Addressing the deficit in grief support: A national response to pandemic-related grief

Submission to the Pre-budget Consultations for the 2021-22 Federal Budget

The Canadian Grief Alliance

The Canadian Grief Alliance (CGA) is a coalition of more than 150 leading health and grief-related organizations across Canada (please see list below) that came together in May 2020 to propose an approach to support grieving Canadians in anticipation of the surge of complex grief from Covid-19-related and affected deaths. The CGA was invited to present to the Standing Committee on Health on January 29, 2021 about the urgent need for a Canadian Grief Strategy. The CGA has had a number of meetings with Health Canada however to date there has been no comprehensive response to the needs of grieving Canadians.

The CGA respectfully submits the following recommendations for addressing the deficit in grief supports: A National Response to Pandemic-related Grief to the Budget 2021 Pre-Budget Consultations.

Recommendations - Brief Overview:

Recommendation 1: That the Government of Canada invest \$100 million over three years to sustain and expand existing community-based grief services across the country with special focus on underserved populations.

Recommendation 2: That the Government of Canada undertake a national public awareness campaign to increase Canadians' understanding of grief and provide education and strategies to help Canadians grieving in isolation to cope.

Recommendation 3: That the Government of Canada invest in a national consultation and \$10 million in the Canadian Institutes for Health Research and the Social Sciences Humanities Research Council to help Canada to better understand and respond to pandemic-related and affected grief. That a portion of the research funding be specifically earmarked for research related to the grief experienced by Indigenous Peoples.

A Pandemic of Grief

The pandemic has brought to the forefront the urgent need to respond to and support grieving Canadians. While grief is the natural human response to significant loss, because of COVID-19, individuals, families and communities across the country have not been able to grieve deaths from all causes — both COVID-19 and non-COVID-19 — in the way we are accustomed. Since the pandemic's start, grieving Canadians have been robbed of final goodbyes, tormented by reports of poor conditions in some facilities, unable to undertake traditional grief rituals, and separated from the critical support of family, friends and community. This severing of the personnel connection that is critical to people coping with grief, is negatively impacting individuals, families, communities, the economy and society as a whole.

Tragically, over 21,000 people have died in Canada from Covid-19 and it is estimated that nearly 270,000 Canadians have died from other causes since the pandemic's start (based on Statistics Canada death rate for 2019). Recent research from Pennsylvania State University tells us that each death directly impacts nine people, meaning that more than 2.6 million Canadians and counting are currently grieving in isolation, with insufficient support. This number does not account for the wider impact of grief on workplaces, schools, businesses, and communities as a whole. Communities disproportionately impacted by the pandemic, including racialized and Indigenous communities, are also being disproportionately impacted by grief.

Grief is Falling Through the Cracks

While the Government of Canada has announced significant pandemic-related investments in mental health, grief falls outside the mandate of the Canadian Mental Health Commission and mental health associations. Traditional mental health interventions such as those aimed at individuals with depression and anxiety don't work for the bereaved and can do more harm. Commonly, mental health interventions for depression and anxiety seek to change people's thinking in order to help them cope. Grief experts who are part of the Canadian Grief Alliance know that for grief, it's not about changing thinking, but about being with people in their deep pain, providing psycho-education, and expert guidance and support. Not only does grief not respond at all to prompts to change one's thoughts, such messages only further alienate and isolate the bereaved. This is why current mental health spending is not addressing the needs of grieving Canadians.

To date, there has been neither an acknowledgment of unsupported grief as an additional looming mental health crisis by the Government of Canada, nor recognition of the impact that failing to act will have on our society and the economy.

Pre-pandemic, grief services across the country were already fragmented and under-resourced. Nearly a year into the pandemic, these services are completely overwhelmed by the volume and complexity of grief, unable to meet skyrocketing demand. In many provinces and territories, publicly funded grief support is either minimally available with months-long waiting lists or entirely absent. The limited, free grief services that are available are offered by not-for-profit organizations that are struggling with sharp declines in charitable donations. Job losses and financial insecurity are creating a significant barrier to accessing private grief counselling. The level of distress and complexity of grief created by the pandemic have dramatically increased the need for immediate access to publicly-funded services.

Without sufficient grief services, the risks for mental health issues to develop for grieving Canadians has increased. Canadians grieving all deaths are at elevated risk of unresolved, complicated and/or prolonged grief. Research tells us that when grief is complicated — if circumstances prevent us from having the supports to grieve, it can transform into depression or anxiety, dependence or addiction, and the risk of suicide.

Grieving Canadians need access to the specialized services and support that can address their specific needs and experiences, and organizations offering these services across the country need assistance to meet the growing demand and complexity of cases.

A Canadian Grief Strategy

Delays in the federal government's response to the pandemic of grief have hampered the ability of bereavement organizations to respond to the growing needs and complexity of grief, and have marginalized the needs of the grieving. Recognizing the importance of bereavement care, encouraging people to access help when needed, increasing awareness of services, improving grief literacy, and removing the stigma associated with seeking support will improve access to timely support and prevent mental health risks. A federal response to the ever-growing needs of grieving Canadians is urgently needed.

Investing in grief now will help to mitigate significant health, mental health, social and economic impacts on society in the medium and long-term. Ensuring grieving Canadians have access to the support and services they need will help them return to work, contribute to economic and societal productivity, and reduce healthcare costs.

Specifically, the CGA is calling on the federal government to immediately implement a three-part, emergency-based response as the first steps of a Canadian Grief Strategy.

Recommendation 1: Increase access to grief services for Canadians now

Invest \$100 million over three years in community-based, grief and bereavement programs to support innovation, best/leading edge practices, capacity building initiatives, and identification and scale and spread of innovative programming. The fund will be administered by the Government of Canada, similar to the recent call by the Public Health Agency of Canada for community-based funding for distress centres. Immediate investment will enable a time-limited, three-year response to pandemic-related and affected grief, providing interventions to reduce downstream costs and multi-year funding to address the grief fallout from the pandemic's first, second, and likely third wave. It will also help mitigate the long-term implications of grieving in a time of public health restrictions. The investment will:

- Sustain and expand services to ensure that existing grief services are adequately resourced and therefore more accessible.
- Develop tailored grief services and resources to meet unmet needs of underserved and disproportionately impacted populations, including racialized communities encompassing Black, Indigenous and People of Colour, children and people living in rural and remote communities.
- Curate, develop and make available a suite of grief services for people working in healthcare for their grief-related work trauma at no cost.
- Curate novel practices adopted by health facilities to create connection between patients and families separated by visitor and travel restrictions or other barriers.

These initiatives will:

- Mitigate the adverse outcomes of unsupported or poorly supported grief, including clinical depression and suicide ideation.
- Provide accessible grief resources and services to support healthcare providers and contribute to their retention in the workforce.
- Reduce significant downstream costs to the healthcare system and the economy that will result if the lack of grief services is not addressed.

Recommendation 2: A National Public Awareness Campaign

A national public awareness campaign rooted in the principles of public health is imperative. Such a campaign will improve Canadians' understanding of grief, including how COVID-19 has changed how we grieve, coping strategies, and ways to support others who are grieving.

Taking a public health approach, the campaign would include both universal and targeted messages. A universal campaign will inform and educate the public on grief and strategies to help Canadians grieving in isolation to cope, including where to find resources, and signs that indicate more help may be needed. Targeted campaigns led by and for racialized and Indigenous communities, and aligned to their unique histories, needs, and experiences, are essential. In addition to increasing Canadians' grief literacy, and thereby assisting communities across Canada to better support grievers, a national public awareness campaign would also acknowledge our collective grief as a country.

Recommendation 3: Research & Consultation to Better Understand and Respond to Pandemic-Related and Affected Grief

Canadians have never experienced this depth and breadth of grief and loss before.

The CGA proposes a rapid, national consultation in the immediate term that would allow us to better understand the needs of grieving Canadians and communities. As the CGA is connected to over 150 leading health and grief-related organizations serving diverse communities across the country, it would be possible to complete such a consultation within two months.

Over the medium to longer term, the CGA calls for dedicated research funding — an investment of \$10 million in the Canadian Institutes for Health Research and Social Sciences Humanities Research Council — to improve Canada's understanding and response to pandemic-related and affected grief. Two million dollars would be earmarked for research on the grief experienced by Indigenous Peoples.

The Canadian Grief Alliance

The CGA began as a group of 36 national leaders in grief and bereavement and has grown to more than 150 leading health and grief-related organizations requesting that the Government of Canada #MakeGriefAPriority. The CGA is convened by The Canadian Virtual Hospice, a charitable organization with a track record for delivering innovative programming to support more than 2.4 million visitors annually.

Organizations supporting the Canadian Grief Alliance

National

Canadian Medical Association

Canadian Nurses Association

Canadian Psychiatric Association

Canadian Association of Social Workers

Canadian Association for Spiritual Care

Canadian Society of Palliative Care Physicians

Canadian Association of Psychosocial Oncology

Canadian Alliance for Grieving Children and Youth

The Enchanté Network

Young Adult Cancer Canada

Pauktuutit Inuit Women of Canada

Canadian Aboriginal HIV/AIDS Network

All Nations Hope Network

Dying with Dignity Canada

Canadian Association for Marriage & Family Therapy

End of Life Doula Association of Canada

The Leukemia & Lymphoma Society of Canada

Canada Bereavement Registry

Canadian Integrative Network for Death Education and Alternatives

Schizophrenia Society of Canada

Melanoma Network of Canada

Canadian Health Advocates Inc.

Canadian Medical Hall of Fame

Alberta

Alberta Hospice Palliative Care Association Covenant Health Palliative Institute Caregivers Alberta Hospice Calgary Red Deer Hospice Hospice Society of Camrose and District Children's Grief Centre Healthy Directions

Transitions Music Therapy Oliver's Funeral Home

British Columbia

BC Hospice Palliative Care Association

BC Centre for Palliative Care

Family Caregivers of BC

Island Health

Vancouver Island Health Authority

BC Bereavement Helpline

Camp Kerry

Kilala Lelum (Urban Indigenous Health & Healing Cooperative)

Comox Valley Hospice Society

Abbotsford Hospice Society

Vancouver Hospice Society

Delta Hospice Society

Hospice Society of the Columbia Valley

Prince Rupert and District Hospice Society

Victoria Hospice Society

Peace Arch Hospice Society

Burnaby Hospice Society

Crossroads Hospice Society

100 Mile District Hospice Palliative Care Society

Sea to Sky Hospice Society

Desert Valley Hospice Society

West End Seniors' Network

Moving Forward Family Services

Life and Death Matters

Honour End of Life Care

Pacific Well-Being

Manitoba

Palliative Manitoba

Rainbow Resource Centre

Two-Spirited People of Manitoba Inc.

Cancer Care Navigation Services - Northern Regional Health Authority

Rock Lake Palliative Care

Peguis Home & Community Care

Robert Smith School

New Brunswick

NB COPES Child and Family Grief Center

Newfoundland and Labrador

Newfoundland and Labrador Palliative Care Association

Nova Scotia

NS Hospice Palliative Care Association Doctors Nova Scotia Caregivers Nova Scotia Hospice Halifax Colchester East Hants Hospice Society Good Grief Halifax

Ontario

Hospice Palliative Care Ontario

Ontario Association of Social Workers

Global Institute for Psychosocial, Palliative and End-of-Life Care, University of Toronto

RNAO Palliative Care Nurses Interest Group

Centre for Education and Research on Aging & Health, Lakehead University

de Souza Institute

Hope House Community Hospice

Dundas County Hospice

Hospice Outreach Programs of Elgin

Hospice Muskoka

McNally House Hospice

Madawaska Valley Hospice Palliative Care

Hazel Burns Hospice

Hospice Wellington

Dr Bob Kemp Hospice and Bereavement Services

Heart House Hospice

St. Joseph's Hospice Sarnia Lambton

St Joseph's Hospice London

Hospice Northwest

Roger Neilson House

Evergreen Hospice

Hospice Peterborough

Matthews House Hospice

Doane House Hospice

Kensington Health

Near North Palliative Care Network

Bereavement Ontario Network

Bereaved Families of Ontario - South Central Region

Bereaved Families of Ontario - Ottawa

Bereaved Families of Ontario – Kingston

Bereaved Families of Ontario - Midwestern Region

Healing Broken Hearts

Good Grief! Bereavement Healing Services

Gilda's Club of Greater Toronto

The Hummingbird Centre for Hope

Grief Recovery Ontario

Dr. Jay Children's Grief Centre

Children and Youth Grief Network

The Lighthouse Program for Grieving Children

Seasons Centre for Grieving Children

Jewish Family and Child Service of Greater Toronto

Victorian Order of Nurses - Oxford

Unity Health Toronto

Selah Resources

Hulse, Playfair & McGarry

Prince Edward Island

Hospice PEI

Quebec

Association québécoise de soins palliatifs

McGill Council on Palliative Care

Maison Michel Sarrazin

Réseau Québécois de recherche en soins palliatifs et de fin de vie

Regroupement des Infirmiers-Infirmières Ressources en don d'organes et de tissus du Ouébec

Palli-aide accompagnement en soins palliatifs Saguenay inc.

Parents Orphelins, l'Association des parents qui vivent un deuil périnatal

Albatros Montréal

Groupe des Aidants du Sud-Ouest Myra's Kids Foundation

West Island Cancer Wellness Center

Hope & Cope

ORA Loss & Living Program, Ste. Genevieve United Church

Unitarian Church of Montreal

ADATH Congregation

Connexions Resource Centre

Saskatchewan

Prairie Hospice Society

Morning Star Lodge, University of Saskatchewan

Augustana Lutheran Church

The Good Foundation Inc.

Territories

| Hospice Yukon | |
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