

## **History of the Quality End-of-Life Care Coalition of Canada**

On June 6, 2000, the Senate of Canada issued the report *Quality End-of-Life Care: The Right of Every Canadian*. This report was an update of the Senate's 1995 report, *Of Life and Death*. In the intervening five years, the Senate discovered that little progress had been made on its 1995 recommendations. The 2000 report contains strong recommendations to ensure that Canadians have access to high quality end-of-life care. The Quality End-of-Life Care Coalition of Canada (QELCCC) supports the recommendations made in the 2000 Senate Report.

The first recommendation of the Senate report is that the federal government, in collaboration with the provinces & territories, develop a Canadian strategy for end-of-life care. The Canadian Hospice Palliative Care Association (formerly the Canadian Palliative Care Association) discussed the Senate report with several of its national partner groups such as the Canadian Cancer Society, the Heart and Stroke Foundation of Canada, the ALS Society of Canada, and the Canadian Association of Retired Persons. It quickly became clear that national voluntary sector groups are concerned about end-of-life care and wish to see a well-funded, sustainable Canadian strategy that would include a strong voice of the voluntary sector and of patients and their families.

In December of 2000, a group of 24 national stakeholders met in Toronto, Ontario to begin to set the groundwork for the development of a Canadian strategy for end-of-life care. The result of this meeting was the creation of the *Quality End-of-Life Care Coalition of Canada (QELCCC)* and a working document entitled *Blueprint for Action (2000)*. Within the Quality End-of-Life Care Coalition of Canada an Executive Committee and four Working Groups were established. The QELCCC has been meeting on an annual basis since 2000. The goal of each annual meeting is to create a Workplan for the coming year based on the *Blueprint for Action*. The membership of the Quality End-of-Life Care Coalition of Canada continues to grow and currently is made up of thirty-one member organizations. (Refer to membership list for details)

In 2001, Health Canada announced the creation of the Secretariat on Palliative and End-of-Life Care with the mandate to move this issue forward. The Secretariat on Palliative and End-of-Life Care is currently funded to a level of approximately \$1 million dollars per year, with no future commitments.

### **Mission and Mandate of the Quality End-of-Life Care Coalition of Canada**

The Quality End-of-Life Care Coalition of Canada believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. The Coalition believes that to achieve quality end-of-life care for all Canadians there must be a well funded, sustainable national strategy for palliative and end-of-life care. It is the mission of the Quality End-of-Life Care Coalition of Canada to work together in partnership to achieve this goal.

## **Why Hospice Palliative Care is an effective Quality End-of-Life Care Strategy?**

The 2000 Senate report strongly advocates access to high quality hospice palliative care for all Canadians. Those working in the field estimate that less than 15% of Canadians have access to such care at the end of life. Many die with inadequate pain treatment, in loneliness, without dignity and in fear. Families, who increasingly bear the burden of care at the end of life as health care services are cut back, need more resources in order to meet the challenge.

Our population is aging. Statistics Canada states that at present, 75% of the 225,000 Canadians who die each year are age 65 or over. This number is expected to grow by over 40% by the year 2025. In addition, a recent Conference Board of Canada report indicated that close to three million Canadians are providing some form of home care to a sick or dying family member, with the average age of family care givers being 42 years old. Patients and future patients such as seniors' groups and persons living with a life-threatening illness are becoming more vocal about their desire to determine the kind of health care that they and their family members receive. Additionally, an Ipsos-Reid poll commissioned by the Canadian Hospice and Palliative Care Association and GlaxoSmithKline Inc. indicates that Canadians estimated that it would take, on average, 54 hours per week to care for a loved one at home. Two-thirds indicated they did not have that amount of time available given their current schedule.

Quality and access to hospice palliative care services varies greatly across Canada. In many cases, this is due to the lack of adequate services. In other cases, it is because a family physician or specialist may be unaware of the services that are available, or unwilling to admit "defeat" when a cure is no longer possible. The Quality End-of-Life Care Coalition of Canada "*Dying for Care*" status report, released in September 2004, highlights many of the inequities that Canadians face when trying to access hospice palliative care services.

An adequately funded, sustainable Canadian strategy for end-of-life care would address the issues of services, resources, education, research, and support for patients and families. It would also address the need for federal-provincial-territorial cooperation and ensure that Canadians have access to a basic level of quality end-of-life care. Since our population is mobile and the extended family system has broken down, sick or elderly Canadians can no longer count on having family members close by to provide care. Even when they do, most women, who are the traditional family caregivers, are now in the workforce. These realities reinforce the need for better provision of care in a coordinated way that includes the involvement of patients, families, care providers and all levels of government.

## **What is Hospice Palliative Care?**

Hospice palliative care aims to relieve suffering and improve the quality of living and dying. It is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with or dying from a life-threatening illness. Care is provided by an interdisciplinary team that supports the patient in their physical, emotional, spiritual, and relational life. It is whole person care. The unit of care is the patient and their circle of loved ones. Support continues during the illness and throughout bereavement. Volunteers are an integral part of hospice palliative care teams.