CMA’s Presentation to the Parliamentary Committee on Palliative and Compassionate Care

Elder Abuse and Disability Hearing

Presented by:

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President

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Check against delivery

A healthy population and a vibrant medical profession
Une population en santé et une profession médicale dynamique
The Canadian Medical Association (CMA) is the national voice of Canadian physicians. Founded in 1867, CMA’s mission is to serve and unite the physicians of Canada and be the national advocate, in partnership with the people of Canada, for the highest standards of health and health care.

On behalf of its more than 73,000 members and the Canadian public, CMA performs a wide variety of functions. Key functions include advocating for health promotion and disease/injury prevention policies and strategies, advocating for access to quality health care, facilitating change within the medical profession, and providing leadership and guidance to physicians to help them influence, manage and adapt to changes in health care delivery.

The CMA is a voluntary professional organization representing the majority of Canada’s physicians and comprising 12 provincial and territorial divisions and 51 national medical organizations.
The Canadian Medical Association (CMA) wishes to commend the multi-party group of Members of Parliament who have come together to form the Parliamentary Committee on Palliative and Compassionate Care.

The challenge we face today in caring for our aging population is only going to get greater. Statistics Canada has projected a rapid increase in the proportion of seniors in the population. The first wave of the baby boom generation turns 65 next year. By 2031, seniors will account for roughly one-quarter of the population, nearly double the 13.9% observed in 2009.¹

Canadians are clearly concerned about their ability to cope with future health care expenses, either their own or those of their parents. Respondents to the CMA’s 2010 Annual National Report Card on Health Care survey anticipate a range of implications associated with our aging population:

- 29% reported that they will likely alter their retirement plans (e.g., work longer) to help pay for their own future costs or those of their parents;
- Almost one in five (19%) anticipates moving their parents into their own home and supporting them financially; and
- One in six (16%) anticipates paying for their parents to live in a nursing home.²

The CMA believes that the federal government could play a key role in allaying Canadians’ concerns about the future by leading negotiations with the provinces and territories and taking direct action on extending access along the continuum of care. These actions should focus on three priority areas:

- Increasing access by all Canadians to affordable prescription drugs;
- Supporting informal caregivers; and
- Increasing access to palliative care at the end of life.

If nothing is done to extend Medicare to cover more of the continuum of care, it will erode over time as a national program. When the Canada Health Act (CHA) was passed in 1984, physician and hospital services represented 57% of total health spending; this had declined to 42% as of 2009.³ While there is significant public spending beyond CHA-covered services (more than 25% of total spending) for programs such as seniors’ drug coverage and home care, these programs are not subject to the CHA principles and coverage across the provinces and territories varies significantly.
Access to Prescription Drugs

The federal government missed an excellent opportunity to modernize Medicare in July 2004 when Premiers called on it to upload responsibility for drug programs. The Premiers stated that “a national pharmaceutical program should immediately be established. The federal government should assume full financial responsibility for a comprehensive drug plan for all Canadians, and be accountable for the outcomes.”

The federal government did not give this offer even fleeting consideration. Instead, the September 2004 10-Year Plan to Strengthen Health Care contained a watered-down version of the First Ministers’ 2003 commitment to ensure that all Canadians would have reasonable access to catastrophic drug coverage by the end of 2005/06.

The 2004 Accord reduced this commitment to the development of costing options for pharmaceutical coverage, as part of a nine-point National Pharmaceuticals Strategy (NPS). Costing options were included in the 2006 progress report of the NPS but they included estimates of the cost of catastrophic coverage wildly exceeding those of Romanow and Kirby, ranging from $6.6 billion to $10.3 billion. Nothing further has been heard about the NPS since stakeholder consultations were held in fall 2007.

As recently as September 2008, the provinces and territories (PTs) were still interested in federal participation in pharmaceuticals. In the communiqué from their annual meeting, the PT health Ministers called for a three-point funding formula to support a national standard of pharmacare coverage, including:

- PT flexibility and autonomy in program design;
- Prescription drug costs not to exceed 5% of net income; and
- Federal and PT governments to cost share 50/50, estimated at $2.52 billion each in 2006.

Again there was no reaction from the federal government. Since then the PT governments have appeared to be giving up hope of federal participation in access to pharmaceuticals. At their June 2009 meeting, the western Premiers announced they would develop a joint western purchasing plan for pharmaceuticals, and more recently at the August 2010 meeting of the Council of the Federation, Premiers agreed to establish a pan-Canadian purchasing alliance for common drugs, medical supplies and equipment. Health Ministers reaffirmed this commitment at their September 2010 meeting. One can speculate that had the federal government taken up the Premiers’ offer in 2004, many aspects of the NPS would be in place by now.

Meanwhile, access to prescription drugs presents a hardship for many Canadians. In the CMA’s 2009 National Report Card survey, nearly one in six (14%) reported they had either delayed or stopped buying some prescription drugs. This ranged from more than one in five (22%) with annual incomes of less than $30,000 to just over one in twenty (7%) of those with incomes greater than $90,000.
The wide geographic disparity in out-of-pocket drug expenditures is shown in the table below, which is compiled from Statistics Canada’s 2009 Survey of Household Spending. Table 1 shows the percentage of households spending more than 3% and 5% of after-tax income on prescription drugs, by province, in the year prior to the survey.

<table>
<thead>
<tr>
<th>Geography</th>
<th>&gt;3%</th>
<th>&gt;5%</th>
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<tbody>
<tr>
<td>Canada</td>
<td>7.6</td>
<td>3.0</td>
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<tr>
<td>Newfoundland and Labrador</td>
<td>11.6</td>
<td>5.4E</td>
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<tr>
<td>Prince Edward Island</td>
<td>13.3</td>
<td>5.8E</td>
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<tr>
<td>Nova Scotia</td>
<td>8.9</td>
<td>3.8</td>
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<td>New Brunswick</td>
<td>9.1</td>
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<tr>
<td>Quebec</td>
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<tr>
<td>Ontario</td>
<td>4.7</td>
<td>2.2E</td>
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<tr>
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<tr>
<td>British Columbia</td>
<td>7.5</td>
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E - Use with caution - high coefficient of variation

Source: Statistics Canada, CANSIM Table 109-5012

Under both thresholds there is a more than two-fold variation across provinces in the incidence of catastrophic drug expenditures. At the 5% threshold the range is from 2.2% of households in Ontario and Alberta to 5.8% in PEI and 5.9% in Saskatchewan. With the growing availability of more expensive drugs, this variation is only likely to be exacerbated in the years ahead.

**Recommendation 1**

The federal government should negotiate a cost-shared program of comprehensive prescription drug coverage with the provincial/territorial governments.

This program should be administered through provincial/territorial and private prescription drug plans to ensure that all Canadians have access to medically necessary drug therapies. Such a program should include the following elements:

- A mandate for all Canadians to have either private or public coverage for prescription drugs;
- Uniform income-based ceiling (between public and private plans across provinces/territories) on out-of-pocket expenditures on drug plan premiums and/or prescription drugs (e.g., 5% of after-tax income);
• Federal/provincial/territorial cost-sharing of prescription drug expenditures above a household income ceiling, subject to capping the total federal and/or provincial/territorial contributions either by adjusting the federal/provincial/territorial sharing of reimbursement or by scaling the household income ceiling or both;
• Group insurance plans and administrators of employee benefit plans to pool risk above a threshold linked to group size; and
• A continued strong role for private supplementary insurance plans and public drug plans on a level playing field (i.e., premiums and co-payments to cover plan costs).

In negotiating this plan, consideration should be given to the following:

• Establishing a program for access to expensive drugs for rare diseases where those drugs have been demonstrated to be effective;
• Assessing the options for risk pooling to cover the inclusion of expensive drugs in public and private drug plan formularies;
• Provision of adequate financial compensation to the provincial and territorial governments that have developed, implemented and funded their own public prescription drug insurance plans; and
• Provision of comprehensive coverage of prescription drugs and immunization for all children in Canada.

**Supporting Informal Caregivers**

As the population ages, the incidence of diseases associated with dementia is projected to increase dramatically. A 2010 study commissioned by the Alzheimer Society of Canada has reported that the 2008 level of an estimated 103,728 new dementia cases is expected to more than double to 257,811 per year by 2038. Over this period, the demand for informal caregiving will skyrocket. In 2008, the Alzheimer Society reports, the opportunity cost of unpaid care giving was estimated at almost $5 billion. By 2038 this cost is expected to increase by 11-fold, to reach $56 billion, as the overall prevalence of dementia will have risen to 1.1 million people, representing 2.8% of the Canadian population.12

The burden of informal care giving extends beyond the costs related to dementia. Statistics Canada’s 2007 General Social Survey has documented the extent to which Canadians are providing unpaid assistance to family, friends or other persons with a long-term health condition or physical limitation.

Nationwide, 1.4 million adults aged 45 or over living in the community were receiving care in 2007. Of this number almost one in two (46.9%) were receiving both paid and unpaid care, almost three in 10 (27.4%) were receiving unpaid care only, and just under one in five (18.8%) were receiving paid care only. This underscores the importance of the informal sector.

In terms of who was providing this care, an estimated four million Canadians were providing care, of whom one million were aged 65 or over, while almost two million (1.8) were in the prime working age range of 45 to 54. The provision of unpaid care represents a significant time commitment.
The caregivers who reported helping with at least one activity spent an average 11.6 hours in a typical week doing so. Those providing care reported significant personal consequences. One in three reported spending less time on social activities (33.7%) or incurring extra expenses (32.7%), almost one in five cancelled holiday plans (18.7%) or spent less time with their spouse (18.7%), and more than one in 10 (13.7%) reported that their health had suffered.

The 2.5 million informal caregivers who were in the paid labour force were likely to report that caregiving had had a significant impact on their jobs. Almost one in four (24.3%) reported missing full days of work and one in six (15.5%) reported reducing hours of work.

Compared to the total population, informal caregivers were more likely to report stress in their lives. Almost three in 10 (27.9%) reported their level of stress on most days to be either quite a bit or extremely stressful compared to fewer than one in four (23.2%) of the total population.13

As the demand for informal care grows, it seems unlikely that the burden of informal caregiving will be sustainable without additional support.

The federal government took the positive step in 2004/05 of introducing Employment Insurance (EI) Compassionate Care Benefits for people who are away from work temporarily to provide care or support to a family member who is gravely ill and at risk of dying within 26 weeks.14 So far, however, this program has had limited uptake. In 2007/08, 5,706 new claims were paid.15 This pales in comparison to the 235,217 deaths that year (although not all of these would be candidates for this type of care).16

**Recommendation 2**

*The federal government should implement measures within its jurisdiction, such as the use of tax credits, to support informal caregivers.*

**Increasing Access to Palliative Care at the End of Life**

The Senate of Canada, and Senator Sharon Carstairs in particular, have provided exemplary leadership over the last 15 years in highlighting both the progress and the persistent variability across Canada in access to quality end-of-life care. The Senator’s 2005 report *Still Not There* noted that only an estimated 15% of Canadians have access to hospice palliative care and that for children the figure drops even further to just over 3%.17 The 2005 report repeated the 1995 call for a national strategy for palliative and end-of-life care. To date, palliative care in Canada has primarily centred on services for those dying with cancer. However, cancer accounts for less than one-third (30%) of deaths in Canada.

Diseases at the end of life, such as dementia and multiple chronic conditions, are expected to become much more prevalent in the years ahead. The demand for quality end-of-life care is certain to increase as the baby boom generation ages. There will be an estimated 40% more deaths a year by 2020. While the proportion of Canadians dying in hospital has been decreasing over the past decade, many more Canadians would undoubtedly prefer to have the option of hospice palliative care at the end of their lives than current capacity will permit.
In the 2004 Health Accord, First Ministers built on their 2003 Accord by agreeing to provide first dollar coverage for certain home care services by 2006, including end-of-life care for case management, nursing, palliative-specific pharmaceuticals and personal care at the end of life. Seven years later we have no comprehensive picture of the availability of end-of-life care across Canada.

The Health Council of Canada’s last detailed reporting on the implementation of the 2003 Accord was in 2006. At that time, the only province to report comprehensive end-of-life care was British Columbia. For most other jurisdictions, end-of-life care was discussed under “next steps.” Since then, the Health Council has ceased comprehensive reporting on the Accord.

In the 2007 National Physician Survey, doctors across Canada were asked to rate the accessibility of the range of services for their patients. Just one in three (32%) rated access to palliative care services as either excellent or very good.

In 2006, the Canadian Hospice Palliative Care Association and the Canadian Home Care Association jointly issued a 35-point “gold standard” for palliative home care, covering the areas of case management, nursing care, pharmaceuticals and personal care, which they commended to governments.

In its April 2009 report, the Special Senate Committee on Aging recommended a federally funded national partnership with provinces, territories and community organizations to promote integrated, quality end-of-life care for all Canadians, the application of gold standards in palliative home care to veterans, First Nations and Inuit, and federal inmates, and renewed research funding for palliative care.

In 2010, the Quality End-of-Life Care Coalition of Canada (QELCC), of which the CMA is a member, released its Blueprint for Action 2010 to 2020. The four priorities are:

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

This blueprint embodies the sound ideas that have emerged over the past decade.

In June 2010, Senator Carstairs released her latest report Raising the Bar, which, while acknowledging some of the achievements that have been made in palliative care, repeats her previous calls for a national role and active engagement of the federal government.

A wide range of stakeholders either have, or should have, a significant stake in the issue of palliative care. They include patients and the organizations that advocate on their behalf, caregivers (both formal and informal), the institutional and community health sectors, and the employer/business community.

**Recommendation 3**

*The CMA urges the federal government to collaborate with the provincial and territorial governments to convene a national conference in 2011 to assess the state of palliative care in Canada.*
Notes