

Quality End-of-Life Care Coalition of Canada
Submission to the 5 year Report of the
Senate Subcommittee final report
Quality End-of-Life Care: The Right of Every Canadian
February 10, 2005

The purpose of this brief is to outline the Quality End-of-Life Care Coalition of Canada's (QELCCC) support for examining the progress that has been made since the 2000 Senate Report, *Quality End-of-Life Care: The Right of Every Canadian*. While the 2000 Senate report recommendations have resulted in significant advancements towards ensuring all Canadians have equal access to quality end-of-life care, the Coalition believes that in order to make sustainable and enduring changes a well-funded, long-term strategy must be an essential part of future plans.

Your request suggests that we answer a number of questions and for clarity they are listed as headlines below.

What progress has been made in implementing the 14 recommendations from the 2000 report?

1. *That the federal government, in collaboration with the provinces, develop a national strategy on end-of-life care.*

The current "strategy's" major deficiency is a lack of adequate funding. Progress on developing and implementing the current work and planning for future activities is limited by not only the inadequate budget of just over \$1 million per year, but also by the uncertainty of continued resources as the current funding is neither long-term nor sustainable. The QELCCC believes this is a significant barrier to the development of a National Strategy and we have voiced our concern through correspondence and meetings with senior bureaucrats and politicians at Health Canada.

As member organizations that represent millions of Canadians, the QELCCC understands the importance of federal and provincial/territorial involvement in discussing end-of-life care issues. To date, the Strategy not engaged the provincial/territorial governments in a meaningful and collaborative manner which is essential given that services are delivered at the provincial/territorial level. We are hopeful that the federal and provincial/territorial governments will work closely together to achieve this outcome.

2. *That the federal government, in collaboration with the provinces, establish a five year plan for implementing this national strategy.*

As a result of the challenges stated above, there is currently not an established national strategy and therefore a five-plan is not in place.

3. *That the federal government prepares an annual progress report on implementing this national strategy.*

Health Canada has prepared an evaluative report on the strategy to March 31, 2004. While not yet available to the public, The QELCCC is hopeful that this report will reflect on what has been accomplished but will also assist in developing next steps to revitalize the strategy.

4. *That the federal government immediately assess the need for home care and pharmacare for the dying, and establish, in collaboration with the provinces, the funding required for these programs.*

The QELCCC is pleased that this recommendation has been actualized with the September 2004 Health Accord announcement for first dollar coverage for some areas of palliative home care. It will be critical to ensure that a comprehensive definition for eligibility to palliative home care services is implemented in all provinces and territories by 2006.

5. That the federal government immediately implements income security and job protection for family members who care for the dying.

The QELCCC strongly believes in the Compassionate Care Benefit and what it provides for Canadians. As such, we are encouraged by the initial program but the QELCCC will be looking at ways to encourage the government to expand this program in the future. Two points of interest for the QELCCC are who is eligible for the benefit and the length of time that benefits are available.

The QELCCC believes that the HRSDC definition of who is eligible for the benefit is too narrow and does not allow a dying person to choose who the best person is to provide end-of-life care. Given the diversity of Canada's families, the current criterion for eligibility does not allow Canadians to make the best choice for their care.

Also, the dying process is unpredictable and although medical practitioners can estimate when a person is in the last stages of life, it is difficult to accurately predict. The current legislation does not allow for this flexibility and with a maximum of only eight weeks (six weeks compensated) available, it does not provide an adequate timeframe for Canadians to care for a dying loved one.

6. *That the federal government, working in collaboration with the provinces and the educational community, explore ways to increase multidisciplinary training and education of professionals involved in end-of-life care.*

The federal government has funded one interdisciplinary education project for family physicians in training. Proposals have been submitted for nursing and social work.

With this work, the QELCCC's Professional Education Committee will continue to work with Health Canada to encourage these groups to work collaboratively and to share the tools that are developed.

7. *That the federal Minister of Health works with the other relevant federal ministers to develop an interdepartmental strategy on end-of-life care.*

An interdepartmental committee was struck but to date the impact is unclear.

8. *That the federal Minister of Health discuss the establishment of a federal, provincial, and territorial strategy on end-of-life care with provincial and territorial counterparts at the next meeting of the Ministers of Health.*

To date this has not happened but this action will be essential if a national strategy is to be successful.

9. *That the federal Minister of Health discusses with provincial and territorial counterparts appropriate measures for funding of end-of-life initiatives.*

In the September 2004 Health Accord, funding was announced for palliative home care. The Coalition is very pleased with this progress and would reiterate that it is important that federal, provincial and territorial governments prioritize funding of hospice palliative care programs and services in other settings including acute care hospitals, long-term care facilities and residential hospices.

10. *That the Canadian Institutes of Health Research (CIHR) be encouraged to establish an institute that focuses on end-of-life issues facing Canadians of all ages with all medical conditions.*

The QELCCC Research Utilization Committee is encouraged by the recent CIHR announcement that nine of their institutes are currently involved in palliative care research initiatives related to end-of-life care, led by the Cancer Institute.

Although no individual institute has been established within CIHR, the QELCCC does see this recent announcement as an important first-step in recognizing the importance of end-of-life care research.

11. *That the Canadian Institute for Health Information (CIHI) be encouraged to develop indicators for quality end-of-life care.*

CIHI does not currently include end-of-life care in their Health Indicators.

12. *That the federal Minister of Health coordinate and implement a multi-dimensional agenda for end-of-life research that involves relevant departments, agencies, and other levels of government.*

CIHR has announced a joint initiative of \$16 million in this area. Although this is an important first step, this research needs to be broadened to include end-of-life care for a spectrum of diseases and populations. Also, sustaining research initiatives in this area will continue to be a problem without a sustainable, long-term strategy acting as a framework.

13. *That the federal government, in collaboration with the provinces, develop a five-year plan for implementing the 1995 unanimous recommendations.*

The one major recommendation that still needs to be addressed from the 1995 unanimous recommendations, and is not covered in the 2000 recommendations, is that the federal government makes palliative care programs a top priority in the restructuring of the health care system. Often when discussing primary health care, palliative and end-of-life care issues are left off the agenda and it is an essential point when discussing the needs of all Canadians at various points on the continuum of care.

14. *That the federal government prepares an annual progress report on the implementation of the unanimous recommendations.*

It is important that the government report to its citizens on the progress it has made on addressing the above recommendation. This needs to include information about the level of discussion as well as documenting the progress that is made.

What progress has been made in implementing the unanimous recommendations in the 1995 report?

After reviewing the unanimous recommendations, the QELCCC would like to comment on the following. All other relevant information is captured in the 2000 report recommendations.

1995 Recommendation - Governments make palliative care programs a top priority in the restructuring of the health care system.

Palliative care services are continually disregarded in primary health care discussions although they are a vital part of the continuum of care. With the current discussions that are happening in restructuring how Canada provides care to its citizens, it is essential that palliative care remains at the top of the agenda.

Are the appendices from the 2000 report up to date?

The appendices included in the 2000 report are substantially out of date in comparing services available to Canadians in each province and territory. There have been changes that are unaccounted for in these summaries as well as some new emerging issues. The Quality End-of-Life Care Coalition of Canada (QELCCC) published a report in July 2004 summarizing provincial variations in end-of-life care. We are attaching the Dying for Care Report as Appendix B.

Where is palliative end-of-life care headed in Canada?

There have been some significant advancements (i.e. The Health Accord), especially at the national level regarding palliative and end-of-life care, but they are not included in a sustainable, long term strategy that will work towards an improved and more systematic provision of hospice palliative care services. The QELCCC is advocating for hospice palliative care programs and services to be integrated into the health care system and not be an additional program that may or may not be available in the community.

The QELCCC wants hospice palliative care services to be comprehensive in nature and include the following six components. Access to:

- Hospice palliative care professionals and volunteers 24 hours per day, 7 days per week in all four care settings: acute care hospitals, long-term care facilities, residential hospices or the home.
- Home care services including home support
- Care for the caregiver often referred to as respite care
- Compassionate leave for the caregiver (financial assistance)
- Prescription medications
- Non-prescribed therapies

The Quality End-of-Life Care Coalition of Canada firmly believes that every Canadian has the right to die with dignity, free of pain, surrounded by their loved ones, in the setting of their choice. As such, the QELCCC also advocates for the coordination of these services so that families are not denied services because they are not aware they exist or are not able to adequately navigate the system. End-of-life care services must be coordinated, comprehensive in nature and integrated into the health care system in a meaningful way. These changes will only occur when all levels of government work together to provide a long-term sustainable strategy.

Where is palliative end-of-life care headed internationally?

The Quality End-of-Life Care Coalition of Canada does not monitor international issues regarding palliative end-of-life care.

Conclusions

Currently, Canadians face excessive hardship when caring for loved ones during the final stages of their life. These hardships are a result of a highly fragmented system that does not provide equitable services and is not reflective of the diversity of situations that Canadians face based on a number of factors including the province or territory in which they reside, whether they live in a rural or urban setting, and the type of disease and symptoms they are trying to manage. These situations are exacerbated by a number of other factors including the financial burden incurred by patients having to pay for non-prescribed therapies, the availability of home care services, and the burden of care that is placed on the family. It is apparent that there have been many gains that have been made including training, research, and palliative home care to name a few. However, these improvements have not equated to better access for Canadians to end-of-life care services.

Although there has been encouraging progress made in supporting Canadians who wish to provide care for a dying loved one, through the Compassionate Care program, there is still much work to be done. It is important that Canadians are able to access this benefit not based on a limited criteria but on being chosen as the best caregiver for a dying loved one. The benefit also needs more flexibility to provide an adequate timeframe for those caring for loved ones to enable them to spend the time needed with their loved ones as the dying process is unpredictable.

If these issues are to be address and equal access to quality end-of-life care is to be available for all Canadians, issues that face marginalized Canadians must also be addressed. The disabled, aboriginals, marginalized populations (homeless people, people in prisons) and cultural minorities all face unique challenges at the end-of-life. The federal government must take a leadership role in moving this agenda forward.

Recommendations

1. An adequately funded, long-term, sustainable national strategy for palliative and end-of-life care that involves the federal, provincial, territorial governments and the health care community. This strategy will include support to hospice palliative care organizations to enable them to play a key leadership role at the national level.
2. All provincial/territorial governments fund a comprehensive, coordinated and integrated set of end-of-life services that would include access to:
 - Hospice palliative care professionals and volunteers 24 hours per day, 7 days per week in all four care settings including acute care hospitals, long-term care facilities, residential hospices or the home.
 - Home care services including home support
 - Care for the caregiver often referred to as respite care
 - Compassionate leave for the caregiver (financial assistance)
 - Prescription medications
 - Non-prescribed therapies

3. All provincial/territorial governments work with the federal government to provide first dollar coverage for a set of core services at end-of-life that includes the 6 listed above. This will ensure Canadians have access to equitable and transferable palliative care services across the country including rural and remote Canada.
4. All provincial/territorial governments create a mechanism to track (funding and volume of usage) what end-of-life services and programs are available throughout their province or territory.
5. That the federal government, continue to work in collaboration with the provinces and the educational community, to explore ways to increase multidisciplinary training and education of professionals involved in end-of-life care.
6. That the federal Minister of Health coordinate and implement a multi-dimensional agenda for end-of-life research that involves relevant departments, agencies, and other levels of government.