BRIEF TO THE PARLIAMENTARY COMMITTEE ON PALLIATIVE AND COMPASSIONATE CARE

BUILDING A CONTINUUM OF CARE:

THE TIME IS NOW

PREPARED BY

THE CANADIAN HEALTH COALITION

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INTRODUCTION

The Canadian Health Coalition (CHC) is a public advocacy organization dedicated to the preservation and improvement of Medicare. Our membership comprises national organizations representing nurses, health care workers, seniors, churches, anti-poverty groups, women and trade unions, as well as affiliated coalitions in nine provinces and one territory.

The Coalition is active in areas related to the health of Canadians, the health care system, the working conditions of workers in the health care field, and related issues as they emerge in public discourse. Specific areas include continuing care, health care financing, the Canada Health Act, privatization, access to pharmaceuticals, the renewal of the Health Accord and health protection issues. At a recent CHC Board meeting, members agreed to strike a sub-committee with a mandate to develop a vision for a continuum of care approach to health care in Canada.

As representatives of the Coalition, we extend our thanks to the *Parliamentary Committee on Palliative and Compassionate Care* for their leadership in undertaking a national discussion on the challenges posed by a fragmented, under-resourced approach to the health care needs of Canadians that lie beyond the scope of our primary and acute health care systems, namely home care, palliative and hospice care, and long-term care. This initiative will be well-received by Canadians who are desperate for national leadership on these health care needs which so dramatically affect their lives – socially, economically and emotionally.

In particular, it will be welcomed by women, given that the majority of caregivers, both paid and unpaid, are women, as are the majority of those requiring home and long-term care. Women are bearing the brunt of the stress and distress that flows from inadequate access to care, a decline in the quality of care and working conditions that promote both intensification of work and exploitation of the caregiver ethos which leads to burn-out and an exit from these fields of care.

Many Canadians will find themselves relying on home and long-term care and palliative or hospice services at some point in their lives. They likely will need to provide care for family members, close friends or neighbours. They expect to have equal access to the services required to meet their health needs. They expect the provision of these services to preserve their independence, dignity and control over care to the greatest degree possible. They expect high quality care.

They are prepared to provide informal care but expect to be supported when doing so. They do not expect to be forced to provide care beyond their level of

capability or comfort. They do not expect paid caregivers to be exploited or have their own health threatened by onerous working conditions. They do not expect that illness – either short or long-term - will result in financial hardship.

The current state of the provision of care in home and long-term care falls far short of what Canadians expect and need. Due to a fractured system of services, and the absence of a national strategy and standards, many Canadian seniors, people with disabilities and chronic disease, and those in need of post-acute care are falling through the cracks when it comes to a continuum of care - assisted living, palliative care, home care, long-term residential care, pharmacare, respite care and support for informal caregivers. Gaps in the health system leave those in need of care trying to navigate the system to get the care they need at a time when they are ill and most vulnerable.

All Canadians deserve the health care they need to live with dignity and respect. The time has come to act – to bring in Phase Two of Medicare as envisioned by Tommy Douglas, the founder of Medicare and by Justice Emmett Hall as expressed in his Royal Commission report.

Despite efforts to shift the values of Canadians from collective responsibility and equality to individual responsibility, Canadians hold true to long-standing values of equity, fairness and solidarity. With respect to health care, this means universal access to appropriate and necessary health care based solely on need, not on ability to pay.

> **The Canadian Health Coalition calls for the implementation of a health care system that is structured as a comprehensive, integrated and seamless continuum of care system. This requires making home care, palliative and hospice care, long-term care and pharmacare subject to the principles, conditions and terms of the Canada Health Act.**

THE SCOPE OF ISSUES

The unmet needs in home and long-term care are widely recognized as evidenced by academic research; reports from national roundtables and stakeholder conferences; testimony from unions whose members work in these fields; the work of health care associations and organizations: from community advocates; from government committees and departmental reports; *The National Forum on Health*, and the Romanow *Commission on the Future of Health Care In Canada*. Most of what was said over the years has come to pass, as outlined below.

The CHC realizes that the Committee will receive submissions that document in detail the many and varied problems in home care, long-term care and palliative care. Therefore, we undertake only to highlight the current realities and major problems in each area which point to the need for developing a continuum of care.

HOME CARE

Home care includes a range of services for Canadians requiring care such as professional nursing, physiotherapy, occupational therapy; personal care such as assistance with daily living needs (bathing, grooming, toileting and transferring), and homemaking support (cleaning, laundry and meal preparation).

Hollander and Walker (1998) provide a useful definition[i]:

maintenance homecare - helps care receivers who have a chronic illness or disability stay in their home at a stable level of health
long-term homecare which substitutes for care in an institution such as a nursing home
acute homecare which usually substitutes for care in a hospital, and is given to people who require or are recovering from significant medical treatment.

Issues and Realities

- Age-related demographic change that pointed to increased care needs is happening now. The population of seniors will double over the next 25 years and will comprise 25 percent of the population, twice their share today (Statistics Canada). Further, the population surviving beyond 80 years of age will double. This population makes up the frail elderly who are likely to have complex, intensive care needs.

- Canadians continue to prefer to receive home care in order to maintain independence, dignity, familial and social relationships as well as power over their own care needs.

- Technological advances allow more care to take place in the home. While positive in some respects, this placed pressure on the availability of home care because funding did not keep pace with the increased volume of care.

- Home care services are not covered by the Canada Health Act. Thus, they fall outside the scope of our national Medicare program. The lack of a national approach to home care, including principles, standards, funding conditions and accountability mechanisms led to and/or exacerbated fragmented, uneven services, disparate levels of funding, the

application of user fees and co-payments, and a shift to a for-profit service delivery model, thereby ensuring that public dollars go to profit rather than to care. Such ad hoc arrangements ensure that Canadians do not have universal and equal access to services on uniform terms and conditions, two fundamental principles at the heart of Canada's approach to Medicare.

- A shift of acute care from the hospital to the community occurred, with patients being discharged quicker but sicker. As a result, the provision of home care is focused increasingly on providing post-acute care at the expense of more traditional home support and longer-term home care supports related to chronic illness and disability.

- Insufficient funding was provided to meet the demand for care (accessibility) or to fully meet the range of care needs (comprehensiveness), resulting in stricter eligibility criteria; cuts to home support services; increased, and in many cases, unaffordable, out-of-pocket costs for recipients and for caregivers; fragmented care; insufficiently trained caregivers, and instances of inappropriate care.

- Work intensification occurred, leading to issues such as a decline in the quality of care, appropriateness of care, skill mix, reduced job security, difficulty in retaining workers at all skill levels, reduced patient satisfaction, and negative health outcomes for both providers and recipients of care.

- Increased expectations on informal caregivers to provide levels of care that go beyond their abilities and comfort level, combined with few supports or respite services, left them overburdened and highly stressed. When family caregivers report health and financial hardship as well as negative impacts on their employment, it is clear that the system is failing to provide sufficient health services.

- As noted in the introduction, women represent both the majority of care givers and care recipients. The concerns are worth repeating here. Women are bearing the brunt of the stress and distress that flows from inadequate access to care, a decline in the quality of care, and working conditions that promote both intensification of work and exploitation of the caregiver ethos. The latter leads directly to burn-out and an exit from these fields of health care.

- While provinces and territories made some efforts to connect care sectors, the current reality is that there is no seamless interface between primary and acute care, and home and long-term care. Effective coordination across the continuum of care will only happen when key

system components are put in place such as multi-disciplinary health teams, electronic health records, evidence-based practices, case management, and information sharing mechanisms, etc.

RESIDENTIAL LONG-TERM CARE

Residential Long-Term Care refers to government-funded and provincially regulated facilities that provide 24 hour a day nursing care. They are sometimes called nursing homes, homes for the aged, special care homes or continuing care centres. Generally, people enter these facilities on the recommendation of a doctor or social service agency.

Governments provide subsidies towards residential long-term care but in almost all cases, funding is provided for only the lowest standard of care, which typically means more than one person to a room. Residents are required to contribute through payments called accommodation costs (facility fees). Fees increase substantially for semi-private or private accommodation. Residents are responsible for a wide range of medical and personal expenses such as hearing aids, foot-care, laundry services, medical supplies, incontinence supplies, etc.

Issues and Realities

- The demographic changes noted above have implications for the increased need for residential long-term care over the next two decades. The degree to which hospital beds are already used for chronic and long-term care services is well documented. Yet, many provincial governments reduced the number of long-term care beds, the exception being Ontario.

  Canadians whose health status warrants admission to these facilities already face unacceptably long wait times. The degree of choice as to what facility in which to reside is shrinking. Increasingly, they are forced to choose a facility far away from family and friends. This has negative repercussions for their health and that of their loved ones. The pressure on access will continue to grow.

- Residential long-term care lies outside the scope of the Canada Health Act, thus, outside the single payer system. The lack of a national approach to residential long-term care, with principles, standards, funding conditions and accountability measures, resulted in the predictable unequal provision of care services for Canadians. There is widespread inequality with respect to access to facilities, prescription drugs and medical care, costs to individuals and quality of care.

- There is a growing recognition that the quality of care overall in residential long-term care is problematic. Concerns include the quality and safety of food, avoidable medical problems such as dehydration and falls, lack of time for personal care such as bathing and grooming, and the lack of time for developing the all-important caregiver and care-receiver relationships. Quality of care in residential long-term care is by far the most important consideration for Canadians. Quality of care is integrally linked to standards and regulations for care, and to accountability requirements, such as inspection and monitoring

- Regulations to govern staffing levels, the skill mix of caregivers and working conditions are integrally connected to quality of care. According to a 2009 report by the Canadian Union of Public Employees, Residential Long-Term Care in Canada, Our Vision for Better Seniors' Care, "*No Canadian province has meaningful legislated minimum staffing levels; provinces have 'target levels' which are not enforceable or their regulated levels are so out of date as to be meaningless…"*[ii]

- Similar to the home care situation, staff reductions and shortages have led to work intensification with all the negative outcomes that implies for workers and residents. As the report, *Dignity Denied, Long-Term Care and Canada's Elderly*, by the National Union of Public and General Employees, states, *"LTC workers know there is a gap between the care they want to provide, and the care they can give. Low levels of funding, staff shortages, poor working conditions, pay inequities and profit taking have created a human resources crisis in the LTC sector."* [iii]

  In a study by Pat Armstrong and Hugh Armstrong, *Women, Privatization and Health Care Reform,* the authors reference a statement made by the Registered Nurses Association of Ontario. "*Long-term care facilities now have to deal with a patient population of whom 60 percent require heavy care, estimated to be at 3.5 hours per day or more."*[iv] The authors go on to note that this is before the transfer of patients out of chronic care and acute care hospitals. Levels of staffing, skill mix and working conditions matter to the quality of care.

  This sector has high rates of staff turnover as does the home care sector. The reasons are similar: low pay and benefits, onerous workloads, insufficient time for needed care, no access to decision-making, on-the-job injury, lack of access to on-the-job education and training, and difficult work schedules. Front line workers bear the brunt of the frustration and anger of care recipients who know they need and deserve better care.

- Both quality of care and working conditions are related to how health care is delivered. A significant body of domestic and international research indicates that providing health care on a for-profit basis results in a poorer quality of care, lower staffing levels, poorer working conditions, an inadequate mix of skilled staff, as well as little transparency or public accountability.

- Many provincial governments are increasing the share of funding directed to for-profit residential long-term care facilities. The Canadian Union of Public Employees states that 35 percent of long-term care beds are provided on a for-profit basis.[v] Other forms of privatization include contracting-out and some assisted living projects. Public tax dollars finding their way to profit means fewer public dollars finding their way to providing care.

PALLIATIVE CARE

Palliative and hospice care are critical components of a health care system grounded in a continuum of care system. Within the last decade or so, advocates for this area of care raised our understanding as to the importance of end-of-life care.

The Romanow *Commission on the Future of Health Care in Canada* deemed palliative home care an essential service and recommended that it fall under the Canada Health Act. Funding for palliative care was agreed to in the 2003 and 2004 Health Accords which led to at least some coverage for nursing care, medical supplies and equipment and pharmaceutical drugs for palliative care. The federal government funded a Canadian Strategy on Palliative and End-of-Life Care from 2001 to 2006 which provided important direction for action.

Issues and Realities

- The projected shift in age-related demographics underpins the urgency of implementing a national approach to end-of-life care.

- Palliative and hospice care, including palliative home care, remains outside the Canada Health Act. As is the case for home care and residential long-term care, palliative care, and those who require it, suffer from the lack of a national approach to such care. The issues are the same: disparate standards; unequal access; unequal services; lack of integration and coordination across and between acute and chronic care and community-based and home care, and insufficient levels of funding.

- Family caregivers are the backbone of the informal care provided to Canada's senior population. According to the 2009 study by Hollander, M.J., Liu, G. and Chappell, N.L., Canada's 2 million informal family caregivers provide $25 billion worth of care, annually. [vi]

- For most family caregivers the rewards are high, but all too often, so are the personal costs, even more so when providing palliative care to their loved one. The costs to informal caregivers are well-documented, ranging from emotional and physical exhaustion to financial hardship to their paid work performance to loss of employment and to their own ill health. Informal care givers contribute so much to the care needs of Canadians, but the absence of a national approach to palliative care deprives them of much needed respite and supports necessary to preserving their own health and well-being.

- Unmet needs with respect to palliative care include the need for more research, education and training for paid and unpaid caregivers, strategies to address the shortage of caregivers, the development of culturally-sensitive approaches to care, dissemination of best-practices and the integration of palliative care across and between all sectors of care.

MEDICARE PHASE TWO: EXPANDING THE SCOPE OF INSURED HEALTH SERVICES UNDER THE CANADA HEALTH ACT

Canadians are steadfast in the value they place on their universal public system of Medicare. Their commitment is based on shared fundamental values of equality, fairness, compassion, collective responsibility (solidarity) and individual responsibility. These values shape the very ethos of Canada as a country and are central to the notion of what it means to be a Canadian citizen.

Canadians view universal access to health care as both a public good and a right of citizenship which necessarily entails access to care on the basis of need, not on the ability to pay.

The 2010 Nanos Research poll commissioned for Canadian Health Coalition shows that 87.3 percent of Canadians support public solutions to health care, while an insignificant minority of 9% oppose public

solutions. Support extends across gender and all age groups, including those between 18 and 29 years of age. [vii]

This represents an extraordinary consensus upon which to build policy and make decisions. The values held by Canadians and their unswerving support for Medicare must guide decision-makers in making choices as to how the unmet health needs of Canadians are to be met.

The Canada Health Act enshrines the principles of universal access based on need - not on ability to pay, the delivery of comprehensive services, the provision of services on uniform terms and conditions and portability of services under a single insurance payer system. These standards prohibit user fees and extra-billing. Currently, the Act covers only medically necessary services that are offered by physicians and hospitals.

This was the first stage of Medicare. It is time to develop the second stage of Medicare by redefining and expanding the range of services within our public system of insured health services. This would begin the process of building a continuum of health care system to which all Canadians have universal equitable accesses.

RECOMMENDATIONS

HOME CARE

Federal Government Role

- Make home care services, including home support services, palliative care services and services for mental illness subject to the principles, terms and conditions of the Canada Health Act, thereby ensuring that these services become single-payer insured health services.

  - Increase federal funding targeted to building a comprehensive, universal and integrated set of home care services with appropriate accountability measures.

  - Facilitate a process through which provinces and territories agree to a set of principles and standards for the delivery of home care services, the range of services provided, eligibility criteria and quality of care standards. Such agreement would include monitoring of and reporting on programs.

- Provide funding for comprehensive quantitative and qualitative research into the delivery of home care services, retention issues, education and training, working conditions and shortages in health care professionals, and ensure that the results of the research is disseminated widely.

- Work with the provinces and territories to develop a national approach to policies and programs to support informal caregivers.

- Re-establish and fund the Canadian Strategy on Palliative and End-of-Life Care.

Provincial and Territorial Government Role

- Expand the range of home care services needed to meet the full range of home care needs.

- Develop a national set of standards for home care services and place these standards in provincial and territorial legislation to ensure that Canadians have universal access to comparable levels and quality of services.

- Provide work environments that are healthy and safe and that support high quality of care, including appropriate staffing levels, wage and benefit parity and fairness, access to education and training, opportunities for co-operation and collaboration between caregivers.

- Develop monitoring and accountability mechanisms.

- Focus on the integration of care into a system of seamless, continuum of care.

- Provide home care services on a not-for-profit basis to ensure that public dollars go to care, not profit.

RESIDENTIAL LONG-TERM CARE

Federal Government Role

- Make residential long-term care services subject to the principles, terms and conditions of the Canada Health Act, thereby ensuring that these services become single-payer, insured health services.

- Provide federal funding targeted to the provision of residential long-term care.

- Facilitate a process through which provinces and territories agree to a set of principles and standards for the delivery of residential long-term home care services, the range of services provided, eligibility criteria and quality of care standards. Such agreement would include monitoring of and reporting on programs.

Provincial and Territorial Government Role

- Expand the range of residential long-term care services to meet the full range of needs.

- Develop a national set of standards for services and place these standards in provincial and territorial legislation to ensure that Canadians have universal access to comparable levels and quality of services.

- Provide work environments that are healthy and safe and which support high quality of care, including appropriate staffing levels, wage and benefit parity and fairness, access to education and training, opportunities for co-operation and collaboration between caregivers.

- Develop monitoring and accountability mechanisms, including reporting to the public.

- Focus on the integration of residential long-term care into seamless, continuum of care system.

- Provide residential long-term care on a not-for-profit basis to ensure that public dollars go to care, not profit.

PHARMACARE

Canadian governments, employers, unions, and patients currently spend more money on prescription drugs (about $25 billion in 2008) than is spent on all services provided by doctors in Canada. There were over 420 Million drug prescriptions filled in Canadian pharmacies in 2007, an amount equal to 12.6 prescriptions per capita. A lot of this spending is on expensive (and often dangerous) new drugs which offer no better therapeutic effect than their traditional and cheaper counterparts.

Canadians need a public, safe and appropriate drug plan they can depend on. Canadians need Pharmacare, a national publicly funded and administered insurance plan that would cover drug costs the same way Medicare covers hospital and doctor costs, providing universal access to safe and appropriate care.

Such a Pharmacare plan has many advantages. It would provide equal access to prescription drugs for all Canadians, replacing our uneven and unfair patchwork of provincial programs and private insurance in the workplace. It would end the current unfairness of Canadians being covered for drugs while in hospital but not when they are receiving home care services.

Recently, a groundbreaking report lays out the economic case for a national pharmacare program. The report, entitled *The Economic Case for Universal Pharmacare*, was authored by Professor Marc-Andre Gagnon and published by the Canadian Centre for Policy Alternatives and Institut de recherche et d'informations socio-économiques.

The report shows that it is possible to implement a universal, first dollar coverage pharmacare program that not only offers coverage to all Canadians but also could save up to $10.7 billion per year, depending on the industrial strategy chosen with regards to the pharmaceutical industry.

The report puts the choice for Canada's decision-makers very clearly. *"Many countries, including France, the U.K., Sweden, Australia and New Zealand have universal drug plans and, as a result, pay far less for drugs than in Canada. The choice is clear: universal Pharmacare that provides all Canadians with more coverage for less money or the status quo, where millions of Canadians go without, while costs rise out of control."*[viii]

The CHC recommends the establishment of a national Pharmacare insurance program, with first dollar coverage, as part of the continuum of care health system.

THE SUSTAINABILITY OF MEDICARE

The issue of the sustainability of Medicare as it is configured today forms a significant part of current public debate. Opponents of Medicare are driving the debate, claiming that public health care costs are out of control. They claim that public health spending is consuming an ever greater share of provincial budgets, is crowding out spending in other areas, and given the change in age-related demographics, this trend will worsen. Their message is clear: Medicare is financially unsustainable. The only option is to allow more private, for-profit delivery of care and to allow private insurance coverage for medical services insured under the Canada Health Act.

Research done by Robert G. Evans, O.C. Ph.D. (Economics), Harvard, shows that Medicare is sustainable. In fact, he reiterates Roy Romanow, the Commissioner of the Commission on the Future of Health Care in Canada, '*Medicare is as sustainable as we want it to be.*' He argues that discussion on the sustainability of Medicare must be on the basis of the facts – what the real cost-drivers are in health care. The facts are outlined below.[ix]

- Medicare spending on doctors and hospitals grew from 4% to 5% of Gross Domestic Product (GDP) between 1975 and 2010.

- Today, total health spending which includes private spending on services not covered by Medicare rose at faster rates and is now about 12% of GDP. The average increase in the cost of private drug plans is 15% annually.

- The reason health spending is taking an increasingly larger share of health care budgets is not uncontrolled health care spending. Rather, it is a result of large tax cuts over the years, cuts to other areas of spending and cuts in federal transfers to the provinces. (Some, but not all of the federal cuts were restored). Between 1997 and 2004, cuts in personal income taxes removed a whopping $170.8 billion from public sector revenues at both the federal and provincial levels of government.

- Population aging is a very small factor in expected health care costs at about 0.8% a year, less than the 1% cost related to population growth and the 2.5% due to inflation.

- We have not done all we can to contain costs, especially the costs around medical imaging, diagnostic tests and the use of other

health technology. There is much to be done to make evidence-based decision-making a reality in how health care is practiced.

The debate on the sustainability of Medicare must be based on hard facts. Sustainability has become a code word for privatization and for-profit care. Saying that public health care is unsustainable opens the door to privatization. Shifting from public spending to private spending shifts the cost burden from the wealthy and healthy to those who are sick, creating huge inequality in access to health care.

Privatization and for-profit care are the routes to increased costs while opening opportunities for public dollars to end up as profits. Health care must and will be provided. The questions are who pays, who benefits and will Canadians have access to care based on need or the ability to pay? Canadians will pay more for public health care as long as the provision of services conforms to the principles of universal access, equity and fairness that govern Medicare.

CONCLUSION

The Canadian Health Coalition thanks the Committee for the opportunity to present our views on these important issues.

We believe that Canadians will welcome the kind of leadership that demonstrates the social responsibility governments have toward its citizens. This is a notion that has been absent from public debate and policy for far too long.

As the Canadian Cancer Society notes, *'There is a need for nation-wide standards for home and community care so that all patients can receive excellent treatment and care regardless of where they live and that the transition between levels of care is invisible for people who are experiencing cancer.'* [x]

This statement poignantly captures the need to develop a continuum of care health system with the national standards and principles that govern Medicare. It frames an important social responsibility that governments have yet to meet fully. With the remarkable degree of consensus among Canadians in support of Medicare, we can achieve this step forward.

The Committee's web site, under O*rigins and Establishment,* says the following:

> Each of the group's members has committed to conducting the Committee's work in a spirit of cooperation and purpose, and to enhance the group's profile within their respective national caucus and broader constituencies. United in a belief that Canada's elected representatives should confront such contentious issues boldly and without recourse to partisanship, the group has already hosted several public consultations in the Capital Region and around the country. (www.pcpcc-cpspsc.ca)

That mandate allows the Committee to reach Canadians with the message that we can expand our system of Medicare to take us closer to our original vision, while preserving the principles and values that Canadians hold dear, a bold message indeed. We look forward to the final report of the Committee.

Endnotes

[i] Hollander, Marcus J. and Walker, E.R. *Report of Continuing Care Organization and Terminology, December 1998*

[ii] Canadian Union of Public Employees, *Residential Long-Term Care in Canada; Our Vision for Seniors' Care,* October, 2009

[iii] National Union of Public and General Employees, *Dignity Denied, Long-Term Care and Canada's Elderly,* February 2007

[iv] Pat Armstrong and Hugh Armstrong, *Women, Privatization and Health Care Reform, the Ontario Case,* national Network on Environments and Women's Health, 2006

[v] Ibid;

[vi] Hollander, M.J., Liu, G. and Chappell, N.L., *Who Cares, and How Much: The Imputed Economic Contribution to the Canadian Health Care System of Middle Aged and Older Unpaid Caregivers Providing Care to the Elderly"* 2009

[vii] Institute for Research on Public Policy, 2010

[viii] Gagnon, Marc-Andre, with the assistance of Hebert, Guillaume, *The Economic Case for Universal Pharmacare*, *Costs and Benefits of Publicly Funded Drug Coverage for all Canadians,* Canadian Centre for Policy Alternatives and Institut de recherche et d'informations socio-économiques, September 2010

[ix] Evans, Robert G., in *Sustainability of Health Care: Facts and* Myths, Canadian Health Coalition, www.medicare.ca.

[x] Cancer Society of Canada, *A National Home Care Program,* December 2009, www.cancer.ca