequate home care services; ensures flexible work options; and supports caregiving research. (Rec. #6)
- Using models such as those used in some of the provinces or the one used by the Canadian Partnership Against Cancer, establish system navigators to assist caregivers and patients in accessing services they need. These navigators would be assigned to them at the time they are diagnosed with a life-threatening illness and would be able to help them navigate through the health and social services systems. (Rec. #10)
- Using the Nova Scotia Caregiver Allowance as a starting point, collaborate with the federal government to establish a national program for those who lose income by engaging in care giving but are not covered by Employment Insurance. (Rec.#12)

## 2011 ALBRECHT, COMARTIN & VALERIOTE

- We recommend that the federal government expand the provisions of the E.I. based compassionate care benefit to a minimum of 26 weeks coverage. We further recommend that the benefit be given flexibility to allow partial weeks to be covered, allowing caregiver leave for episodic care giving needs i.e. 5 or 6 days a month to allow a parent to stay in hospital with a child as they undergo chemotherapy. We recommend that the qualifying criteria be changed from “significant risk of death” to “gravely ill” so as to allow the hope of caregivers to be kept alive when applying for the caregiver benefit. Finally the government should look at raising the maximum payment cap to a higher amount, more in line with the costs of living and care giving. (Rec. #9)
- We recommend that the federal government establish a refundable tax credit for family caregivers, to help families, with the high costs of care giving. The Caregiver credit and the infirm dependent credit could be made refundable for caregivers below a certain income level. (Rec.#10)
- We recommend that the federal government set up a Canada Pension credit for family caregivers, so that those who are long term unpaid caregivers receive annual pension credit worth half their average annual salary from the years leading up to full time unpaid care giving. The annual credit could have a maximum capped amount, and a minimum amount for those who had small incomes leading up to the care giving years. (Rec. #11)

## 2012 OGILVIE

- That the federal government work with provincial and territorial governments to develop a pan-Canadian Homecare Strategy, which would include a focus on reducing the burdens faced by informal caregivers. (Rec. #17)

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## C. QUALITY OF CARE

### 1995 NEIMAN

- The Committee recommends the development and implementation of national guidelines and standards be continued.
- The Committee recommends the training of health care professionals in all aspects of palliative care be increased.
- The Committee recommends research into palliative care, especially pain control and symptom relief, be expanded and improved.

(cont'd on next page)

- The Criminal Code be amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life.
- The division of Health Canada responsible for health protection and promotion, in cooperation with the provinces, territories and the national associations of health care professionals, develop guidelines and standards for the provision of treatment for the purpose of alleviating suffering where that may shorten life.
- Education and training with respect to pain control be expanded and improved for all health care professionals.
- The division of Health Canada responsible for health protection and promotion, in cooperation with the provinces, territories and the national associations of health care professionals, develop guidelines and standards for the practice of the total sedation of patients.
- The federal government, in cooperation with the provinces and territories, undertake a study in order to determine the frequency and conditions under which total sedation is practised.

## 2000 CARSTAIRS

- That the federal government, working in collaboration with the provinces and the educational community, explore ways to increase multidisciplinary training and education of professionals involved in end-of-life care. (Rec. #6)
- That the Canadian Institutes of Health Research be encouraged to establish an institute that focuses on end-of-life issues facing Canadians of all ages with all medical conditions. (Rec. #10)
- That the Canadian Institute for Health Information be encouraged to develop indicators for quality end-of-life care. (Rec. #11)
- That the federal Minister of Health coordinate and implement a multi-dimensional agenda for end-of-life research that involves relevant departments, agencies, and other levels of government. (Rec. #12)

## 2005 CARSTAIRS

- The federal government support the development of multi-disciplinary education and training with respect to palliative and end-of-life care and support an integrated and coordinated approach to palliative and end-of-life care across care settings. (Rec. #5)
- Health care providers be educated on the practice of providing treatment for the purpose of alleviating suffering that may have the unintended effect of shortening life and the circumstances in which the withholding and withdrawal of life sustaining treatment is legally acceptable. (Rec. #6)
- That the Canadian Institute for Health Information be encouraged to develop indicators for quality end-of-life care. (Rec. #9)
- That the Canadian Institutes of Health Research undertake research into the socio-economic issues of palliative and end-of-life care, including the physical, mental and economic impact on informal caregivers. (Rec. #10)

## 2009 CARSTAIRS

- That the federal government apply the gold standard in palliative home care developed by the Canadian Hospice Palliative Care Association and the Canadian Home Care Association to veterans, First Nations and Inuit, and federal inmates. (Rec. # 12)
- That Canadian Institutes of Health Research funding for palliative care be renewed beyond 2009. (Rec. #13)

## 2010 CARSTAIRS

- Establish a Canadian Palliative Care Capacity Building Fund of at least \$20 Million annually for 5 years to undertake priority health care provider and public engagement and capacity building activities, including:
  - The establishment of a health human resources workforce plan to address workforce needs;

- Creation and implementation of nationally standardized volunteer training package;
- Research and knowledge translation;
- Dissemination of best practices; and
- Development and implementation of culturally sensitive, interdisciplinary education and training materials and programs for all health care providers. (Rec. #8)
- Professional organizations such as the Royal College of Physicians and Surgeons of Canada, the Canadian Medical Association and the Canadian Society of Palliative Care Physicians, in partnership with the Canadian Hospice Palliative Care Association, must promote an early referral system designed to educate and support physicians in referring patients to palliative care services at the time of diagnosis of a life-threatening illness. (Rec. #15)
- The Royal College of Physicians and Surgeons of Canada, the College of Family Physicians of Canada and the Canadian Society of Palliative Care Physicians work together to recognize palliative care as a speciality. (Rec. #16)
- Professional organizations work together to adopt nationally standardized core competencies in palliative care for all disciplines. (Rec. #17)

#### 2011 ALBRECHT, COMARTIN & VALERIOTE

- We recommend that the federal government provide stable funding to the Pallium Project and the Canadian Virtual Hospice, two important examples of innovation; while developing an easily accessible venue for funding other innovative programs. (Rec. #3)
- We recommend that the federal, provincial and territorial governments along with the various NGO stakeholders (i.e. The Canadian Pain Society) develop and implement a National Pain Strategy, to provide a unified approach in the delivery of pain control methods. (Rec. #7)

#### 2012 OGILVIE

- That the federal government work with provincial, territorial governments and other relevant stakeholders to develop indicators to measure the quality and consistency of home care, end-of-life care, and other continuing-care services across the country. (Rec. #13)

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## D. ADVANCE CARE PLANNING & PUBLIC AWARENESS

#### 1995 NEIMAN

- The Committee recommends those provinces and territories that do not have advance directive legislation adopt such legislation.
- The Committee recommends the provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

#### 2005 CARSTAIRS

- Those territories that do not have advance directive legislation adopt such legislation, and all provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories. (Rec. #7)
- Health Canada, in cooperation with the provinces and territories and the hospice palliative care community, sponsor a national campaign designed to inform the public about end-of-life care, including information on: palliative and end-of-life care services available in their region; advance directives and end-of-life care planning; the compassionate care leave benefit and how to apply for it; their legal rights with respect to the withdrawal and withholding of life sustaining treatment; and caring for the dying as an informal caregiver. (Rec. #8)

**2010 CARSTAIRS**

- Work in partnership with the federal government and the community to establish a national public awareness campaign on advance care planning and palliative care to raise awareness on end-of-life issues and start the dialogue among Canadians. This campaign could include a public schools component where discussions could begin among younger Canadians. (Rec. #11)

**2011 ALBRECHT, COMARTIN & VALERIOTE**

- We recommend that the federal government either through Health Canada or the recommended Palliative Care Secretariat fund a national public awareness campaign on palliative and end-of-life care. An aspect of this campaign should be to encourage Canadians both to talk about end-of-life care, and go through the process of advance care planning. The Canadian Hospice Palliative Care Association (CHPCA) Advanced Care Planning program is an existing resource which could be utilized in educating the public about advanced care planning. (Rec. #4)

**2012 OGILVIE**

- That Health Canada, taking the lead, work with provinces and territories to create and implement an awareness campaign for Canadians about the importance of planning end-of-life care. (Rec. #16)

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**E. FEDERAL RESPONSIBILITY****2009 CARSTAIRS**

- That the federal government address the needs of First Nations and Inuit seniors and their communities, including the need for:
  - More and improved housing; Increased attention to safe drinking water, diet, foot care and other diabetic needs;
  - Measures to ensure wage parity among providers;
  - Increased home care and hospice palliative care services;
  - More support for informal caregivers;
  - The removal of the funding cap for the Non-Insured Health Benefits Program; and
  - Measures to fully integrate the range of programs currently available to seniors on First Nations reserves and in Inuit communities into a seamless system comparable to that employed by Veterans Affairs Canada. (Rec.#31)

**2010 CARSTAIRS**

- Recognize and accept the federal government role as a direct provider of health care to certain populations under federal responsibility and ensure appropriate programs and funding for these populations, most especially for our First Nations and Inuit peoples. (Rec. #2)

**2011 ALBRECHT, COMARTIN & VALERIOTE**

- We call upon the federal government to strengthen the home care delivery program for First Nations, Métis and Inuit communities, developing home delivered palliative care resources, sensitive to community, cultural, familial and spiritual needs. Research, training and capacity building, are required for First Nations, Métis and Inuit peoples to receive the high quality palliative and end-of-life care they deserve. (Rec. #5)

## Appendix B – Quality End-of-Life Care Coalition Reports

### JUNE 2004

#### *Dying for Care, Quality End-of-Life Care Coalition of Canada*

##### RECOMMENDATIONS

- All provincial/territorial governments work with the federal government to provide quality end-of-life services that enables Canadians to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice.
- All provincial/territorial governments fund a comprehensive, coordinated and integrated set of end-of-life services that would include access to:
  - Hospice palliative care professionals and volunteers 24 hours a day/7 days a week
  - 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
  - Non-prescribed therapies
- All provincial/territorial governments work with the federal government to create a “basket of services” at end-of-life that include the six listed above. This would then assist in having a universal, equitable and transferable set of services across the country.
- All provincial/territorial governments create a mechanism to track (i.e. funding, volume of usage) what end-of-life services and programs are available throughout their province or territory.

### DECEMBER 2006

#### *The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-life Care at Home, The Canadian Hospice Palliative Care Association and the Canadian Home Care Association*

##### RECOMMENDATIONS

- Adopt strategies that will give their citizens timely access (i.e., 24 hours a day, seven days a week) to hospice palliative care at home – including appropriate pharmaceuticals and equipment – so they feel confident that they can choose to die at home.
- Establish interdisciplinary hospice palliative care teams that make effective use of the skills of each member to support clients/patients and families/caregivers.
- Support ongoing hospice palliative care education for members of the health care team and family caregivers.
- Invest in home care case management and information systems that support the interdisciplinary teams and provide information that can be used to evaluate home care services at end of life.
- Support ongoing research into best practices for hospice palliative care at home, including the cultural, ethical and spiritual aspects of care.



## AUGUST 2007

### *A Pan Canadian Partnership for Palliative and End-of-Life Care, Quality End-of-Life Care Coalition of Canada*

#### RECOMMENDATIONS

- Develop a pan-Canadian comprehensive consultation, involving not only Health Canada, and other relevant federal government departments, such as Human Resources and Skills Development, First Nations and Inuit Health, Veteran Affairs and Corrections, but also provincial, territorial and community governments, with the creation of an action plan as its immediate goal.
- Develop a broad-based advisory committee to offer guidance and direction in the development of new policies and strategies
- Recognize the need for more research to understand end-of-life care issues. Continue to support the necessary research by making available initiative and research grants and contribution funding in the form of a multi-level partnership.

## MAY 2008

### *Hospice Palliative Home Care in Canada: A Progress Report, Quality End-of-Life Care Coalition of Canada*

#### RECOMMENDATIONS

##### CASE MANAGEMENT

- Make consistent use of a valid assessment tool within and across provinces.
- Ensure that eligibility for hospice palliative home care is based on need and not on an arbitrary time limit.
- Ensure clients and families are referred to hospice palliative home care in a timely manner, maintain records of wait lists and times, and use this information to plan/fund services.
- Gather information on the number of Canadians receiving hospice palliative care or dying in hospitals, long-term care homes, respite beds and other settings whose needs could have been met through hospice palliative home care.
- Continue to develop active outreach programs to educate the public and providers about hospice palliative home care, rather than relying on passive strategies such as web sites.

##### NURSING CARE/PERSONAL CARE

- Identify creative and effective ways to ensure that Canadians dying at home and their families have access to case management, nursing and personal support service 24 hours a day, seven days a week.
- Ensure that all members of the hospice palliative home care team receive appropriate ongoing education and training, and have access to support from specialized hospice palliative care teams.

##### PHARMACEUTICALS

- Work with schools of pharmacy and pharmacy associations and colleges to develop education programs for pharmacists who provide consulting services for hospice palliative home care.
- Ensure that all Canadians receiving hospice palliative home care have access to the full range of prescription and over-the-counter pharmaceuticals required for pain and symptom management and comfort care at end-of-life.
- Ensure that access to pharmaceuticals for hospice palliative home care is based on need and not restricted by arbitrarily imposed time limits or cumbersome processes for requesting drugs or uses not covered by provincial/territorial formularies.



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## NOTES

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## THE WAY FORWARD INTEGRATION INITIATIVE

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