



Palliative Care
Coalition of Canada
Coalition canadienne
des soins palliatifs

Palliative Care Coalition of Canada Terms of Reference

January 2025

“Advocating for better hospice palliative and end-of-life care for all Canadians”

Background:

The Palliative Care Coalition of Canada (PCCC) is a group of 35+ national stakeholder organizations dedicated to improving end-of-life care for all Canadians. The Coalition believes that all Canadians have the right to quality hospice palliative care, including grief and bereavement supports. To achieve this, there must be a well-funded, sustainable national strategy for hospice palliative care. It is the mission of the PCCC to work together in partnership to achieve this goal.

During the last 10+ years, the PCCC has been involved with some remarkable successes (listed chronologically):

- Canadian Institutes of Health Research (CIHR) Palliative and End-of-Life Care Initiative (2009): This targeted research investment started building clinical research capacity and partnerships with stakeholders and the community, including decision-makers and patients.
- Canadian Partnership Against Cancer (CPAC) Advance Care Planning Initiative (2013): This initiative raised the awareness of Canadians about the importance of Advance Care Planning (ACP) and equipped them with the tools they need to effectively engage in the process through the Speak Up! Campaign.
- In response to the continuing increase of the seniors population and caregivers receiving the Compassionate Care Benefits (CCB), the Coalition sent a letter to the Minister of Employment and Social Development of Canada (ESDC) inquiring about how and when the update to the CCB will be applied by the government. The Coalition asserted that the implementation of the benefit must be done in a way that will fully inform Canadian citizens of their rights. The Liberal government announced the extension of the CCB from 6 to 26 weeks effective January 2016. A social media initiative was completed in January 2016 that resulted in increased awareness amongst Canadians.
- Palliative Care Coalition of Canada (PCCC) The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care Project (2016), funded by Health Canada: This roadmap for an integrated palliative approach to care highlighted community effort and information on the current hospice palliative care landscape in Canada. A number of discussion papers were developed for this initiative, including a thorough description of the palliative approach to care, a review of health economics, considerations for caregivers, and best practice models from within Canada and internationally.



- Health Canada established the Framework on Palliative Care in Canada (2018) and Action Plan on Palliative Care (2019) which serve as a blueprint to help shape planning, decision making, and organizing change related to hospice palliative care in Canada. This framework recognized the Coalition as an 'expert' in the field of hospice palliative care due to the work it had accomplished, and lists the PCCC in the resource section.
- Bill C-220 received Royal Assent (June 2021): Bill C-220 amended the Canada Labour Code so that any eligible Canadian is able to receive ten (10) days of compassionate care leave. The QELCCC was supportive of the MP during the Bill's debate and spoke to all political parties to see this Bill be passed.

Purpose:

The PCCC is an informed network of leading stakeholder organizations who are united and aligned around key issues in hospice palliative care and work collaboratively to identify and to suggest specific issues to the federal government/the Council of the Federation that impact millions of Canadians, and influence policy and funding decisions in alignment with the Framework on Palliative Care in Canada and the Blueprint for Action.

It is also a valued forum for generating and exchanging knowledge on numerous topics pertaining to hospice palliative care (e.g., caregiver support, grief and bereavement, training and professional development) and a catalyst for bi-lateral or multi-lateral collaboration among members.

Its activities include:

- 1) **Advocacy** – The PCCC provides a forum to develop and amplify a collective voice on issues of importance in hospice palliative care to all or a subset of members at the Federal level, including raising awareness of the importance and urgency of palliative care among the public at large or with specific stakeholders, responding to issues/opportunities in a timely manner, and supporting policy development/refinement. This group can serve to amplify the voices of health care providers, (clinician) researchers, and millions of patients, caregivers, and family members.

Examples may include:

- Drafting pre-budget submissions
- Preparing briefing notes and key messages on issues for all members
- Engaging in national (social) media campaigns promoting sector awareness days/week
- Hosting a 'Day on The Hill'

- 2) **Collaboration** – The Coalition provides a forum for members to identify and to initiate opportunities for collaboration based on areas of shared interest. This collaboration could be bi-lateral (i.e., organization to organization) or multi-lateral (i.e., among several interested organizations).

Examples may include:

- Collaboration on national initiatives/programs of shared interest
- Supporting activities linked to National Hospice and Palliative Care Week



- Writing letters of support for grant applications
- 3) **Knowledge Creation** – The PCCC will generate, collect, organize, analyze, and share the collective knowledge and wisdom of its members to improve hospice palliative care in Canada. This may include analyses, white papers, research and evaluation projects, etc. from individual members, a subset of members, or all PCCC members alongside knowledge synthesis to inform advocacy initiatives/the *Blueprint for Action* priorities.

Examples may include:

- Knowledge generation and synthesis that inform future direction of PCCC's goals and objectives and White Papers toward *Blueprint for Action* priority areas
 - Knowledge translation activities in support of advocacy initiatives/*Blueprint for Action* priorities
 - Development of the next iteration of the *Blueprint for Action*
- 4) **Knowledge Exchange** – The PCCC provides a national forum for members to share information, spark discussion, and receive feedback and advice related to current and future activities in hospice palliative and end-of-life care in which their organizations are interested and/or involved.

Examples may include:

- Members providing updates on their plans associated with key events or dates (e.g., National Grief and Bereavement Week, National Hospice and Palliative Care Week, etc.) or national developments of interest (e.g., legislation, pre-budget submissions, etc.)
- Presentations from member organizations (or invited guest speakers) on relevant topics of interest (e.g., complementary therapies)

Priorities and Core Values of the Coalition:

In line with the current iteration of the *Blueprint for Action*, the PCCC will focus on four priorities, listed in no particular order:

1. Increasing public awareness around hospice palliative care's benefits, issues, and areas needing improvement, including support for caregivers and those experiencing grief and bereavement.
2. Ensuring health care providers, volunteers, communities, caregivers, and others have access to education and training to ensure they possess the required competencies to provide optimal care.
3. Contributing to research and systematic, standardized data collection on hospice palliative care with special interest including formal and informal caregivers, and grief and bereavement.
4. Advocating for universally accessible and culturally safe access to hospice palliative care for under-served populations and those who provide caregiving and experience grief and bereavement.



Member participation in the Coalition is guided by the following core values:

- Members represent the views of their organizations and are encouraged to be agents of positive change, building on known strengths, assets, and resources. Members in turn are responsible to share information stemming from the Coalition within their organizations/networks
- Each member organization is a conduit to its individual community and stakeholders and will communicate according to its own policies
- Exchange of and respect for all forms of knowledge (e.g., Indigenous, quantitative, practical, qualitative, lived experience) related to hospice palliative and end-of-life care is encouraged to increase the capacity to generate, synthesize, and use knowledge, and to advance action through participatory community-driven approaches
- Diverse backgrounds, experiences (e.g., cultural and lived experience), and opinions of members are valued equally and enhance discussion and potential collaboration
- Members generate an environment in which there is a willingness to provide (and receive) respectful and timely feedback from all members, when appropriate

Membership:

The membership of the Coalition is comprised of national stakeholder organizations who have demonstrated a commitment to advancing hospice palliative and end-of-life care nationally. Membership is intended to be as inclusive and diverse as possible. See Appendix A for the most current Membership List.

Each member organization is expected to identify one primary representative to actively participate in bi-annual meetings to reflect their organization's views. Member organizations are encouraged to identify an alternate should their primary representative be unable to attend meetings, recognizing that it is the responsibility of the primary representative to provide their alternate with the context and information they may need to actively participate. Recognizing that representation from member organizations may change over time, member organizations agree to notify the Secretariat in a timely manner of any changes to their primary representative and/or alternate.

Members are asked to commit to attending the two Coalition meetings each year. If a member seems to be facing challenges with participation, they will be invited to engage in a dialogue with one or more Executive Committee members to explore renewing their commitment or stepping away from the Coalition.

In addition to participating in the Coalition meetings, members are also expected to actively contribute to at least one Working Group that aligns with their personal interests and expertise and/or organizational priorities.

Membership Criteria

To be considered for membership in the Coalition, an organization must:

- Be currently involved in activities related to hospice palliative and/or end-of-life care at a national level, or conduct work that can influence the national agenda



- Acknowledge the Coalition's Priorities and Core Values as outlined in these Terms of Reference
- Commit to actively participating in bi-annual Coalition meetings and actively contributing to the work of at least one Working Group to support the mandate of the Coalition
- Agree to disseminate information shared through the Coalition to their organization/networks, when appropriate

New Members

Potential new members may be identified in one of two ways:

- 1) Facilitated by the Executive Committee, the **annual membership review** is a multi-step process that includes both a scan of current organizational representation, and a member survey assessing perceived gaps in representation. The results of the scan, including identified gaps, and survey will be shared with members. The Executive Committee will research and propose a list of potential organizations within each of the priority gaps in representation. A brief synopsis of each prospective member (e.g., mission, vision, mandate, current/ongoing relevant work, interests, etc.) will be presented to the Coalition for consideration. Members will be invited to engage in an open dialogue to assess each prospective member's fit and alignment with the Coalition. The Executive Committee will reflect on this feedback and propose a final list of new members to invite to join the Coalition at the Annual General Meeting (AGM).
- 2) In addition, existing members may also receive an **ad-hoc expression of interest** from a prospective member who is interested in joining the Coalition. If the expression of interest is received within the two months leading up to the annual membership review, discussions will be deferred to the annual membership review and the prospective member will be notified of the timeline for consideration. If the expression of interest is received more than two months prior to the next annual membership review, it will be addressed individually on its merits. Members of the Executive Committee will review the application, and if in agreement, bring forward the membership request to the attention of all members via email with final confirmation at the following Coalition meeting. Members will be provided with a brief synopsis of the prospective member and invited to engage in an open dialogue (as above), while also reflecting on the most recent annual membership review conducted.

Regardless of the mechanism by which a potential new member is identified, if the Coalition agrees with a proposed invitation, a Letter of Agreement (see Appendix B) will be extended to the new member.

Governance:

The work of the Coalition is structured and championed with the support of an Executive Committee, Working Groups, and a Secretariat.



Executive Committee

The Executive Committee is composed of the Chairs (or Co-Chairs) of the Working Groups and the Chair of the Secretariat. The Chair of the Secretariat will also act as Chair of the Executive Committee. Each of these individuals brings unique skills, expertise, and resources to this Committee, along with a commitment to provide direction and to share responsibility for leadership of the Coalition.

Executive Committee responsibilities may include:

- Coordinating Coalition meetings including:
 - Soliciting suggestions for agenda items
 - Reviewing and approving agendas, meeting materials, and minutes
 - Chairing meetings on a rotating basis
 - Encouraging member participation at meetings
 - Offering input to determine meeting dates and/or location
- Conveying information and decisions that affect the Coalition
- Facilitating synergy between and ensuring Working Groups have what they need to succeed
- Overseeing the Coalition's membership including:
 - Reviewing any requests for membership
 - Identifying any gaps in representation (including soliciting and reflecting on member feedback)
 - Orienting new members
 - Engaging in a dialogue with members facing challenges with participation
- Receiving and addressing member feedback to help enhance the Coalition's functioning, including conducting an annual member survey
- Facilitation of the PCCC Award
 - Hon. Sharon Carstairs, P.C. Award of Excellence in Advocacy
- Providing direction to and oversight of the Secretariat including:
 - Direction toward the facilitation of the Coalition's business between full Coalition meetings
 - Providing suggestions toward the logistics of full Coalition meetings
 - Vetting of Secretariat documentation including the Coalition's Financial Statement prior to the Annual General Meeting
- The Executive Committee will review the Coalition's Terms of Reference on an annual basis prior to the Annual General Meeting of the Coalition

Executive Committee members meet at least quarterly and in advance of the cycle of all regularly scheduled Working Group meetings. Executive Committee meetings will be chaired on a rotating basis among Executive Committee members. Full Coalition meetings will be chaired by the Secretariat.

Executive Committee members are required to attend at least 50% of the meetings held each calendar year. Should an Executive Committee member attend less than 50% of the meetings in a calendar year, a discussion regarding the member's ability to continue as a member of the Executive Committee will be initiated with the member by the Secretariat.

The Executive Committee will meet prior to the Annual General Meeting and 6-Month Meeting to discuss the content of these meetings. The Secretariat will make every effort to ensure that



these meetings of the Executive Committee are scheduled at a time when all Executive Committee members are available to attend to ensure all Executive Committee members are aware of and can provide input on the content and agenda for the Annual General Meeting and 6-Month Meeting.

Working Groups

The bulk of the Coalition's work occurs within Working Groups, each focused on a distinct priority area in line with the *Blueprint for Action* and determined by discussion and voting (as necessary) among members. Members are encouraged to identify and actively contribute to at least one Working Group that best aligns with their personal interests and expertise and/or organizational priorities. Further Ad-Hoc Working Groups can be created for a limited time to address emerging issues as directed by Membership between Full Coalition meetings.

Each Working Group is chaired/co-chaired by up to two Coalition members. Meeting frequency is determined within each Working Group, but each Group commits to meeting three times a year at a minimum in order to carry out its Work Plan and to facilitate updates to the Executive Committee/the full Coalition. Each Working Group is responsible for establishing their own Terms of Reference (ToR) and Work Plan which will be reviewed by the Executive Committee for consistency.

Chair/Co-Chair responsibilities include:

- Facilitation of the establishment of Terms of Reference and a Work Plan
- Developing Working Group meeting agendas
- Chairing Working Group meetings
- Corresponding with Working Group members
- Scheduling Working Group meetings
- Disseminating Working Group meeting materials
- Reporting back to the Executive Committee and/or the full Coalition
- Recording Working Group meeting minutes or action items – duty to be shared among Working Group members

Secretariat responsibilities include:

- Supporting the Working Group Chair/Co-Chairs

Working Group member responsibilities include:

- Participating in Working Group meetings and attending a minimum of 50 per cent of meetings a year
- Share administrative responsibilities of working group
- Providing timely feedback within the timeframe determined by the Working Group chairs/co-chairs seeking feedback, or within the timeframe determined by the Executive Committee for all other feedback
- Exchanging knowledge and resources
- Actively contributing to the Work Plan activities articulated by the Group

Each Working Group will exist until its goal(s) have been achieved or the Coalition agrees by consensus to reprioritize its focus at an Annual General Meeting.



To facilitate a seamless transition of the Coalition, the Working Group structure will come into effect following the adoption of a new Blueprint for Action (2025 onwards). In the interim period, the Coalition will continue with the Committee structure, maintaining the three current Committees: Advocacy, Research and Knowledge Translation, and Education. All terms applicable to Working Groups as outlined in these Terms of Reference will apply to Committees until the transition to Working Groups.

Secretariat

The Secretariat is the organization entrusted with carrying out administrative duties and maintaining records on behalf of the Coalition. This role is currently held by Pallium Canada until September 1, 2025, at which time another PCCC member organization will assume duties of the Secretariat. The Secretariat's role is to facilitate the ongoing operations and day-to-day management of the Coalition by coordinating teleconferences and/or videoconferences and in-person meetings, conveying information and decisions, maintaining the membership list, and providing the infrastructure for the Coalition's functioning including preparation of the Coalition's meetings. This does not include funding the activities or Work Plans outlined by the Working Groups.

To support and facilitate the work of the Coalition, the Secretariat is responsible for the following specific activities:

Logistical coordination of full Coalition, and Executive Committee meetings:

- Maintaining and distributing calendar invitations
- Confirming members' availability
- Distributing Agendas, meeting materials, and Meeting Minutes
- Drafting and distributing any necessary communications required between meetings including drafts of the Coalition's Annual Report in collaboration with the Executive Committee and Working Groups
- Coordinating logistics for in-person meetings including:
 - Printing meeting materials such as Agendas, presentations, background materials, forms, etc.
 - Booking meeting rooms and arranging notetakers, catering (as required), translation, etc.

Record keeping:

- Maintaining membership lists (Coalition, Executive Committee, and Working Groups) and sharing updated membership lists as follows:
 - Chair/co-chairs of Working Groups: Working Group membership list upon any change to their Working Group's membership
 - Executive Committee: Executive Committee membership list upon any change to the Executive Committee membership or Coalition membership list upon changes to Coalition member organizations
 - Coalition: Coalition membership list at the Annual General Meeting of the Coalition
- Maintaining a record of all meeting dates (Coalition, Executive Committee, and Working Groups)



- Retaining a copy of all meeting Agendas and Minutes (Coalition, Executive Committee, and Working Groups)
- Recording and distributing minutes for Coalition and Executive Committee meetings
- Developing common tools and templates to support Working Groups with record keeping
- Facilitating revisions to the Terms of Reference
- Maintaining a web-based portal to house key Coalition materials

Infrastructure:

- Teleconferencing and/or videoconferencing technology
- Materials for face-to-face meetings
- Maintenance of a web-based portal/website presence, and social media activities
- Support for advocacy events as needed

Operations:

Meeting Frequency and Structure:

The Coalition will convene twice a year, either virtually (via teleconference or videoconference) or in-person (where safe and possible to do so, and with adequate funding secured). One meeting will be designated as the Annual General Meeting (AGM).

All members are welcome (and encouraged) to propose agenda items for discussion. At a minimum, each meeting will consist of updates from the Executive Committee as well as an opportunity to discuss and exchange feedback on activities taking place within each Working Group or any other matter relevant to the Coalition and its mandate.

Coalition meetings will be open to member organizations only, with an exception for guest speakers who will only remain for the duration of their presentation and related question and answer/discussion period, if applicable. This is to ensure free and open discussion among the Coalition. It is the responsibility of the Secretariat to ensure compliance with this requirement.

Language:

While the bulk of the Coalition's discussions and correspondence occur in English, reasonable efforts will be made to remove barriers for Francophone members to actively engage in the Coalition's work.

Equity, Diversity, Inclusion and Accessibility:

The Coalition and its members are committed to creating a respectful, diverse, inclusive, and healthy environment as they work to advance the Coalition's mandate and objectives.

The Coalition, through the Secretariat, aims to promote an equitable, inclusive, and accessible environment for all. Given that the Coalition is volunteer-based and does not have a dedicated budget, the Coalition's, and Secretariat's ability to do so is limited. Where financially and



otherwise possible, the Coalition, through the Secretariat, will make reasonable efforts to accommodate requests related to equity, inclusivity, and accessibility.

Decision-making:

PCCC is a Coalition that strives to make decisions by consensus and where necessary, through majority decision-making.

While members decide PCCC's direction and priorities, a member organization may decide to opt out of specific projects or activities if these do not match their organization's strategic priorities. For written submissions and communications, the option to opt out of specific projects or activities will be provided when it is proposed that individual organization names or logos be included in the written submission or communication.

Feedback, review of documentation, and/or sign-on/off is to be provided within the timeframe requested by the Working Group (Co-)Chair(s) and/or Executive Committee members, as applicable.

Working Groups Leadership:

To ensure seamless succession of Working Groups Leadership, the Chair/Co-Chairs will:

- 1) Chair/Co-Chair terms will be limited to two years. Should no expression of interest from working group members be presented, Chair/Co-Chairs may remain for additional two-year term.\
- 2) Email all Working Group members asking for expressions of interest to become Co-Chair by a certain date
- 3) If there are multiple expressions of interest, the entire Working Group will be made aware of the multiple expressions of interest/who they are, creating the space for members to further opt-in or out of the process
- 4) If necessary, a secret ballot process to vote anonymously to select the new Chair/Co-Chair will be initiated

Feedback:

To enhance the Coalition's functioning, all members are encouraged to share open, constructive feedback via an Executive Committee member and/or during the annual member survey/the Coalition meetings.

Review of Terms of Reference:

The Executive Committee will review the Terms of Reference on an annual basis. Significant changes (i.e., those beyond updates to the Membership List) will be reviewed and approved at the following Annual General Meeting of the Coalition.



Appendix A: Membership List

- ALS Society of Canada (ALS Canada)
- Alzheimer Society of Canada (Alzheimer Society)
- Canadian AIDS Society (CAS)
- Canadian Association for Spiritual Care (CASC)
- Canadian Association of Occupational Therapists (CAOT)
- Canadian Association of Psychosocial Oncology (CAPO)
- Canadian Association of Social Workers (CASW)
- Canadian Breast Cancer Network (CBCN)
- Canadian Cancer Society (CCS)
- Canadian Home Care Association (CHCA)
- Canadian Hospice Palliative Care Association (CHPCA)
- Canadian Lung Association (CLA)
- Canadian Network of Palliative Care for Children (CNPCC)
- Canadian Nurses Association (CNA)
- Canadian Palliative Care Nursing Association (CPCNA)
- Canadian Partnership Against Cancer (CPAC)
- Canadian Physiotherapy Association (CPA)
- Canadian Society of Palliative Medicine (CSPM)
- Canadian Society of Respiratory Therapists (CSRT)
- Canadian Virtual Hospice (CVH)
- Catholic Health Alliance of Canada (CHAC)
- Christian Medical and Dental Association (CMDA)
- College of Family Physicians of Canada (CFPC)
- HealthCareCAN
- Heart and Stroke Foundation of Canada (Heart & Stroke)
- Huntington Society of Canada (HSC)
- Kidney Foundation of Canada (Kidney Foundation)
- Mental Health Commission of Canada (MHCC)
- National Initiative for the Care of the Elderly (NICE)
- Ovarian Cancer Canada (OCC)
- Pallium Canada (Pallium)
- Pan-Canadian Palliative Care Research Collaborative (PCPCRC)
- Realize
- Royal College of Physicians and Surgeons of Canada (RCPSC)
- SE Health
- Speech-Language & Audiology Canada (SAC)



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Appendix B: Letter of Agreement

Organization Name
Organization Contact
Address
City, Province/Territory
Postal Code

Date

Re: Letter of Agreement

Dear **Contact Name**,

As fellow members of the Palliative Care Coalition of Canada (PCCC), we wish to express our gratitude to your organization in its commitment to working together to improve hospice palliative and end-of-life care for all Canadians in a meaningful way.

In order to continue our efforts, we respectfully ask each member to sign this Letter of Agreement acknowledging:

- a. Acceptance of the attached Terms of Reference; and
- b. An ongoing commitment to the Palliative Care Coalition of Canada.

We hope that **Organization Name** will facilitate and encourage your continued participation within the Palliative Care Coalition of Canada.

We ask that you indicate **your/your organization's** commitment in writing below. Please kindly sign and return this document by **Date** to:

[Secretariat admin name]
Title
Organization
Address

Member/Member Organization Name: _____
Primary Representative Name/Email: _____
Alternate Representative/Email: _____

Signature: _____ Date: _____

Sincerely,

On behalf of the Executive Committee, Palliative Care Coalition of Canada