

Home and Community-Based Palliative Care Shaping the future from lessons learned during the COVID-19 pandemic

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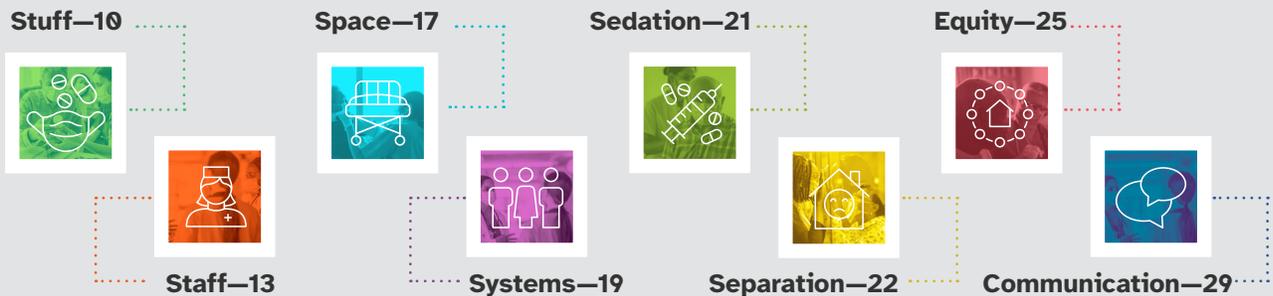
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Thank you to the representatives from community organizations and government agencies as well as the researchers involved in palliative care who participated in interviews to help build this document.

The **views** and **opinions** expressed in this report reflect what was heard from respondents who participated in discussions focusing on the impacts of COVID-19 on home and community palliative care, including barriers to care, and actual or promising responses and innovations to respond to these barriers. They do not reflect the opinions of the authors, of Health Canada, Healthcare Excellence Canada, the Canadian Partnership Against Cancer, Canadian Home Care Association, Pallium Canada, Canadian Virtual Hospice, or of the organizations where participants work. Assumptions made within the analysis are not reflective of the position of any Government of Canada department or organization.

Executive Summary

The Coronavirus disease 2019 (COVID-19) has caused 23,623 deaths in Canada since January 2020 at the time of printing (April 19, 2021), and continues to pose an ongoing threat to Canadians of all ages. Early pandemic planning focused on the hospital sector and later shifted to the long-term sector as infection and death rates soared. Patient discharges from hospitals, cancellation of non-essential services and procedures, and people's reluctance to receive care in institutional care settings, led to a skyrocketing demand for home care services. COVID-19 further strained already limited palliative care resources and exposed pre-existing gaps and systemic vulnerabilities in palliative care delivery across in-home and community-based settings across Canada.

Unprecedented demand for in-home and community-based care provided both challenges and opportunities for the palliative care sector. While initially largely overlooked in early pandemic planning, home and community-based palliative care has proven to be of paramount importance in caring for people during this crisis. The sector demonstrated a high degree of flexibility and was able to pivot quickly to assume an essential role in the provision of increasingly complex palliative and end-of-life care. The pandemic further illuminated the importance of greater cross-sectoral collaboration and highlighted the need to ensure that equity remains a top priority in future planning.

This report speaks to some of the challenges posed by the pandemic in the delivery of home and community-based palliative and end-of life care, but most importantly it highlights many of the promising practices and innovative tools that emerged during this time. It is intended for front-line teams, health educators, and administrators and utilizes a framework to optimize palliative care delivery during a pandemic.

Some key findings include:

1. Caregivers who cared for a loved one at home experienced a sharp increase in caregiving duties at a time where there were limited supports. The need for greater psychosocial, physical, and practical supports for caregivers has previously been identified as a priority and requires focused and sustained attention beyond the pandemic.
2. The pandemic amplified the importance of timely access to palliative care education and training for community healthcare providers. The ability of national, regional and local organizations to provide widespread, virtual palliative care education, tailored to needs of diverse healthcare provider groups, was instrumental in building the skills and capacity of primary care and community clinicians to deliver high quality palliative care.
3. The demand for grief and bereavement support was magnified during this period. Spiritual care resources and the increased uptake of virtual grief supports/resources were instrumental in addressing both caregiver and staff needs. Given the losses endured in the pandemic, there is a pressing need for these supports to be enhanced and sustained in the coming months.
4. The pandemic highlighted existing inequities in timely and fair access to high quality palliative care. Those facing homelessness, those in rural and remote communities, and Indigenous peoples faced the most hardship, particularly with isolation protocols and the shift to virtual care. Community care organizations worked quickly to reach out to provide tools, shelter and care to their most vulnerable clients in innovative ways. Improved access to technology and the need to embed a palliative approach to care within all health and social services, along with increased inter-sectoral collaboration were identified as priorities moving forward.
5. Working to full scope of practice became both a necessity and an opportunity during acute staffing shortages. The pandemic further served as an impetus for teams to come together to reorient roles and strengthen interprofessional collaboration in order to improve patient and caregiver experience.
6. Advanced care planning and goals of care discussions became imperative during this period. Adoption of new and existing tools/resources provided an opportunity to better address patients' wishes during this period of crisis but also highlighted the additional work is required to streamline communication across healthcare settings and incorporate virtual technologies into these sensitive discussions.

The pandemic had a profound impact on the provision of home and community-based palliative care, highlighting existing inequalities in the distribution of scarce resources and access to care. At the same time though, it magnified the pivotal role that home and community-based services play in caring for those with palliative and end-of-life care needs. The learnings and creative solutions applied during the COVID-19 pandemic will have an impact on how home and community palliative care is defined and shaped in the years to come.

Key informant participants work in or shared experiences from a variety of home and community-based palliative and end-of-life care settings from across jurisdictions. However, facility-based care, such as nursing homes and long-term care homes, were not included in the consultations to inform this report.

Introduction

COVID-19 has strained resources exposed gaps and systemic vulnerabilities in palliative care delivery and supportive care more broadly across all settings in Canada - in hospitals, as well as in home and community care settings. As a result, Canadian healthcare workers, administrators, and organizations have risen to the occasion to respond. They have identified newly arising or long-existing concerns, and developed innovative ways to work around the problems to ensure the best possible supportive palliative care was provided despite the difficult conditions created by the pandemic. While a great deal of attention has been given to studying why long-term care and nursing home settings have suffered tragic losses and the greatest toll from COVID-19 both nationally and internationally, very little attention has been given to the impacts of COVID-19 on home and community palliative care outside of long-term care facilities. By sharing some of the best practices and tools that were shared in interviews it is hoped that readers from all jurisdictions in Canada will be inspired to use and adapt them as required, or come up with and share their own innovations. By working together, Canada's pandemic responses, and palliative and supportive care more generally, will come out of the pandemic stronger and more resilient than ever.

COVID-19 impact on home and community-based palliative care

Early pandemic planning and response efforts to reduce and contain transmission of the virus during the first wave prioritized making room in hospital for COVID-19 patients. Patients were discharged from hospital whenever possible, and non-essential medical services and procedures were cancelled or postponed. In some cases, medical and supportive equipment was reassigned from home and community-based care settings to hospital settings. All of this placed further strain on home and community-based palliative care resources.

To exacerbate matters, organizations that provide community support services to people with palliative care needs and their caregivers were closed or changed the way their services were provided. Visiting and travel restrictions kept many people living with life-limiting illness apart from families and caregivers, and separated from much needed palliative care supports, leaving them with a sense of isolation and desperation.

The purpose of this report is to understand how COVID-19 and the response to the pandemic have affected palliative care delivered in the home and the community, and to inform pandemic planning in the future. Recognizing that in the time of a pandemic, it is important to plan palliative care delivery for individuals with progressive, life-limiting conditions, as well as for patients who become rapidly and terminally ill as a result of COVID-19, this report intends to do this by:

1. identifying gaps to access home and community palliative care;
2. identifying helpful ways to address these gaps, including promising practices and innovative solutions developed in response to the new and existing challenges of COVID-19;
3. sharing the findings with the palliative care and home care providers and communities across Canada, including a toolbox containing samples and examples of tools and resources to support the adoption of these promising practices.

The findings from this work are intended to provide real-time feedback on gaps and actual workarounds for knowledge dissemination, rather than produce definitive conclusions.

Approach and Method

Health Canada in partnership with Healthcare Excellence Canada, the Canadian Partnership Against Cancer and the Canadian Home Care Association, hosted a series of group interview calls with key informants between September 1 and October 1, 2020 to discuss the lessons learned on the impact of COVID-19 on home and community palliative care. The key informants included palliative care stakeholders from across Canada and represented a variety of different perspectives. These interviews, along with a number of written submissions from stakeholders who were not able to attend, form the basis of this report. Because this document is a compilation of many key informant interviewees, it reflects a diversity of perspectives and terminology common to where they work (i.e., jurisdiction or organization).

We sincerely thank all those who participated in our key informant discussions for their time and expertise, and for generously sharing their tools, which we have included in the Toolbox.

We would also like to extend our appreciation to Pallium Canada and Canadian Virtual Hospice for supporting this project.

Who can use this guide?

Many individuals, groups and organizations are interested in ensuring Canadians have comfort and quality care at end of life, reducing stress of caregivers and family members, and supporting well-being of healthcare providers. Those with an interest in improving access to, and quality of, palliative care in home and community settings who may find this report of value include:



Guiding Framework

The key findings of the stakeholder engagement are presented using an adapted version of the palliative care pandemic plan framework outlined in the April 2020¹ CMAJ article, *Pandemic palliative care: beyond ventilators and saving lives* by Arya, Buchman, Gagnon and Downar, which is comprised of eight components: stuff, staff, space, system, sedation, separation, communication, and equity.

The revised framework provides a practical and multi-pronged approach to guide pandemic preparedness in order to optimize the delivery of palliative care in home and community settings. To meet our objective to share lessons learned from the initial wave of the pandemic, the definitions of the eight categories have been broadened to be inclusive of identified gaps, leading practices and innovations:



Stuff refers to the medications and the means to administer them, equipment, supplies and personal protective equipment (PPE) for all palliative care providers in all home and community care settings.



Staff refers to identifying and mobilizing all healthcare providers with palliative care experience; managing and supporting healthcare providers, caregivers, allied health professionals and spiritual counsellors through education and training on palliative care skills, including symptom management, virtual care, psychological as well as grief and bereavement supports.



Space includes optimizing the use of beds in hospice and palliative care units, provision of care in home and community settings, and avoiding unnecessary transfers between care settings.



Systems involves adopting a triage system to allocate clinicians who could provide both specialist and primary palliative care, forming palliative care provider “groups” including social workers, emergency responders, etc. that can provide mutual support and coverage, maximizing the use of telemedicine, virtual platforms, and the systems that govern how human resources are employed (employees vs. self-employed contractors, full or part-time).



Sedation refers to the use of palliative sedation for persistent symptoms.



Separation addresses patient isolation by connecting patients with family members, caregivers and clinicians, and the provision of grief and bereavement supports and resources to patients, families, caregivers and healthcare providers.



Equity considers the unique palliative care needs of underserved and marginalized groups and addressing systemic inequity in the healthcare system.



Communication refers to the discussion and understanding of patient wishes, expectations and values via advance care planning and articulation of goals of care, as well as communication between healthcare providers and patients, and the sharing of information such as availability of resources

While COVID-19’s devastating consequences have been felt across the country, certain groups and cultures in Canada are suffering from disproportionate numbers of illness, deaths and negative consequences from the disease and from a lack of access to appropriate supportive care. These populations include people with underlying health conditions, older and frail seniors, women, socio-economically underprivileged, healthcare workers, First Nations, Inuit and Métis peoples, people of colour, people living in crowded conditions, vulnerably housed or homeless, and others impacted by social determinants of health. This report aims to take an equity lens as it looks to provide insight into the gaps, the restrictions and practices that were put in place to fight this deadly virus, and promising practices and innovations developed to improve access to palliative and supportive care.

How do I find what I'm looking for?

Under each of the eight components of Home and Community Palliative Care planning mentioned above, you will find two segments:

1. Barriers

includes problems and issues that impacted the delivery of home and community palliative care and that arose or were highlighted by the pandemic.

2. Responses/Tools

offers some practical ways that have proven successful in working around the difficulties; as well as, where possible, links and references to actual tools developed and shared by informants, as well as resources that were suggested. This segment also refers the reader to a Toolbox, which is a separate document in which we have assembled a number of tools and resources identified during the discussions.

The Toolbox



Health Canada, Healthcare Excellence Canada, the Canadian Partnership Against Cancer and the Canadian Home Care Association have also developed a complementary *Toolbox*, with the support of Pallium Canada and the Canadian Virtual Hospice. The *Toolbox* contains practical tools and resources to help action-minded individuals, care providers and administrators learn from colleagues who have found and shared innovative ways to get around COVID barriers. These tools are superb examples from across Canada of work plans, time lines, checklists, potential teaching tools and guidelines to help implement and assess progress in providing home and community palliative care in a safe and equitable manner. As healthcare systems across the country are unique and vary from province to province and even from region to region within each jurisdiction, these tools may serve as a foundation to work from, and are adaptable to support palliative care in each area.

Throughout the text, you will see references to the Toolbox. Each tool in the Toolbox has been numbered for easy identification.

What we heard: lessons learned in home and community palliative care



The views and opinions expressed here are those of the focus group participants focusing on the impacts of COVID-19 on home and community palliative care, including barriers to care, and actual or promising responses and innovations to respond to these barriers. The findings from this work are intended to provide feedback for knowledge dissemination, rather than produce definitive conclusions.

Stuff

The medications and the means to administer them, equipment, supplies and personal protective equipment (PPE) for all palliative care providers in all home and community care settings.



Barrier: Medication Shortages

Timely access to appropriate medications used in palliative and end-of-life care is imperative in order to alleviate distressing symptoms, promote comfort and mitigate undue suffering. Many of the home and community-based palliative care providers we spoke to reported that medication shortages during the pandemic presented significant challenges to adequate pain and symptom management. The stockpiling of medications in the acute care sector, given that many medications used in the treatment of COVID are also frequently used in palliative care, reportedly exacerbated shortages. Some community practitioners spoke of difficulties in tracking which pharmacies were short of which medications on any given day. Some expressed frustration with select safety policies and protocols that restrict the ability to re-direct unused medications, characterizing this as contributing to major wastage during a period of acute drug shortages.

INNOVATIVE RESPONSES/TOOLS



Develop and/or increase utilization of specialized “palliative symptom management kits” that are either kept with a community healthcare provider, or at the patient’s home, which include medications to alleviate pain, dyspnea, nausea, delirium, excess respiratory secretions, and distress. For delivery of the medications, the kits may include subcutaneous cannulae and other relevant infusion mechanisms, e.g., pumps and syringe-drivers, as required.



Practitioners and pharmacies work together to ensure appropriate and timely access to symptom management kits in-home by the visiting physician/ nurse practitioner (NP), home care nurse or paramedic to help support those dying at home and avoid an emergency hospital admission.

- Palliative home-care drug programs enable patients to remain at home for as long as possible **Nova Scotia Health and Wellness Pharmacare Palliative Care Drug Program. [Toolbox - Tool #1](#)**



Adapt the contents and distribution processes of symptom management kits to meet the needs of the populations served and better fit the context in which care is provided

- Health PEI – Prince Edward Island’s Terminal Care Drug COVID-19 Kit. **[Toolbox - Tool #2](#)**
- Health PEI – COVID Last Days of Living Order Set. **[Toolbox - Tool #3](#)**
- **Cancer Care Ontario – Palliative Care Symptom Management Pocket Guide. [Toolbox - Tool #4](#)**

-  Flexibility in content of the kit is required. Kits should be tailored to an individual patient and include the option of a separate prescription to modify the composition of symptom management kits, which also allows for timely adjustment to respond to shortages of specific medications
 - BC Interior Health – **Community “Just in Case” symptom management toolkit.** [Toolbox – Tool #5](#)
-  Allow pharmacists to do auto-substitutions and reduce amounts dispensed to respond quickly to address impending drug shortages. A large-scale strategy deployed in some provinces whereby all prescriptions were filled for a maximum 30 days as opposed to the regular 90 days, regardless of whether or not the medication was in short supply.
-  Enhance processes for communicating medication shortages. Teams across Canada established formal communication mechanisms with their pharmacy partners in order to pro-actively address impending shortages for specific medications
 - **BC Provincial Current Drug Shortages List.** [Toolbox – Tool #6](#)
 - **Pallium Canada – Managing Potential Palliative Care Medication Shortages During the COVID-19 Pandemic.** [Toolbox – Tool #7](#)
 - Pallium Canada – Shortage of Palliative Medications during COVID: Options Webinar – **Video or Text.** [Toolbox – Tool #8.](#)
-  Explore policy guidance that would allow for the re-direction/ recycling of unused palliative medications. In the United Kingdom, the NHS has been working with government to change the legislation to allow unused medications to be re-directed.
-  Provide training related to evaluating respiratory distress to entire care teams, including physicians, pharmacists, and nurses, working with COVID-19 patients. Medication Guides for COVID-19 corresponding to the Respiratory Distress Observation Scale for Patients Unable to Self-report Dyspnea, for various settings.
 - **McMaster Protocol: Hospital Management of Dyspnea for Patients with COVID-19.** [Toolbox – Tool #9](#)
 - **Ontario Palliative Care Network – Symptom Management for Adult Patients with COVID-19.** [Toolbox – Tool #10](#)
 - **Les soins palliatif adaptés au contexte de la pandémie (Slides).** [Toolbox – Tool #11](#)
 - **Les soins palliatif adaptés au contexte de la pandémie).** [Toolbox – Tool #12](#)

Barrier: Medical Supplies and Equipment Issues

As care shifted to home and community settings, there was a concurrent increase in the demand for medical supplies and equipment. Interviewees reported that the pandemic amplified pre-existing barriers related to the availability and delivery of equipment in the home, and this was felt most acutely in rural areas. Timely access to supplies and equipment were compounded by: a) lack of staff to assemble order sets and equipment packages, b) additional time required for cleaning and reprocessing of equipment to ensure compliance with infection prevention and control (IPAC) standards, and c) a lack of available delivery drivers. As such, family members were often called upon to address these gaps by picking up equipment that was urgently needed, burdening already stressed caregivers. Front-line practitioners also spoke of shortages of key equipment in the community, such as hospital beds, medication infusion pumps and infusion supplies (e.g., tubing).

INNOVATIVE RESPONSES/TOOLS



Practitioners described the need to be resourceful in how care was delivered: To address infusion pump shortages, change medication delivery mechanisms away from intravenous infusion to subcutaneous infusion. This could free up nursing resources and reduce medication wastage.



Implement alternate medication strategies that are not dependent on continuous infusion.

Barrier: Personal Protective Equipment (PPE) Availability

Home and community-based practitioners reported issues related to access to mask-fit testing and rapidly changing protocols for PPE use, particularly earlier in the pandemic. The front-line providers we spoke to reported frustration when mask fit-testing centres were shut down and hospitals limited entry to home and community care providers for mask fit-testing, which they described as putting community providers at unnecessary risk. Limited and inconsistent access to PPE in community-based home care settings was reported as a significant issue as hospital access to PPE was prioritized over the home and community care sector.

Rationing of PPE supplies across all parts of the health system presented additional concerns. Interviewees reported that a lack of coordination across the system exacerbated problems and led to further inequities, particularly given that some home and community-based providers did not have sufficient experience in procuring PPE, or possess adequate knowledge of IPAC practices and safe use of PPE. Community physicians reported having limited access to PPE and had to draw on hospital resources through existing relationships or procure PPE privately at much greater cost. In jurisdictions where PPE supplies were linked to individual patients, nurses and personal support workers (PSWs) reported feeling poorly protected as they were moving between patients' homes in which there were no PPE supplies. Family and caregiver access to PPE received inadequate attention and remains an issue in many jurisdictions.

INNOVATIVE RESPONSES/TOOLS



Participants stressed the importance of a coordinated, cross-sectoral and regional approach to distribution of PPE and IPAC education. Home and community care organizations could work closely with health system partners to ensure equitable and timely access to PPE. PPE kits must be readily available to all home and community care workers, including allied health staff, volunteers, and spiritual care workers.

- Processes should be in place to determine who needs PPE
- All providers should receive guidance on how to access and replenish PPE supplies
- Clear accountabilities must be established for the supply chain
- Facilitate access to PPE to patients and caregivers as appropriate.



Provide education and training on IPAC protocols and PPE usage for all staff on an ongoing basis. Practices should be consistent across settings

- **Pallium Canada – PPE in the Home Webinar** [Toolbox – Tool #13](#)



Provide patients and caregivers with basic education about IPAC practices and PPE usage in order to reduce levels of anxiety about fear of spread and foster supportive therapeutic interactions.



Local governments can work with community organizations to ensure that vulnerable populations, e.g., persons with palliative care needs living in rooming houses or shelters, receive PPE and education.

Staff

Identifying and mobilizing all healthcare providers with palliative care experience; managing and supporting healthcare providers, caregivers, allied health professionals and spiritual counsellors through education and training on palliative care skills, including symptom management, virtual care, psychological as well as grief and bereavement supports.



Barrier: Staffing Challenges

Family caregivers and palliative care practitioners reported significant staffing shortages throughout the pandemic. Shortages occurred due to a number of reasons including restrictions placed on staff to limit the spread of the virus by ensuring they were not working across multiple sites, e.g., in patient's homes, Long Term Care Homes, and in clinics. The restrictions resulted in a significant shortage of non-regulated staff (e.g. PSWs) and home care nurses but also extended to specialist palliative care practitioners (physicians and NPs) who work across settings in consultation roles. Palliative care practitioners acknowledged that staffing shortages impacted the ability to provide consistent high-quality palliative care. Family caregivers reported lack of staff added to the significant strain they were experiencing in caring for their loved one at home.

Sickness, burnout, and pay inequity across health care sectors further contributed to staffing shortages. Participants reported the pandemic has drawn attention to issues around the precarious working conditions for PSWs and community-care nurses and call for pay equity and improved job conditions for these provider groups. Given that many nurses and PSWs are female, role strain was identified as a consideration in staffing where women were also fulfilling caregiving roles at home, particularly those with school-age children who were home-schooled during the pandemic, further highlighting the disproportionate impact of COVID-19 on women.

Some regions reported difficulty in coping with the sudden increase in home and community-based palliative care referrals, and had to rely more heavily on other services to meet patient needs. Additionally, many home and community-based healthcare providers are generalists; hence, there was an exponential need for palliative care education and training across various healthcare professional groups. Conversely, palliative care specialists in other jurisdictions described being underutilized, which they attributed to a lack of understanding of their role, and complex compensation models which inhibited timely re-deployment to other settings where they felt they could have provided much needed support.

INNOVATIVE RESPONSES/TOOLS

Respondents addressed staffing shortages through several mechanisms including interdisciplinary care, expansion of scope of practice, and pivoting to virtual care.



Maintain records of healthcare workers who have received palliative care training to enable employers to quickly identify and mobilize staff quickly to provide essential home-based palliative and end-of-life care.

 Equip all healthcare providers with generalist palliative care competencies, and where possible, adapt existing training modules to on-line training. Pallium Canada adapted a suite of their curriculum to online and waived fees for six months to support rapid capacity building. They saw significant uptake with approximately 11,000 registrants completing the courses.

- **Pallium Canada – Learning Essential Approaches to Palliative Care (LEAP) courses.** **Toolbox – Tool #14**
- **Pallium Canada – LEAP Paramedic.** **Toolbox – Tool #15**
- **Pallium Canada – LEAP Long-Term Care.** **Toolbox – Tool #16**
- **Pallium Canada – Palliative Approaches to Care in Long-Term Care during COVID-19.** **Toolbox – Tool #17**
- **Pallium Canada, with the Canadian Medical Association.** **Toolbox – Tool #18**
- **Pallium Canada – COVID-19 Response Impact Report.** **Toolbox – Tool #19**

 Refine and develop local training and resources, and further improve distribution and delivery mechanisms to ensure staff have adequate access to palliative care training.

 Develop tools and other resources to provide education and information about caring for palliative care patients with COVID symptoms in the home as well as how to address palliative needs in the home during a pandemic

- **Pallium Canada – Palliative Care in the Home: Lessons from COVID.** **Toolbox – Tool #20**
- **COVID-19: Guidance for the Extra-Mural Program.** **Toolbox – Tool #21**

 Create healthy, equitable workplaces, for example, by coordinating pay and benefits to ensure fair compensations for all frontline workers.

- Temporary pandemic pay was provided in some regions. The program aimed to provide additional support and relief to frontline workers, encourage staff to continue working and attract prospective employees and help maintain safe staffing levels and the operation of critical frontline services.
- One province was able to mobilize quickly at the beginning of the pandemic to centralize the allocation of long-term care staff, so that staffing was sufficient to meet patient care needs. Furthermore, the province ensured that workers worked at only one facility, to prevent the spread of COVID-19, compensated care home workers as full-time workers, with living wages, and increase job protections²

 Increasing numbers of patients with palliative care needs, in conjunction with staffing shortages, resulted in community-based teams identifying innovative ways to respond to these issues by leveraging interdisciplinary care and optimizing scopes of practice, e.g., maximizing and extending the role of community paramedics for rapid symptom management.

 Increased deployment of nurse practitioners for more complex palliative symptom management

- **The Canadian Home Care Association: High Impact Practices.** **Toolbox – Tool #22**

-  Change medication delivery mechanisms away from intravenous infusion to subcutaneous infusion. This frees up nursing resources and reduces medication wastage in community settings and reduces the burden on family caregivers in the home (IVs require monitoring every few hours vs subcutaneous medication infusion which can run for 48 hours).
-  Consider alternative ways of conducting diagnostic testing in order to accommodate patients' and family caregivers' wishes to stay out of hospital and ambulatory settings.
 - Offering mobile COVID-19 testing, bloodwork and in some jurisdictions extending services to point of care ultrasounds at the patient beside, thereby avoiding visits to clinic or hospital which may put patients further at risk.
-  Expand the role of spiritual care teams to address acute psychosocial needs.
-  Support opportunities for interdisciplinary care and optimizing scopes of practice.
 - **BC Centre for Palliative Care: Inter-professional palliative symptom management guidelines.** **Toolbox – Tool #23**
 - **Prince Edward Island Paramedics Program.** **Toolbox – Tool #24**
 - **New Brunswick Extra-Mural Palliative Care Project's Interdisciplinary Approach.** **Toolbox – Tool #25**
-  Where implemented, Whole Community Palliative Rounds (WCPR) were optimized as a means of supporting rapid clinical problem solving for patients with acute and complex palliative care needs by leveraging an interdisciplinary approach to shared decision-making and care planning. WCPR are an innovative, inclusive approach to supporting shared clinical problem-solving, decision-making and communication within an expanded interprofessional care team. Participants are involved in active discussions and bring their relevant experience, knowledge and expertise to inform decisions about care planning and resource alignment to improve the quality of care and respond to identified patient needs.
 - Canadian Home Care Association: High Impact Practice **Whole Community Palliative Care Rounds (WCPR).** **Toolbox – Tool #26**

Barrier: Lack of support for staff in the field

Increased work volumes, staff shortages, and the stresses of caring for increasingly sick patients with more complex palliative care needs during a pandemic were described by many practitioners as contributing to staff distress and burnout. Palliative homecare nurses reported working over capacity and described the acute moral distress they experienced when they were not able meet burgeoning demands for care, feeling that they had somehow failed their patients and families. A lack of in-person connection prompted teams to establish alternate means of supporting each other in the field. Respondents were adamant that there is growing demand for innovative approaches to address the resultant mental health needs and the emotional toll precipitated by the impacts of the pandemic.

INNOVATIVE RESPONSES/TOOLS



Optimize and encourage the use of Employee Assistance Programs.



Create informal debriefing mechanisms with colleagues, e.g., the creation of grief support groups and grief circles for frontline providers. The Palliative Education and Care for the Homeless (PEACH) program held Grief Circles as a response to the grief they were seeing among inner city workers providing care for people experiencing homelessness. They developed a process based off a reference from spiritual care literature called the “4Rs”: remember, reflect, recover and plan to reinvest. The Grief Circle facilitator walks through these four stages with each group through open-ended questions. These circles can help address burnout, moral distress, and provider grief.



Leverage spiritual support services, where available, to provide support and connection with staff.



Whole Community Palliative Rounds were also leveraged as a support for team members
- **Whole Community Palliative Care Rounds (WCPR)**. **Toolbox - Tool #26**



Strengthen organizational cultures to better support individuals who are dealing with grief or caregiving burden
- **The Compassionate Workplace Campaign**. **Toolbox - Tool #27**

For additional tools and resources on grief supports for healthcare providers please refer to Tools 39-41 and 48-51 in the Toolbox.



Space

Optimizing the use of beds in hospice and palliative care units, provision of care in home and community settings, and avoiding unnecessary transfers between care settings.



Barrier: Avoidance of Healthcare Facilities and Congregate Care Settings

During the pandemic, patients with life-limiting illness from across the country avoided healthcare facilities and care shifted predominantly to home settings. Fear of infection and potential isolation from family and friends also had an impact on hospice occupancy rates. For example, a survey administered by Alberta Palliative and End-of-Life Care reported a decrease of 20% in overall hospice occupancy from March to May 2020.³

As more people with complex care needs (including those nearing end of life), chose to remain and/or die at home, home-based palliative care programs demonstrated remarkable adaptability in responding to increased demand and the increased acuity of patients. We heard that business closures and financial assistance for those who were out of work allowed more family members to help care for loved ones. This provided the much needed support to already exhausted primary caregivers. We also heard optimism from participants, as this was evidence that with the proper supports, it is possible for more seriously ill patients to be well cared for at home and in the community, and to die at home as they choose.

Clinicians serving homeless and vulnerably housed populations reported that many of their clients with complex medical and palliative care needs were also avoiding shelter settings, making it increasingly difficult to provide consistent care.

Barrier: Transitions

Rapid discharges that occurred in the first wave of the pandemic highlighted the need for streamlined referral processes and better integration with home and community-based palliative care services, particularly for physically vulnerable populations (e.g., paediatric and frail elderly) and for those who are structurally vulnerableⁱ, (e.g., vulnerably housed) requiring multiple services to meet complex needs. In some jurisdictions, available resources were insufficient to meet the demand for services, which resulted in crisis management.

ⁱ Structural vulnerability refers to the intersecting social and structural forces (i.e. race, socioeconomic status, poverty, housing, etc.) that constrain decision-making, frame choices and limit options to make people vulnerable to risk and adverse outcomes.

INNOVATIVE RESPONSES/TOOLS



Community coalitions can identify temporary housing and shelter sites that are able to provide appropriate services, supplies and staffing.⁴ A number of urban regions used empty hotel space to provide temporary shelter and COVID isolation spaces for those who are homeless. For example, if families and individuals living in Ottawa shelters were unable to self-isolate given the shared bathroom and kitchen facilities, the City of Ottawa secured hotel rooms for families, women and youth staying in shelters, and a community centre was repurposed as an overflow facility for a men's shelter. These efforts were mobilized early and quickly. Practitioners advocated strongly for the extension of temporary COVID- housing beyond the pandemic.



Hospices may consider working with patients, caregivers, and community partners to refine essential visitor policies in order to mitigate fears related to separation and recognize the important role of hospice care for those not requiring highly specialized and complex hospital palliative care services or for situations in which a home death is not viable. One hospice developed visitation policies that included a patient education protocol. It respected the needs of patients and families while also respecting transmission regulations. The facility worked with families to ensure that no patient died alone and reported no cases of the virus during the first wave. It was felt that strong visitor education provided by health facilities and healthcare workers in the home was key to successfully prevent virus transmission.

- **COVID-19 Visitation Policies Support.** [Toolbox - Tool #28](#)



Several respondents proposed that financial and social supports for family caregivers be improved and eligibility expanded to allow more friends and family members of people with life-limiting illness to provide care. This would allow more people living with life-limiting illness to remain at home longer and respect their wishes to die at home if possible.



Participants suggested that caregiver benefits extend beyond the death of the loved one to include the grieving process, and that these changes carry on after the pandemic.



Screen and test patients for COVID-19 before transitioning into hospice or acute care settings.



Build palliative care capacity in all communities and settings through strengthening and supporting the Compassionate Communities model

- **BC Centre for Palliative Care - Compassionate Communities Toolkit**

[Toolbox - Tool #29](#)

- **Pallium Canada - Compassionate Communities Toolkit.** [Toolbox - Tool #30](#)

- **Pallium Canada - Compassionate Workplace Campaign.** [Toolbox - Tool #31](#)

Systems

Adopting a triage system to allocate clinicians who could provide both specialist and primary palliative care, forming palliative care provider “groups” including social workers, emergency responders, etc. that can provide mutual support and coverage, maximizing the use of telemedicine, virtual platforms, and the systems that govern how human resources are employed (employees vs. self-employed contractors, full or part-time).



Barrier: Limitations of Virtual Approaches to Palliative Care

Interviewees reported that the pandemic amplified existing health system inequities, highlighted the impacts of chronic funding shortfalls, and increased fragmentation of home and community-based palliative care services. Front-line practitioners spoke to increased surge in patient volumes due to hospital avoidance and discharges from institutional healthcare settings. Home care services were further responsible for ambulatory care patients as hospitals focused on acute care services only in an effort to keep as many people as possible out of the hospital.

In many cases, providers explored the use of virtual approaches to provide palliative care services. In spite of the successes of virtual care initiatives, respondents spoke of the challenge of positioning virtual care as the solution to palliative care delivery, particularly in rural and remote communities where issues of connectivity and training precluded widespread use. Many patients and caregivers required assistance with technologies. Additional strategies were implemented to support patients and families who faced cultural and linguistic barriers. Practitioners also reported that virtual visits were sometimes inadequate to foster therapeutic relationships considered integral to the delivery of palliative care. As reported by one of the patient respondents, technology may inhibit interactions and limit non-verbal cues to assessing illness severity; she described being so acutely sick by the time she received an in-person visit, she ended up in the hospital for three weeks. However, there was general acknowledgment of the convenience offered by virtual visits. From a provider perspective, fee-for-service compensation models did not historically cover virtual care provision but since the outbreak of the pandemic, there have been workarounds leading to the creation of new policy and billing codes in some jurisdictions. These were positively regarded.

In contrast to this, we also heard that having access to a reliable secure virtual platform was a big improvement over in-person visits when it came to the initial assessment visit by the clinician. We heard from one physician that virtual care allowed for far more initial home assessment visits in a single day, for medications to be ordered during the visit and delivered to the patient’s home within a couple of hours, which was much faster than the 24- to 48-hour delay with in-person initial visits and resulted in better client satisfaction.

INNOVATIVE RESPONSES/TOOLS

-  In spite of the challenges posed by the pandemic, there was considerable appreciation for the crucial role played by home and community-based services in the provision of high-quality palliative care, particularly given the sector's demonstrated ability to care for patients with increasingly complex needs. The health system was dependent on the ability of these services to be able to respond quickly to the pandemic crisis. Regional Incident Management System structures also recognized the need for inclusion of specialized palliative care representatives in ensuring a coordinated response to the pandemic.
-  Develop broad principles around pandemic preparedness plans in palliative care that are tailored based on the region.
-  Strengthen cross-sectoral integration, e.g., home care, community palliative care organizations, hospices, and EMS
 - **Canadian Home Care Association – Guidelines for Implementing Innovation Practices in Home-Based Palliative Care. [Toolbox – Tool #32](#)**
-  Provide virtual palliative care as a means of optimizing efficiency, reducing transmission of the virus, and providing an opportunity to utilize staff who were required to self-isolate or quarantine.
 - **Pallium Canada – Télémédecine en soins palliatifs en temps de pandémie). [Toolbox – Tool #32](#)**
-  In response to the COVID-19 pandemic, provincial and territorial governments and medical associations moved rapidly to adapt physician-billing codes to meet the emerging needs of physicians and their patients during the pandemic, especially for virtual care services. Videoconferencing was widely adopted with practitioners utilizing various technology platforms according to availability and regional policy.
-  The *IIT Reacts* platform is an integrated solution with tools that allow multi-stream videoconferencing, file sharing, etc. that allowed for more visits with patients in their homes, faster access to prescriptions and improved patient and family satisfaction
 - **Reacts: (Remote Education, Augmented Communication. [Toolbox – Tool #34](#)**
-  Traditional phone calls were another failsafe mechanism to connect with patients and caregivers and were reportedly more accessible to seniors less familiar with new technologies.
-  William Osler Health System Relief App enables palliative designated patients to self-report their symptoms remotely. The goal is to accurately assess patients in their home, to provide timely intervention and appropriate treatment.
 - **William Osler Health System and uCarenet – Relief App. [Toolbox – Tool #35](#)**
-  One region reported using the ESAS-r platform (Patient Symptom Assessment) – a patient-reported on-line assessment of their symptoms which allowed for improved triage and symptom management. Use of ESAS and Palliative Performance Scale (PPS) was recognized as imperative in triaging patients for visits and avoiding crisis
 - **Health PEI – Symptom self-assessment tool. [Toolbox – Tool #36](#)**

Sedation

The use of palliative sedation for persistent symptoms



Barrier: Uncontrollable Symptoms and Reluctance to Enter Healthcare Facilities

The increased provision of palliative sedation in the community was reported as being linked to patients' and caregivers' reluctance to enter hospice or palliative care facilities, even in situations where symptoms could not be effectively controlled in the community. For some patients, where symptoms were not alleviated by available medications and interventions, patients opted for palliative sedation in order to relieve distress and suffering, and enhance their comfort at the end-of-life. This subsequently led to improved protocols around palliative sedation in the community.

INNOVATIVE RESPONSES/TOOLS



Provide additional practical and emotional support to patients receiving palliative sedation in the home and community.



Provide education and training for staff and family caregivers to provide palliative sedation in home and community settings. Many regions provided enhanced education and training, and protocols for palliative sedation were improved, including focused attention to ethical considerations

- **BC Interior health palliative sedation toolkit.** [Toolbox - Tool #37](#)

Separation

Addresses patient isolation by connecting patients with family members, caregivers and clinicians, and the provision of grief and bereavement supports and resources to patients, families, caregivers and healthcare providers.



Barrier: Issues of Separation and Caregiver Stress

Isolation and visitor restrictions in institutional settings further shifted care to home settings as patients faced the prospect of dying alone. Moving care to the home facilitated the wishes of many patients who wished to die in familiar surroundings with loved ones close by. In tandem, practitioners reported that work-from-home directives potentially increased the availability of caregivers to support care.

However, this shift had a profound impact on the expectations placed on caregivers in the home, particularly given the scarcity of in-home palliative care services. Moreover, many patients and caregivers were fearful of staff coming into the home and the potential for COVID-19 transmission. Travel restrictions and social distancing measures further limited the support of friends and volunteers to provide much needed respite.

Overall, participants (healthcare providers and family members) reported an over-reliance on caregivers to fill gaps. Frontline practitioners reported seeing a considerable increase in caregiver burnout and compassion fatigue. With the stresses of the pandemic, and caring for loved ones with complex symptom management needs, or requiring end-of-life care, it was evident that the families were fatigued and burnt out. Staff were worried about the impact on caregiver mental health. These concerns were reflected in the Canadian Cancer Society's Patient and Caregiver Survey (July 2020) in which approximately 80% of caregivers surveyed reported increases in anxiety.

INNOVATIVE RESPONSES/TOOLS

-  Leverage frontline practitioners and caregiver support groups to provide education and training to caregivers with a focus on the practical aspects of care, e.g., responding to symptoms, promoting comfort, basic medication management, providing care at end-of-life, etc.
-  Maximize existing psychosocial and spiritual care resources to better support families.
 - **Ontario Palliative Care Network. Mental Wellness and COVID-19.** [Toolbox - Tool #38](#)
 - **Mental Health Commission of Canada - Caregiver Resources.** [Toolbox - Tool #39](#)
 - **Ontario Caregiver Coalition Resources.** [Toolbox - Tool #40](#)
 - **National Initiative for the Care of the Elderly.** [Toolbox - Tool #41](#)
-  Provide family caregivers with the adequate social and financial supports to allow people to be cared for at home.
 - COVID restrictions and income benefits (e.g. Compassionate Care Benefits) allowed many people to have their caregiving needs met and to be cared for and die at home.⁵

 Recognize the value of caregivers as essential care partners. Establish or update policies and procedures for managing, screening, educating, and training visitors in all care settings

- **Canadian Foundation for Healthcare Improvement Webinar Series: Patient Partnership in a Time of COVID-19**. **Toolbox – Tool #42**

Barrier: Grief and Bereavement Needs

Respondents reported concerns related to disruption in normal grief and bereavement processes during the pandemic, referencing an impending “grief tsunami,” with impacts felt long after. As more patients chose to be cared for at home rather than in hospital or hospice due to the pandemic, their families may not have had access to the resident psychosocial spiritual counsellor. We heard that often, families do not realize that they could benefit from speaking with a counsellor. For example, we heard “Clients have trouble self-identifying their need for this mode of care. On a recent visit with a family (fourth session), one family member said, ‘we didn’t know how much we needed to talk with you until we talked with you!’”

Isolation and the disruption or absence of end-of-life rituals, in conjunction with reduced access to grief and bereavement supports, were described as potential contributing factors to complicated grief and related physical illnesses. Patients and families were not able to access traditional end-of-life rituals that are sacred to their world-view and culture. Access to these rituals was identified by respondents as a priority. The absence of these rituals does harm to identity, healthy bereavement, family coping, and adjustment to loss. Respondents also acknowledged the need for greater grief supports for healthcare professionals.

INNOVATIVE RESPONSES/TOOLS

 Leverage the expertise of spiritual care staff and social workers to provide supportive counselling to address existential suffering, grief, spiritual distress, and emotional health for patients, families and staff

- **Canadian Association of Social Workers (CASW) – Grief in the time of COVID**. **Toolbox – Tool #43**

 Where available, spiritual care teams provided one-on-one support to staff who were personally struggling during the pandemic.

 Develop training and tools related to providing grief and bereavement support for patients, families, and staff

- **Pallium Canada – The Psychological Impact of COVID on Health Care Professionals Webinar**. **Toolbox – Tool #44**
- **Pallium Canada – Role of Grief and Bereavement in the Care of Health Care Providers and their Families Webinar during COVID-19**. **Toolbox – Tool #45**
- **Ontario Palliative Care Network – Managing Bereavement around the Coronavirus (COVID-19)**. **Toolbox – Tool #46**
- **Canadian Hospice Palliative Care Association (CHPCA) – Grief and Bereavement Resource Repository**. **Toolbox – Tool #47**
- **Centre for Loss and Life Transition**. **Toolbox – Tool #48**

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 A respondent described the integration of Comfort Care Rounds into a suite of new resources. Comfort Care Rounds involve all members of the care team getting together to discuss and reflect on deceased residents and/or those who are transitioning to or receiving palliative care. Comfort Care Rounds provide the opportunity to review, reflect and debrief on resident deaths, engage in case-based discussion and planning, and provide supplementary palliative care education and resources.⁶
- 
 Implement strategies to provide virtual grief support. Canadian Cancer Society ensured continuous operation of support services including CancerConnection online discussion groups and the Cancer Information Service phone line to allow people with cancer to talk to other people about their experiences
 - **Canadian Cancer Society – “CancerConnection” and Cancer Information System (CIS) Phone lines.** [Toolbox – Tool #49](#)
- 
 Provincial Caregivers Organizations offer a range of supports for unpaid caregivers
 - **Tool 50: Provincial caregiving organizations that provide virtual grief support.** [Toolbox – Tool #50](#)
- 
 Canadian Virtual Hospice (CVH)’s *MyGrief* platform usage increased by 68% in April to May 2020 compared with February to March 2020, with a concurrent uptick in general usage of CVH resources
 - **CVH MyGrief.** [Toolbox – Tool #51](#)
 - **CVH Repositories of Resources.** [Toolbox – Tool #52](#)
- 
 CVH launched a webinar series with a number of grief experts, such as one entitled Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty
 - **CVH Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty – Webinar Series.** [Toolbox – Tool #53](#)
 - **CVH Palliative practice and COVID-19: Life and work in the time of COVID-19 – Webinar series.** [Toolbox – Tool #54](#)
 - **CVH Complicated grief following a death in the ICU: New challenges in the COVID-19 era – Webinar.** [Toolbox – Tool #55](#)
 - **The Children and Youth Grief Network.** [Toolbox – Tool #56](#)
 - **KidsGrief.ca.** [Toolbox – Tool #57](#)
 - **Lighthouse – Grief Support for Children and Teens.** [Toolbox – Tool #58](#)
- 
 Facilitate the opportunity to participate in end-of-life ceremonies and rituals in compliance with IPAC standards. The Palliative Outreach Response Team (PORT) has held memorial services for their clients, in which staff and chosen family could come together to grieve (delivered via Zoom).

Equity

Considers the unique palliative care needs of underserved and marginalized groups and addressing systemic inequity in the healthcare system providers.



Barrier: Structural Vulnerability

Inequities in access to high quality palliative care became even more evident during the pandemic. Participants serving structurally vulnerable populations; groups living in poverty, homeless or vulnerably-housed, racialized, experiencing stigma because of mental illness of substance use, spoke of the exacerbation of long-standing challenges in providing care and finding resources for clients who were further isolated by COVID. Structural vulnerability refers to the intersecting social and structural forces, such as race, socioeconomic status, poverty, and housing, that constrain decision-making, frame choices and limit options to make people vulnerable to risk and adverse outcomes. People impacted by social and structural inequities are known to be at greater risk for poor health outcomes, inadequate access to healthcare services, and early or premature death.ⁱⁱ

Providers working with newcomers and immigrant populations described how the pandemic magnified pre-existing issues to accessing care and stressed that the widespread adoption of virtual care had the unintended consequence of widening the chasm where communication and language barriers were involved. Palliative care practitioners working with homeless and vulnerably housed populations described how the pandemic further amplified inequities and stressed that “palliative care happens everywhere, whether it is a room, a shelter, or the street” and thus agencies need to be flexible in care provision. Volunteer services providing care to vulnerably housed clients were put on hold during the height of the pandemic and caseworkers noticed a significant decline in their clients’ mental health. Lack of access to PPE and fear of contracting COVID led to many clients choosing to leave the shelter system.

INNOVATIVE RESPONSES/TOOLS

-  Position health and system equity as integral components of pandemic planning and response efforts
 - **Chief Public Health Officer of Canada’s Report – From Risk to Resilience: An Equity Approach to COVID-19**. **Toolbox – Tool #59**
-  Provide equitable access to virtual care and virtual technologies
 - **Canadian Virtual Hospice – Living My Culture**. **Toolbox – Tool #60**
-  Inner City Health Associates (ICHA), a group of physicians working in shelters and drop-ins across Toronto, forged a partnership with Telus, a Canadian telecommunication company, to provide cell phones that enabled care providers to connect with vulnerable clients.

ii Stajduhar K, & Mollison A. **Too Little, Too Late: How we fail vulnerable Canadians as they die and what to do about it.**

-  Tech-literacy training sessions were developed and delivered in order to equip vulnerable clients with technology skills as an enabler to virtual care.
-  Integrate palliative care into all elements of health and social services – as stated by one interviewee: “it is everyone’s responsibility to do a little bit of palliative care.” Food and grocery delivery services were established to meet challenges related to food access.
-  Improve cross-sectoral integration, as there are many agencies / systems involved in the lives of street-involved people, (e.g. the care teams, home and community care, palliative supports and specialists).
 - **Inner City Health Associates’ Palliative Education and Care for the Homeless (PEACH) mobile palliative care team. [Toolbox – Tool #61](#)**
 - **Inner City Health Associates – PEACH Resource for Frontline Workers Caring for Clients Experiencing Homelessness in COVID-19. [Toolbox – Tool #62](#)**
 - **Equity in Palliative Approaches to Care (ePAC)’s Palliative Outreach Response Team (PORT) program. [Toolbox – Tool #63](#)**
 - **ePAC – Equity-Informed Advanced Care Planning [Toolbox – Tool #64](#)**
-  Ensure that virtual care options incorporate flexibility to switch to in-person care in recognition of barriers faced by patients/caregivers whose language is not English or French, and for patients and caregivers with cognitive impairment.
-  Recognize and support the role of patient navigators as integral in the delivery of home and community palliative care for structurally vulnerable populations. Inner City Health Associates (ICHA) launched effective campaigns and successfully engaged community partners, philanthropists and donors for funding, eventually receiving funds to create a Health Navigator role to serve those most vulnerable.

Barrier: Lack of Culturally Safe and Relevant Care for Indigenous Peoples

Indigenous representatives spoke about the persistent challenges of accessing culturally relevant and safe care during the pandemic, stating that separation from family and community due to restrictive visitor policies contributed to distress and heightened feelings of vulnerability, and were potentially re-traumatizing. Access to culturally safe care was impacted by jurisdictional policy, at times limiting on-site support and advocacy for Indigenous patients in healthcare institutions. Indigenous Patient Navigators, previously embedded in health services, were reportedly “locked out of hospitals” during the pandemic due to IPAC policies. Interviewees reported that lack of access to family and cultural supports and fear of racism or of institutions based on residential school trauma meant that some declined hospital care. In fact, we heard of one patient who, after being assaulted in the hospital, left the hospital and refused to return, which prevented their access to life-prolonging treatment and/or pain and symptom management support.

Transfer of care across jurisdictions was also described as problematic and is illustrated by the account of a patient receiving palliative care from a large Indigenous Community Health Centre whose final wish was to return to his family’s Indigenous territory to be with his family.

His wish required transfer of his care. Unfortunately, although he was transferred to another jurisdiction, none of the essential palliative services followed him and he was unable to access medication for his pain in his final days.

As many health and social services and resources moved away from in-person service delivery and turned to virtual means, many Indigenous people living in remote and rural locations were cut off, as they did not have access to high-speed internet.

INNOVATIVE RESPONSES/TOOLS



All policies, programs and tools designed to serve Indigenous peoples must be designed by or in consultation with those Indigenous peoples, to ensure culturally safe care. Respect the “Nothing about us without us” philosophy.



Indigenous clinicians should be involved in palliative care delivery, supporting Indigenous patients and incorporating traditional healing and culturally relevant care.



Provide cultural sensitivity and humility training to all healthcare staff. The Indigenous Teaching Through Art Program was created by McMaster University’s Department of Family Medicine in collaboration with local Indigenous colleagues to fill a knowledge gap about the history of Indigenous people in Canada. “The hope is that clinicians and staff equipped with this new knowledge and different ways of knowing would be able to provide culturally appropriate care by being aware of and addressing the root causes of inequity.”

- **McMaster University The Indigenous Teaching Through Art (ITTA) Program).**

Toolbox – Tool #65



Embed Indigenous Patient Navigators in health services as essential members of the healthcare team, with the flexibility to provide support both on and off reserve. Participants also noted that Indigenous Patient Navigator positions should be filled by Indigenous people.⁷

- **Cancer Care Ontario – Indigenous Navigator Role Statement).** **Toolbox – Tool #66**



Develop resources and guidance documents with local indigenous communities to ensure that they are culturally relevant and meaningful, and linguistically diverse. Documents should be translated into languages spoken by the Indigenous populations served by that authority, and phone options should be available alongside on-line resources.

- **Developing Palliative Care Programs in First Nations Communities Workbook).**

Toolbox – Tool #67

- **First Nation Health Authority (FNHA) – Staying connected during the pandemic).**

Toolbox – Tool #68



Cancer Care Ontario has an Indigenous cancer care unit that is developing a set of culturally appropriate end-of-life and palliative care tools and resources

- **Cancer Care Ontario Palliative Care Toolkits for Indigenous Peoples).**

Toolbox – Tool #69



Canadian Virtual Hospice's pre-ACP tool for Indigenous Peoples called *Coming Full Circle*. This resource was developed by Indigenous Peoples to ensure their values, beliefs and wishes for future care are heard and respected.

- **Canadian Virtual Hospice (CVH) – preACP tool for Indigenous Peoples – Coming Full Circle: Planning for your care (advance care planning).** **Toolbox – Tool #70**



Health Authorities and facilities should recognize Friendship Centres as innovative access points for Indigenous peoples. Parry Sound Friendship Centre collaborated with the local public health unit to facilitate direct conversations with the Associate Medical Officer. This ensured that the distinct needs of Indigenous peoples were addressed. Some Friendship Centres are working towards developing a tech lending library that will also facilitate access to virtual care.



Ensure equitable and timely access to COVID-19 testing. Anishnawbe Health Toronto, an Aboriginal community health centre in Toronto, was instrumental in conducting mobile testing for COVID-19.

Communication

The discussion and understanding of patient wishes, expectations and values via advance care planning and articulation of goals of care, as well as communication between healthcare providers and patients, and the sharing of information such as availability of resources.



Barrier: Challenges in Undertaking Advanced Care Planning and Identifying and Understanding Goals of Care

Participants reported that Advanced Care Planning (ACP) and Goals of Care (GOC) discussions appeared to be more prominent earlier in the pandemic, which they partially attributed to fear of dying from COVID-19 and decision-making related to life-saving interventions. Some participants felt that the pandemic actually served to highlight the importance of ACP, whereas others felt that they had lost ground on the prior work they had done on ACP with discussions now delayed until the last few days of life or at a point of crisis. Additionally, given that patients were discouraged from in-person visits with their primary care practitioner or palliative specialist, ACP and GOC conversations may have been further delayed as appointments were deferred. Some practitioners reflected that the switch to virtual care served as a barrier to building the interpersonal relationships that serve as a foundation for these discussions, while a few respondents referred to ACP as an iterative and ongoing process throughout the course of illness.

In situations where patients were receiving care in a healthcare facility, separation also had a profound impact on a caregiver's ability to serve as a substitute decision maker in situations where their loved ones were deemed incapable to make care-related decisions. As one caregiver described: "How do you expect me to make this decision when I haven't seen [my loved one] in a month?"

Respondents shared the importance of communicating GOC and ACP discussions with caregivers, family members and other care providers, and that these goals and decisions must remain flexible and responsive to changes in the patient's condition. It is equally important for healthcare providers to explain to patients and families that caring for a person at the end-of-life can be very difficult and exhausting, and that it is possible to transfer the patient to a community care hospice facility if the task becomes overwhelming. Some family members experienced anxiety and guilt about transferring patients to hospices, feeling they were betraying a trust knowing the patient expressed a desire to remain in the home, even though it became beyond the capacity of the family to cope with the level of care required.

Communication challenges in home and community-based care settings were also amplified during the pandemic, particularly where information needed to be communicated rapidly, e.g., as seen with changing protocols related to IPAC practices and PPE usage as more information became available about the virus.

INNOVATIVE RESPONSES/TOOLS



Develop and refine existing policies and protocols related to ACP and GOC discussions. ACP tools and resources were developed to address challenges around COVID-19 in the healthcare setting (e.g. The ACP resource Living Well, Planning Well).

- **Living Well, Planning Well. [Toolbox - Tool #71](#)**
- **CHPCA Speak Up Canada. [Toolbox - Tool #72](#)**
- **Pallium Canada: Advance Care Planning and Goals of Care Discussions: Getting us all on the same page. [Toolbox - Tool #73](#)**



Guidelines were developed across a number of jurisdictions for virtual ACP and GOC discussions in order to mitigate practitioners' discomfort in having these discussions.



ACP and GOC discussions should include the scenario where a home care patient may need to be transferred to a hospice or hospital. Patient consent allowing the clinician to help the family make this decision in the presence of caregivers is advised, as this will help to alleviate feelings of guilt in caregivers.



Provide COVID-19 communications (e.g. public health guidance) in multiple languages and formats to reach all Canadians.



Implement and maintain mechanisms for in-home and community COVID testing for both patients, caregivers, and staff. Protocols for communication and mechanisms for tracking positive results are urgently required, as they remain fragmented.

Conclusion: Looking Forward



COVID-19 has had a dramatic impact on communities throughout Canada and has fundamentally shifted the way in which we think of health care delivery. As the pandemic unfolded, the health system saw a rapid shift from hospital and institutional care to home and community-based care, particularly for those with palliative and end-of-life care needs. In spite of the difficulties posed by the pandemic, the home and community care sector rose to the challenge and witnessed a rapid growth in interdisciplinary and cross-sectoral collaboration as clinicians worked together to address the needs of patients and caregivers. Also evident was a remarkable flexibility and willingness to innovate and trial new modes of care delivery, especially in relation to virtual care and supports.

Many of the innovations highlighted in this report will extend well beyond the life of the pandemic and will shape the future of home and community-based palliative care. As the country moves through oncoming waves of this pandemic and looks towards the future, it will be important to continue to scan for new and innovative ways of delivering palliative home and community in order to improve the lives of Canadians in need of palliative care and at end of life, caregivers, and staff.



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APPENDIX A: METHODOLOGY

Approach and Method

Health Canada (HC) in partnership with Healthcare Excellence Canada (HEC), the Canadian Partnership Against Cancer (CPAC) and the Canadian Home Care Association (CHCA), hosted a series of group interview calls with key informants between September 1 and October 1, 2020 as part of a lessons learned exercise on the impact of COVID-19 on home and community palliative care. This report is primarily based on interviews with palliative care stakeholders across Canada representing a variety of different perspectives. Stakeholders were identified through established HC, HEC, CPAC, and CHCA networks and included: palliative care specialists, home care and community-based providers involved in palliative and end-of-life care (physicians, nurses, and allied health staff), pharmacists, healthcare educators, program administrators, spiritual care counsellors, and patient and caregiver representatives. A discussion guide was drafted and sent to all participants prior to the videoconference calls.

A total of 11 interviews with 56 participants were conducted via videoconference; interviews ranged between 60-90 minutes in length. Additionally, one of the organizations distributed the discussion guide by email to a number of their members, which resulted in the inclusion of an additional eight respondents who provided written feedback; resulting in feedback from 64 respondents.

Participants were invited to contribute their personal thoughts and expertise, rather than represent specific organizations or communities. The interviews were designed to represent a range of perspectives and provide insight into some of the unique challenges faced by the home and community care sector in providing palliative and end-of-life care during a pandemic. The interviews focused on:

1. identifying challenges and gaps to access to home and community palliative care during the first wave of the pandemic;
2. identifying helpful ways to address these gaps, including promising practices and innovative solutions developed in response to the new challenges of COVID-19.

We would like to extend our appreciation to Pallium Canada and Canadian Virtual Hospice for their support for this project.

APPENDIX B: GLOSSARY OF TERMS

As with any health care domain, palliative care has a wide and diverse terminology. This glossary is designed to help readers understand its content, language, and terminology. ⁱⁱⁱ

Advance Care Plan

Is a verbal or written summary of a capable adult's wishes or instructions about the kind of care they want or do not want in the event that they cannot speak for themselves. It sets out a person's preferences about health and personal care, and preferred care settings, in accordance with applicable laws.

Advance Care Planning

Is the process of reflection and communication that a person goes through to let others know their future health and personal care preferences. (Framework)

Caregiver

A caregiver is a person who provides personal care, support and assistance to another individual of any age who needs it. They usually have no formal training. While they are expected to follow certain ethical norms, they are not accountable to professional standards of conduct or practice. A person is not considered a caregiver if they are paid for these services, a volunteer for an organization or caring as part of a training or education program (see "Care Providers"). Caregivers are often family members and friends. However, an individual is not a caregiver merely because they are a spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care.

Care Provider - or Health Care Provider

Is a person that provides a health care service. This term is broader than health care professional, and may also include individuals providing health care services that are not regulated in Canada (e.g., personal support workers, also known as health care aides and a number of other titles across Canada). While health care providers are usually paid for providing health care services, a comprehensive definition could also include volunteers.

Community-Based Care

Care provided in the community rather than in hospital. It may include home care or care in a long-term care facility or group home. (Note that no interviewees who informed this report came from nursing homes or long-term care homes.)

End-of-Life

Referring to a final period (hours, days, weeks, months) in a person's life, in which it is medically obvious that death is imminent or a terminal moribund state cannot be prevented. Palliative care is provided before this stage, through it, and continues on afterwards, supporting family and caregivers with bereavement supports.

ⁱⁱⁱ Definitions of terms were taken from the Framework on Palliative Care in Canada.

Health Care Professionals

All members of the Palliative Care and inter-professional team of care providers, including physicians (primary care and specialist), nurse practitioners, nurses, social workers, psychologists, chaplains, pharmacists, and physical or occupational therapists; also known as health care providers or formal caregivers.

Home Care

Includes an array of services for people of all ages, provided in the home setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for family caregivers. It is usually provided by public or private health care providers. (See "Community-Based Care").

Palliative Care vs. a Palliative Approach to Care

For the purposes of this Lessons document, palliative care is a type of care that can be offered along the full time continuum of any life-limiting illness, including bereavement of family, friends and caregivers. It includes services such as pain and symptom management, addresses psychological and spiritual concerns, supports family and caregivers, and enhances quality of life. It is provided by primary health care providers, disease specialists, and palliative care specialists.

The palliative approach to care is a philosophy and set of principles that apply to all people living with and dying from a life-limiting illness. The palliative approach integrates the philosophies and principles of palliative care into primary care, long-term care and all mainstream health services.

The term "public health approach to palliative care" is the application of public health sciences (epidemiology, health research, and policy analysis) to develop and deliver palliative care services. It has a slightly broader set of guiding principles compared to the palliative approach to care, as described in the [BC Centre for Palliative Care white paper](#) on the topic.

Toolbox



The views and opinions expressed in this report reflect what we heard from respondents who participated in discussions focusing on the impacts of COVID-19 on home and community palliative care, including barriers to care, and promising responses and innovations to respond to these barriers. They do not reflect the opinions of the authors, of Health Canada, Healthcare Excellence Canada, the Canadian Partnership Against Cancer, Canadian Home Care Association, Pallium Canada, Canadian Virtual Hospice or of the organizations where participants work. Assumptions made within the analysis are not reflective of the position of any Government of Canada department or organization.

Introduction

Health Canada, in partnership with Healthcare Excellence Canada, the Canadian Partnership Against Cancer and the Canadian Home Care Association, have put together this *Toolbox*, with the support of Pallium Canada and the Canadian Virtual Hospice. The *Toolbox* contains many practical tools, resources and innovations to help address the barriers to home and community palliative care that were highlighted during the coronavirus pandemic.

The toolbox is a twin document to *Home and Community-based Palliative Care: Shaping the Future from Lessons Learned During the COVID-19 Pandemic* (Report), which reflects what we heard during discussions with home and community palliative care experts, caregivers and people with lived experience on how COVID-19 and affected supportive care delivered in the home and the community. It is intended to share innovative responses and promising practices, and to inform pandemic planning in the future. This Toolbox contains samples and examples of tools and resources to support the adoption of these promising practices, and is not meant to represent exhaustive list.

We sincerely thank all those who participated in our key informant discussions for their time and expertise, and for generously sharing their tools included in the Toolbox.

Who can use this Toolbox?

Many individuals, groups and organizations are interested in improving access to and quality of palliative care in home and community settings, and by doing this, allowing more people to have the type of care and end of life they deserve, reducing stress of caregivers and family members, and supporting well-being of healthcare providers. Interested people include:

- people with life-limiting illness, their caregivers and family members
- healthcare providers
- pandemic planners
- hospital, hospice, home and community-based care health administrators
- healthcare professional educational faculties, organizations and colleges
- community leaders and organizations.

Guiding Framework

This toolbox includes over 60 tools, including guidance documents, charts, and promising practices that were created or publicly available and were proposed as promising practices during the key informant discussions. They are set out in a manner that is consistent with the Guiding Framework used in the Report. The key findings are presented using an adapted version of the palliative care pandemic plan framework outlined in the April 2020^{iv} CMAJ article, *Pandemic palliative care: beyond ventilators and saving lives* by Arya, Buchman, Gagnon and Downar, which is comprised of eight components: stuff, staff, space, system, sedation, separation, communication, and equity.

iv Arya, A., Buchman, S., Gagnon B., & Downar, J. Pandemic palliative care: beyond ventilators and saving lives. CMAJ 2020;192: E400-E404. This framework stems from the 2008 US Task Force on Mass Casualty Critical Care (MCCC) framework comprised of four elements: stuff, staff, space and system. The authors adapted and updated the MCCC framework to the palliative care context to encompass four additional elements, including sedation, separation, communication, and equity.

For the purposes of this effort to share lessons learned from the initial wave of the pandemic, the definitions of the eight categories have been broadened to be inclusive of identified gaps, leading practices and innovations:



Stuff refers to the medications and the means to administer them, equipment, supplies and personal protective equipment (PPE) for all palliative care providers.



Staff refers to identifying and mobilizing all clinicians with palliative care experience; managing and supporting healthcare providers, caregivers, allied health professionals and spiritual counsellors through education and training on palliative care skills, including symptom management, virtual care, psychological as well as grief and bereavement supports.



Space includes optimizing the use of beds in hospice and palliative care units, provision of care in home and community settings, and avoiding unnecessary transfers between care settings.



Systems involves adopting a triage system to allocate clinicians who could provide both primary and specialist palliative care, forming palliative care provider “groups” including social workers, emergency responders, etc. that can provide mutual support and coverage, maximizing the use of telemedicine, virtual platforms, and the systems that govern how human resources are employed (employees vs. self-employed contractors, full or part-time).



Sedation refers to the use of palliative sedation for persistent symptoms.



Separation addresses reducing patient isolation by connecting patients with family members, caregivers and clinicians, and the provision of grief and bereavement supports and resources to patients, families, caregivers and healthcare providers.



Equity considers the unique palliative care needs of underserved and marginalized groups and addressing systemic inequity in the healthcare system.



Communication refers to the discussion of patient wishes, expectations and values via advance care planning and articulation of goals of care, as well as communication between healthcare providers and patients, and the sharing of information such as availability of resources.

How to find the tool you are looking for

Throughout the accompanying Report, you will find references to the 73 specific tools of this *Toolbox*, grouped under each of the eight components identified above. Each tool in the Report is numbered, and can be found under the same component of the guiding framework in the *Toolbox* as in the Report. For example, Tool 1 under Stuff in the Report will be Tool 1 under Stuff in the *Toolbox*. Each Tool includes a short description, a preview of the first page, where possible, and a hyperlink to access the full document.

The findings from this work are intended to provide feedback for knowledge dissemination, rather than produce definitive conclusions. By sharing some of the leading practices and tools, it is hoped that readers from all jurisdictions in Canada will be inspired to use and adapt them as required, or come up with and share their own innovations. By working together, Canada’s pandemic responses, and palliative and supportive care more generally, will come out of the pandemic stronger and more resilient than ever.

Stuff

The medications and the means to administer them, equipment, supplies and personal protective equipment (PPE) for all palliative care providers.



- TOOL 1:** **Nova Scotia Health and Wellness Pharmacare Palliative Care Drug Program.** The Palliative Care Drug Program helps cover the cost of drugs needed for end-of-life care at home.
- TOOL 2:** Health PEI - Prince Edward Island's Terminal Care Drug COVID-19 Kits. Developed smaller kits that would be able to be stored for patients at risk of COVID. Please contact Health PEI for access to this document at palliativeadmin@ihis.org.
- TOOL 3:** Health PEI - COVID Last Days of Living Order Set. This is a standardized COVID-19 care order sheet to be completed by the attending practitioner upon admission or transfer to the hospital unit, designed for patients in their last days and expected to die of COVID-19, and who cannot take oral medications. It offers a range of possible orders that can be quickly checked off in all care areas including diet, oxygen therapy, DNR status, medication orders for pain and symptom management, comfort measures, and consults, including pastoral care and social workers, etc. Please contact Health PEI for access to this document at palliativeadmin@ihis.org.
- TOOL 4:** **Cancer Care Ontario.** Palliative Care Symptom Management Pocket Guides help healthcare providers monitor and manage their patient's pain symptoms more effectively.
- TOOL 5:** BC Interior Health - Community "Just in Case" symptom management toolkit. An in-home individualized palliative symptom management kit where there may be limited access to clinicians and medication, and potential rapid decline in health status. It supports anticipatory planning for symptom emergencies where a person might otherwise end up in the Emergency Dept.
- **Palliative Just in Case Symptom Management Kits Webinar** (video)
 - **Palliative Just in Case Medication Kit Supplies List**
 - **Eligibility and Opioid Diversion Risk Screen**
 - **Client/Family In-Home Medication Record**
 - **In-Home Palliative Just in Case (JIC) Medication Log** (821470)
 - **Palliative Just in Case Medication Kit** (821471)

- **Palliative Just in Case (JIC) Symptom Management Kit (SMK) Prescription Request** (821472)

- **Palliative Just in Case (JIC) Symptom Management Kits (SMK) Standardized Process** (821473)

- **Palliative Just in Case (JIC) Symptom Management Kit (SMK) Education Checklist** (821474)

- **Just in Case Palliative Symptom Management Kits Pharmacy Communication Sheet**

- TOOL 6:** **Provincial (BC) website** that shared drug shortage information and listed alternatives for British Columbia's (BC's) publicly funded drug coverage program, PharmaCare. The website provides a Current Drug Shortages List that gives health professionals and the public up-to-date information about PharmaCare-covered drugs that are in short supply in BC community pharmacies. The list does not include shortages of drugs PharmaCare does not cover or drugs dispensed in hospitals. There is an updated weekly spreadsheet and a list of alternatives to choose from.
- TOOL 7:** **Pallium Canada – Managing Potential Palliative Care Medication Shortages During the COVID-19 Pandemic.** In collaboration with several healthcare professionals from across Canada, Pallium Canada has created a guide to managing potential palliative care medication shortages during the pandemic. This guide shares a number of strategies to manage drug shortages, and additional links and resources regarding symptom management protocols.
- TOOL 8:** **Pallium Canada – Shortage of Palliative Medications during COVID: Options Webinar.** This webinar explores shortages of key medications used in palliative care. It explores options available to clinicians, using a panel to brainstorm ideas and considerations, and input from participants to build a repository of possible options. **PDF of webinar**
- TOOL 9:** **McMaster Protocol: Hospital Management of Dyspnea for Patients with COVID-19.** The Division of Palliative Care, Department of Family Medicine, McMaster University developed this outline of a protocol for the management of dyspnea in COVID-19 patients.

- TOOL 10:** **Ontario Palliative Care Network- Symptom Management for Adult Patients with COVID-19.** The Ontario Palliative Care Network provides a poster setting out recommended medications and dosages for COVID-19 symptoms (dyspnea and anxiety).
- TOOL 11:** **Les soins palliatif adaptés au contexte de la pandémie (Slides).** This Powerpoint presentation provides information, protocols and tools to help physicians and nurses to assess symptoms of patients with COVID-19 and suggests medications, doses and administration methods to treat patients based on their symptoms.
- TOOL 12:** **Les soins palliatif adaptés au contexte de la pandémie.** Dre. Marjorie Tremblay, a Quebec palliative care physician and leader in hospital and community care, was asked to present her findings (see Tool 11) and lessons learned from their experience during the first wave of COVID-19 at a conference in France. Her presentation includes statistics, innovations and tools including medication delivery methods and symptom management.
- TOOL 13:** **Pallium Canada - PPE in the Home Webinar.** This webinar provides insight on how to use Personal Protective Equipment (PPE) when providing home-based palliative care for those situations where a home visit is required.

Staff

Identifying and mobilizing all clinicians with palliative care experience; managing and supporting healthcare providers, caregivers, allied health professionals and spiritual counsellors through education and training on palliative care skills, including symptom management, virtual care, psychological as well as grief and bereavement supports.



- TOOL 14:** **Pallium Canada- Learning Essential Approaches to Palliative Care (LEAP) courses.** Pallium Canada’s LEAP courses provide learners with the essential, basic competencies of the palliative care approach.
- TOOL 15:** **Pallium Canada – LEAP Paramedic.** LEAP Paramedic is a learning course for paramedics and Emergency Medical Service professionals that teaches the essential practical knowledge, attitudes and skills to provide a palliative care approach on-site. Local paramedic experts and experienced palliative care practitioners teach this course.
- TOOL 16:** **Pallium Canada – LEAP Long-Term Care.** LEAP Long-Term Care is an interprofessional course that provides healthcare professionals with an in-depth learning experience on essential skills and competencies of the palliative care approach with course modules and case studies contextualized to the long-term care setting.
- TOOL 17:** **Pallium Canada – Palliative Approaches to Care in Long-Term Care during COVID-19.** This webinar covers how COVID-19 has affected long-term care (LTC) residents, their families, and staff. Topics discussed include approaches to symptom management, family caregiver issues and essential conversations in the LTC setting.
- Tool 18:** **Pallium Canada, with the Canadian Medical Association** - Palliative Care for COVID Illness – Module A and Palliative Care for COVID Illness – Module B are available for free to all health care professionals either as a recorded webinar or in PowerPoint format. The modules are self-directed and completed at your own pace. Access these modules by logging in to Pallium Central and clicking on the COVID-19 palliative care resources icon.
- TOOL 19:** **Pallium Canada – COVID-19 Response Impact Report.** This impact report provides a snapshot of the achievements that have been made to support front-line health care providers working in urban, rural and remote communities and connect them to vital COVID-19 palliative care education to help equip them to navigate these unprecedented health care circumstances.
- TOOL 20:** **Pallium Canada – Palliative Care in the Home: Lessons from COVID.** This webinar reflects on how COVID-19 has affected the delivery of palliative care in patient’s homes, both positively and negatively. Panelists share insights stemming from their own work and the work done in their

respective communities. This webinar also solicits input from the panelists and participants on what palliative care in the home could look like over subsequent waves of the pandemic.

- TOOL 21: COVID-19: Guidance for the Extra-Mural Program.** A New Brunswick resource guide for staff highlighting the key points of caring for palliative care patients with COVID-19 symptoms in the home and caring for palliative care patients in the home during a pandemic.
- TOOL 22: The Canadian Home Care Association:** The CHCA's Building Operational Excellence in Home-based Palliative Care Program has identified and shared 22 innovative and leading practices to address common challenges in home care.
- TOOL 23: BC Centre for Palliative Care: Inter-professional palliative symptom management guidelines:** The B.C. Palliative Symptom Management Guidelines were developed to support clinicians to provide effective symptom management for patients with life-limiting illness without a referral to a palliative specialist. Using this reference, the authors hope clinicians feel both confident and competent to care for patients and families, enabling them to receive the majority of their care from their trusted primary care providers.
- TOOL 24: Prince Edward Island Paramedics Program.** This program supports palliative patients and their families/caregivers who have chosen to receive palliative and end-of-life care at home. Through the program, trained paramedics can provide palliative patients with pain and symptom management at home.
- Prince Edward Island Paramedics Providing After Hours Care at Home Brochure.** This six-page brochure provides additional information on the Paramedics Providing After Hours Care program to patients and families who are registered in the Provincial Integrated Palliative Care Program.
- TOOL 25: New Brunswick Extra-Mural Palliative Care Project's Interdisciplinary Approach.** Will enable paramedics to provide palliative care at home as well as a mechanism to collaborate with EMP practitioners in the seamless delivery of person-centric care.

TOOL 26: Whole Community Palliative Care Rounds (WCPR). Profiled as a Canadian Home Care Association High Impact Practice, this initiative enhances the quality and effectiveness of home-based palliative care. Through the WCPR strategy, inter-professional care teams participate in purposeful and timely communication, via in-person and/or virtual meetings, to engage in shared decision-making and collaborative care planning.

Tool 27: The Compassionate Workplace Campaign. This campaign is designed to ignite a movement across Canada and create more supportive environments for the increasing number of employees who are caregiving, grieving or dealing with a serious illness.

Space

Optimizing the use of beds in hospice and palliative care units, provision of care in home and community settings, and avoiding unnecessary transfers between care settings.



- TOOL 28:** COVID-19 Visitation Policies Support:
- Winnipeg Health Authority | Office régional de la santé de Winnipeg.
Guideline for Palliative Care Visitor Restrictions applicable to Palliative Care Units and Hospice.
 - Summary of COVID-19 measures and restrictions for New Brunswick Adult Residential Facilities and Nursing Homes.**
- TOOL 29:** **BC Centre for Palliative Care - Compassionate Communities Toolkit.**
The Compassionate Community Toolkit guides organizations and groups interested in building a caring, supportive network for people affected by serious illness, end-of-life, caregiving, and grieving.
- TOOL 30:** **Pallium Canada - Compassionate Communities Toolkit.** Pallium Canada's Compassionate Community Start-up Toolkit equips you with essential information, resources, and templates to launch a Compassionate Community. Compassionate communities provide physical, emotional, social, spiritual and practical supports to patients facing life-limiting illnesses and their families and caregivers.
- TOOL 31:** **Pallium Canada - Compassionate Workplace Campaign.** Pallium Canada's Compassionate Workplace Campaign is designed to create more supportive environments for the increasing number of employees who are caregiving, grieving or dealing with a serious illness. The campaign includes tools, activities, and communication materials that make it easy for any workplace to become more compassionate and supportive.

Systems

Adopting a triage system to allocate clinicians who could provide both primary and specialist palliative care, forming palliative care provider “groups” including social workers, emergency responders, etc. that can provide mutual support and coverage, maximizing the use of telemedicine, virtual platforms, and the systems that govern how human resources are employed (employees vs. self-employed contractors, full or part-time).



- TOOL 32: Canadian Home Care Association - Guidelines for Implementing Innovation Practices in Home-Based Palliative Care**: The Framework and User Guide for Implementing Innovative Practices in home-based palliative care developed by the Canadian Home Care Association provides a ten-step strategy for a successful implementation collaborative, from selecting a leading practice to developing a change package, identifying practice teams, and planning for its sustainability.
- TOOL 33: Pallium Canada - Télémédecine en soins palliatifs en temps de pandémie**. In this webinar, the presenters will discuss in French the effect of the pandemic on the delivery of palliative care, and how telemedicine has enabled them to adapt care.
- TOOL 34: Reacts (Remote Education, Augmented Communication)**. A paid subscription-based secure, integrated, collaborative platform with unique interactive tools designed to suit the multiple collaborative needs of healthcare professionals and patients.
- TOOL 35: William Osler Health System and uCarenet - Relief App** enables palliative designated patients to self-report their symptoms remotely. The goal is to accurately assess patients in their home, to provide timely intervention and appropriate treatment.
- TOOL 36:** Health PEI - Symptom self-assessment tool. Health PEI uses the Edmonton Symptom Assessment System-revised (ESAS-r) online self-assessment form for palliative care patients, to help healthcare providers assess severity of symptoms. The ESAS-r tool has been developed and used widely across Canada. It has proven to be successful in improving care for patients.

-Guidance Information Page

-Esas-r

Sedation

The use of
palliative sedation
for persistent
symptoms.



TOOL 37: BC Interior Health has prepared a palliative sedation toolkit containing many resources including:

- **Palliative Sedation Therapy Decision Algorithm**
- **Respiratory Distress Observation Scale - RDOS**
- **Pain Assessment in Advanced Dementia Scale - PAINAD**
- **Richmond Agitation Sedation Scale - Palliative Version (RASS-PAL)**
- **Palliative Sedation Therapy Monitoring Record**
- **Palliative Sedation Therapy (PST) Checklist**
- **Delirium Information for Palliative Care patients and their families Self Learning Module (Bruyere)**

Education – Public: **Palliative Sedation Patient and Family Information**

Education – Staff: **Palliative Sedation Clinician Video**

Separation

Reducing patient isolation by connecting patients with family members, caregivers and clinicians, and the provision of grief and bereavement supports and resources to patients, families, caregivers and healthcare providers.



- TOOL 38:** Ontario Palliative Care Network. Mental Wellness and COVID-19 – Tips and Considerations – This information sheet developed by the Assembly of First Nations for First Nations.
- TOOL 39:** Mental Health Commission of Canada – Caregiver Resources. Repository of resources from across Canada that may help families and family caregivers of loved ones living with a mental health problem or illness find support.
- TOOL 40:** Ontario Caregiver Coalition Resources. Repository of a number of different organizations, groups, and websites that exist in Ontario that can provide support and resources for family caregivers. This is a list of starting points that family caregivers can contact to inquire about local services or to find peer support
- TOOL 41:** National Initiative for the Care of the Elderly. Talk2NICE is a COVID-19 response that supports isolated seniors by offering free, over the phone friendly outreach and brief support services for older adults and persons with disabilities. It is not a crisis line but meant to provide friendly conversation.
- TOOL 42:** Canadian Foundation for Healthcare Improvementⁱ Webinar Series: Patient Partnership in a Time of COVID-19. The webinars bring patient partnerships and lived experience to specific and emerging issues, policies and practices that are rapidly developing and being implemented in response to COVID-19. These issues have direct impact on patients, families and caregivers and risk the quality and safety of care for both those receiving and delivering it.
- TOOL 43:** Canadian Association of Social Workers (CASW) – Grief in the time of COVID. This webinar addresses what social workers can do in the time of COVID-19 to be more grief literate.
- TOOL 44:** Pallium Canada – The Psychological Impact of COVID on Health Care Professionals Webinar. This webinar explores in more detail the psychological impact and effective approaches to help healthcare providers care for themselves and their colleagues.

ⁱ Since development of this publication, the Canadian Foundation for Healthcare Improvement has amalgamated with the Canadian Patient Safety Institute to become Healthcare Excellence Canada.

- TOOL 45:** **Pallium Canada – Role of Grief and Bereavement in the Care of Health Care Providers and their Families Webinar during COVID-19.** This webinar spotlights the experiences of Spain’s healthcare providers during the COVID-19 pandemic. It covers the grief experienced by healthcare providers and how they may care for themselves, as well as a team approach to well-being.
- TOOL 46:** **Ontario Palliative Care Network – Managing Bereavement around the Coronavirus (COVID-19).** This handout for families facing grief and bereavement during the pandemic provides information on grief and complicated grief, as well as supports and resources.
- TOOL 47:** **Canadian Hospice Palliative Care Association (CHPCA) - Grief and Bereavement Resource Repository.** This repository of grief and bereavement resources is a collection of useful links and resources to help Canadians cope with grief.
- TOOL 48:** **Centre for Loss and Life Transition.** Organization led by death educator and grief counselor Dr. Alan Wolfelt dedicated to helping people who are grieving and those who care for them.
- TOOL 49:** Canadian Cancer Society – ‘CancerConnection’ and Cancer Information System (CIS) Phone lines.
- **CancerConnection** is an online community where people facing cancer and their supporters can share experiences and build relationships to help them cope.
 - **The CIS** is a national, toll-free helpline available to cancer patients, caregivers, families and friends, the public and healthcare professionals. This helpline provides information about cancer treatment and side effects, clinical trials, coping with cancer, emotional support services, prevention, help in the community, and complementary therapies.
- TOOL 50:** Provincial caregiving organizations provide virtual grief support through valuable programs and services to help support unpaid caregivers.
- **Caregivers Nova Scotia**
 - **Quebec Caregivers**
 - **Ontario Caregiver Organization**
 - **Alberta Caregivers**
 - **BC Family Caregivers**

TOOL 51: **Canadian Virtual Hospice (CVH) -MyGrief.ca**. An online resource for grieving adults launched by the Canadian Virtual Hospice in 2016. It aims to help people work through their grief from the comfort of their own home, at their own pace.

TOOL 52: Canadian Virtual Hospice (CVH) – Repositories of Resources. The Canadian Virtual Hospice aggregates grief and bereavement resources for the public and for people working in healthcare. Resources include webinars, posters, articles and infographics on various topics related to grief and bereavement, including supporting children through grief, and grieving during COVID-19.

-For Professionals

-For the Public

-Webinar - KidsGrief Q&A Webinar: Talking with Kids about COVID-19

-Article - Supporting Children through serious illness and grieving during COVID-19

-Article - Grieving during COVID-19

-Article - Physical distancing and dying: When you can't be at the bedside

-Infographic - Staying well on the frontlines of COVID-19: A Resource for those working in healthcare

-Infographic - COVID-19 Advanced Illness and Palliative Care

-Infographic - Canadian Virtual Hospice (CVH) and Morning Start Lodge - Processing Grief During COVID-19

TOOL 53: Canadian Virtual Hospice (CVH) – Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty- Webinar Series:

-April 3, 2020 - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and certainty

-April 9, 2020 - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and certainty

-April 17, 2020 - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and certainty ...

- **April 24, 2020** - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty

- **May 8, 2020** - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty ...

- **May 22, 2020** - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty

- **June 5, 2020** - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty

- **June 30, 2020** - Grief and COVID-19 for healthcare providers: Staying connected in a time of loss and uncertainty

TOOL 54: Canadian Virtual Hospice (CVH) – Palliative practice and COVID-19: Life and work in the time of COVID-19 – Webinar Series:

- **May 4, 2020** - Palliative practice and COVID-19: Life and work in the time of COVID-19

- **June 2, 2020** - Life and work in the time of COVID-19 - The Conversation Continues

TOOL 55: Canadian Virtual Hospice (CVH) - Complicated grief following a death in the ICU: New challenges in the COVID-19 Era – Webinar:

- **June 16, 2020** - Complicated grief following a death in the ICU: New challenges in the COVID-19 era

TOOL 56: **The Children and Youth Grief Network**. Advocates for educational opportunities and support services that will benefit children and youth who are grieving the dying or the death of someone they care about. Resources include handbooks, Grief and Death Education toolkits, tip sheets and podcasts, and infographics.

TOOL 57: **KidsGrief.ca**. A free online resource that helps parents support their children when someone in their life is dying or has died. It equips parents with the words and confidence needed to help children grieve life's losses in healthy ways.

TOOL 58: **Lighthouse – Grief Support for Children and Teens**. The Lighthouse offers facilitated peer support groups to help children, teens and their families after a death in their family. Activities include Bereavement Support Groups, Workshops for Caregivers, Grief Training and Resources, and Consultations.

Equity

The unique palliative care needs of underserved and marginalized groups and addressing systemic inequity in the healthcare system.



- TOOL 59: Chief Public Health Officer of Canada's Report - From Risk to Resilience: An Equity Approach to COVID-19.** Report describes COVID-19's broader consequences and is a call to incorporate a health equity approach into pandemic preparedness, response and recovery
- TOOL 60: Canadian Virtual Hospice Living My Culture.ca.** Through short videos, people from various cultures share their stories and wisdom about living with serious illness, end of life and grief to support others.
- TOOL 61: Inner City Health Associates' Palliative Education and Care for the Homeless (PEACH) mobile palliative care program.** This program operates as a mobile unit, providing palliative care on the streets, in shelters and with community-based collaboration with Toronto Central Community Access Centres and aims to meet the needs of homeless and vulnerably-housed patients with life-limiting illness.
- TOOL 62: Inner City Health Associates - PEACH Resource for Frontline Workers Caring for Clients Experiencing Homelessness in COVID-19.** This guide is for frontline social and healthcare workers focusing on the unique palliative care needs of people experiencing homelessness during the COVID-19 pandemic. This document will help guide this work and is intended to help start conversations about what is important to your client when thinking about their end-of-life.
- TOOL 63: Equity in Palliative Approaches to Care (ePAC)'s Palliative Outreach Response Team (PORT) program.** A service that provides mobile end-of-life care support to people living in poverty in Victoria BC.
- TOOL 64: ePAC - Equity-Informed Advance Care Planning.** A series of tools and resources specifically designed to help structurally vulnerable individuals begin to think about their values, wishes and beliefs regarding future health care.
- TOOL 65: McMaster University - The Indigenous Teaching Through Art (ITTA) Program.** The ITTA program was created by McMaster University's Department of Family Medicine in collaboration with Indigenous colleagues. The goal of the program is to equip clinicians and staff with new knowledge and different ways to provide culturally appropriate care by being aware of and addressing the root causes of inequity. Participants engage in art and storytelling, hear stories from residential school survivors, and they learn and share with each other.

- TOOL 66: Cancer Care Ontario - Indigenous Navigator Role Statement.** This document provides an overview of an Indigenous Navigator position, including the varied responsibilities, qualifications, and competencies required for such role. Please contact BC Cancer for full access to this document at warren.clarmont@bccancer.bc.ca
- TOOL 67: Developing Palliative Care Programs in First Nations Communities Workbook.** This workbook provides an outline for creating local palliative care programs in First Nations communities. It offers a process for community development, practical guides, ideas and lessons learned.
- TOOL 68: First Nation Health Authority (FNHA) - Staying Connected during the Pandemic.** This document provides helpful tips and ideas to stay connected with our families and communities during the pandemic.
- TOOL 69: Cancer Care Ontario Palliative Care Toolkits for Indigenous Peoples.** This toolkit includes resources and reference material for First Nations, Métis and Inuit families and communities. It can be used to support people with cancer who have palliative care needs.
- TOOL 70: Canadian Virtual Hospice (CVH) - pre-ACP tool for Indigenous Peoples - Coming Full Circle: Planning for your Care (Advance care planning).** Three other versions are being adapted from this booklet: 2SLGBTQ+ (in progress), Southeast Asian population (with BC Centre for Palliative Care), and People with dementia (with BC Centre for Palliative Care).

Communication

The discussion of patient wishes, expectations and values via advance care planning and articulation of goals of care, as well as communication between healthcare providers and patients, and the sharing of information such as availability of resources.



TOOL 71: Speak Up Canada (CHPCA) - **Speak Up** and the **BC Centre for Palliative Care** developed a complementary “**Living Well, Planning Well**” resource for the public. This resource intends to help you understand your rights and the legal requirements for planning for your future care. The information within this resource is intended as a guideline only and is not legal advice.

-**English**

-**French**

TOOL 72: Speak Up Canada (CHPCA) – has a number of resources to support advance care planning. Some examples include:

-**Why Advance Care Plan?** This is an Advance Care Planning poster designed to support Indigenous Peoples in advance care planning discussions.

-**My Speak Up Plan:** is an online interactive workbook with information to guide you through the steps of creating your advance care plan. It is downloadable for sharing with others.

TOOL 73: **Pallium Canada: Advance Care Planning and Goals of Care Discussions: Getting us all on the same page (plus practical tips!).** This webinar discusses overall purpose, approaches and outcomes of advance care planning (ACP) and goals of care discussions (GOCD), the relationship and differences between ACP and GOCD, what is involved with each, and how values-based decisions can be made. Practical guides and communication tips will also be addressed.

REFERENCES

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- 2 Broadbent Institute. BC's swift response to long-term care crisis sets the bar for other provinces. https://www.broadbentinstitute.ca/bc_s_swift_response_to_long_term_care_crisis_sets_the_bar_for_other_provinces
- 3 Alberta Health Services: <https://albertahealthservices.ca/assets/info/peolc/if-peolc-newsletter-2020-08.pdf>
- 4 Isolation and recovery programs as part of the COVID homeless response: <https://www.peelregion.ca/coronavirus/housing/peel-housing-services-covid19-response-program.pdf>
- 5 EI Caregiving Benefits and Leave. <https://www.canada.ca/en/services/benefits/ei/caregiving.html>
- 6 Comfort Care Rounds provide a forum for case-based discussions about deceased or dying patients. The focus is on providing palliative care education, reflection on cases and peer support for staff and volunteers. https://www.palliativealliance.ca/assets/files/Alliance_Resources/Communication/Comfort_Care_Rounds-Jan_162013.pdf
- 7 Sheppard, AJ, Antone, C, Logan A, & Kewayosh A. (2019). "In a good way": Going beyond Patient Navigation to ensure culturally safe care in the cancer system for First Nations, Inuit, Métis, and urban Indigenous patients in Ontario. International Journal of Indigenous Health, 14(2), 293-307. DOI 10.32799/ijih.v14i2.31995.