# Collaborative Action Plan

for accessible, appropriate, and equitable grief and bereavement support in British Columbia

An Evidence-Informed Approach



# About this Document:

Collaborative Action Plan for Accessible, Appropriate, and Equitable Grief and Bereavement Support in British Columbia: An Evidence-Informed Approach is an initiative led by the BC Centre for Palliative Care. This project aimed to co-design evidence-informed strategies with experts, knowledge users, and people with lived experience that would improve access to supports for individuals experiencing grief as a result of the death of someone they cared about.

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# Acknowledgements

# **Territory Acknowledgement**

We would like to acknowledge that the BC Centre for Palliative Care is located on the unceded shared traditional territories of the Coast Salish Peoples, including the territories of the x<sup>w</sup>məθkwəỳəm (Musqueam), Skwxwú7mesh (Squamish), and Səlílwəta?/Selilwitulh (Tsleil-Waututh) Nations.

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# Special Thanks to Roundtable Participants

We would also like to acknowledge the organizations and individuals who participated in the province-wide roundtable. The following list includes the names of the organizations and individuals who consented to be identified in the final roundtable report.

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- British Columbia Hospice Palliative Care
  Association
- Bulkley Valley Hospice Society
- Canadian Hospice Palliative Care Association
- Canadian Virtual Hospice
- Canuck Place Children's Hospice
- Chilliwack Hospice Society
- Cowichan Hospice
- Cranbrook Kimberley Hospice Society
- End of Life Doula Association of Canada
- Family Caregivers of BC
- Foundry Central Office
- Health Canada End-of-Life Care Unit
- Hospice Society of the Columbia Valley
- Island Health Palliative & End of Life Care

- Langley Hospice Society
- Lumara Grief & Bereavement Care Society
- Mission Hospice Society
- Moms Stop the Harm
- Moving Forward Family Services
- Nanaimo Community Hospice Society
- Nelson & District Hospice Society
- Pacific Rim Hospice Society
- Peace Arch Hospice Society
- Prince George Hospice Palliative Care Society
- Prince Rupert & District Hospice Society
- Providence Health Hospice Palliative Care Services
- Rotary Hospice House
- The Children's Grief Foundation of Canada
- Vancouver Coastal Health Vancouver Community Hospice Palliative Care Services
- Victoria Hospice

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# Introduction

Grief is a universal experience. Throughout the course of our lives, nearly everyone experiences the death of someone they care about, whether it is a family member, friend, pet, work colleague, or otherwise. Each person has a unique way of coping with their grief when they are bereaved.

During bereavement, many turn to their families, friends, or other members of their social circle for comfort and support. The bereaved also turn to their communities, including faith-based and cultural communities, among others. Some also seek grief and bereavement service providers, either through community hospice societies, Employee and Family Assistance Programs, or other non-profit and for-profit grief and bereavement service providers. In combination, social circles, informational, and service provider supports help bereaved people manage and integrate their grief into their lives as they move forward.

Since the onset of the COVID-19 pandemic, nearly 50,000 Canadians have died from the virus or complications associated with COVID-19.<sup>2</sup> It is estimated that for every COVID-19 death, nine people are affected by bereavement.<sup>3</sup> The increased mortality rate, combined with physical distancing restrictions and lockdown measures, has contributed to changes in how people experience illness, death, and bereavement.<sup>4</sup> Visitation restrictions in long-term care homes and health care institutions, implemented with the intent of protecting residents and patients from the spread of the virus, also limited their contact **Bereaved** means to be suffering from being deprived of someone you care about because of their death, whereas **bereavement** is defined as the period of time following a death, during which a person experiences grief and mourning.<sup>1</sup>

**Grief** specifically includes a wide variety of responses to loss, including losses other than through death (e.g., anticipatory grief which is grief that occurs prior to the death).

with the people close to them.<sup>5,6,7,8</sup> As a result, people lacked the ability to communicate directly with those dying and their health care providers, leaving them feeling less involved in important care decisions.<sup>5,6,7</sup> Moreover, being unable to visit or communicate with those dying contributed to feelings of guilt and anger at being unable to be present, express their love, and say goodbye.<sup>6,9</sup> After the death occurred, the bereaved were often unable to celebrate traditional post-death rituals such as funerals in-person.<sup>6,9</sup> They experienced higher levels of social



isolation because the health and safety measures in place limited people's ability to see their families and friends.<sup>6,10</sup> Their access to grief and bereavement service providers changed as well, with the rapid transition to virtual services.<sup>6</sup> In sum, the pandemic had a significant impact on British Columbians and their experiences of grief and bereavement, which may result in a greater complexity of grief experienced by the bereaved. In this context, the BC Centre for Palliative Care set out to better understand the impacts of COVID-19 on the bereaved in British Columbia. With funding from the Michael Smith Health Research BC, the BC Centre for Palliative Care launched an initiative with the objectives of identifying the needs of the bereaved, and co-designing solutions that would lead to enhanced, equitable access to effective grief and bereavement supports for all British Columbians.

## About the Roundtable Project

The roundtable on enhancing equitable access to effective grief and bereavement supports for all British Columbians brought together individuals who had experienced the death of someone they cared about, grief and bereavement service providers, researchers, community leaders, and policy decision-makers to co-create a province-wide, evidence-informed approach to better support bereaved British Columbians. The objectives of the conversations that guided this initiative were to:

Discuss and exchange knowledge about the current state of grief and bereavement services in British Columbia from various perspectives;

Identify and prioritize actions that can be taken to address the needs of bereaved people, the challenges caused by the COVID-19 pandemic, and existing gaps in grief and bereavement services; and

Recommend strategies to enable equitable access to effective grief and bereavement supports for all British Columbians.



The strategies recommended by participants in this initiative formed the basis of the **Collaborative Action Plan** for Accessible, Appropriate, and Equitable Grief and Bereavement Support in British Columbia: An Evidence-Informed Approach.

It is our hope that this report will inform future action, research and policy development, guide quality improvement initiatives focusing on grief and bereavement care, and enable interagency collaboration that leads to enhanced access to grief and bereavement supports across British Columbia.



# About the BC Centre for Palliative Care

The BC Centre for Palliative Care is a provincial organization funded by the British Columbia Ministry of Health. Their mission is to work with partners in the health system and community along with researchers and policymakers to accelerate the spread of innovations and best practices in palliative care and improve associated experiences to palliative care including living with a serious illness and bereavement. Their vision is that people affected by these experiences have the best possible quality of life, supported by care that reflects their goals and wishes. Their core areas of work include promoting effective conversations and processes that help people get care consistent with their wishes, enabling enhanced access to a palliative care approach in all settings, and inspiring and partnering with communities to provide emotional, practical, spiritual, and bereavement supports close to home.



# Approach

# A Human-Centred Design

Human-centred design is an approach to problem-solving that places people with lived experience at the centre of all aspects of the solution development process.<sup>11</sup> Human-centred design processes generally involve four distinct phases. The first phase focuses on understanding the problem from the perspective of individuals with lived experience. In this phase, project activities aim to better understand what the problem is, how it manifests itself, and how it impacts the person who experiences it. The second phase explores the system within which the problem operates and that people interact with. The goal in this phase is to map out what is working well, what is not working well, and where opportunities exist for meaningful change. In the third phase, based on a solid understanding of the problem that was generated in the first and second phases. In the final phase, the proposed solutions are prototyped in the real world, and rapidly reviewed and adapted based on regular feedback loops.

### **Methods**

The BC Centre for Palliative Care leveraged the human-centred design process in the development of this Action Plan. In order to centre the project in the lived experiences of bereaved people in British Columbia, the project team engaged in numerous primary and secondary research activities.

#### **Literature Reviews**

The initiative began with a literature review that aimed to understand how the COVID-19 pandemic affected grief and bereavement experiences, as well as to identify best practices in effective supports for people experiencing bereavement during the pandemic and in other relevant situations (e.g., previous epidemics or large-scale crises) (see https://www.bc-cpc.ca/about-us/activities/new-projects/bereavement/). A second literature review was completed that aimed to understand the bereavement experience in those experiencing houselessness or vulnerable housing.

#### **Surveys and Interviews**

Following the literature review, a survey and a series of interviews were conducted with grief and bereavement service providers in British Columbia. The survey was completed by 43 non-profit, for-profit, and individual professionals in grief and bereavement supports, and explored their challenges and experiences with providing services to people who had experienced a death of someone they cared about during the pandemic. Thereafter, interviews were conducted with 16 grief and bereavement service providers to explore similar themes in more depth.

A survey and series of key informant interviews were also conducted with individuals who live in British Columbia and experienced the death of someone they cared about during the pandemic. There were 182 participants in the survey, as well as 20 individuals who were interviewed about their grief and bereavement experiences. A final survey was conducted to explore the dual experience of bereavement coupled with houselessness from the perspectives of frontline workers. There were 72 frontline workers who provide health or social support for individuals experiencing houselessness and/or vulnerable housing in British Columbia that participated in the survey. Questions were focused specifically on their perception of the bereavement experience of individuals accessing services, how the COVID-19 pandemic impacted their clients' grief, and what can be done to provide better support.



#### **Public and Provider Symposia**

The results from the primary and secondary research activities were leveraged to inform the design of

symposia with bereaved citizens and grief and bereavement service providers. These collective engagement activities had the dual objectives of improving our understanding of the experiences of British Columbians who have suffered the death of someone they cared about during the COVID-19 pandemic, and identifying the gaps and challenges in grief and bereavement supports in order to recommend priority actions for equitable access to grief and bereavement services for all British Columbians.

There were 27 participants (representing 25 different organizations) who attended the virtual grief and bereavement service provider symposium and 11 participants who attended the citizen symposium. The sum of these research activities enabled us to generate a deep understanding of the unique lived experiences of bereaved people, as well as the strengths and challenges of the systems and services in place to support them.

#### **Province-Wide Roundtable**

In the final activity of this initiative, a virtual province-wide roundtable was convened to co-design solutions and prioritize actions for future improvements to grief and bereavement supports. The roundtable event brought together 33 experts and leaders from 32 different organizations in British Columbia, as well as two public partners with bereavement experience to explore strategies that would improve equitable access to effective grief and bereavement supports for all British Columbians. To better understand the knowledge user's perspectives on the priority action items, we followed up the roundtable with a survey. A total of 29 people from the roundtable completed the survey (83% response rate). The visions for change and the actions co-designed and recommended at the roundtable event form the final component of this report.

For a visual summary of the project methodology, see the **Project Roadmap** on the following page.

# Project Roadmap

#### Literature Review – May 2021

 To identify practices that have been effective in supporting bereaved people during the COVID-19 pandemic or large-scale crises

#### Bereavement Service Provider -July 2021

- With bereavement service providers in British Columbia
- Survey: 43 participants Interview: 16 participants

#### Bereaved Survey & Interviews – November 2021

- With bereaved individuals in BC who experienced a death of someone that was important to them during the pandemic
- Survey: 182 Participants Interviews: 20 Participants

Frontline Service Perspectives: Bereavement in the Context of Being Unhoused - August 2022

 With frontline workers who support people that are unhoused/vulnerably housed

Survey: 72 participants

#### Province-Wide Roundtable -November 29 & 30, 2022

- The roundtable identified priority actions to address the needs of bereaved people and recommended strategies to improve bereavement support in BC
- 35 participants

#### Behavioural Research Ethics Board Approval from University of British Columbia – July 2021

#### Aichael Smith Health Research BC

Funding Awarded Sept. 2021 Health Research BC

#### Literature Review - July 2022

 To gather current and relevant information on how bereavement is experienced within the context of being unhoused

#### Bereavement Service Providers Symposium – October 3, 2022

- The aim was to validate the project's findings and identify any additional gaps and challenges
- · 27 participants

#### Bereaved Citizens Symposium – October 13, 2022

- The aim was to validate the project's findings and identify any additional gaps and challenges
- 11 participants

# Part 1. Summary of Findings

# British Columbians Experiencing Grief and Bereavement Impact of COVID-19

Individuals who experienced the death of someone they cared about during the COVID-19 pandemic faced several differences in the bereavement process. Before the occurrence of death, fear of spreading the disease resulted in limited physical contact or lockdowns at many care facilities. Accordingly, family members and friends were either completely unable, or limited in their ability, to visit the person(s) they cared about who were residing in a hospital, long-term care home, or hospice.

"I was unable to be with and say goodbye to my loved ones because of COVID which has made the grief worse for me." Pre-death contact restrictions had two main effects on the bereavement process. First, the bereaved had limited opportunity to form for the person(s) they cared about, while simultaneously relying on them to communicate information about the health of the person residing in their hospital, long-term care home, or hospice.

The lack of relationship, combined with the pressures of an overburdened health care system, left the bereaved with little information about the well-being of the person(s) they cared about and, in some cases, a sense of uncertainty about the care decisions made by their attending health care providers. Second, and more importantly, contact limitations stripped people of the ability to be present for the last days of the person(s) they cared about, as well as the chance to say goodbye. As a result, bereaved people experienced feelings of guilt and sadness about not being there at the end, and missed an important opportunity for meaning-making in the final moments of the person's life.

After the death of the person they cared about, bereaved people were further impacted by pandemic restrictions. Physical distancing measures prevented the practice of traditional burial rites and death rituals like

funerals and other cultural, gathering-based traditions. Where funerals were held, in-person attendance was limited, and virtual alternatives did not always bear the same meaning for everyone. Some individuals highlighted the benefits of Zoom funerals, as they enabled broad participation of family members and friends who would not have been able to attend otherwise due to health or geographic limitations. Others discussed

"We haven't been able to organize a memorial. It was and still is a nightmare with no real sense of closure."

connection and audiovisual challenges to online participation that negatively impacted their experience. In cases where burial services were postponed, some individuals expressed feeling as though their grief was on pause and that death anniversaries were more difficult to acknowledge, having never held the initial ceremony.



The COVID-19 pandemic also had negative effects on the ability of bereaved people to cope with their grief. Physical distancing measures and fear of contracting the virus limited the social support that individuals could receive from family and friends. Expressions of support and care through physical touch, such as hugs, handholding, etc. were also limited, and the bereaved had fewer opportunities to engage in self-care activities or distractions like going to the gym, restaurants, or other social gathering venues. Given the restrictions on how the bereaved could cope, there seemed to be an increase in coping by the use of avoidant/escapist means (like drug or alcohol use). Many bereaved individuals also experienced secondary losses during the pandemic, such as job loss, loss of work or school relationships, etc.

The combined effects of pre-death contact limitations, canceled or delayed death rituals, and restricted coping mechanisms resulted in changes to the complexity of the grief experienced by many bereaved individuals.

"Multiple losses - The whole family, community are dealing with "stacked" grief - we barely have a chance to process one loss when there's news of another - this is accelerating." As a result, many bereaved people may be more susceptible to experiencing prolonged grief disorder<sup>12,13</sup>, a maladaptive grief response that has recently been added to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as part of their March 2022 revisions.<sup>14</sup> Prolonged grief disorder is considered a clinical disordered grief response due to its impairment of many areas of functioning, and the duration and severity of the symptoms, which exceed the norms of the context in which the bereaved individual lives.

### **Experiences with Grief and Bereavement Supports**

In British Columbia, individuals grieving the death of someone they cared about can access a combination of social circle, informational, and service provider grief and bereavement supports. Social circle supports include family members, friends, work colleagues, pets, neighbours and other acquaintances. Informational supports refer to books and other print materials, podcasts, internet resources, and social media supports. Grief and bereavement service providers include individual counselling, peer support (through an organization), group support (through an organization or counsellor), memorial events (through an organization), physician services, religious leader supports, grief and bereavement retreats or camps, grief and bereavement helplines, grief and bereavement talks, seminars, conferences, or workshops, and crisis intervention services. The following sections describe bereaved persons' reported experiences with social circle, informational, and service provider supports during the COVID-19 pandemic, as well as their challenges in accessing the care they need.

#### **Social Circle and Informational Supports**

In the bereaved survey conducted by the BC Centre for Palliative Care at the start of 2022, most bereaved people reported relying on interpersonal relationships with family members (86.2%) and friends (84.5%) for support after experiencing the death of someone they cared about. Further, when asked about the supports they most appreciated during the symposium in October 2022, bereaved people highlighted the importance of the family members and friends who were able to be there for them, especially those who "stuck it out" consistently and checked in regularly as time went on. They also emphasized the support they received from their pets, who provided unconditional love and a significant source of comfort



for them during their bereavement, and other members of their social circle such as neighbours and community members who would check in on them, particularly for people who lived in rural areas.

In addition to interpersonal supports, bereaved people also relied on media and print-based resources for independent reflection. In the survey, 30.9% of respondents indicated accessing internet-based resources and 23.8% indicated reading books and brochures for support. With respect to internet-based resources, participants in the symposium discussed social media groups, tribute sites where they can write messages about the person that died, listservs that send them daily inspirational emails, and grief and bereavement applications as some of the online resources they turned to. For print-based resources, bereaved people spoke of books and journaling as important tools to help them process their grief. For a complete list of responses regarding the social circle and informational supports that bereaved people relied on during the COVID-19 pandemic, see Table A.



#### **Table A. Social circle & informational supports**

"My work overall was very unhelpful in the sense that I felt there was an expectation for me to get back in the swing of things. Too much stress."

Many bereaved people spoke of normalizing talking about death, loss, and grief so that their family members, friends, and others can better understand how to support them through their bereavement. They shared negative experiences where the people around them minimized their loss, gave unhelpful advice, or avoided the topic with them because they did not know what to say or how to be supportive. They also spoke of a lack of support in the workplace, particularly if the loss they experienced was not an immediate family member. Cultural barriers to talking about grief was also mentioned.

Given the strong reliance on interpersonal relationships, bereaved people reported a desire for greater access to their families, friends, and other members of their social circles for grief and bereavement support during the COVID-19 pandemic (see **Table B**). However, they also highlighted a need for improved grief and bereavement literacy within their social circles and communities.



In short, bereaved people felt that enhancing the overall grief and bereavement literacy of the population would de-stigmatize conversations about death, and better equip the people in their lives to support them through their grief.



#### Table B. Percentage of bereaved who wished for greater access to

#### **Service Provider Supports**

Grief and bereavement service providers include psychosocial services such as individual counselling, peer support (through an organization), group supports (through an organization or counsellor), physician visits, guidance from religious leaders, memorial events (through an organization), grief and bereavement retreats or camps, grief and bereavement helplines, grief and bereavement talks, seminars, conferences, or workshops, and crisis intervention services. Respondents to the BC Centre for Palliative Care November 2021 survey indicated that service provider support that was the most relied upon was individual counselling services (42.5%) followed by group support (18%), and support from their physician (16.2%). For a complete list of responses regarding the service provider supports that bereaved people relied on during the COVID-19 pandemic, see Table C.



#### Table C. Service provider supports



Individual and group counselling sessions were identified as spaces where bereaved people could share their feelings, process their emotions, and normalize their grief experience with trained professionals who assisted them in working through their grief. Counselling sessions also provided an outlet for processing feelings away from families and friends, who may be grieving themselves or may not have had the tools needed to adequately support the bereaved. The bereaved expressed that group counselling and peer support (through an organization) helped them feel less alone, as they were able to hear the stories of others who had experienced similar loss in their lives. During the symposium, bereaved people shared several positive experiences with grief and bereavement service providers:

"Memorial activities such as the bereavement walks organized by the Vancouver Hospice Society offered an unregulated opportunity to talk to other people with a shared lived experience."

"Joining a virtual grief group for spouses created lasting relationships. The group ran for eight weeks over Zoom, but when it ended, the members decided to continue meeting on their own. Two years later, the group still gives them a safe space to share feelings that they may not be comfortable discussing with family members or other friends."

"Counselling services available through the Employee and Family Assistance Program at work were helpful. They were free, the counsellor was located nearby, and the bereaved could speak to a relative stranger about their emotions instead of feeling like a burden to their family members or friends." Given the benefits of grief and bereavement service providers, bereaved people were also asked about the supports that they wished they had greater access to. In this case, nearly 40% of survey respondents indicated that they wished they had greater access to group support, while 36.6% and 26.4% identified a desire for individual counselling and grief and bereavement talks, seminars, conferences, or workshops respectively. See **Table D** below for a complete breakdown of responses regarding enhanced access to service provider supports.



#### Table D. Percentage of Bereaved who wished for greater access to

To improve the experience with grief and bereavement service providers, bereaved individuals in British Columbia identified the need for:

#### 1. Improved grief and bereavement literacy among health care professionals: The bereaved

discussed a desire for debriefing with health care professionals after a death has occurred, to better understand what happened and to help identify available grief and bereavement resources, such as service providers and informational supports. However, due to lockdowns and contact limitations,

they often were not able to see or speak to the physician caring for the person(s) they cared about after death had occurred. As a result, they wanted more communication following the death experience and

described the communication they received as insufficient. Moreover, in some cases, health care professionals

lacked knowledge and training on how to support bereaved people through their grief. Instead of providing navigation support toward appropriate resources, some health care professionals were quick to pathologize the grief being experienced by the bereaved. Participants felt that enhanced grief and bereavement literacy among health care professionals would improve the communication and support received by the bereaved following the death of someone they cared about.

"Physician visit was unhelpful. Both times she was telling me I am depressed, and I need antidepressants. She was uneducated in grief." 2. Enhanced awareness of existing resources: A common theme throughout the engagement activities with the bereaved was the lack of awareness of available informational and service provider supports. Participants regularly reiterated that they did not know what resources existed or how to find them.

They articulated the need for a resource hub, where information about all the grief and bereavement supports throughout the province could be found in a single place, as well as improved outreach in schools, workplaces, and through social media to ensure that people who have experienced the death of someone they cared about can find out about the resources available to them. Specific outreach initiatives for diverse population groups (such as people who are elderly and residents who do not speak English) were also emphasized as necessary, as these groups may be disconnected from traditional support settings and may not have other means of finding supports.



**3.** Faster access to grief and bereavement supports: The length of waitlists for access to service provider supports was raised repeatedly by individuals who had experienced the death of someone

"There was no other help available to me in my community, as the local Hospice Society said they were "full" and did not follow up as promised. 18 months later, I have still not received a follow-up call!" they cared about, particularly with respect to individual and group counselling. Limited funding for grief and bereavement support services affects the number of spots available for programs and the number of counsellors who are trained in providing grief and bereavement services. Thus, bereaved people end up on waitlists for months or years before they can begin to access the support they need.

4. Greater access to free or affordable supports: The bereaved discussed the need for more free or affordable grief and bereavement service provider supports. They noted that few services were available for free, and the ones that were have long waitlists. Counselling supports, especially individual counselling, can be very expensive. Although some people have access to employee benefit plans, they are often limited in the number of sessions that can be reimbursed, if they have coverage for counselling at all. Greater access to free or affordable resources, or financial support for individuals who need services, is needed to ensure equitable access to grief and bereavement supports throughout the province.

#### 5. Specificity in group counselling membership:

With respect to group counselling, the bereaved raised the need for services to be organized with greater specificity in membership. The biggest perceived benefit of group supports was the ability to connect with others who have a shared lived experience. Thus, organizing group services based on the type of relationship (e.g., "Being in a group that was not made from the same type of loss death (suicide). People didn't understand".

parents, children, siblings, friends, etc.), or the nature of the death (e.g., pregnancy loss, suicide, medical assistance in dying, toxic drug-related death, etc.) could better connect bereaved people to others who have had similar experiences.

6. Greater availability of grief and bereavement supports: Bereaved people conveyed a significant need for more choice in the format and availability of grief and bereavement supports. They discussed the need for access to different types of supports, such as individual counselling, group sessions, and drop-in services, as well as the availability of both in-person and online services. Bereaved people also indicated that



supports should be available 24 hours per day, 7 days per week, all year round, as grief can come and go at any moment. Some people may need support in the middle of the night, others may not be ready for services immediately after the loss, and still others cannot fit an eight-week program into their current employment or education schedule. Making a variety of grief and bereavement supports available at any given time would better enable people experiencing grief to get the help they need, when and how they need it.

7. Cultural appropriateness of grief and bereavement supports: In the context of equitable access to grief and bereavement supports, individuals who had experienced the death of someone they cared about expressed the importance of culturally sensitive services. They discussed the need for services to be available in multiple languages, so that individuals can receive support in the language in which they receive the most comfort. Additionally, the bereaved emphasized the need for cultural sensitivity training among service providers, as well as access to service providers who are from different cultural backgrounds that better reflect the diversity of the communities that they live and work in.



8. Flexibility of service providers: Bereaved people explained that their grief does not conform to the systems in place to support them. However, programs and services are often structured around a fixed schedule. The bereaved highlighted the need for service providers to be more flexible with the programs they offer, require less commitment to events, groups, and dates, and be more compassionate and understanding when it comes to rescheduling appointments in order to make the available supports more accessible to each person's unique needs.

**9. Other forms of support:** Bereaved people identified other forms of support that would be helpful for individuals experiencing grief. Some spoke of the need for more spiritual resources that support meaning-making. Some highlighted supports for completing the legal and financial paperwork after someone has died. Others emphasized more compassion at work, as well as longer and flexible bereavement leaves as helpful supports.

### In Brief

The COVID-19 pandemic had a significant impact on people who experienced the death of someone they cared about. Lockdowns and physical distancing measures restricted contact with the person(s) they cared about before their death, leaving unanswered questions about their care and feelings of guilt about not being present with them for their final moments. Infection prevention and control measures also impacted traditional



death rituals, stripping the bereaved of the opportunity to say goodbye. Lastly, pandemic restrictions impacted the abilities of the bereaved to cope, as they had limited access to their friends, family, and regular places of social gathering.

There are a range of social circle, informational, and service provider grief and bereavement supports available in British Columbia. Social circle supports include family members, friends, work colleagues, pets, neighbours and other acquaintances, whereas informational supports include books and other print materials, podcasts, internet resources, and social media supports. Service provider supports include individual counselling, peer support (through an organization), group support (through an organization or counsellor), memorial events (through an organization), physician services, religious leader supports, grief and bereavement retreats or camps, grief and bereavement helplines, grief and bereavement talks, seminars, conferences, or workshops, and crisis intervention services.

However, many bereaved people indicated a desire for greater access to social circle, informational, and service provider supports throughout the pandemic. They also highlighted a range of challenges to accessing the grief and bereavement support they needed.

#### Challenges to accessing grief and bereavement support:

- A lack of grief and bereavement literacy among their families, friends, and health care professionals
- A limited awareness of the grief and bereavement supports available to them
- Long waitlists for individual and group grief and bereavement supports
- · Unaffordability of available grief and bereavement counselling services
- · An inability to connect with and learn from people with similar lived experiences
- · A lack of support services available in the right format and at the right time
- A need for culturally sensitive services that are available in multiple languages
- · Inflexibility regarding the timing of programs and supports
- · Unavailability of other forms of support such as legal services, spiritual supports, and workplace benefits

# Part 2. The Grief & Bereavement Support System in British Columbia

In British Columbia, the COVID-19 pandemic had a profound impact on health and community care services. The demand for grief and bereavement supports was already increasing beyond existing capacity before the pandemic. The gaps in available supports widened to chasms during the COVID-19 pandemic, as the infection spread across populations who were at greater risk of complications from the virus and the death toll rose. Health and community care resources were stretched past their breaking point and the shortage of health care professionals became a veritable crisis across Canada. In fact, in the survey with bereaved people, 87.1% of respondents reported that their grief experience, and the supports they used or attempted to access, were affected by the COVID-19 pandemic.

Addressing the challenge of enhancing access to equitable grief and bereavement supports for all British Columbians requires a deep understanding of both the lived experiences of the bereaved, and the system within which they live, work, and access supports. In the previous section, the experiences of the bereaved highlighted challenges such as a lack of grief and bereavement literacy among the general population and health care professionals, limited awareness and inaccessibility of available grief and bereavement supports, and the unavailability of culturally sensitive and death-specific resources or other quasi-bereavement supports (e.g., legal services) that would have been helpful to them after the death of someone they cared about. The following sections explore the perspectives of service providers regarding the current system of grief and bereavement supports. Each theme considered will discuss current challenges, the impacts of COVID-19, and the potential opportunities for change that have arisen since the start of the pandemic.

# Accessible Grief and Bereavement Supports

#### Awareness

Bereaved people and grief and bereavement service providers may be unaware of available resources and not know how to access them. Grief and bereavement service providers highlighted that there is no comprehensive database of information on existing supports and services for each geographic and demographic community

in British Columbia. Consequently, they struggle to find ways to get the word out about the supports they offer, and health care professionals have limited knowledge of the general and specialized grief and bereavement supports available for referrals. Moreover, many individuals experiencing grief have not been informed that they do not require a referral to access grief and bereavement supports, nor do they know how to navigate the multiple search directories or databases to identify the right supports for their unique needs.



However, the significant losses resulting from the COVID-19 pandemic has led to heightened public awareness and interest in grief and bereavement. Service providers pointed to an increasing number of public events and opportunities for drawing in collective voices that are fueling a growing conversation about challenges and lived experiences. Given the current spotlight, grief and bereavement service providers believe there is potential to leverage the momentum in this space into the creation of an interactive, evidence-informed central repository on grief and bereavement supports in the province.



The database could map out existing resources, link service providers and members of the public to the information they need, and act as a referral resource for frontline workers who regularly come into contact with bereaved people.

#### **Availability**

The demand for grief and bereavement supports in British Columbia is increasing, however funding and human resources continue to impact the availability of services. Grief and bereavement service providers who participated in the symposium and roundtable events highlighted that long waitlists were a challenge prior to the outset of the pandemic. Nevertheless, in the survey with service providers, nearly 80% reported noticing changes in the demand for grief and bereavement services since the start of COVID-19, with many stating demand increased. Overall, the key factors discussed as impacting service availability were government funding for programs and human resource shortages.

#### **Government Funding and Supportive Policies**

Grief and bereavement service providers expressed that they would offer more programs and services if greater investments could be made by the provincial government and/or the health authorities. Although grief is a universal experience, no single government entity with a human service portfolio holds responsibility for it. Thus, there is no public accountability for grief and bereavement support, resulting in limited funding for programs and a lack of consistency in reporting on services and outcomes across the province.

In British Columbia, grief and bereavement supports are largely funded through unsustainable community funding sources including fundraising, donations and grants. Hospice societies and other non-profit organizations explained that they have trained facilitators supported by counsellors who can offer grief and bereavement services, but not enough funding for program administration. They emphasized that sustainable and sufficient funding is needed to offer more supports that better meet the needs of bereaved individuals.

#### Human Resource Shortages

Grief and bereavement supports are provided by community organizations, hospices, and health care professionals including counsellors, physicians, etc. Health care professionals were heavily relied upon to provide supports during the COVID-19 pandemic. Some health care professionals were often responsible for providing updates on health status and health care, as they were the only mechanism for communication between the dying and their family and friends. Many also became responsible for organizing important moments preceding the death of their patients due to lockdown and physical distancing measures. Combined with existing human resource shortages in hospitals and long-term care homes, these additional responsibilities further strained health care professionals whose capacity was already stretched to its limits. As a result, many health care professionals struggled to accomplish their primary responsibilities and were unable to spend the time they needed to adequately support the bereaved.

In the context of community-based organizations, grief and bereavement service providers explained that human resource shortages pre-date the COVID-19 pandemic. There are few counsellors trained in grief and bereavement support, and access is limited for many individuals across the province. Many non-profit grief and bereavement supports are provided by trained volunteers, who play a significant role in strengthening community capacity to respond to grief and bereavement. However, there are a limited number of volunteers, and while they are able to provide some one-to-one support such as peer mentoring, many bereaved people have complex needs that require services beyond the scope of volunteer practice.



Accordingly, grief and bereavement service providers are significantly limited in the number of programs they can run, and the number of people they can serve, all while facing an increased demand for care in their communities.

While these challenges continue to act as significant barriers to the provision of appropriate and equitable grief and bereavement supports throughout British Columbia, participants in the province-wide roundtable on bereavement supports shared optimism that a shift in government policy was underway. Several participants highlighted that the recent change in government presents an opportunity to advocate for effective grief and bereavement supports as a priority issue in the years to come. Others noted the emphasis placed by the current government on community-based supports throughout their budget consultation. Participants felt that this potential shift in policy priorities toward enhanced community-based services could result in greater public funding for grief and bereavement supports moving forward.

#### Virtual Care

At the outset of the COVID-19 pandemic, health and social care systems across Canada rapidly pivoted towards the adoption of virtual care. Given physical distancing restrictions, digital tools such as telephones, videoconferences, and secure messaging applications enabled service providers to continue to provide care and supports to their clients while minimizing the risk of spreading the virus. Although virtual care has now become a core service for many service providers, digital delivery brought both new benefits and new challenges to supporting the bereaved.

According to grief and bereavement service providers, virtual delivery has rendered grief and bereavement supports more accessible for many British Columbians. Throughout the engagement activities, grief and bereavement service providers highlighted that virtual care enabled them to broaden the geographic boundaries of their services and reach more people. It also facilitated access to a greater number and diversity of grief and bereavement supports for the bereaved, who were no longer limited to accessing the programs available in their local communities. New virtual support groups for specific types of losses were able to be formed, and individuals who were typically harder to reach, such as people living in rural communities, etc. accessed supports in greater numbers. For some, virtual supports were and continue to be preferred over in-person resources, as the bereaved can get the help they need without leaving the comfort of their own homes while they are grieving.

#### **Rural and Remote Communities**

Individuals living in rural and remote communities can face particular challenges to accessing grief and bereavement supports. Many communities outside of urban centres have limited access to palliative care and few resources to provide support if a sudden or tragic death occurs. Additionally, transportation to grief and bereavement service providers can be a challenge for those without vehicles, as public transportation is limited or non-existent in some places. While virtual care can enable some to receive services from outside of their community, not everyone has equal access to smart devices or the internet. Participants expressed a need to consider how new and existing grief and bereavement supports can better reach individuals living in rural or remote areas of British Columbia.



Despite the accessibility benefits of virtual grief and bereavement supports, the transition to online services also raised new challenges for the bereaved and service providers. First, not all people in British Columbia have equitable access to digital platforms. For bereaved people living in rural and remote communities, or those from low-income households, internet

access and cellphone service can be more limited. Additionally, some bereaved individuals expressed a preference for accessing support in-person and struggled with the lack of company and physical touch in virtual services. Technical challenges and concerns about privacy impacted service availability and the level of comfort that bereaved people had in expressing their emotions. Some service providers found it more difficult to facilitate one-to-one and group programming online, as they faced new struggles to creating a safe and supportive

"I will say that the increase of virtual care has swamped our counselling team - we are providing access to way more people, which is fantastic, but we really need to increase our resources."

environment and did not have the tools needed to manage emotions or signs of distress over a video call. Furthermore, the demand for support increased as services became more accessible, but resources did not. Grief and bereavement service providers shared that, while they were now able to reach more people than ever before, their teams were overwhelmed, and their programs were full. They also had to make significant efforts to support the transition of their services to online platforms, including pivoting written tools to online materials, developing new resources to support virtual death rituals and remembrance ceremonies, and adding new mechanisms of communication to prepare and engage the bereaved in the programs and services they would receive.

Given the benefits of virtual services, many grief and bereavement service providers expressed the intent to continue delivering programs online. The resulting increase in accessibility to service providers and specialized services can continue to have positive impacts on the bereaved. However, grief and bereavement service providers articulated the need to work better together. Exploring all of the available services, leveraging successful programs, and avoiding duplication of work would allow the province to build a robust system for virtual grief and bereavement supports.



### Appropriate Grief and Bereavement Supports

#### Public Health Approach to Grief and Bereavement Literacy

Bereaved people and grief and bereavement service providers equally highlighted the need for enhanced grief and bereavement literacy in their homes, communities, and health care institutions. As a society, we do not know how to talk about death, grief and bereavement. The bereaved explained that their friends and family members often did not know how to support them, or what to say, after they had experienced the death of someone they cared about. The acuity of these challenges heightened with stigmatized deaths, such as a toxic drug-related death, suicide, medical assistance in dying, or even deaths resulting from COVID-19.

Moreover, health care institutions are centred around a medical model of care that tends to focus solely on the patient, failing to see the people around them who may also need support. Health care professionals and other frontline service providers are not trained on how to interact with the bereaved, and our systems fail to acknowledge families of choice in the provision of grief and bereavement supports. Further, grief and bereavement service providers discussed the system's tendencies to pathologize grief as a mental health disorder, prescribing medical treatments where psychosocial supports would be more appropriate. They explained that when the bereaved do not receive the services they need, their grief can become maladaptive and ultimately lead to prolonged grief disorder, further impacting their physical and mental health.

A paradigm shift is needed toward professionals and communities that are grief-informed. Nearly everyone will experience loss and grief in their lifetimes. Thus, a public health approach to grief and bereavement literacy is needed; by raising awareness and educating people in schools and workplaces, along with improving training for health care professionals and grief and bereavement service providers, British Columbia can become a province where everyone has access to the grief and bereavement supports they need.

#### **Education in Schools and Workplaces**

Education in grief and bereavement needs to begin in schools. Roundtable members emphasized that grief and bereavement education and supports should be offered in schools at all levels, as some children may be exposed to a death of someone they cared about at an early age. Outside of their homes, schools are the primary community for children who have experienced the death of someone they cared about, as well as an important access point for their parents or caregivers.



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Roundtable members shared that training teachers, guidance counsellors, and school administrators in grief and bereavement would enable them to better support students and their parents or caregivers through experiences of loss. Furthermore, exploring themes of grief and bereavement in the school setting could better prepare children for these experiences if and when they occur, by giving them the vocabulary they need to express themselves, support their peers, and normalize their grief. Grief and bereavement education in school curricula can enable British Columbians to raise a generation of people who understand grief and bereavement, and have the tools needed to support themselves and others following the death of someone they cared about.

Education in grief and bereavement, as well as access to grief and bereavement supports, needs to continue beyond schools and into places of employment. Roundtable members shared the belief that employers should be required to offer grief and bereavement education and put in place grief and bereavement plans as part of their occupational health and safety strategies. Educational strategies could be focused on self-care, how to access grief and bereavement supports, and how to support someone else in the workplace after experiencing the death of someone they cared about. Grief and bereavement plans could address shortcomings in equitable and flexible bereavement leaves and enable employees to access the grief and bereavement supports available through Employee and Family Assistance Programs or other sources. Combined, these efforts would improve the grief and bereavement literacy of the general population and enhance equitable access to appropriate grief and bereavement supports for British Columbians.

#### **Education and Training for Volunteers and Professionals**

Grief and bereavement supports are provided by a range of volunteers and professionals throughout British Columbia. However, there are currently no standards in place for education, training competencies or service delivery to ensure that bereaved people receive appropriate care that meets their needs. Roundtable members discussed how, despite the overreliance on volunteers for grief and bereavement supports, there are no education requirements, competency standards or scope-of-practice regulations to guide their service provision. Likewise, health care professionals receive little to no education or training on grief and bereavement and are not well-equipped to communicate with bereaved people or guide them toward the resources they need.

More education and training are needed for volunteers and professionals to strengthen their abilities to identify grief, communicate with the bereaved, and assess the level of care they need. Standardized competencies should be developed based on respective scopes of practice, along with training resources on grief and bereavement literacy, prolonged grief disorder, and available grief and bereavement supports in British Columbian communities. Resources could be offered through a provincial or national learning hub, with tailored and specific information available at the community-level to assist with navigation of grief and bereavement resources, such as service providers and informational supports.

### **Equitable Grief and Bereavement Supports**

Throughout the engagement process and the roundtable event, participants stressed the importance of equity as a foundational principle for accessible and effective grief and bereavement supports. They shared that equity, diversity, and inclusion must be woven into our grief and bereavement system in British Columbia in three ways.

First, there is a need to incorporate cultural sensitivity training across all programming and for all levels of service providers. The current lack of cultural knowledge and limited language capacities has resulted in cases where service providers refer clients to cultural organizations who do not have the resources to offer grief and bereavement supports. For Indigenous Peoples in particular, there is a need for service providers to un-learn

Western ways of healing and work to actively decolonize support services. By earmarking a specific percentage of annual training for cultural sensitivity-based learnings, and actively spending time with the cultural groups they are serving, grief and bereavement service providers can better ensure that the diversity of people who live in the province receive supports that respect their cultures, faith, traditions, and worldviews.

Secondly, greater efforts must be made to recruit diverse people in service provider organizations. Participants expressed that grief and bereavement service providers often do not reflect the diversity of the communities that they serve. Strengthening representation among grief and bereavement service provider organizations would improve the overall cultural sensitivity and safety of the organization, as well as enhance the province's abilities to provide supports in the language of comfort of the person receiving care.

#### Supporting Bereaved Persons who are Experiencing Houselessness

Roundtable members discussed the need to provide different grief and bereavement supports for people experiencing houselessness. Given their mistrust of the system, the different nature of their relationships with their "street family", and the layered trauma they have experienced, bereaved persons experiencing houselessness need safe spaces to memorialize the person or pet that has died. They also need providers who are trained in trauma-informed practice and capable of supporting them with concurrent issues such as substance use, housing, etc.



Lastly, grief and bereavement supports need to be tailored to the type of loss an individual has experienced. A toxic drug-related death or suicide remain highly stigmatized, and the death of a child is not the same experience as the death of a sibling, or a parent or friend. The bereaved emphasized that service providers needed greater grief and bereavement literacy when it came to dealing with different types of deaths, and that bereavement groups in particular needed to be centred around the type of death experienced. For example, roundtable members discussed the unique challenges of people who have experienced the death of a child, as well as those of health care professionals who are grieving the death of their patients:

- **Death of a child:** Parents, siblings, and others who experience the death of a child often do not know where to go to find the supports they need. The death of a child tends to be sudden and unexpected, leaving the bereaved without the chance to wrap their mind around the loss they have experienced, and without the time or presence of mind to find resources to help them through such a difficult experience.
- Death of a patient: Health care professionals, particularly those working in hospice and end-of-life care, can spend a significant amount of a time with a person before they die. Although death may be expected in many cases, when their patients die, health care professionals also need to cope with their death, while continuing to provide care to others. The lack of space to debrief and time to grieve can negatively impact health care professionals, leaving them burned out and affecting their capacity to continue to provide care to others.

These examples illustrate two contrasting experiences of grief and bereavement. While one tends to be sudden and deeply personal, the other may be expected but misunderstood and undervalued by the people surrounding the bereaved. Providing separate spaces for the bereaved to come together and unique supports based on the type of loss experienced is critical to ensuring an equitable and appropriate approach to grief and bereavement services.



#### In Brief

The grief and bereavement support system in British Columbia has many challenges for the bereaved and their service providers. However, there are also meaningful opportunities for change on the horizon.

#### Accessibility

Participants in this initiative spoke of the lack of awareness of available grief and bereavement supports throughout the province, as well as the difficulties that bereaved people face in attempting to navigate the system to find the resources they need. At the same time, they highlighted that the COVID-19 pandemic raised awareness of grief and bereavement supports among the general public, potentially shifting the tides toward greater knowledge, collaboration, and resourcing. Similarly, availability of supports has been limited due to lack of dedicated public funding and a shortage of volunteers and trained grief and bereavement support professionals. Yet the newly elected government has demonstrated greater interest in community-based supports and more willingness to invest in new programming. Finally, while virtual care brings with it new challenges for some, it has also opened the doors for the bereaved to access services outside of their communities, thereby enhancing access to a variety of programs and services that may not be available at a local level.

#### **Appropriateness**

The bereaved leveraged a combination of social circle, informational, and service provider supports to help them through their grief. Greater grief and bereavement literacy is needed among their social circles and service providers to ensure the bereaved are getting the help they need. A public health approach to grief and bereavement literacy could benefit the entire population. By teaching grief and bereavement education in schools and incorporating grief and bereavement education and training in workplaces, British Columbia can undergo a paradigm shift that normalizes conversations about death, grief, and bereavement and, ultimately, results in a grief-informed population. Furthermore, educating health care professionals and frontline service providers, and developing standardized training competencies and scope of practice regulations would ensure that the right supports are being offered at the right time, in the right place, and by the right provider.

#### Equity

Roundtable members expressed that equity must be at the source of all efforts to improve grief and bereavement supports. By incorporating cultural sensitivity training for all grief and bereavement service providers, hiring a more diverse workforce in hospices and other grief and bereavement service organizations, and tailoring resources to the specific forms of loss experienced, the province can better ensure that all British Columbians receive the supports they need, in a manner that respects their culture, beliefs, traditions, religions, and worldviews.

# Part 3. Action Plan

At the close of the province-wide roundtable on bereavement, participants were asked to co-design actions that could be taken to address the challenges identified by both the bereaved and grief and bereavement service providers. This Action Plan contains an overview of the ideas proposed by participants in the roundtable. Combined, these actions establish a roadmap toward a future where accessible, appropriate, and equitable grief and bereavement supports are provided to all British Columbians who have experienced the death of someone they cared about.

# Pillar #1: Accessible Grief and Bereavement Supports

#### Vision

Grief and bereavement supports are accessible: British Columbians are aware of existing services, able to find the resources they need, and able to access the right supports for them, at the right time in their experience, and through the service delivery mechanism best suited to their needs.

### **Action Plan: Awareness**

Members of the roundtable commit to enhancing awareness and improving navigation supports for existing grief and bereavement supports by:

#### Developing **a roadmap** for bereaved people on what to do after death.

After someone dies, bereaved people become responsible for organizing death rituals, closing estates, distributing property, and more. Most individuals are unaware of the steps that need to be taken and the forms that need to be filled in after a death has occurred, leaving them to navigate complex systems while they are grieving. A roadmap tool should be developed that illustrates the steps that must be taken after a death has occurred. The roadmap could exist in print and digital formats and be made available through multiple locations such as libraries, hospices, funeral homes, hospitals, etc. for distribution to the bereaved.

# Engaging in **proactive outreach** to connect bereaved people to grief and bereavement supports.

Leveraging caregiver support groups, hospice societies, and the Regional Health Authorities, proactive outreach should be conducted to raise awareness of, and connect people to, available grief and bereavement supports before they experience loss. Resources such as the BC Bereavement Helpline and the Canadian Virtual Hospice could be established as entry points to navigating the system of grief and bereavement supports available in British Columbia.

# **S** Establishing a **central navigation resource** for bereaved people.

Bereaved people need to know what resources exist, and how to access the grief and bereavement supports they need. Leveraging lessons learned from leading organizations in system navigation such as the Bereaved Families of Ontario, the First Nations Health Authority, NavCare, Compass, and others, a provincial entity should be established with responsibility for creating and maintaining a central repository of grief and bereavement supports available in each community across British Columbia. Resource maps could be developed in an interactive online format and made available to both service providers and the bereaved to assist them in identifying the supports available.

## Creating **a resource hub** for grief and bereavement service providers.

Grief and bereavement service providers and volunteers also need greater access to information, tools, and other resources to provide evidence-informed grief and bereavement services. The BC Bereavement Helpline or the Canadian Grief Alliance could become resource hubs that provide information and support to volunteers, hospices, and counsellors regarding best practices in grief and bereavement services, working with diverse populations and varying experiences of grief, and more.

### Establishing **Regional Navigators** for grief and bereavement services.

The grief and bereavement resources (e.g., service providers and informational supports) vary in each region, as do the needs of the bereaved over time. The creation of Regional Navigators (reporting to provincial and national navigators) would enable us to more effectively identify the resources available across communities as well as the gaps or needs that are not being met.

The navigator would be a living resource manual - not someone responsible for delivering services, but primarily

someone who knows what resources exist and how to access them. These individuals could also speak to needs and trends in their communities and they could be brought together to inform provincial mapping and planning exercises.



#### **Action Plan: Availability**

Members of the roundtable commit to advocating for funding and resources to improve the availability of free or affordable, flexible, and evidence-informed grief and bereavement supports by:

### Enhancing the availability of **free or affordable, flexible grief and bereavement support** options to bereaved people.

Bereaved people identified the need for greater access to free or affordable, flexible grief and bereavement support options including 24/7 access to a toll-free helpline, in-person support, virtual support, one-to-one support, group support, and more. The support provided by the BC Bereavement Helpline, for example, can be expanded and leveraged to provide crisis and navigation support for bereaved people. Currently, the Helpline is available via phone and email. Extended hours of operation, and the addition of a



text and chat function, would enable the Helpline to operate 24 hours per day, 7 days per week, all year round. It would also enhance availability of grief and bereavement services to individuals residing in rural and remote communities.

### Advocating for funded grief and bereavement supports **as a universal benefit under Medicare**.

Grief is a universal experience. However, counselling services and grief and bereavement supports can be costly, and many people do not have the funds or insurance coverage through their employers to pay for services. Advocating for increased government funding for non-profit grief and bereavement supports, or for reimbursements of private supports, would improve accessibility of services for everyone who needs them.



# Strengthening access to grief and bereavement service providers **in long-term care homes and hospitals**.

Ensure all long-term care homes have access to a trained grief and bereavement service provider, such as a counsellor, an end-of-life doula, a hospice society trained staff member, etc. whose role is to better prepare people for loss and address anticipatory grief. This individual should be available to residents, family, and staff.

# Advocating for an **enhanced bereavement leave benefit** for employees.

In British Columbian legislation, an employee is entitled to an unpaid leave of absence of up to three days to grieve, attend a funeral, and take care of issues relating to the death of a member of their "immediate family". Given the established burden of loss on the person's mental health and well-being, enhancing the bereavement leave benefit to include extended timelines beyond the current three-day allowance and broader eligibility criteria that includes individuals without a biological or marital connection to the deceased, is necessary. The bereavement leave benefit should also include an allowance that can be put towards grief and bereavement supports or counselling services for those who need them.

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### Promoting the establishment of **a provincial government Ministry for the Bereaved**.

Funding and support for grief and bereavement organizations often falls through the cracks in government decision-making, as there is no single Ministry responsible for the bereaved. In the United Kingdom, a Ministry of Loneliness was put in place in recent years to demonstrate their government's commitment to addressing the public health challenge of social isolation. Leveraging the lessons learned from the UK, promotion for the establishment of a ministry dedicated to grief and bereavement could ultimately lead to improved funding allocation and standards of care in grief and bereavement supports.

# Drafting **a Bill of Rights** for bereaved people.

Prepare a Bill of Rights that outlines the basic entitlements that bereaved people should have access to during their grieving period. The Bill of Rights could build upon the work of Dr. Alan Wolfelt or other models like the Montreal Children's Grieving Statement. This tool would form the basis of advocacy initiatives toward improved funding and support from public bodies for enhanced availability of grief and bereavement support programs.


## Pillar #2: Appropriate Grief and Bereavement Supports

#### Vision

Grief and bereavement supports are appropriate: British Columbians are informed about death, grief, and bereavement throughout their life-course, and grief and bereavement service providers, health care professionals, and other frontline workers receive the education and training needed to deliver high-quality grief and bereavement supports based on accepted standards of care.

#### **Action Plan: Grief and Bereavement Literacy**

Members of the roundtable commit to collaborating on education and training resources that lead to improved grief and bereavement literacy within schools and workplaces, among health care and frontline professionals, and for the general population as a whole by:

#### Enhancing basic grief and bereavement literacy for all health care professionals.

Education is needed for health care professionals on how to support and communicate with bereaved people and their families. Training for health care professionals should educate them about grief, bereavement, and prolonged grief disorder; teach them how to engage with individuals who are bereaved; and inform professionals about how to connect their patients to available grief and bereavement supports in their communities.



# Enhancing grief and bereavement literacy for students, teachers, and counsellors in schools.

Schools are the primary communities for children who have experienced the death of someone they cared about, as well as an important access point to services for parents and caregivers, some of whom may be children.

Exploring themes of grief and bereavement in the school setting can better prepare children for the experience of death and give them the vocabulary needed to express themselves and normalize their grief. Grief and bereavement literacy could be provided by teachers, by students who are trained as volunteer peer supports, or by outreach programs.

Training for teachers and school counsellors on grief and bereavement literacy, combined with grief and bereavement education curriculum and grief and bereavement supports could equip schools with the resources they need to support students, parents, and caregivers. Training could be provided during teacher professional development days or through reserved seats for teachers and school counsellors in hospice training sessions.

Grief and bereavement literacy in schools would ensure that we raise a generation who understands grief, and how to support their friends, family members, and others through experiences of loss.

#### Developing and implementing **targeted promotional opportunities** to introduce grief and bereavement literacy materials to the general public.

Considering grief as a universal experience, introducing targeted content to the general public would raise awareness and improve the population's overall grief and bereavement literacy.

Materials could be developed in bite-sized content, such as short five-minute videos that people can watch to learn about different types of losses, grief and bereavement support, etc. Additionally, grief and bereavement service organizations could run grief and bereavement pop-up booths at local markets, events, or shopping centres that draw people in with free comfort food and beverages while providing basic information about death and bereavement.

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## Developing resources and training materials to enhance grief and bereavement literacy **in workplaces**.

Employees who have experienced a death of someone they care about require support from their workplace to engage in self-care activities and to feel safe accessing grief and bereavement supports.

Organizations could receive training and resources on how to support their employees through experiences of grief. For example, a Grief-to-Go kit could be developed and provided to employees along with workplace training sessions after an employee has experienced a loss. The Grief-to-Go kit would be provided to everyone in the organization and include a list of what not to say, instructions on setting up a safe space, how to structure facilitated conversation, a candle, information on grief, exercises for people to do, etc.

Further, workplaces can put in place measures that support their staff to engage in self-care, such as policies and procedures, group self-care activities like yoga and more. Organizations that establish measures to support bereaved people could be recognized through a Compassionate Companies designation, enabling them to outwardly demonstrate their commitment to being a safe and healthy workplace for everyone.

# 5

## Creating **a provincially coordinated marketing and communications strategy** for grief and bereavement.

Improving grief and bereavement literacy and raising awareness of grief and bereavement supports requires long-term collaboration. Developing a coordinated communications strategy with consistent messaging and well-defined roles and contributions from every organization in the sector would improve the collective impact of marketing and advertising initiatives.

The focus of the communications strategy should be on shifting the paradigm to raise awareness that grief impacts everyone, everyone grieves differently, and supports are available in every community.

The strategy should be led by a provincial organization and developed in consultation with media experts. It could include paid advertisements (billboards, busses, washrooms, libraries, pharmacies, and local newspapers), marketing campaigns (e.g., bar coasters that say, "I'm dying for a beer" and have information about grief on the back), adding the term "grief supports" to hospice society logos and taglines, targeted columns in local newspapers, shared blogs, and more.



#### **Action Plan: Education and Training**

Members of the roundtable commit to co-designing a grief and bereavement support framework, as well as the associated standards and resources necessary to enable all grief and bereavement service providers to offer appropriate services by:

Collaborating on the development of evidence-informed **training opportunities** for all service providers.

Many organizations have developed different grief and bereavement support training programs for their employees and volunteers, based on their own experiences and their unique needs.

By bringing together all hospices, community organizations, and others with grief and bereavement expertise and consolidating the various training resources available, a single evidence-informed educational platform could be created.

The platform could host several training programs based on such criteria as the level of need or the role of the provider (e.g., volunteer, program facilitator, counsellor). The training programs could be made available to all community organizations and private grief and bereavement service providers throughout British Columbia.





#### Establishing standards for grief and bereavement service delivery.

Grief and bereavement supports are provided by a range of professionals and volunteers throughout the province. Currently, there are no standards in place for service providers to ensure that all bereaved people are receiving the same quality of care.

Establishing standards for grief and bereavement supports would ensure that all programs offered are evidence-informed, safe, and appropriate for the needs of the bereaved. Standards would also minimize geographic and demographic variability in grief and bereavement care.



Developing standardized **competencies** for volunteer grief and bereavement service providers.

Volunteers should have a standardized training program and manual on grief and bereavement literacy and support provision.

The training program would outline the necessary competencies for volunteers in grief and bereavement support, as well as explain their scope of practice, ensuring volunteers are providing services that are within their education, training levels, and abilities. It would also offer a menu of options for achieving the competencies necessary for their work and form the baseline for the development of future training programs.

## Developing a Grief and Bereavement **Support Ladder Framework**.

Each experience with grief is different, creating different levels of need for services among the bereaved. A framework should be designed that identifies different potential levels of need and the corresponding services required at each level.

Generally, the framework could be organized as a pyramid, with the lowest level of needs being grief and bereavement literacy and universal services that can be accessed by anyone to improve their understanding of grief and bereavement. The second tier of the pyramid would be community services provided by volunteers, such as peer support, companionship, and validation, for individuals who need some form of connection to shared experiences. The third tier of the pyramid would be services for individuals with higher needs, such as one-to-one or group counselling. The fourth tier would be specialized grief and bereavement services for people with complex needs. The final tier would be individuals who require mental health services or medical treatment for complex grief or prolonged grief disorder.

### Pillar #3: Equitable Grief and Bereavement Supports

#### Vision

Grief and bereavement supports are equitable: All British Columbians receive supports that are tailored to their unique needs and experiences, and respectful of their diverse cultures, beliefs, religions, traditions, and worldviews.

#### **Action Plan: Equity**

Members of the roundtable commit to developing and delivering culturally appropriate, tailored grief and bereavement supports that reflect the unique needs of different individuals and communities by:

#### Enhancing grief and bereavement supports for **children**.

Children experience grief differently and require supports that meet their developmental needs. The supports available for children who are grieving could be enhanced by: establishing resources in schools, such as grief and bereavement groups for students who have experienced the death of someone they care about (facilitated by a trained volunteer or staff member); teen mentoring groups for students who want to be a trained grief and bereavement volunteer for their peers; grieve-and-tell programs for students to come together and share their experiences of grief; and Grief and Bereavement Coordinators as dedicated point people responsible for planning events and hosting training sessions.



Schools should also involve social media resources through YouTube, TikTok and other platforms as some students may not feel comfortable going to their teachers for help. Grief and bereavement supports need to be creative and go beyond counselling – they should incorporate arts, drama, and music – with a special emphasis on supporting siblings of children who have died, as they often grieve alone since the focus of grief and bereavement service providers is on their parents or caregivers. Launching an awareness campaign in schools that targets siblings of children with the message, "go ahead and ask" could be used to give space to siblings to express their grief.

## **2** Offering **culturally tailored and non-traditional** grief and bereavement supports.

Each demographic, linguistic, ethnic, and cultural community has different needs when it comes to grief and bereavement supports. Their needs are also affected by the type of loss they have experienced.

Developing grief and bereavement supports that meet groups where they are at in their journeys and go beyond traditional counselling formats can enable equitable access to grief and bereavement supports throughout the province. For example, relaxation training, smashing things, drum circles, and other activities could be incorporated into existing grief and bereavement support programs.



## Supporting Indigenous Peoples through cultural humility.

Grief and bereavement service providers must reach out to local Indigenous communities to learn about their beliefs, traditions, and language surrounding grief and bereavement.

Organizations should initiate relationships by going to the community, attending events, and participating in Indigenous circles. Service providers can learn from these experiences about Indigenous knowledge and beliefs. This can lead to collaborating and co-designing grief and bereavement resources with Indigenous Peoples, so as to better reflect the languages and values of Indigenous communities.

#### Enhancing grief and bereavement supports for **health care professionals and frontline care workers** who experience the death of a patient or client.

Frontline care workers (such as health care professionals, paramedics, doctors, nurses, health care aides, and people who support those experiencing houselessness) may suffer from vicarious trauma and grief and often do not have a place to express themselves. In fact, they may not realize the impacts grief has on their lives.

Introducing supports in their workplaces, such as compassionate care rounds (debrief opportunities with coworkers), sharing circles, and Grief-to-Go kits are opportunities for low-cost, high impact supports that enable them to better process their grief following the death of someone they cared about. Additionally, a Compassionate Resilience toolkit has been developed that includes modules on grief and bereavement. Delivering resiliency training to health care providers will provide them with the knowledge and tools they need to process their own grief after experiencing the death of a patient or client.

# Enhancing training for outreach workers who support individuals experiencing **houselessness**.

People experiencing houselessness, or who are housing insecure, often also experience challenges such as substance use, mental health issues, or trauma. Outreach workers regularly provide grief and bereavement care to people experiencing houselessness. Acknowledging their important roles and providing them with trauma-informed training on mental health, addictions, and grief and bereavement support would enable them to provide wrap-around care for the people they work with.

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#### Creating safe spaces for bereaved people experiencing **houselessness** to grieve.

Grief and bereavement service providers need to create safe spaces or leverage existing environments (such as outreach centres, needle exchange centres, friendship centres, etc.) to meet individuals experiencing houselessness where they are at, provide them with supports, and give them an opportunity to grieve.

For example, bi-weekly open grief and bereavement groups could be facilitated in outreach centres by counsellors who are also qualified in mental health and addictions support. Information cards could be handed out to people, and memorial spaces could be setup so that individuals experiencing houselessness can remember and pay tribute to those that they cared about who have died.

# 7

#### Hiring more Indigenous Elders in grief and bereavement organizations.

Leveraging the lessons learned from Lumara Grief & Bereavement Care Society, and in partnership with the First Nations Health Authority, grief and bereavement service providers should aim to establish positions for Elders-in-Residence in different grief and bereavement service organizations.

The Elder-in-Residence would be responsible for guiding Indigenous and non-Indigenous service providers through the delivery of culturally sensitive and appropriate grief and bereavement supports.



# Moving Forward Together

At the close of the roundtable, two key outcomes were highlighted:



There is a lot of work that needs to be done to ensure that all British Columbians have equitable access to effective grief and bereavement supports, and



Collective action is needed to make significant improvements.

Given the large breadth of initiatives identified in this Action Plan, the BC Centre for Palliative Care distributed a survey to roundtable participants after the event to prioritize first steps following this important work. Participants identified these five actions as the most important initiatives within each pillar:

1	Accessibility:	Develop a roadmap for bereaved people on what to do after death
2	Availability:	Enhance the availability of free or affordable, flexible bereavement support options to bereaved people
3	Grief & Bereavement Literacy:	Enhance basic grief literacy for all health care professionals
4	Education & Training:	Collaborate on the development of evidence-informed training opportunities for all service providers
5	Equity:	Enhance grief supports for children

For more details on the survey results, see **Appendix A.** 

Overall, the prioritized actions will inform province-wide efforts as knowledge users work together to enable equitable access to effective grief and bereavement supports for all British Columbians. Further research studies may still be necessary to better understand certain aspects of what is needed to implement an action item (e.g., interviewing those with lived experience of bereavement and houselessness), as well as research studies to assess the programs, resources, and policies that will be developed. For more details on potential future research priorities, see **Appendix B**.

The BC Centre for Palliative Care is hopeful that this report will be a helpful resource to guide improvements

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# Appendix A. Considerations for Implementation

To better understand the knowledge user's perspectives on the top priority action items, a survey was distributed following the roundtable event. Participants were asked to consider each pillar of the Action Plan and to rank the potential solutions therein according to their perceived priority level. The potential solutions were grouped under five categories within the Pillars, each of which have equal weight. A total of 29 people from the roundtable completed the survey (83% response rate).

For each of the five categories, the ranking of the priority actions was determined by using a weighted calculation. For example, if a category had five action items to choose from, the most important ranked action would be assigned five points, the second ranked item would be assigned four points, etc. The lowest ranked item would be assigned one point. The overall highest number of points would determine the overall ranking of that action item in the category. In case of a tie, the one with the most top rankings will be ranked higher.

## Pillar #1: Accessible Grief and Bereavement Supports



#### **Awareness**

The rank order for the most important action items for the category of Accessible Grief and Bereavement Supports - Awareness are shown in the table below. Overall, participants ranked Developing a roadmap for bereaved people on what to do after death as being the most important action item in this category.

Accessible Grief and Bereavement Supports – Awareness	Weighted Scores
Develop a roadmap for bereaved people on what to do after death	96
Proactive outreach to connect bereaved people to grief and bereavement supports	88
Establish a central navigation resource for bereaved people	88
Create a resource hub for grief and bereavement service providers	82
Establish Regional Navigators for grief and bereavement services	81

Graph A illustrates the number of selected ranks for each action item.





#### **Availability**

The rank order for the most important action items for the category of **Accessible Grief and Bereavement Supports – Availability** are shown in the table below. Overall, participants ranked Enhance the availability of free or affordable, flexible bereavement support options to bereaved people as being the most important action item in this category.

Accessible Grief and Bereavement Supports – Availability	Weighted Scores
Enhance the availability of free or affordable flexible grief and bereavement support options to bereaved people	138
Advocate for funded grief and bereavement supports as a universal benefit under Medicare	117
Strengthen access to grief and bereavement service providers in long- term care homes and hospitals	106
Advocate for enhanced bereavement leave benefit for employees	103
Advocate for the establishment of a provincial government Ministry for the Bereaved	78
Draft a Bill of Rights for bereaved people	67

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Graph B illustrates the number of selected ranks for each action item.



Rank 1 Rank 2 Rank 3 Rank 4 Rank 5 Rank 6

#### Graph B. Accessible Grief and Bereavement Supports - Availability

support options to bereaved persons

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	3
7	5
Advocate fo funded grief bereavemen supports as universal ber under medic	& access to t & bereave a support lefit providers i



## Pillar #2: Appropriate Grief and Bereavement Supports

#### **Grief and Bereavement Literacy**

The rank order for the most important action items for the category of *Appropriate Grief and Bereavement Supports - Grief and Bereavement Literacy* are shown in the table below. Overall, participants ranked Enhance basic grief literacy for all health care professionals as being the most important action item in this category.

Appropriate Grief and Bereavement Supports – Grief and Bereavement Literacy	Weighted Scores
Enhance basic grief and bereavement literacy for all health care professionals	108
Enhance grief and bereavement literacy for students, teachers, and counsellors in schools	103
Develop and implement targeted promotional opportunities to introduce grief and bereavement literacy materials to the general public	79
Develop resources and training materials to enhance grief and bereavement literacy in workplaces	79
Create a provincially coordinated marketing and communications strategy for grief and bereavement	66

Graph C illustrates the number of selected ranks for each action item.



Rank 1 Rank 2 Rank 3 Rank 4 Rank 5

6





11

6



resources & training materials to enhance grief & bereavement literacy in workplaces

7



Create a provincially coordinated marketing & communications strategy for arief & bereavement

#### **Education and Training**

The rank order for the most important action items for the category of Appropriate Grief and Bereavement Supports - Education and Training are shown in the table below. Overall, participants ranked Collaborate on the development of evidence-informed training opportunities for all service providers as being the most important action item in this category.

arief &

to the general public

bereavement

literacy materials

Appropriate Grief and Bereavement Supports – Education and Training	Weighted Scores
Collaborate on the development of evidence-informed training opportunities for all service provider	87
Establish standards for grief and bereavement service delivery	69
Develop standardized competencies for volunteer grief and bereavement service providers	68
Develop a Grief and Bereavement Support Ladder Framework	66

Graph D illustrates the number of selected ranks for each action item.

#### Graph D. Appropriate Grief and Bereavement Supports - Education and Training

Rank 1 Rank 2 Rank 3 Rank 4



evidence-informed training opportunities for all service providers

bereavement service delivery

for volunteer grief & bereavement service providers

framework



### Pillar #3: Equitable Grief and Bereavement Supports

The rank order for the most important action items for the category of *Equitable Grief and Bereavement Supports* are shown in the table below. Overall, participants ranked Enhance grief supports for children as being the most important action item in this category.

Equitable Grief and Bereavement Supports	
Enhance grief and bereavement supports for children	142
Offer culturally tailored and non-traditional grief and bereavement supports	133
Support Indigenous Peoples through cultural humility	117
Enhance grief and bereavement supports for health care professionals and frontline care workers who experience the death of a patient or client	113
Enhance training for outreach workers who support individuals experiencing houselessness	
Create safe spaces for people experiencing houselessness to grieve	106
Hire an Indigenous Elder in grief and bereavement organizations	88

Graph E illustrates the number of selected ranks for each action item.



#### **Graph E. Equitable Grief and Bereavement Supports**

Rank 1 Rank 2 Rank 3 Rank 4 Rank 5 Rank 6 Rank 7



# Appendix B. Potential Future Research Studies

During the symposia, participants were asked about their priorities for future grief and bereavement research projects. Time to explore this was not possible during the roundtable. The areas of research that were suggested to better our understanding of the British Columbia landscape were:

- A 5-year post-COVID study to see how people have processed bereavement during the pandemic in the long-term.
- A national project to identify number of grieving and bereaved children.
- Research on grief and bereavement in the workplace policy, procedures, training, bereavement worker needs, etc.
- Research supporting grief and bereavement in the context of houselessness and the vulnerably housed.
- Research on grief and bereavement in adult children (aged approximately 18 to 30) after the death of middle-aged parents.
- Grief and bereavement after a toxic drug-related death, suicide, and medical assistance in dying.

