

Target population: People requiring palliative and end of life care, grieving and their carers

Mission: To build compassionate communities where everyone assumes responsibility to care for each other during times of crisis and loss.

Context

Prof. Allan Kellehear was the first to develop a contemporary public health approach to palliative and end-of-life care. To help support champions in cities and communities around the world, he released the Compassionate City Charter (CCC) in 2015, as a guide to achieve community wide engagement around issues of caregiving, serious illness, dying, and grieving. The charter is at the centre of the Compassionate Communities (CC) movement and countries around the world have since adopted this theory of practice.

Recently, with a growing senior population, high incidence of chronic diseases, and an overburdened health care system, quality palliative care has enjoyed a renewed focus. Beyond considering only people for whom death is imminent (end of life care), palliative care also includes individuals whose death from a chronic illness may take years. Six in ten Canadians suffer from a chronic illness or have a sufferer in their immediate family, and chronic illness accounts for 89% of deaths, thus generating considerable palliative care needs. Yet only 16% to 30% of dying Canadians have access to, or receive, palliative and end-of-life care services.

Compassionate Ottawa recognizes that care for one another at times of crisis and loss is everyone's responsibility

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Seventy-five per cent of Canadians recently polled say they want to die at home. Seventy per cent actually die in the hospital. Why is there such a large gap between our end of life wishes and the actual outcome? That's a question being asked by Claudia Chouinard and other members of the new Compassionate Ottawa initiative. "My husband was in a chronic care cancer ward," said Chouinard. "He was actively dying. He said, 'I want to go home.'" Chouinard was embelished and overwhelmed by years of caregiving. "How was I going to fulfil his last wish? Time was very short," she said. "With a lot of effort and persi-



Compassionate Ottawa co-chairs, Jim Nimonger and Jackie Holzman, with the Honourable Sharon Carstairs, centre.

deliber any professional services itself, but will work with health and social care organizations already in our community to link these resources with those in need. Compassionate Ottawa will be an independent operation of the OutCare Foundation, which is chaired by the Honourable Sharon Carstairs. OutCare will provide an office and charitable status that will help them raise funds. They have also applied for a Community Foundation of Ottawa grant to launch the initiative. According to the Compassionate City Charter, "Compassionate Cities are communities that recognize that all natural cycles of sickness and health, birth and death, and love and loss occur every day with-

What this initiative is about

Compassionate Communities is a social model of palliative care, rooted in community development processes. It is a theory of practice for Health Promoting Palliative Care, developed to form policy and practice coalitions of support for everyone affected by end-of-life events. This is achieved through the empowerment of community members and stakeholders, increase in death literacy, and the focus on quality of life while dealing with a death journey. To ensure sustainability, there is a focus on top-down initiatives such as policy changes and, critically, bottom-up initiatives (such as increasing death literacy through art galleries) that leverage existing community strengths/assets.

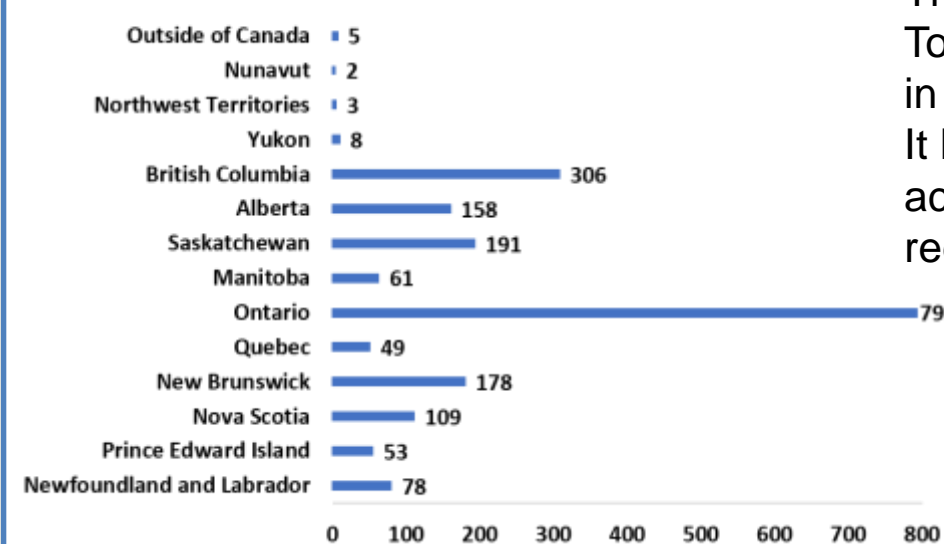
All-natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits of its institutions and regular activities - Prof. Allan Kellehear

In a CC it is everyone's responsibility to care for each other during times of crisis and loss, and not simply the task of health professionals. The Compassionate City Charter, then, is a tool used to build CCs which includes thirteen areas (e.g., schools, faith groups, institutions) in which social change is fostered.



Pallium Canada is helping communities across the country understand and adopt the CC model, through knowledge translation, project support, connectivity, and leadership. This palliative care approach includes early, compassionate and effective palliative care for all to better support their quality of life. Moreover, it focuses on physical, cultural, psychological, social, and spiritual needs for patients, families (caregivers), and those who grieve, regardless of age or disease trajectory.

CC Startup Toolkit Downloads Total = 1994



The CC Startup Toolkit downloads in just over a year. It has been accessed in every region in Canada.

Impact

- Evaluating volunteer-led projects operating within the CC model has been a challenge because many initiatives are not-for-profit and volunteer based, and resources allocated to develop evaluation tools has been limited.
- However, having an evaluation is key when CCs are applying to many funding streams. Pallium is partnering with CC initiatives and provincial agencies across the country, to develop common, flexible evaluation tools, which will allow CCs to more easily assess their project impact and contribute to a common understanding of their impact across the country.
- The Compassionate Communities movement in Canada has seen a steady increase in engagement since 2015. Pallium's Compassionate Communities Startup toolkit has now been downloaded in every province and territory with almost 2000 downloads in just over a year.
- At the end of August, Health Canada released the Action Plan on Palliative Care which acknowledges Compassionate Communities as a way to achieve their goal of building greater care capacity in communities.
- More recently, the Federal government has launched initiatives through the Public Health Agency of Canada and New Horizon for Seniors Program that align well with CCs, but there is still a need for a more reliable, sustained network of funders to help the movement grow.

Insights (Key learnings)

To support the palliative care approach, medical professionals, caregivers and community members need to be included in the continuum of care. The addition of community members helps to create a wraparound effect to better support the patient and family dealing with a diagnosis pertaining to a life-limiting and/or life-threatening illness.

Focusing on areas needed to ensure these volunteer led initiatives are sustainable is key. Some of the best practices for community development that we have found to be essential include:

- Finding and supporting passionate community champions.
- Ensuring the champions understand and apply the principles of community development.
- Creating opportunities for connection and mentorship.
- Creating free supportive resources for the volunteer champions.
- Making available appropriate and flexible funding and resource supports as CC initiatives launch and grow.

Instances where countries have tried to mobilize the CC concept but have seen low participation is often due to limited use of best practices in community development such as those listed above.

Governance & management

Every CC in Canada is different as each is rooted in the community and grow organically based on local resources/strengths and the vision of the local champion. As the CC gains traction in the community, often a leadership team or steering committee, comprised of experienced leaders from the community, is created to further grow the initiative. Some CCs have incorporated as their funding support grows.

Funding

Funding support for CC initiatives comes from a variety of sources. Often during the inform and consultation phase, resource needs can be met by volunteers and in-kind supports or small seed/micro grants. As the CC grows resources for professional coordination, events, etc. may be provided by local charities, donors, hospices, community foundations, and provincial bodies. In more established CCs, funding sources have included research grants, private foundations, and provincial health authorities.