House of Commons, Standing Committee on Finance Pre-budget Consultation 2009 Submission

Planning for Investments in Support of the Seriously-ill and Dying as a Public Policy Response to Sustaining Canadian Productivity, Economic Competitiveness and Quality-of-Living

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on behalf of

The Pallium Foundation of Canada

(a community of academic, health services delivery, voluntary sector, government and citizen leaders working together throughout Canada to build palliative and end-of-life capacity as part of sustainable health systems and healthy, secure communities)

and the Canadian Society of Palliative Care Physicians (CSPCP)

Executive Summary

How Canada's governments and other stakeholders proceed in crafting sensible supports for the seriously-ill and dying will shape Canadians' quality-of-living and dying, the nation's productivity and economic competitiveness, and the sustainability of existing delivery systems. Responses to supporting the dying and most vulnerable persons in our society will also reflect the values and practices transmitted to future generations.

Enlightened and responsive public policy, including appropriate public investments in support of the seriously-ill and dying, is essential for Canada's elected officials to 'get right.' Given the universality of dying, it is also one of the few contemporary public policy issues where there ought to be sufficient shared interest in quality process outcomes to enable the kind of functional, easy-to-understand, and constructive all-party responses so many Canadians desperately seek from their elected leaders.

This submission responds to the House of Commons, Standing Committee on Finance pre-budget consultation question of 'What federal tax and program spending measures are needed to ensure <u>prosperity</u> and a <u>sustainable future</u> for Canadians from an <u>economic</u>, <u>social</u> and/or environmental perspective?' Within the Parliament of Canada's pre-budget consultation process, this brief challenges Canada's elected officials to consider <u>an investment-based</u>, <u>strategic approach to priority concerns about complex chronic conditions and dying and presents two social investment recommendations</u>. Those recommendations are:

Recommendation 1 – That the Government of Canada extend its research investment in palliative and end-of-life care, through at least a five-year *Palliative and End-of-life Policy Research Innovations Fund,* in an amount of at least \$16 million, to enable the Canadian Institutes for Health Research (CIHR), the Social Sciences and Humanities Research Council (SSHRC) and the Canadian Health Services Research Foundation (CHSRF) to collaboratively support priority areas of clinical, socio-economic and health services research and application-oriented innovation.

Recommendation 2 – That the Government of Canada establish a one-time Canadian Palliative and Endof-Life Care Capacity-Building Fund of at least \$20 million annually for a period of at least five years, to undertake priority health-provider and public engagement and capacity-building activities, essential for Canada to sustain productivity of local economies, national prosperity and quality-of-living in the face of historically unprecedented demographic changes.

Canada has enjoyed widely-held, international respect for its early leadership and advances in palliative and end-of-life clinical research, policy and programmatic innovations. Canadians have only started to explore the outer boundaries of what well-designed, developed and executed palliative and end-of-life care can do. Sensible, focused and time-limited investments in enhanced Canadian palliative and end-of-life care research and knowledge/service infrastructure capacity are essential to sustaining Canadian productivity, economic competitiveness and quality-of-living.

Issues about serious-illness and dying are understandably complex, but the conclusion about public investment is simple. Sensible, focused and sustained investments in enhanced Canadian palliative and end-of-life care research and public and health care provider engagement and capacity-building are essential to sustaining Canadian productivity, economic competitiveness and quality-of-living. Canada can invest in priority infrastructures to support the seriously-ill and dying now, or it will predictably pay much higher financial and human-suffering costs within the foreseeable future.

Respectfully submitted,

Josè L Pereira, MBChB, DA, CCFP, MSc., on behalf of the stakeholders of the Pallium Foundation of Canada and the Canadian Society of Palliative Care Physicians (CSPCP)

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Introduction

As Canada emerges from the greatest economic crisis since the Great Depression, it is understood the country is at a cross-roads in how leaders think about, and act on, collective abilities and responsibilities for sustaining a rapidly changing society. Emerging from the Great Depression and World War II period, 'rights-based' policies, supports and systems debated in the 1950s, and implemented in the 1960s/70s¹, have shaped Canadian values and collective culture. Several generations have embraced the ideas, ideals and program outcomes of this era as core to what it means to be 'Canadian.'

Sustaining what many hold to be core to Canadian identity, however, comes with a commensurate responsibility to invest strategically, including accounting for bona-fide social and economic returns accrued from public investments. There is much to celebrate about public policies and institutional design that has left our nation's economic and financial infrastructures comparatively unscathed relative to other nations. We are, however, faced with a reality that governments at all levels are now challenged to be sensible, pragmatic and accountable for how scarce public resources are deployed for the public good.

Within the Parliament of Canada's pre-budget consultation process, this brief challenges Canada's elected officials to consider an investment-based, strategic approach to priority concerns about complex chronic conditions and dying and presents two social investment recommendations. Effectively responding to serious-illness and dying will be a defining socio-economic policy issue of the next decade and beyond. This submission responds to the House of Commons, Standing Committee on Finance pre-budget consultation question of 'What federal tax and program spending measures are needed to ensure prosperity and a sustainable future for Canadians from an economic, social and/or environmental perspective?'

How Canada's governments and other stakeholders proceed in crafting sensible supports for the seriously-ill and dying will shape Canadians' quality of living and dying, the nation's productivity and economic competitiveness, and the sustainability of existing service delivery systems. Responses to supporting the dying and most vulnerable persons in our society will also reflect the values and practices transmitted to future generations. It will be a measure by which today's leaders will be judged by future generations. Planning for appropriate public investments is especially urgent in a context of: 1) aging populations whose personal retirement wealth has been greatly compromised; 2) large-scale generational retirement and replacement of health care providers over the next decade²; and 3) working age populations whose time, attention, skills and availability for productive employment, and hence contributions to the tax base, are at a premium.

Enlightened and responsive public policy, including appropriate public investments in support of the seriously-ill and dying, is essential for Canada's elected officials to 'get right.' Given the universality of dying, it is also one of the few contemporary public policy issues where there ought to be sufficient shared interest in quality process outcomes to enable the kind of functional, easy-to-understand, and constructive all-party responses so many Canadians are desperately seeking from their elected leaders.

Recent Policy Experience and the Emerging Canadian Context of Serious-illness and Dying

Canadians are expecting that they will be able to live longer and well in their communities. This has been established³ and recently acknowledged by the Government of Canada.⁴ Expectations about what health care providers can deliver are high and influenced by what they experience in popular media and read.⁵ Since the 1995 Special Senate Committee on Euthanasia and Assisted Suicide, catalyzed in large part by Sue Rodriguez's high-profile experience of dying with Amytrophic Lateral Sclerosis (ALS), it has been well-understood that contributing factors to Canadians' concerns about facing the prospect of slow, painful, undignified and poorly-supported dying experiences include: 1) slow evolution of the infrastructures required to support Canadians in the face of serious-illness and death; 2) inadequate federal/provincial/territorial collaboration; and 3) insufficient attention to the end-of-life health care needs of Canadians.⁶ Quality End-of-Life Care as a Canadian policy innovation has been established for

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nearly a decade, expanding the essential concepts of cancer-based palliative care to include all end-of-life situations.⁷

Since 2001, some foundational elements identified in the 1995⁶ and 2000⁷ Senate of Canada reports have been engaged by the Government of Canada through 'ad hoc,' one-time investments. A modestly-funded, Health Canada administered palliative and end-of-life care strategy commenced in late 2002 and expired on March 31, 2007⁸. This strategy relied heavily on highly-leveraged professional service contributions of Canada's first generation of palliative care program and clinical leaders through a Hospice Palliative Care 'community,' issues-engagement strategy. It resulted in some important outcomes, including the first-ever Hospice Palliative Care indicators for Accreditation Canada's, health service accreditation processes, as well as early research priority setting and educational needs assessment.

At mid-decade, the Canadian Institutes of Health Research (CIHR) collaborated in pooling some \$16 million in federal research funding to address palliative and end-of-life care research, largely through onetime New and Emerging Team (NET) grant funding processes that are now concluding. This investment has significantly enhanced early capacity of the Canadian palliative care academic community, collaborating with other sectors, to conduct groundbreaking palliative care research. The discovery work, for example, of Dr. Max Harvey Chochinov's team in Manitoba and collaborators across the country to enhance a dying patient's sense of dignity^{9,10} has been important, internationally-recognized pioneering work. The Canadian Pallium Project has facilitated rapid collaboration, innovative local professional development and practical evidence-informed, point-of-care decision-making tools for clinicians at the local levels of Canada's 13 provinces and territories. 11,12 The Pallium Project work has been achieved through a \$250,000 rural health innovation project (2001-02) and later with Canada's, single-largest public capacity-building investment to-date, a \$4.3 million investment from the National Envelope of the Primary Health Care Transition Fund, which concluded March 31, 2007. As of March 31, 2008, Canada's seventeen medical schools concluded an intensive agenda of essential curricular reforms through a well-leveraged \$1.2 million, Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) project, funded by Health Canada's, Inter-Professional Education for Collaborative-Centred Care (IECPC) health human resources initiative.

By mid-decade, however, Canadian palliative and end-of-life care leaders accrued key insights about short-duration federal project and program funding. Federal investments to-date, while welcomed and well-implemented, feed a cycle of 'start and stop' dynamics which have been problematic. The result is a patch work of responses of insufficient duration and scale to catalyze and embed 'self-sustaining change' within federal, provincial and territorial service delivery systems. One-time federal investments to-date have not enabled Canadian palliative and end-of-life care stakeholders to achieve a sufficient knowledge and community infrastructure 'critical mass' to support service delivery system sustainability, nor have they enabled the federal/provincial/territorial collaboration required to support Canada's society and economy during predicted increases in serious-illness and dying over the next two decades. Inadequate investment in public engagement and education strategies to-date also result in Canadians remaining misinformed about palliative and end-of-life care as being supportive and health-affirming in nature. This inadvertently limits choice. It also limits the benefits of earlier intervention for well-managed pain and symptom control as well as holistic issues engagement in the face of serious-illness and dying, including the making of end-of-life choices, preparations and decisions in a context which mitigates much of the extreme duress and personal and family crises currently experienced by too many Canadians.

In May 2005, during the 38th Session of Parliament, Canada's Hospice Palliative Care leaders actively engaged the Hon. Ujjal Dosanjh, then Minister of Health, in focused conversations about a \$20 million per annum, Canadian strategy on palliative and end-of-life care to be focused on addressing well-identified knowledge, policy and capacity gaps. This never materialized. During the 39th Session of Parliament, on February 15, 2007, member organizations of the Quality End-of-Life Care Coalition of Canada (QELCCC)

tabled an updated framework document entitled, *The time to meet the needs of dying Canadians is now!*¹³, with then Minister of Health, the Hon. Tony Clement. This document also outlined a \$20 million per annum pan-Canadian strategy on palliative and end-of-life care. To-date, these recent efforts of engaging the Government of Canada have ebbed and flowed with the volatility of Canada's minority parliaments and the understandable 'way finding' of federal political parties in a longer-term minority government context. They have not, however, to-date been engaged in a meaningful way by the Government of Canada and other elected parliamentarians.

Investing for Predictable Population Health Change

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At a macro-level, the policy challenges of an aging society in Canada have been well-studied. The Government of Canada has acknowledged many of these challenges, including health disparities of living in a geographically-vast, sparsely-populated country with skilled health human resources (HHR) gaps and a growing prevalence of complex chronic conditions as a leading cause of death. ^{3,4,14,15,16,17}

Calendar Year/ Age Group	Deaths					Proportion of Deaths (%)				
	0-64	65-74	75-84	85+	Total	0-64	65-74	75-84	85+	Total
1925	72,000	15,400	14,300	5,700	107,400	67.0	14.3	13.3	5.3	100.0
1950	58,400	27,900	26,000	11,400	123,700	47.2	22.6	21.0	9.2	100.0
1975	61,200	37,500	41,000	27,200	166,900	36.7	22.5	24.6	16.3	100.0
2005	53,500	41,400	71,600	64,100	230,600	23.2	18.0	31.0	27.8	100.0
2025	47,500	57,900	94,400	125,300	325,100	14.6	17.8	29.0	38.5	100.0
2050	41,600	53,500	118,700	291,800	505,600	8.2	10.6	23.5	57.7	100.0

37,000 45,900 117,500 330,000 530,400

Table 1 ¹⁸
Mortality Projections for Social Security Programs in Canada

As Canada's Chief Actuary, Jean-Claude Ménard,¹⁸ has helped illustrate through the data in Table 1, it is now well-understood that Canada is experiencing a profound shift in the longevity of its population. It is becoming a society characterized as one of many citizens living into very old age. In 2004, Statistics Canada reported some 226,584 Canadians died¹⁷, with estimates that by 2020 there will be a 33% increase in deaths approaching some 330,000 deaths each year.¹⁹ What aggregated statistics can not qualitatively or substantially describe, however, are important changes to how large numbers of Canadians will live and die²⁰, including impacts on persons, families and communities, as more persons live longer with a range of complex chronic conditions.

7.0

8.7

22.2

62.2 100.0

The challenge of serious-illness and dying within Canada's population is much larger than the current capacity of Canada's palliative and end-of-life care community to effectively respond. Continuing with a 'business as usual' approach will soon overwhelm existing capacity, which has been largely-based in cancer-based palliative care service traditions. Canada's palliative and end-of-life care leaders however have been, and are committed to, furthering practical, effective ways of extending their expertise within health and social care systems and throughout communities. Moreover, there exists a robust local voluntary movement to support much of the palliative care being delivered across the country. But relying too heavily on volunteerism and local charity will be an insufficient, incoherent and unsustainable policy response of federal and provincial/territorial public officials.

Canada is experiencing rapid growth in persons living with, and dying from, complex chronic conditions^{16,17}. Decision-makers have been informed about a significant decrease in health human resources (HHR) at all skills levels and across settings of service delivery². This will increase pressure on

persons living with serious- and/or terminal-illness as well as their families. There is a clear and present danger to the sustainability of Canada's public-funded health care delivery and other social care systems. An early indicator of these sustainability risks will predictably re-emerge through renewed concerns about 'wait times' and spiralling cost-escalation associated with sub-optimal utilization of traditional service delivery systems. The ability to provide seamless, managed continuity of care for seriously-ill and dying persons across settings of service delivery (i.e., home, hospital, hospice, long-term and continuing care, and settings of historic marginalization including the homeless and isolated Aboriginal communities) is also suboptimal in many of Canada's urban²¹, rural and remote communities^{14,15}.

Canadians have also become more sophisticated, pragmatic and critical consumers of public services. This has fuelled a range of rights-based and social-justice related concerns about end-of-life issues. These concerns are becoming co-mingled amongst burgeoning public confidence crises about Canadian service delivery systems. This includes the ability of said delivery systems to, when needed, provide responsive supports and services to assure dignity during serious-illness and dying, including security of the person and reasonable, ethical and legally-sanctioned mitigation of pain and suffering.

Recognizing the important role Canadian families and other community-resources have been assuming as supportive, largely-uncompensated caregivers of persons living with serious-illness, as well as to the actively dying, it is known that there are and will be predictable impacts for caregivers' health status, skills availability, productivity and employment-availability/maintenance, especially for a middle-aged workforce now commonly referred to in popular culture as the 'Sandwich Generation.' Hence, the policy reference frame of palliative and end-of-life issues is shifting from a narrowly-defined 'health care issue' once solely the domains of health ministries, to a broader 'socio-economic challenge' with productivity and competitiveness implications. This emerging socio-economic view demands practical and focused population health and 'whole of government' approaches^{14,22}, rooted in principles and practices of social innovation and social return on investment (SROI)²³.

With this brief context, the stakeholders of the Pallium Foundation of Canada, reflective of a wide-range of active collaborators throughout Canada working together to improve the quality of living and dying, and the Canadian Society of Palliative Care Physicians (CSPCP) encourage parliamentarians to give due consideration to the following recommendations in the pre-budget consultation process:

Recommendation 1 – That the Government of Canada extend its research investment in palliative and end-of-life care, through at least a five-year Palliative and End-of-life Policy Research Innovations Fund, in an amount of at least \$16 million, to enable the Canadian Institutes for Health Research (CIHR), the Social Sciences and Humanities Research Council (SSHRC) and the Canadian Health Services Research Foundation (CHSRF) to collaboratively support priority areas of clinical, socio-economic and health services research and application-oriented innovation.

At least three broad priority areas of research and innovation are crucial. These are:

1) Priority research questions to address policy-making about euthanasia and assisted suicide – This research ought to address the reasons why people ask for euthanasia and assisted suicide. It would focus on constructs including 'burden,' 'hopelessness', 'loss of meaning,' 'depression,' 'tired of living,' 'dignity' and 'autonomy.' It would go beyond the 'why' (i.e., scholarship of discovery), to the pragmatic 'how can we better address these needs' (i.e., scholarship of integration and application), by finding new treatments and care approaches that can be implemented in every day practice.

Research in this thematic area also ought to identify gaps in services and how said gaps affect requests for euthanasia and assisted suicide. In its most recent CMA Policy on Euthanasia and Assisted Suicide (Update 2007)²⁴, the Canadian Medical Association has specifically cited the need for a Canadian study of medical decision-making during dying, noting that relatively little is known about the frequency of various

medical decisions made near the end of life, how these decisions are made and the satisfaction of patients, families, physicians and other caregivers with the decision-making process and outcomes. Research would then specifically inform the state of Canadian practice, gaps and policy-oriented change. It is inter-professional in nature, requiring the contributions of clinicians, clinical researchers, sociologists, ethicists, and medico-legal scholars.

Policy research in this area ought to also include applied economic research and supporting engagement strategies to help better identify and communicate the direct and indirect cost of serious-illness and dying to the Canadian economy. Outcomes ought to include well-vetted policy options which help Canadian governments, business, labour, and social sector leaders improve productivity and economic competitiveness in the context of an aging population characterized by complex chronic conditions.

- 2) Delivery-systems focused clinical research to improve the knowledge dissemination/uptake in everyday practice of advancements in pain and symptom control and dignity-enhancing practices, AND targeted health service research for delivery-system re-design to improve continuity of care across home, acute/active treatment, hospice and long-term and continuing care and settings of marginalization There has been considerable clinical research in palliative and end-of-life care, with pervasive gaps between what is known to be effective in alleviating undue pain and suffering and what is actually done to alleviate undue pain and suffering. Research in this area ought to focus on effective practitioner practice change, including systemic, cultural and other barriers limiting effective pain and symptom relief and dignity-maintenance. Applied health systems research and innovation support is specifically required to transcend the historic 'silo' boundaries that prevent persons from seamlessly moving across delivery systems to the most appropriate setting of care for their needs at any given time during an illness. Research in this theme area also ought to be sensitive to, and sensible about, responding to the realities of many persons with significant disabilities and complex chronic conditions living longer lives in community settings, with emphasis on mitigating a risk of vulnerability including various forms of abuse and threats to personal security.
- 3) Focused inter-disciplinary social science research to better respond to Canada's changing population, with special emphasis on family studies, public/community engagement and education, and economic research about the macro-economics of serious-illness and dying Research and innovation support in this area ought to address priority questions of better informing the experience of family and community care giving. It ought to also help policy-makers and program implementers to better understand the reasons that so many Canadians hold wide-spread myths and misconceptions about palliative and end-of-life care, including discovery of significantly-improved public and community engagement strategies for addressing important practical and care planning issues about serious-illness and dying earlier than is the present norm. Many Canadians, for example, do not know that they have a right to request withdrawal of futile life sustaining treatments and often confuse this with euthanasia.

In framing these priority areas, we are convinced that Canada is far from reaching the limits of what well-designed palliative and end-of-life care can provide. In the same way that Canada is challenged to invest in 'pushing the envelope' to find new treatments to cure/control cancer and other serious-illness, so too must the nation invest in finding more effective ways of reducing the burden of suffering for the seriously-ill and dying. Targeted Canadian investments in these areas of research and innovation will not only improve services, but extend Canada's status as a global leader in alleviating the burden of suffering.

Recommendation 2 – That the Government of Canada establish a one-time Canadian Palliative and Endof-Life Care Capacity-Building Fund of at least \$20 million annually for a period of at least five years, to undertake priority health-provider and public engagement and capacity-building activities, essential for Canada to sustain productivity of local economies, national prosperity and quality-of-living in the face of historically unprecedented demographic changes.

There is a range of sensible, practical 'shovel ready' type health care provider capacity-building and public engagement strategic initiatives. These include outreach education and professional development, point-of-care (i.e., just-in-time, bedside) decision tools, an array of communication and change management tools as well as local community capacity-building strategies. A decade of applied research and development, effective knowledge translation strategies, and the thoughtful use of practical knowledge management, innovation and collaborative strategies are ready to support deployment throughout Canada, in both official languages, major Aboriginal languages and in many remote communities. Additional specific, one-time investments are required to improve tools and service delivery for long-term and continuing care, complex chronic care and other non-cancer contexts.

Additional investments are also needed for a range of palliative and end-of-life care stakeholders to collaborate in meaningful public engagement of palliative and end-of-life issues. This includes new tools at the community-level to address practical planning (e.g., estates, funeral, post-death daily living transitions, etc.) and advance care planning, through traditional media, new/social media as well as local community-based organizations in which Canadians frequently engage and invest trust about important decisions in their lives. Strategic investments in community capacity-building, including innovative public education and engagement, are critical aspects of sharing decision-making and enabling autonomy and accountability among citizens and those with specialized palliative and end-of-life care expertise.

A focused, collaborative investment over a five period would further enable Canada's palliative and end-of-life care community to complete essential tool development, leverage and codify the 'wisdom and insights' of a retiring generation of palliative and end-of-life care professionals into shared, pan-Canadian 'tool kits' suitable for use on a multi-jurisdictional basis. Common toolkits would be made broadly available in Canada using emerging models of royalty-free, 'creative commons' type licensing, ensuring broad availability of standards-based, collaboratively-negotiated and developed tools to support palliative and end-of-life.

Concluding Statement

Issues about serious-illness and dying are understandably complex, but the conclusion about public investment is simple. Canada can invest in priority infrastructures to support the seriously-ill and dying now, or it will predictably pay much higher financial and human-suffering costs within the foreseeable future. The longer issue engagement and strategic public investment is delayed, the greater the risk to sustainability of essential social and economic infrastructures. Canada has enjoyed widely-held, international respect for its early leadership and advances in palliative and end-of-life clinical research, policy and programmatic innovations. Canadians have only started to explore the outer boundaries of what well-designed, developed and executed palliative and end-of-life care can do. Sensible, focused and time-limited investments in enhanced Canadian palliative and end-of-life care research and knowledge/service infrastructure capacity are essential to sustaining Canadian productivity, economic competitiveness and quality-of-living.

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