



**Palliative Care
Coalition of Canada
Coalition canadienne
pour les soins palliatifs**

Annual Report 2023





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Background and History of the Palliative Care Coalition of Canada

In December of 2000, a group of 23 national stakeholders met 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 Palliative Care Coalition of Canada (the 'Coalition') and a working document entitled *Blueprint for Action (2000)*.

Within the Coalition, an Executive Committee and three Working Groups were established. The Coalition has been meeting on an annual basis since 2000. The goal of each annual meeting is to create a work plan for the coming year based on the current iteration of the *Blueprint for Action*. The membership of the Coalition remains strong and is currently made up of 31 member organizations.

Since its establishment in 2000, the Coalition has seen some remarkable successes. These successes include:

- a role in the establishment of the Secretariat on Palliative and End-of-Life Care in 2001.
- the production of *Hospice Palliative Home Care in Canada: A Progress Report* and *Dying for Care – Status Report*.
- participating in the development of the report *Not to be Forgotten: Care of Vulnerable Canadians*.
- production of the *Blueprint for Action: 2010-2020*, and its 2020-2025 update.
- participation in the development of the *Advanced Care Planning Framework* and the *Speak Up* campaign.
- spearheading *The Way Forward: An integrated palliative approach to care in Canada initiative*.
- strong support for Bill C-277 until its Royal Assent in December 2017.
- and assisting MP Charlie Angus with Motion M-456.

The Coalition members have also attended countless parliamentary events, round table discussions, educational conferences, and research symposia – all in the interest of advancing palliative and end-of-life care in Canada.

In 2009/2010, the Coalition produced the document *Blueprint for Action 2010-2020*. Through this report and other endeavours, the Coalition aims to change the standard of end-of-life care in Canada.

The latest version of the [Blueprint for Action \(2020-2025\)](#) is available on the PCCC website (www.palliativecarecoalition.ca), and outlines the following priorities:

- Increasing public awareness around hospice palliative care's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement.
- 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.
- Contributing to research and systematic, standardized data collection on hospice palliative care with special interest including formal and informal caregivers, and grief and bereavement.
- Advocating for universally accessible and culturally safe access to hospice palliative care for underserved populations and those who provide caregiving and experience grief and bereavement.

Mission and Mandate of the Palliative Care Coalition of Canada

The Coalition 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 also believes that to achieve quality end-of-life care for all Canadians, there must be a well-funded, sustainable national strategy for an integrated palliative approach to care. It is the mission of the Coalition to work together in partnership with other like-minded national organizations and institutions to achieve their goal.

Member Organizations (31)

ALS Society of Canada	Canadian Partnership Against Cancer
Alzheimer Society of Canada	Canadian Virtual Hospice
Canadian AIDS Society	Catholic Health Alliance of Canada
Canadian Association for Spiritual Care	Christian Medical and Dental Association
Canadian Association of Occupational Therapists	College of Family Physicians of Canada
Canadian Association of Psychosocial Oncology	HealthCare CAN
Canadian Association of Social Workers	Healthcare Excellence Canada
Canadian Breast Cancer Network	Heart and Stroke Foundation of Canada
Canadian Cancer Society	Huntington Society of Canada
Canadian Frailty Network	Kidney Foundation of Canada
Canadian Home Care Association	Mental Health Commission of Canada
Canadian Hospice Palliative Care Association	National Initiative for the Care of the Elderly
Canadian Network of Palliative Care for Children	Pallium Canada
Canadian Society of Palliative Care Physicians	Realize
Canadian Society of Respiratory Therapists	SE Health
Canadian Palliative Care Nursing Association	

Palliative Care Coalition of Canada (PCCC)

For more information about the PCCC, please visit www.palliativecarecoalition.ca.

2023 Activities and Committee Reports

1. Executive Committee Report

The Coalition has four active subcommittees:

- Executive Committee
- Advocacy Committee
- Research and Knowledge Translation (KT) Committee
- Education Committee

The chairs of the three main sub-committees, as well as the Coalition Secretariat (Pallium Canada) make up the members of the Executive Committee. The Coalition Secretariat chairs the Executive Committee. Members of the Executive Committee include:

- Jeffrey Moat (Secretariat / Executive Committee Chair)
- Chris Klinger
- Christina Vadeboncoeur
- Leah Salvage
- Daniel Nowoselski
- Julie Wilding
- Carolyn McCoy (new Education Committee Co-Chair)
- Nadine Henningsen (past Education Committee Co-Chair)

The Executive Committee oversees the work of the Coalition and manages the efficient and effective administration of the Coalition, as well as seeks opportunities and develops partnerships that actively promote access to quality palliative care in Canada.

The Executive Committee members met 10 times between January 1 and December 31, 2023. Over the past year, the Executive Committee's activities included:

- Successful rebranding of the coalition to the *Palliative Care Coalition of Canada (PCCC)*.
- Formal announcement of name change made at CHPCA's conference on October 12, 2023.
- Secured new URLs (www.palliativecarecoalition.ca and www.coalitionsoinspalliatifs.ca) and creation new dedicated PCCC website which was launched on October 12, 2023.
- Sought input and consensus from the Coalition on the PCCC's 2024 Federal pre-budget submission.
- Adjudicated the Honourable Sharon Carstairs Palliative Care Award of Excellence in Advocacy.

- Communication to all members:
 - Key messages on the importance of competencies and training for interdisciplinary teams during National Hospice Palliative Care week. Sent on May 4, 2023.
 - Request for PCCC members to promote their work to advance palliative care, and for the government to recognize these contributions accordingly as part of Health Canada's upcoming Report to Parliament on the State of Palliative Care. Sent on July 14, 2023.
 - Financial request to support PCCC's first in-person lobbying day on Parliament Hill since prior to the pandemic.
 - Invitation to all members to attend Parliament Hill event in honour of National Grief and Bereavement Day 2023 sent on November 21, 2023 (CHPCA).
 - New e-blast reinstated and sent on November 29, 2023.
- Financial reconciliation for 2023.
- Preparing a pre-read package for the January 26, 2024, Annual General Meeting of the Palliative Care Coalition of Canada, including securing a keynote speaker and special presentation from Health Canada.

2. Advocacy Committee Report

Daniel Nowoselski (Co-Chair)	Leah Salvage (Co-Chair)
Diana Rasmussen	Kimberly Thibodeau
Rochelle Blackwood	Daniel Nowoselski
Laurel Gillespie	Dr. Romayne Gallagher
Dr. Kim McMillan	Arlen Keen
Laurence Worthen	Amanda Nash
Carrie Thibodeau	Ken Miller

Objective:

The Advocacy Committee leverages opportunities to develop and execute advocacy strategies to ensure access to quality hospice palliative care in Canada, in every setting. There are thirteen PCCC member organizations represented on the Committee. The Committee met seven times in 2022. The Committee also carries out its activities through sub-groups of committee members responsible for carrying out specific tasks, such as drafting PCCC's pre-budget submission. These sub-groups also met several times throughout the year, as needed, to complete their work, reporting back to the Committee.

1. Budget 2024 Advocacy

- Advocacy Committee members prepared a submission as part of the Standing Committee on Finance's Pre-Budget Consultation in Advance of the 2024 Budget. The three recommendations included in the pre-budget submission are:
- To improve palliative care data
- To Increase education and training in palliative care
- To continue to invest in palliative care research, including grief and bereavement.
- Advocacy efforts with government officials in support of our budget recommendations continue, including through meetings with MPs and government officials.

2. Breakfast on the Hill Event

- Hosted event on Parliament Hill on May 11, 2023.
- Attendees included senators and MPs from 4 political parties.
- It was well received by attendees.
- Planning for the 2024 event is well underway (April 30, 2024).

3. Health Canada Report Advocacy

- No formal consultation opportunity to influence Health Canada's report.
- Shared submission opportunity to provide examples of progress in palliative care as part of Health Canada's report back to Parliament on the Framework on Palliative Care in Canada.
- Prepared summary of findings from the report will seek other communications, and outreach opportunities to talk about the findings in the report.

3. Education Committee Report

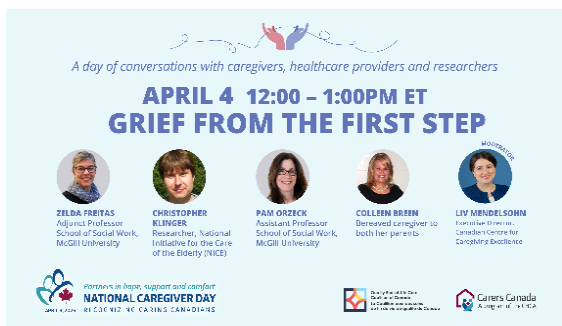
Julie Wilding (Co-Chair)	Nadine Henningsen (Past Co-Chair)
Diana Rasmussen	Camryn Berry
Peter Barnes	Judy Donovan-Whitty
Nadine Henningsen	Kristen DeCaria
Carolyn McCoy	Cheryl Cameron
Hazel Markwell	Karla Thorpe
Deborah Francis	

Objective:

- Facilitate awareness of educational / training resources of PCCC members and other organizations.
- Inform and support activities of advocacy and research committees.

Goal: Advance the broader goals of the PCCC by focusing on the palliative care pillars: Education / Training and Caregivers.

2023 Highlights / Awareness Campaigns



The committee supported the awareness campaign for April 4, 2023, National Caregiver Day, titled '**Partners in Hope, Support, and Comfort,**' by creating and sharing social media messages and visuals. Members of the PCCC were also invited to participate in the feature panels on that day, which focused on 'Grief from the First Step' and 'Conversations throughout the Journey.'



For **National Hospice Palliative Care Week** (May 7 – 15, 2023), the Education Committee developed messaging and visuals that highlighted the importance of interdisciplinary teams and competency training. Their work emphasized the need for developing core competencies and an understanding of a palliative approach to care across all practice settings and disciplines, which was crucial for providing integrated palliative care.

Educational Resources

In addition to sharing resources with committee members, the national projects led by Pallium Canada and Health Canada were profiled in our work. The members continue to champion the National Palliative Care ECHO Project, with many organizations creating new ECHO Hubs, advancing existing Hubs, and presenting in Pallium-supported learning sessions. Members were introduced to the Learning Journey App and the process for identifying and submitting possible resources to this invaluable tool.

Following a presentation to the committee by Health Canada in May, committee members continue to explore how to promote and disseminate information about the Palliative Care Awareness Campaign (phase one and two) to health care professionals and the public.

Advocacy Brief: The Need for Training and Education in Palliative Care

To support the Advocacy work, the committee created an advocacy brief, dated May 4, 2023, that emphasizes the critical need for training and education in palliative care. It highlights the benefits of palliative and end-of-life care, stressing its holistic approach that caters to physical, emotional, social, and spiritual needs, thereby enhancing patient satisfaction and quality of life. The brief underlines the importance of interdisciplinary collaboration and education for effective palliative care delivery. It calls to action for federal government support, proposing specific actions like developing national standards for palliative care education, integrating palliative care competencies into health care education, and funding training programs. The goal is to improve access to quality palliative care across Canada, especially in light of challenges such as the COVID-19 pandemic.

Canadian Interdisciplinary Palliative Care Competency Framework

The PCCC Education Committee's survey, conducted in November 2023, aimed to identify the most valued domains within the Canadian Interdisciplinary Palliative Care Competency Framework among its members. The survey sought input from the members on the importance of 12 competency domains, asking them to rank each from most to least important. The results revealed the top three domains as Loss, Grief, and Bereavement; Principles of a Palliative Approach to Care; and Communication. Conversely, Care Planning and Collaborative Practice, Self-Care, and Virtual Care were ranked as the least important. These insights are instrumental in shaping future work plans and discussion for the committee going forward.

Palliative Care for Underserved Populations

Aligning with the Competency Framework initiatives, the committee worked toward how to promote resources relating to cultural humility/competency/safety, inclusive and equitable care. The committee identified the relevance of exploring palliative care for those with intellectual disabilities. Moving forward the plan is to identify, relevant research (potential to align with research committee's work plan and goals), resources, ways to disseminate information through the committee and broader PCCC membership.

4. Research and Knowledge Translation (KT) Committee

Christopher Klinger (Co-Chair)	Christina Vadeboncoeur (Co-Chair)
Diana Rasmussen	Carol Barrie
Maria Judd	Rebecca McGuff/Chelsy Martin
Kate Murzin	

Objective:

The Research and KT Committee will facilitate research and knowledge translation toward the PCCC and its member organizations and engage in broader stakeholder consultations in the area.

There currently are five PCCC member organizations represented, including pediatric palliative care. Four Committee meetings were held since January 2023, identifying three Work Plan items with linkages to the Advocacy Committee and the Executive ones. Christina Vadeboncoeur succeeded Noush Mirhosseini in the Co-Chair role following the 6-Month Meeting.

1. Advocacy, further knowledge synthesis, and knowledge translation to provide an evidence base.
 - Further knowledge translation activities around the scoping reviews - especially toward caregiving and grief and bereavement care - were conducted, including a webinar in connection with National Caregiver Day (*Grief from the First Step*) in April 2023 and an oral presentation (*Interventions for Grieving and Bereaved Caregivers: Further Implications from A Scoping Review of the Canadian Literature*) at the 2023 Canadian Hospice Palliative Care Conference in Ottawa, Ontario in October. Committee members (again) served as judges for the Conference's *Best Poster Award*. Furthermore, a revised *Blueprint for Action* poster was created and presented – it is available for further conference use via the PCCC Secretariat.
 - An infographic toward the results of the scoping review on supporting informal caregivers was produced alongside a Policy Brief and shared with the Advocacy Committee for further utilization. More efforts toward an accessible and effective respite care system are needed.
 - The scoping review on gaps in hospice palliative care research (<https://www.hindawi.com/journals/jar/2020/3921245/>) has surpassed 5,000 views, been cited eight times, and has been referenced in Health Canada's recent *Report on the State of Palliative Care in Canada*.

2. Enhance the evidence base through knowledge synthesis activities and coordinated research efforts with the Pan-Canadian Palliative Care Research Collaborative (PCPCRC).
 - Attended the Spring and Fall meetings of the Pan-Canadian Palliative Care Research Collaborative (PCPCRC) to enhance opportunities for collaboration and to create further awareness toward the PCCC as a potential knowledge translation (KT) partner for researchers. The results of relevant PCPCRC studies could be included in the PCCC's advocacy work in support of the evidence base.
3. Work with Health Canada (HC) toward a joint (virtual) meeting with all (new) Canadian Institutes of Health Research (CIHR) Institute Heads and the joint CIHR - Social Sciences and Humanities Research Council (SSHRC) Committee to stress the importance of palliative care research across the continuum and to discuss the potential re-establishment of the CIHR Palliative Care Review Panel as part of the College of Reviewers.
 - Work with Health Canada on setting up a meeting with the (new) Institute Heads of the Canadian Institutes of Health Research (CIHR) and the joint CIHR - Social Sciences and Humanities Research Council (SSHRC) Committee to stress the importance of palliative care research across the continuum and to discuss the potential re-establishment of the CIHR Palliative Care Review Panel as part of the College of Reviewers continues.
 - Ask for (further) investment in palliative care research (especially toward seed/proof of concept grants without matching funding) has been included into the PCCC's Pre-Budget Submissions and Response to Health Canada's *Report on the State of Palliative Care in Canada*.

A special thanks to Pallium Canada for the ongoing support of Committee activities and facilitating the role of the Secretariat. The Research and Knowledge Translation (KT) Committee is actively inviting participation and is hoping to grow again in size next year.