



Terms of Reference

1. **Name:**

Quality End-of-Life Care Coalition of Canada (QELCCC)

2. **Membership**

Types of membership:

The structure and/or composition of the membership are dependant on resource and capacity availability. There are two types of membership in the Coalition:

Full membership – This membership is open to any national organization that supports the principle of quality end-of-life care for all Canadians. Full members are also eligible to have their involvement in Coalition activities (i.e. face-to-face annual meeting) subsidized. There are no annual membership fees.

Associate membership – This membership is open to those who support the principle of quality end-of-life care for all Canadians but are not a national organization or cannot participate fully in the Coalition's committee structure. These members involvement in Coalition activities will not be subsidized. There are no annual membership fees.

Coalition members will support the principle of quality end-of-life care for all Canadians and participate in the decision-making and initiatives of the Coalition to the extent of their ability and resources.

Coalition members will communicate Coalition decisions and positions to their provincial and/ or local constituencies and provide feedback to the Working Group based on consultations with the provincial and/or local constituencies.

Coalition members are free to express their disagreement with a position taken by the members of the Coalition and to opt out of specific initiatives of the Coalition after expressing their position in a clear, respectful way in writing (electronically or by mail).

3. **Constituency**

Through its members, the QELCCC represents all Canadians including: professional and family caregivers; volunteers; health care professionals (nurses, pharmacists, social workers, spiritual advisors etc); Canadians with terminal illnesses, their families and other Canadians with an interest in quality end-of-life care.

4. **Mandate of the Coalition**

The Coalition's primary mandate is to act as an advocate for quality end-of-life care for all Canadians.

To accomplish this mandate, the Coalition may:

- a. Act on behalf of member groups in consultations with the federal government, other levels of government, and other organizations on the provision of quality end-of-life care including, but not restricted to, implementing the recommendations of the June 2000 Senate report *Quality End-of-Life Care: The Right of Every Canadian*.
- b. Gather information from members for the purpose of preparing briefs, discussion papers and position documents for advocacy and consultation.
- c. Disseminate information to members
- d. Consult with members on major policy directions and opportunities.
- e. Contribute to public education and raising public awareness about end-of-life issues.
- f. Contribute to other educational initiatives as needs are identified.
- g. Act as an information clearinghouse on end-of-life issues within the bounds of its resources.
- h. Communicate positions and news about end-of-life issues to the media
- i. Conduct research on end-of-life care issues as resources permit and disseminate the results of its research to members.

Nothing within this mandate restricts the freedom of any member organization from conducting its own advocacy and research activity on end-of-life care issues.

5. **Functioning as a Coalition**

The Coalition members will work in one of five committees. Each of the five committees will designate one member to sit on an executive. This committee representative will bring information of the work of that committee to the other committees via the executive. This information will inform all committees' work. This executive will act on resolutions and decisions of the Coalition and reporting back to their committee/coalition members.

The Executive will:

- a. Follow through on initiatives agreed on by Coalition members and committees and report to the Coalition members regarding its progress.
- b. Develop proposals for establishing and promoting advocacy and education initiatives to be brought to the committees/coalition members
- c. Propose effective means of communication between the Coalition and the members of Working Group
- d. Meet with government and other officials on behalf of the Coalition as required, where possible, Coalition members will be invited to attend these meetings.
- e. Participate in forums that will promote initiatives such as the implementation of the June 2000 Senate Report.
- f. Liaise with Health Canada and other relevant departments.

- g. Meet by teleconference and at face-to-face meetings when warranted and when resources permit.
- h. Keep accurate records of meeting and its work.
- i. Perform other duties as agreed by Coalition members

The Coalition has agreed that the Canadian Hospice Palliative Care Association will take the lead in supporting the work of the Coalition and the Working Group including drafting proposals and bringing to the Coalition for approval and input as well as implementation of Coalition projects.

6. Communication and Meetings

The committees will meet once by teleconference (and as needed) and then will communicate via email. The Executive will meet when possible by teleconference. At other times, communication will be done via e-mail, fax and other efficient and affordable means. If funds are available, face-to-face meetings can be held.

Meetings will be accessible for persons with disabilities.