

BRIEF TO ROY ROMANOW, COMMISSIONER FUTURE OF HEALTH CARE IN CANADA

April 30, 2002

SUBMITTED BY:

**The Quality End-of-Life Care Coalition
ALS Society of Canada
Arthritis Society
Canadian AIDS Society
Canadian Association for Community Care
Canadian Association of Social Workers
Canadian Association of the Deaf
Canadian Association on Gerontology
Canadian Breast Cancer Network
Canadian Cancer Society
Canadian Healthcare Association
Canadian Home Care Association
Canadian Hospice Palliative Care Association
Canadian Pharmacists Association
Caregiver Network Inc.
CARP: Canada's Association for the Fifty-Plus
Childhood Cancer Foundation (Candlelighters)
Coalition of National Voluntary Organizations
Frosst Health Care Foundation
GlaxoSmithKline Foundation
Heart and Stroke Foundation of Canada
Huntington Society of Canada
National Advisory Council on Aging
National Council of Women of Canada
VON Canada**

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**.BRIEF TO ROY ROMANOW, COMMISSIONER
FUTURE OF HEALTH CARE IN CANADA**

Purpose of This Brief

The purpose of this brief is to outline our support for a long-term sustainable, high quality, universally accessible, publicly administered health care system in Canada. We believe that improving end-of-life care in Canada as outlined in the Senate Report *Quality End-of-Life Care: The Right of Every Canadian* (June 2000) and the priorities identified by the Quality End-of-Life Care Coalition is critical to achieving these objectives. End-of-life care is also imperative for achieving and supporting the values that resulted in the creation of a national health care system in Canada.

Canadians abhor the social and economic hardships that result from the current system of end-of-life care in Canada that can be characterized as a patchwork of inadequate and inequitably available services. Access to these services is influenced by the type of disease a person has, whether they live in a city or rural area, which province they reside in, whether they have a disability which excludes them from available services, whether they are part of an employment based health insurance plan, and whether they have adequate personal wealth.

As outlined in the Senate Report on end-of-life care in Canada, current health care policies have tremendous impacts on many people. End-of-life policies most obviously have impacts on people who are dying and their family members. These policies disproportionately influence women who bear a heavy proportion of the burden of caring for people who are dying. They also have a significant impact on people with disabilities or marginalized in our society.

The Quality End-of-Life Care Coalition believes that the federal government has an important position in supporting the development of good end-of-life care in Canada:

- It has the lead role in setting national health care standards in collaboration with the provinces and territories that ensure that all Canadians have access to good end-of-life care. The Canada Social and Health Act is a vital instrument for maintaining these standards equitably across our country.
- The federal government has an important role in working collaboratively with the provinces and these sectors to ensure a flexible approach to achieving these standards in different communities. These standards must recognize that good end of life care must be developed and delivered in partnership with the voluntary and private sectors to that it meets the needs of individual communities.
- Good end-of-life care requires an adequate number of trained volunteers and professionals to be effective. The federal government has a lead responsibility in convening

discussions with professional bodies across Canada to ensure that adequate training is available and that professional caregivers are fairly compensated.

- Research is required to evaluate interventions to ensure the continuous evolution of high quality service delivery. The federal government has a key role as a significant funder of research both directly, and through the agencies it funds. In addition, the federal government can provide leadership in the collection of data on a national level to inform decision-making and policy development.
- The federal government has a vital role in supporting family caregivers through its income security policies to ensure that these caregivers are not put at social or economic risk as a result of providing care for a dying family member.

We implore the Commission on the Future of Health Care in Canada to recommend that end-of-life care be recognized as an important component of the health care system in Canada. We strongly recommend that the Senate Report Recommendations on end-of-life care be implemented and that the federal government continue to take a lead role in these strategies.

Background on the Quality End-of-Life Care Coalition

The Quality End-of-Life Care Coalition, comprising 23 national stakeholder organizations from the private and voluntary not-for-profit sectors, was formed in December 2000 to develop a national strategy for quality end-of-life care in Canada. The Coalition represents a broad cross-section of stakeholders who wish to be part of the process of creating a national strategy for end-of-life care and who have a great deal to contribute on behalf of the millions of Canadians that they represent. The Canadian Hospice Palliative Care Association is an active participant in the Coalition and was designated by the partner organizations as the lead organization and secretariat.

The Coalition strongly supports the implementation of the June 2000 Senate report *Quality End-of-Life Care: the Right of Every Canadian*. In December, 2000 these national associations and other end-of-life stakeholder groups met in Toronto to identify, collectively, the key priority recommendations for end-of-life care in Canada. These stakeholders all share the belief that “death should be peaceful and free of pain and that a person should feel safe, comfortable and cared for”.

These stakeholders agreed that to achieve the goal of quality end-of-life care, five priorities must be addressed:

- Availability and access to end-of-life care
- Support for families and caregivers
- Professional education

- Expanded research and data collection
 - Public education and awareness

A *Blue Print for Action* has been developed to address these priority areas. A copy is attached and the *Blueprint* is available on the Canadian Hospice Palliative Care Association's website at <http://www.cPCA.net/>

Dying in Canada Today

The Senate Report *Quality End-of-Life Care: The Right of Every Canadian* (June 2000) provides an overview of dying and end-of-life care in Canada. It indicates that:

- Over 220,000 Canadians die each year
- 75% of all deaths are people over the age of 65 years
- 25% of deaths are related to cancer
- 75% of deaths take place in hospitals and long term care facilities

Of these people who die:

- Only 5% receive integrated and interdisciplinary palliative care
- Cancer patients receive 90% of the palliative care services that are provided although they account for only 25% of patients who die
- There are a range of preferences as to where people want to die

End-of-Life care services are limited:

- The number of palliative care beds has been cut as a result of health care restructuring
- Few provinces have designated palliative care as a core service
- Limited services such as sign language provision are available for people with disabilities
- Most costs and other burdens of homecare are assumed by the family
- Palliative care relies disproportionately on charitable donations

We also recognize that end-of-Life care occurs in a complex environment.

- The average lifespan of Canadians is increasing so those doing the caregiving are also aging and are required to care for those people are living longer with chronic conditions and require end-of-life care.
- People are being discharged from hospitals earlier, but these people still require ongoing care. This care is frequently provided by family members who are untrained and unsupported as they provide this care. Often this requires that they make difficult choices and sacrifices.
- There are not enough trained health care professionals to meet the end-of-life care needs of people and there are inadequate community supports and training for family members.

Key Challenges and Priorities For the Future of Canada's Health System

1. Ensuring Universally Accessible Health care: Availability and Access to End-of-Life Care

End-of-life care is an integral component of a universal, accessible health care system. We believe that end-of-life care must be available to all groups in Canada and not limited by disease, disability, age, socio-economic status, or geographic location. End-of-Life care must be universally available in all settings including community care, and should not be an add-on that is provided in some jurisdictions and regions and not in others.

The provision of end-of-life care at the current time focuses most resources on people with cancer since this is the field hospice palliative care developed from. People dying from other diseases would benefit significantly from the types end-of-life and hospice palliative care that are currently available to people with cancer. Hospice palliative care services need to be available to all Canadians.

We believe it is vital that end-of-life care be available to people in their own communities, and in the environment that is preferable to them. Many people prefer to have palliative care provided in their own home as part of home care services. Other people prefer or need palliative care in hospitals, long term care facilities and hospices. We believe that these preferences and needs should be supported as much as possible.

At the present time this type of care is not available because palliative home care is not a service that is funded by all provinces. Many people are unable to obtain the drugs that they require for quality end-of-life care because there is no national pharmacare policy in Canada and they are otherwise ineligible for drug coverage due to age, lack of insurance coverage or employment status.

We believe that respect for individual preferences should not create additional hardships for family members. At the present time the approaches used to provide end-of-life care in many parts of Canada result in social and economic hardships for both the person who is dying and their family members.

At the current time access to end-of-life care is much less available to certain groups in society, or is provided only as an "add-on". In particular, there are people with disabilities for whom access is limited to even basic health care from professionals who are trained to communicate with them. We believe that lack of appropriate palliative care creates even further social hardships for these people and that services should be designed so that they meet the needs of these people.

2. Providing Support for Families and Caregivers

Reducing Social Hardship

In addition to the pain and suffering of having a family member dying, in many parts of the country, Canadian families are forced to provide much of the care that the dying person requires.

Many palliative care patients prefer to have certain types of personal care provided by professionals rather than family members. Having family members provide this care results in emotional distress for both the person who is dying and for the family member.

While many family members provide this care willingly and compassionately, they are most often untrained for these activities, inadequately prepared for providing them and inadequately supported. Because average lifespan is increasing, the family caregivers are also older. The lack of training and support often leads to caregivers “burning-out”, leaving caregivers exhausted, in poor health and unable to care for themselves or other family members.

Provision of palliative home care relies heavily on women family members, and frequently results in a significant impact on their job security and family income. As a result, we support Recommendation #5 of the Senate Report that states “the federal government immediately implement income security and job protection for family members who care for the dying”. We support the policy direction of the federal government as outlined in the Speech from the Throne at the Opening of the 37th Parliament which stated “No Canadian should have to choose between keeping their job and providing palliative care to a child”. We believe that this policy should cover palliative care for all family members.

Where family members do provide end-of-life care, policies are required that protect the income security of these people so that they do not become impoverished and unable to support themselves as a result of caring for other people.

Reducing Economic Hardship

The current approach to end-of-life care results in significant economic hardships and financial barriers to health care for Canadians. Families can lose their farms, their homes, and economic security at the same time that they lose their spouse, parent or child. Under the current model of end-of-life care, economic hardships result from the costs of drugs and professional care for the person at the end-of-life and from loss of income as they care for the dying person..

While couples over 65 years of age have the highest median net worth in Canada, (single elderly individuals have a significantly lower net worth) a substantial portion of this net worth is the value of their principle residence. (Assets & Debts of Canadians: An overview of the results of the survey of financial security. Statistics Canada, Cat No. 13-595-XIE). As a result, many older couples and single older people are unable to purchase end-of-life care privately unless they sell their home. For couples this would mean that the death of one would also result in the loss of their home for the other. This is problematic on two counts:

- It undermines the preference of people wanting to remain in their own home during the end-of-life; and
- It forces people out of their home to pay for health care for other family members which is unfair to the surviving family members and does not fit with the compassionate and caring approach supported by Canadians.

Single people, which disproportionately includes people with disabilities, and lone-parent families under the age of 65 years make up almost 30% of family units@ (as defined by Statistics Canada). This group has the lowest median net worth and income in Canada and would be unable to purchase end-of-life care. These groups are also more likely to require purchased services because they are not part of a nuclear family group that is available to provide family support.

Parents frequently provide full-time care for a dying child, taking extended leaves of absence, or quitting their job during this highly stressful process. Lack of job security if they take a leave of absence, and lack of income during an extended leave or if they quit their job, leaves these families economically vulnerable. The Speech from the Throne at the opening of the 37th Parliament recognized this.

As a result, we believe that universally available and publicly funded end-of-life care is critical to reducing social and economic hardships when a person is dying. This must include both home care and pharmacare. These are required to support equitable access to health care without creating financial or other barriers as described in the Canada Health Act. We also endorse the government position of developing Employment Insurance policies or other income security measures to reduce the economic impacts that result from caring for a dying child, but believe that these policies must be extended to include family members caring for a dying spouse or parent.

3. Improving Quality of Care: Support for Education, Research and Data Collection

We believe that education and research is important for creating a high quality end-of-life care and health care system. The priorities identified by the Quality End-of-Life Care Coalition have focused on these.

There is strong support for the view that high quality end-of-life palliative care will improve the quality of health care in general and reduce waste in the current system. Reports from the Institute for Clinical Evaluative Services in Toronto and the Saskatchewan Commission on Medicare (the Fyke Report, April, 2001) indicate that considerable resources are squandered because of conflicting incentives in the health system, lack of services to meet the care requirements of different groups and lack on integrated systems. We believe that this is very much the case in end-of-life care.

Education

High quality end-of-life care, delivered by well-trained staff and volunteers, is critical for a number of reasons. First and foremost, it is only through provision of high quality end-of life care that dying people will feel safe, comfortable, well treated and cared for so that their death is peaceful and free of pain. Secondly, high quality end-of-life care and high quality health care go hand in hand.

Lack of quality end-of-life care results in health care professionals outside the hospice palliative care field providing inappropriate services, at the wrong time, to dying people. Often services provided are too late to be effective in supporting the patient and family members, and frequently the services are more expensive and intrusive than is wanted or justified, but without effective alternative systems, the health professionals involved will try desperately to help, irrespective of cost or appropriateness. An obvious example of this is the hospitalization of a dying person after the person and their family cannot cope anymore. In many situations, appropriate early intervention with home care and pain management would have been more effective and desirable, as well as being less expensive.

To be most effective, we believe considerable work is required to improve the systems of primary and specialized palliative care. This will require expanded professional education for all health professionals in primary care to provide them with the skills required in palliative care. Additional professional education is also required to ensure that there are sufficient numbers of specialists to provide advice in the more complex aspects of end-of-life care such as pain and symptom management. The members of the Quality End-of-Life Care Coalition have been active leaders in the development of the Palliative Care Consensus Standards in Canada and the development of training programs for home support workers, volunteers, physicians, nurses and other health care providers. Much more work is needed in these and other areas to strengthen the skills of practitioners.

There is ample evidence that provision of high quality end-of-life care requires increased training of all professionals who work with dying people. As a result, we recommend that national standards of training and service delivery be established for palliative care. The development of integrated service delivery systems is critical for delivery of quality care. We believe that expanding professional training on end-of-life care in the curriculum of training programs for all health professionals is critical for creating an effective delivery system. This training must be expanded across all people working in the health system, from health care aides through undergraduate and continuing education professional programs.

We believe that skilled palliative care professionals should be available in adequate numbers across Canada to meet the needs of people living in their communities. There should also be enough of these people specifically trained so that they are able to work effectively with people with disabilities.

We believe that more training should be provided to volunteers and family and other caregivers.

Research and Data Collection

We believe that achieving the goal of high quality health and end-of-life care requires the development and support of a research agenda that will continuously guide the implementation of system and clinical care improvements and innovations. There is a need to invest in existing capacities and to create and support new capacities to ensure that adequate data is collected for identifying effective service models and clinical interventions. While there are some pockets of excellence in Canada, greater support for this work is needed.

The result of strengthening the provision of end-of-life care will have a number of benefits. The most obvious will be that people receive better care in the latter stages of life. We believe that it will also reduce the demand for other services that are of marginal or no benefit to patient, resulting in an improvement in the overall quality of care and a reduction in costs.

4. Increasing Public Education and Awareness – A Key to a Sustainable Health System

The coalition endorses the development of a public education and awareness strategy for end-of-life care. We believe that Canadians need to be informed about their care choices and need to recognize that they have a role in creating these choices. This recognition that we all have a role in creating the system is a critical underpinning to Canadians recognizing their stake in supporting the health system. It is also important that Canadians recognize that the health system cares. We believe that when quality end-of-life care is available people will see the health care system as more caring and there will be more public support for the public system.

Conclusions and Recommendations

The health of Canadians and the availability of a high quality, universally accessible health care system in Canada requires commitment, collaboration and investment by multiple stakeholders. Health is influenced by many factors outside the health care system. As a result, we recognize the importance of the multiple stakeholders across Canada involved in creating a healthy environment for all Canadians. The Quality End-of-Life Care Coalition encourages all of the stakeholders to participate in creating a healthy environment in which all Canadians can live.

This healthy environment requires that Canadians are able to die peacefully and free of pain and that a person should feel safe, comfortable and cared for. Poor quality health care, lack of access to end-of-life care, social and economic hardships all take away from an environment in which we are able to die well. These factors also reduce the support that Canadians have for our health care system.

We encourage the Commission on the Future of Health Care in Canada to strengthen end-of-life care in Canada for many reasons.

Firstly, it is the right thing to do: every Canadian will be affected directly and indirectly by end-of-life care.

Secondly, quality end-of-life care will improve the quality of health care in Canada by making better use of resources. A shift to an appropriate model of care will result in higher quality and make available additional resources from within the current system by reducing ineffective, undesired and inappropriate care.

Finally, we believe that the social and economic hardships that result from our current approach undermine the support that Canadians have for our universal health care system.

The Quality End-of-Life Care Coalition believes that the federal government has an important position in supporting the development of good end-of-life care in Canada:

- It has the lead role in setting national health care standards in collaboration with the provinces and territories that ensure that all Canadians have access to good end-of-life care. The Canada Social and Health Act is a vital instrument for maintaining these standards equitably across our country.
- It is the responsibility to ensure that the Charter of Rights and decisions of the Canadian Human Rights Commission are upheld regarding accessibility to services for people with disabilities.
- The federal government has an important role in working collaboratively with the provinces and these sectors to ensure a flexible approach to achieving these standards in different communities. These standards must recognize that good end of life care must be developed and delivered in partnership with the voluntary and private sectors to that it meets the needs of individual communities.
- Good end-of-life care requires an adequate number of trained volunteers and professionals to be effective. The federal government has a lead responsibility in convening discussions with professional bodies across Canada to ensure that adequate training is available.
- Research is required to evaluate interventions to ensure the continuous evolution of high quality service delivery. The federal government has a key role as a significant funder of research both directly, and through the agencies it funds. In addition, the federal government can provide leadership in the collection of data on a national level to inform decision-making and policy development.
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