
Advancing palliative and end-of-life care in Alberta

Palliative and End-of-Life Care Engagement
Final Report

NOVEMBER 2021

Alberta 

Advancing Palliative and End-of-Life Care in Alberta | Alberta Health

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MESSAGE FROM THE MINISTER OF HEALTH



Each year in our province many people experience losing a loved one to a life-limiting illness. The Alberta government is acting on its commitment that Albertans have access to the highest quality palliative and end-of-life care. This includes enhancing effective services and supports for Albertans at end-of-life, when and where they need them, as well as for their families and caregivers during these personally difficult and intimate times.

Accessible and compassionate palliative and end-of-life care requires a holistic approach that focuses on the person at the end-of-life. It relies on strong partnerships between the individual and their family, caregivers, friends, neighbours, service providers, community organizations and government.

Alberta is a national leader in the provision of palliative and end-of-life care, work that has been underway for several years through the *Palliative and End-of-Life Care Alberta Provincial Framework* (2014) and the most recently released addendum in April 2021. However, we must do more to achieve our vision for better services and supports for Albertans. In 2019, our government committed \$20 million to address four priority areas related to palliative and end-of-life care initiatives.

In September 2020, our government appointed Dan Williams, MLA for Peace River, to engage with citizens and interest groups across Alberta to gain further insights into our palliative and end-of-life care system and recommend how the government should allocate funding.

The **Advancing Palliative and End-of-Life Care in Alberta** final report captures Albertans' feedback and recommendations. This report is the culmination of the work led by MLA Williams that will help to strengthen palliative and end-of-life care delivery in our province. I am grateful for his support and commitment to this initiative.

Based on the findings in the final report, the government will continue to work with our health system partners and other citizens and interest groups to build a strong palliative and end-of-life care system, one that advances a caring and supportive community for Albertans.

Jason Copping
Minister of Health

MESSAGE FROM MLA DAN WILLIAMS



In September 2020, I began engaging Albertans to understand our palliative and end-of-life care system better. A focused engagement was fundamental to this process, allowing us to have intimate and frank conversations about challenges, opportunities and the victories of those who use, work in and support palliative and end-of-life care.

For eight months, I met with people across Alberta, who were able to provide their views and feedback through a variety of platforms. I had the opportunity to speak with patients, their families and caregivers, frontline service providers, Alberta Health Services, Covenant Health, Primary Care Network leaders, researchers, continuing care associations and several community organizations, such as hospice organizations, the Alzheimer Society of Alberta and Northwest Territories and the Canadian Cancer Society.

This was a rewarding and enlightening experience for me. The people, providers and communities who deliver palliative care in Alberta are committed, passionate and resilient. Two consistent messages rang loud and clear for me - palliative and end-of-life care should start as early as possible for the individual, and we must keep individuals in familiar settings for as long as possible, in their homes and their communities alongside their families and caregivers.

While Alberta's palliative and end-of-life care system has many strengths, there are still some challenges to address. Reconsidering how the system can be transformed to reflect the needs and expectations of Albertans is an issue of paramount importance to our province and the well-being of all its citizens.

With this in mind, I am pleased to present the final report summarizing feedback and recommendations related to our palliative and end-of-life care system, entitled: **Advancing Palliative and End-of-Life Care in Alberta**.

I am grateful to the team at Alberta Health whose insightful guidance and knowledge allowed us to complete this project successfully.

Lastly, I would like to thank everyone who participated and took the time to reflect on these important matters. Appropriate and timely palliative and end-of-life care is essential and we are moving in the right direction to support palliative care patients with dignity and comfort.

Dan Williams

Member of the Legislative Assembly for Peace River

EXECUTIVE SUMMARY

Albertans with chronic and life-limiting illnesses are living longer than ever before. To preserve dignity, well-being and quality of life, the time spent with a life-limiting illness must be as comfortable as possible. Therefore, it is essential to establish the palliative approach to care and integrate it within the overall health care system.

As a national leader in the design and implementation of palliative and end-of-life care (PEOLC), in 2014, Alberta Health Services (AHS) established a provincial PEOLC framework and initiatives to improve outcomes for those with life-limiting illnesses and better support their families and caregivers. In 2019, the Government of Alberta committed \$20 million over four years to enhance PEOLC delivery.

In September 2020, former Minister of Health, Tyler Shandro, appointed MLA Dan Williams (Peace River) to engage PEOLC citizens and interest groups in Alberta. The citizens and interest groups that participated in the review included: PEOLC patients, their families and caregivers; frontline service providers (AHS, the Provincial Palliative and End-of-Life Innovations Steering Committee, Covenant Health's Palliative Institute, Primary Care Networks' (PCN) Executive Directors, Continuing Care Associations, PEOLC Physicians, Indigenous Health representatives); researchers at both the University of Alberta and the University of Calgary; and, community organizations such as hospice societies, Alzheimer Society of Alberta and Northwest Territories, and the Canadian Cancer Society.

Over eight months, these participants identified that transitioning from a reactive, treatment and therapy-based approach for life-limiting illnesses to a more proactive, holistic, integrated and interdisciplinary palliative approach requires a systemic shift. Work continues to address the outstanding 2014 provincial PEOLC framework initiatives, as well as the prioritized gaps and challenges to support these needed changes.

The four recommendations to advance PEOLC in Alberta are:

RECOMMENDATION 1 – Earlier Access

Primary care (PCNs, physician offices, and community health centres) and continuing care (home care and facility-based continuing care) providers should adopt the palliative approach to care once an individual is diagnosed with a life-threatening or life-limiting condition, including age-related chronic conditions such as dementia. This includes establishing quality standards and standards of practice for these care settings.

RECOMMENDATION 2 – Education and Training

PEOLC competencies, the palliative approach to care and its benefits and serious illness conversations should be incorporated into health care and allied service provider entry-to-practice curricula and continuing professional development. Health service providers and/or community organizations should develop standardized training for families, caregivers and volunteers to increase their capacity to care for their loved ones at home and in their communities.

RECOMMENDATION 3 – Community Supports and Services

Government, AHS, and their partners, should grow and expand community-based PEOLC services via home and community care programs and facility-based continuing care. This includes establishing effective caregiver supports, such as respite, and offering high-quality grief and bereavement services.

RECOMMENDATION 4 – Research and Innovation

Government should invest in establishing additional navigation and care pathways for the transition of chronic disease management to PEOLC while considering access, barriers to services and addressing social determinants of health.

INTRODUCTION

Albertans are living longer than ever beforeⁱ. Many individuals suffering from severe chronic illnesses and life-limiting conditions have longer lifespans than those in past generationsⁱⁱ.

Such conditions and their treatments negatively impact quality of life despite advancements in medical science and technology. Albertans with life-limiting diseases would benefit from the palliative approach to care early on in their disease trajectory as well as accessing and receiving timely and quality PEOLC.

To anticipate these evolving needs, AHS developed the [Palliative and End-of-Life Care Alberta Provincial Framework](#) (2014). The framework was developed to help address gaps in programs and services where they existed across the province and to increase access to quality PEOLC regardless of geography. There were 36 initiatives recommended in the framework to help fill these needs and improve outcomes for those with life-limiting illnesses and better support their families and caregivers. To date 21 of the 36 initiatives have been completed. In addition, an addendum to this framework was published in April 2021. [The PEOLC Alberta Provincial Framework Addendum](#) outlines what Alberta has achieved since the development of the framework in 2014, where we are today (inclusive of a current state analysis), gaps, challenges, and recommendations for future work.

In 2019, the Government of Alberta committed to investing \$20 million over four years to:

- continue the shift from hospital to community-based home and hospice care;
- establish and implement palliative-care education, training, and standards for health professionals;
- develop effective caregiver supports to help patients remain in their homes and community; and
- raise public awareness of palliative care and knowledge of how and when to access it.

In September 2020, former Minister of Health, Tyler Shandro, appointed MLA Dan Williams (Peace River) to engage PEOLC citizens and interest groups in Alberta. These individuals included patients, families, frontline service providers, researchers, and community organizations such as hospice societies. MLA Williams was tasked to look at what aspects of PEOLC services were working well, which should

be improved, and what additional services should be established to support the four platform commitments. This review did not assess the structure of PEOLC service delivery, including but not limited to funding mechanisms, health workforce, physician compensation and other operational aspects.

Between October 2020 and May 2021, more than 35 virtual meetings with approximately 100 participants were held with PEOLC groups across Alberta (Appendix 1). The participants were asked to assess the delivery of services in Alberta, identify gaps and provide recommendations. They shared a wealth of experience in receiving and providing PEOLC in Alberta.

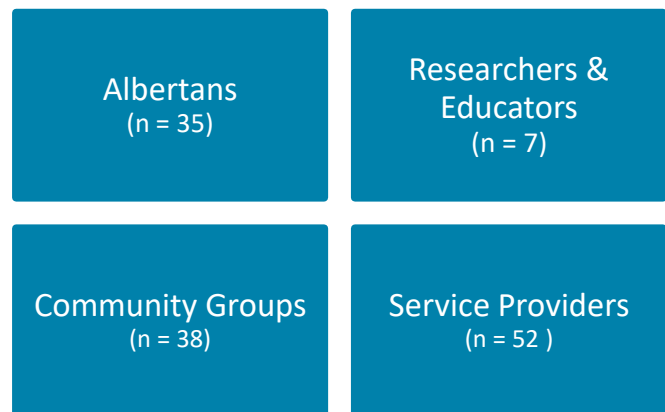


Figure 1. Summary of stakeholder groups contacted by type

The information heard serves as the basis for this report. The numerous comments and recommendations all had an underlying thread: the palliative approach to care can and should be integrated into care for every individual with a life-limiting condition. Additionally, it was clear from the feedback received that planning and implementation must be constructed around two focal points for Albertans to benefit fully from PEOLC:

- It should start as early as possible, close to the initial diagnosis of a life-limiting illness; and
- A primary goal should be to keep individuals in their homes and their communities, wherever and whenever possible.

BACKGROUND

PEOLC is a philosophy and approach to care that enables all individuals with a life-limiting or life-threatening illness to receive integrated and coordinated care across the continuum.

This care incorporates patient and family values, preferences and goals of care, and spans the disease process from early diagnosis to end-of-life, including bereavementⁱⁱⁱ. Engaging palliative consult teams early in the disease trajectory, can assist with pain and symptom management, which improves quality of life and the patient experience. To clarify, the purpose of palliative care is to reduce suffering, not intentionally end life. The provision of Medical Assistance in Dying (MAID) is a practice separate and distinct from the palliative approach to care.

PEOLC is best provided in a person's setting of choice, whether at home or in a hospice, a continuing care facility (designated supportive living or long-term care) or a hospital. As long as interdisciplinary supports are available and accessed, an individual's home is often the preferred choice for PEOLC patients and improves the patient-family experience. However, families are often the primary caregivers, particularly in the case of children with life-threatening conditions. This unexpected role can be a heavy burden.

"The palliative approach"^{iv} to care focuses on the person and family, and their quality of life throughout the illness trajectory, in advance of and not just at the end-of-life. The palliative approach to care can occur simultaneously with disease-directed treatment.

This includes supporting and managing:

- illness comprehension and coping
- symptoms and functional status
- advance care planning and the patient's preferred method of decision making
- coordination of care
- support for family/caregivers

"Palliative care" aims to improve the quality of life for patients and their families facing the problems associated with a life-limiting illness through the prevention and relief of suffering by means of early identification, comprehensive interdisciplinary assessments, and appropriate interventions^v.

"End-of-life care" is provided to patients and their families when they are approaching a period of time closer to death, which may be exemplified by an intensification of interdisciplinary services and assessments such as anticipatory grief support, and pain and symptom management^{vi}. Although many patients are admitted to hospital or intensive care units towards the end of their life, most end-of-life patients—up to 70 per cent, according to the Canadian Academy of Health Sciences—prefer less aggressive treatment and a greater focus on comfort.

"Hospice care" is a specialized service that provides 24/7 facility-based care to those who are approaching end-of-life and whose needs can best be met in this location (based on assessed needs, patient preferences, and available bed capacity). It is provided in designated/supported community spaces, which may include a) stand-alone community hospice beds or b) designated/supported end-of-life care beds in long term care, designated supportive living, or other health care facilities located in the community. Hospice care is provided to both the adult and pediatric populations and may include respite^{vii}.

Historically in Canada, palliative care developed as a way to meet local needs. It grew out of the increasing numbers of cancer cases that occurred in the 1970s, which were addressed by the formation of palliative care units within acute care hospitals for patients requiring end-of-life care.^{viii} Thus in Alberta, as in Canada generally, palliative care originated in acute care settings. Then, between 1988 and 1998, Albertans saw improvements in access to adult PEOLC and home care support services. As a result, acute care beds were utilized less frequently by end-of-life cancer patients in Calgary and Edmonton. In 1995 and 1996, Edmonton and Calgary organized multiple locations for integrated adult palliative-care programs, which gave many Albertans improved options for care and offered more support to health care providers. Hospice and palliative care units were recognized as essential components of this comprehensive, integrated palliative care model that existed to a varying extent across Alberta. Since that time there has been significant growth in the types of PEOLC services and resources that are available across Alberta for patients and their families. In particular, there has been increased access to quality PEOLC in North, Central, and South Zone, as well as pediatric programs and services.

Currently, Albertans can access PEOLC services in their home, designated acute care beds within hospitals, tertiary beds in Edmonton, Calgary and Red Deer, and a facility-based continuing care setting (supportive living, designated supportive living or long-term care). In addition, Albertans can access residential stand-alone hospice beds, as well as hospice beds integrated into facility-based continuing care settings. Services are provided by a range of health care providers including, but not limited to, palliative consult teams (inclusive of palliative care physicians, clinical nurse specialists, palliative nurses) regulated nurses, health care aides, paramedics, social workers and other professionals.

As the provincial health authority, AHS manages access to all publicly funded palliative services and acute and community palliative beds for pediatric and adult patients living in five geographically defined administrative zones: North, Edmonton, Central, Calgary, and South. The urban centres in Calgary and Edmonton are recognized as having the most established, integrated and comprehensive PEOLC programs, whereas the types of services and level of integration of services vary from zone to zone in rural areas. Since the implementation of provincial PEOLC initiatives, North, Central and South Zones have increased the integration and comprehensiveness of PEOLC programs. As of March 31, 2021, there were 126 publicly funded acute designated palliative care beds and 257 publicly funded community designated palliative beds in Alberta^{ix}. An additional 12 privately funded hospice beds are located in Edmonton. These community-designated palliative beds are located in either facility-based continuing care settings or stand-alone hospices. A breakdown of publicly-funded community designated beds by zone is provided in Table 1.

Table 1: Publicly Funded Community Designated Palliative Care Beds by Zone

Zone	Number of spaces
North zone	13
Edmonton zone	85
Central zone	18
Calgary zone	121
South zone	20

Source: Alberta Health Services 2021

Community designated PEOLC beds and stand-alone hospice beds offer specialized end-of-life care to individuals in their last weeks to months of life. The majority of hospices are operated by AHS or via contract by non-profit hospice societies. Of the current 257 publicly funded community-designated palliative care beds, 58 are located in five stand-alone hospices. Unlike the development and operation of acute and facility-based continuing care spaces, stand-alone hospices are grassroots in nature and obtain the majority of capital, and a portion of operational funding, through community fundraising. Additionally, some community hospice societies, partner with AHS and local facility-based continuing care, to fund co-located hospice suites, as is the case with the Olds District Hospice Society, AHS and Seasons Encore Olds.

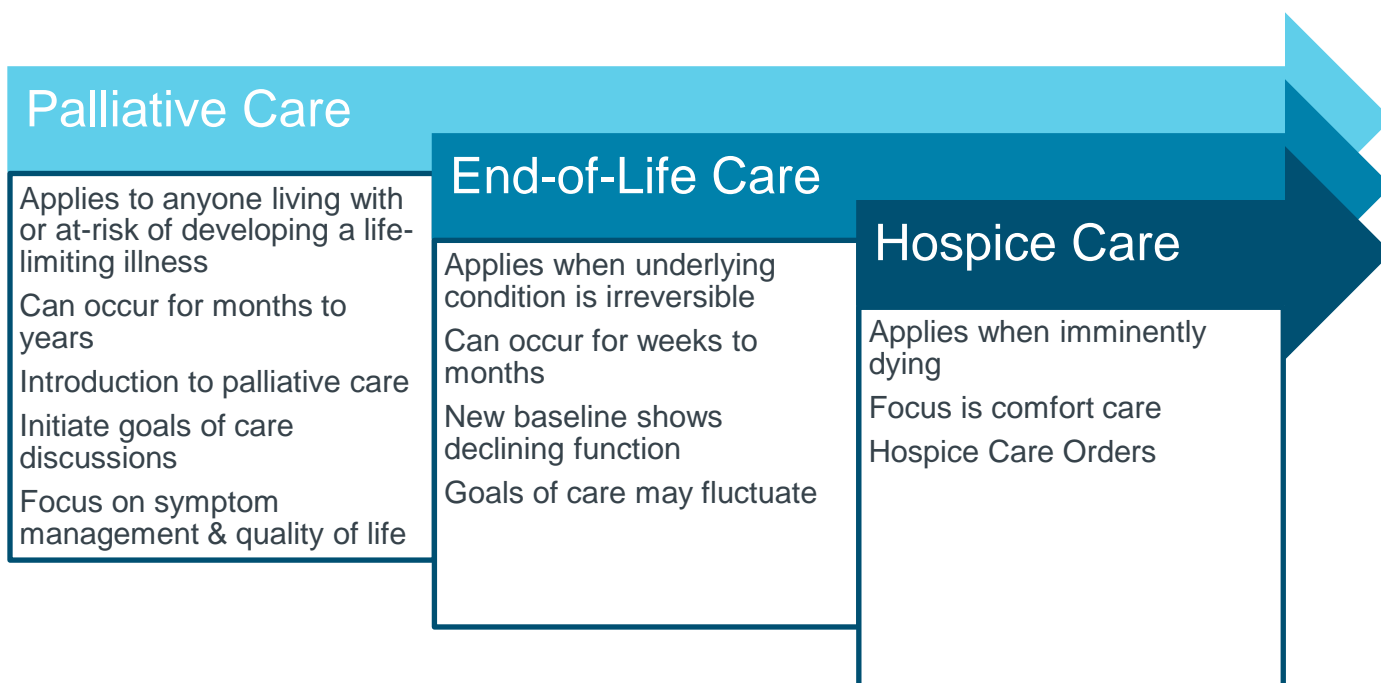


Figure 2: Spectrum of PEOLC in Alberta

CHALLENGES AND EMERGING ISSUES IN PEOLC

Despite Alberta’s robust approach to PEOLC, several systemic challenges and emerging issues will impact the delivery of services in the immediate and medium-term.

Demographic Shifts

Alberta’s population grew to 4.4 million in 2020, up from 3.6 million in 2011, a 22 per cent increase over nine years. This trend is expected to continue as the population grows and people live longer. It is projected that individuals aged 65 years and above will represent 20 per cent of Alberta’s total population by 2046, just 25 years from now^x. A 2020 study^{xi} projects that by 2046 the average age of an Albertan will be 41.5 years, up from 38.3 today. Life expectancy will increase by 3.4 years to 87 years for women and by 4.7 years to 83.7 years for men. It is projected that over the next 25 years, the share of the population 80 years or older will more than double, reaching as much as 7 per cent of the total Albertan population.

Table 2: Projected changes in demographics in Alberta

	2020	2046
Total population	4.4 million	6.3 million
Average age	38.3 years	41.5 years
Life expectancy (f)	83.6 years	87.0 years
Life expectancy (m)	79 years	83.7 years
Total 80+ years	136,000	441,000

Source: *Population Projects: Alberta and Census Divisions, 2020—2046. Treasury Board and Finance. 2021*

Each year, over 270,000 Canadians, including 27,000 Albertans, die; 90 per cent of these deaths are caused by a chronic condition such as cancer, heart disease, organ failure, dementia or frailty. As the adoption of the palliative approach to care increases, more non-cancer patients will use such services. Currently, cancer’s trajectory and the relationship between palliative care and cancer care are relatively well understood. However, learning how to support non-cancer patients better and ensure appropriate education and training for the health providers who care for them will be challenging. By 2036, the annual number of deaths in Canada is projected to increase to 425,000. According to the Canadian Hospice Palliative Care Association, only 16 to 30 per cent of Canadians currently have access to or receive PEOLC services when they are dying. Despite Canadians’ wishes to die at home, 60 per cent die in hospitals^{xii}. The need for PEOLC services will only continue to grow, and it is necessary to plan for increasing services and providers in Alberta.

Populations of Interest

In 2014, cancer-related deaths accounted for 85 per cent of palliative care services. A growing and ageing population will inevitably increase the number of new cancer cases and the numbers of Albertans living with cancer. According to AHS^{xiii}, in 2018 there were around 20,068 new cancer cases in Alberta, accounting for 0.4 per cent of the total population at the time. A 2007 study by the Alberta Cancer Board^{xiv} estimated that one in two Albertans will develop cancer during their lifetime and that one in four will die from it. New cases of invasive cancer in Albertans are estimated to reach 27,640 a year by 2030, almost triple the 11,283 new patients diagnosed in 2000^{xv}.

While individuals with cancer represent the most significant cohort of PEOLC patients, people of all ages and backgrounds can be affected by life-limiting or life-threatening illnesses. Two emerging populations of interest include:

Pediatric Populations

Ten to 15 of every 10,000 children (under 18) in Alberta (900 to 1400 children) require pediatric palliative care^{xvi}. Life-threatening conditions in children are rare; however, they are varied and often complex. Additionally, palliative antenatal care may be necessary for pregnant women whose fetuses have specific illnesses or conditions.

Indigenous Populations

The 2016 census by Statistics Canada indicates that 14 per cent of Canada’s First Nations population lives in Alberta, almost 137,000 people. Indigenous people experience barriers in accessing high-quality, culturally appropriate care. Shorter life spans due to health disparities and a high incidence of chronic-disease related deaths emphasize the value of access to PEOLC for Indigenous communities. However, many Indigenous communities are in rural settings, with little access to health centres adequately equipped to administer PEOLC services and a shortage of services incorporating Indigenous cultural practices. This leads to Indigenous individuals not necessarily being offered PEOLC or its uptake being low.

Cost of Delaying the Palliative Approach to Care

Palliative care can save between **\$7,000** and **\$8,000** per patient compared to acute care by reducing:

- the length of hospital stays and moving patients to lower-cost home care;
- intensive care unit admissions;
- unnecessary diagnostic testing; and
- inappropriate disease targeting interventions.

Source: Canadian Society of Palliative Care Physicians. *Economics of Palliative Care*. 2017.

To meet the needs of a growing and ageing population and mitigate higher costs for Alberta's health care system, it is necessary to strategically plan health care spending to use finite financial resources in the most cost-effective way.

Many recent US and Canadian^{xvii} studies on the health system's aggregate costs have concluded that palliative care is an effective way of using health care resources, reducing the cost of caring for people with life-limiting illnesses and freeing up much-needed hospital beds.

The Canadian Hospice Palliative Care Association cited an Ontario study that^{xviii} estimated that if just 10 per cent of end-of-life patients in acute care were transitioned to home care, \$9 million a year could be available for reinvestment into the health system. In addition, a study of seven US hospitals^{xix} found that instituting palliative care services reduced the cost of admissions and re-admissions. Overall cost avoidance was 1.5 times greater than the cost of administering palliative care services.

Between 2014, when the provincial PEOLC framework was introduced in Alberta, and January 31, 2021, the number of designated palliative care beds in acute care (hospitals) has decreased from 133 to 126. Over the same time period, publicly funded community designated palliative care beds increased by 35 to 257, due to a shift towards enhancing care in the community for PEOLC patients. Although this is progress, moving individuals from health care facilities to home care shifts some of the cost of care to families or caregivers through loss of income, equipment and supply purchases and missed financial opportunities. These impacts must be taken into account and supports for caregivers must be included within the provincial PEOLC framework.

Nevertheless, adopting the palliative approach to care when life-limiting diseases are diagnosed is an effective way of managing health care spending. It reduces the cost of delivering care, frees up acute care capacity and improves quality of life for patients with life-limiting illness and their families.

Public Perception

A 2016 IPSOS study^{xx} showed that only 50 per cent of Canadians know about palliative care. Moreover, there can be a perception among members of the public that participating in palliative care or discussions around it means that a patient is losing hope. A rejection of the idea of "imminent death" leads many individuals and their families to ignore or push back on palliative and end-of-life conversations. Furthermore, this study identified that the distinction between palliative care and end-of-life care is not always clear to the public. This understandable confusion can be heightened by clinical definitions of palliative care that define it as beginning when an individual only has a few months left to live. Another 2016 study^{xxi} found that such perceptions and misconceptions were common. Study participants were not fully aware of what palliative care provided or associated it with being bed-ridden and dying. Consequently, they rejected it, as they did not identify themselves as being at end-of-life.



Only half of Canadians are aware that PEOLC is available as a health service.

COVID-19

Lastly, COVID-19 continues to present an unprecedented challenge to Alberta's health care system and PEOLC. At the beginning of the pandemic, challenging restrictions on visiting loved ones at the end-of-life unequivocally and negatively impacted the health and well-being of patients, residents and their families. Feedback received during Chief Medical Officer of Health telephone town halls, from PEOLC operational leadership and hospices as well as feedback from families and residents, indicated the need to ease visitor restrictions at end-of-life. These changes made a profound difference to patients, residents, families and health care professionals. As we reflect on what we have learned during the past 20 months and move forward from this pandemic response, it will be critical to continue to balance physical safety and quality of life for those at the end-of-life.

WHAT WE HEARD

Early Palliative Care and Advance Care Planning

Albertans identified early palliative care as vital to maintaining quality of life. Early palliative care reduces aggressive interventions at the end-of-life. It improves patient outcomes by fully understanding illness and prognosis and bridging active treatment to palliative care. Additionally, ensuring accessible, timely, and appropriate access to quality palliative care may alleviate pain and suffering thereby potentially preventing or delaying Albertans' need to access MAID.

As the pathway to palliative care for Albertans receiving care for a non-cancer diagnosis is less clear than for individuals with cancer, early serious illness conversations are all the more vital when there are symptoms and indicators of shifts in condition. Nevertheless, patients tend to come into palliative care in crisis, making it challenging to provide quality care.

Although serious illness conversations are difficult, when palliative care is adopted early, it reduces negative impacts on the individuals and their families and decreases unnecessary admissions to intensive care or the emergency room. Tools such as the *Serious Illness Conversation Guide*^{xxii} exist to raise awareness and train health care providers to hold these essential yet difficult discussions.

An additional strategy that can better prepare Albertans with a life-limiting illness and their families to have a high-quality death is establishing an advance care plan. Advance Care Planning (ACP) is a process that supports adults in any state of health in understanding and determining their values, life goals and preferences for future medical care. Goals of Care Designations (GCD) are also important and are a medical order that specifies general care intentions, location of care and transfer opportunities for current and future care, and is signed by the most responsible health practitioner (usually a treating physician or nurse practitioner)^{xxiii}. With the rollout of the provincial ACP/GCD policy in 2014, which is inclusive of the Green Sleeves program, a significant emphasis was placed on education about, and promotion of, ACP.

The Green Sleeve is a plastic pocket that holds important ACP documents and other forms that outline a patient's goals for health care. It is given to patients cared for in AHS who have had discussions, or completed documents, that refer to decision-making about their current or future health care.

In September 2020, the Ministry of Justice and Solicitor General and Covenant Health started work to increase ACP adoption by embedding it into the social fabric and educating Albertans. Most recently, they engaged various government ministries and programs to identify opportunities to embed ACP into government initiatives to increase awareness and adoption.

The Palliative Approach to Care in Clinical Practice

The definition of PEOLC states it is an approach to integrated and coordinated care provided as a continuum over an illness trajectory. But the clinical focus remains on end-of-life care, which begins after a patient is given a six-month prognosis; end-of-life care is also frequently referred to as palliative care. This clinical approach creates confusion over the separate roles, stages and benefits of PEOLC and means that the system as a whole continues to be structured around this limited understanding. Additional considerations include the health care provider's lack of comfort or knowledge about conditions aside from cancer that can be treated with palliative care. Despite initiatives such as specialty supportive clinics and educational efforts to raise public and professional awareness of palliative care for non-cancer life-limiting illnesses in Alberta, there is still a need to educate providers about the prompt identification of individuals who would benefit from the palliative approach to care.

The Importance of Community

Community providers, such as hospice societies, play an essential role in the delivery of PEOLC. Over 27 societies exist across the province, with various service models. For example, they may support the operations of a stand-alone or community hospice bed(s); provide community palliative care services only; or, offer community palliative care services and sponsor palliative beds within a local continuing care facility. Many of the societies are volunteer-run and operate via donations and fundraising, which results in a strong grassroots presence. Hospice societies provide a wide range of services. They offer home visits and grief support, fund educational opportunities and work with local providers. In rural settings, they often provide resources for large geographic areas and work closely with AHS to support those who receive hospice services close to home. They face increasing demand and unpredictable funding (if they are not contracted with AHS). For those societies that provide psychosocial, grief and bereavement support, appropriately training volunteers is a challenge.

Infrastructure and Effective PEOLC Support in Rural Communities

It is necessary to carefully plan palliative home care capacity to buttress the early adoption of palliative care for Albertans, particularly in rural and remote settings. Due to the lack of palliative supports, many people need to leave their communities to access hospice care. Although this is a general problem for all rural Albertans, its effects are felt with particular severity in remote and Indigenous communities.

Through increasing home care capacity, building upon already established resources, such as the provincial Rural Palliative Care In-Home Funding Program and adopting innovative models such as self-directed care, several opportunities exist to increase access to PEOLC in the community. Planning must be integrated and consider health workforce, transportation and access to community supports (e.g. pharmacies and equipment) as these remain challenges in keeping Albertans close to home or within their communities.

Capacity planning, therefore, should be carried out in an integrated manner to build upon the specialized palliative home care model. While the way services are delivered in rural areas may not be identical to how they are provided in cities, these models will be more responsive to specific needs.

Alberta has a territory of almost 662,000 square kilometres for a population of 4.4 million inhabitants. Although its population density of 6.6 people per square kilometre is average for a Canadian province, more than 1.2 million Albertans, 29 per cent of the total population, live in rural zones. These areas have lower population densities, for example, the North Zone, only one person per square kilometre.

Training and Education

All participants agreed that increased education and training for health care professionals, families, caregivers and volunteers is fundamental to improving PEOLC, whether at home or in a health centre setting.

After attending undergraduate health professional training, health care providers typically require specific training in PEOLC to better understand and implement symptom control and medication management. However, not all health care providers may treat a large enough volume of patients to maintain this training. Moreover, in rural settings, attending training often requires travelling to a larger centre, hotel costs, and time off work. These are all barriers, especially if these costs are not reimbursed or subsidized by the employer.

Several review participants noted that palliative educational programming is part of the portfolio of training courses available at AHS; however, these courses are not readily available to non-AHS providers (i.e. primary care, some continuing care, and community organizations). Nevertheless, often the courses do not have dedicated instructors, relying instead on clinician time. The reliance on clinicians is also problematic because ensuring that the content is updated and supported by evidence requires time. Nevertheless, there was a consensus that the Learning Essential Approach to Palliative care (LEAP) program is a valuable training option in Alberta. LEAP is an evidence-based interdisciplinary education program offered across the province that is widely seen as beneficial in teaching essential PEOLC skills. It supports interdisciplinary teams, targeting different health providers and practice areas such as long-term care, paramedics and the emergency department, and can also be delivered online.

Moreover, physicians attend LEAP readily as it is attached to continuing education credits, and residents complete the program during their time with PEOLC consult teams. As LEAP is a proprietary program the associated costs can be a barrier to access, particularly for health care aides and allied service providers.

Supports for Families and Caregivers

Families and caregivers, who play a vital role in supporting the death and dying process, lauded the committed healthcare providers who remained by their side throughout the process. While experiences were mostly positive towards the end-of-life, many patients and their families reported facing obstacles during the early diagnosis period and interactions with the health care system. Lack of communication and information created confusion and uncertainty for families. They indicated they would have benefited from frank conversations with healthcare providers, so they could adequately prepare for the death and dying process. Additionally, receiving written and clear pathways describing the treatment journey (i.e. what to expect), available resources, and post-death grief and bereavement support would significantly improve their experience. Finally, following the death of a loved one, the abrupt disconnection from the healthcare system after establishing such an intimate relationship with healthcare providers was often jarring.

“When my wife died, my relationship with her care team ended as well. I felt alone and without purpose. Grief and bereavement support saved my life.”

– Family member

The Impact of Community-Based Health Care Services

Across the province, many initiatives have been developed to increase Albertans' access to PEOLC. The review participants identified four community-based health services that made or have the potential to make significant impacts to keep individuals at home or in their community as long as possible.

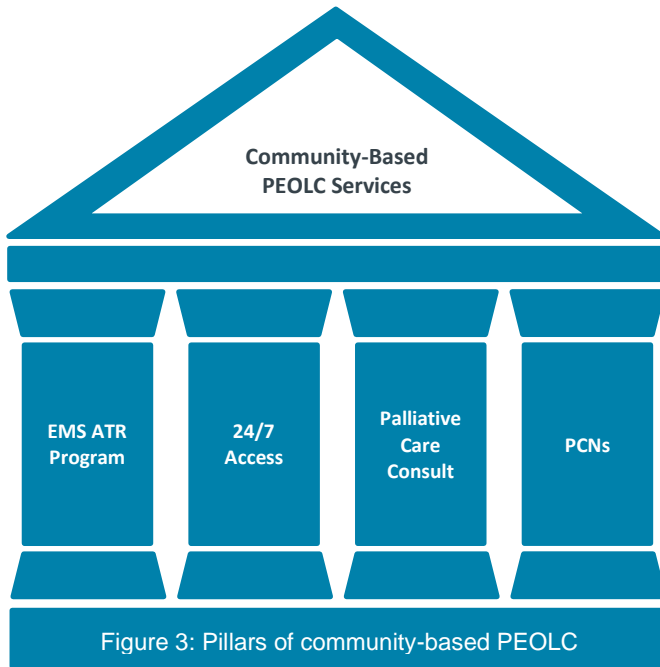


Figure 3: Pillars of community-based PEOLC

AHS Emergency Medical Services PEOLC Assess-Treat-Refer Program

The AHS Emergency Medical Services PEOLC Assess-Treat-Refer program is designed to support people and their families who have chosen to remain at home for PEOLC. This is a non-lights and sirens response where paramedics can assist the health care professional to manage symptoms with additional medications as well as collaborate on the phone with the palliative physician on call or an online medical consult. The goal is to manage the patient's symptoms in order to support staying in the current setting of care and avoid transfer and admission to the emergency department. This program is also available to the pediatric population and individuals who live on reserves^{xxiv}. Unequivocally, all review participants who had experience with the program benefited from these services. The program is working and helping to keep individuals with life-limiting illnesses at home, but its reach can be insufficient. Participants indicated that around Camrose and Red Deer, for example, action radius is limited to 50 kilometres. This is particularly limiting for rural Albertans, reducing the possibility of receiving quality care at home or in the community.

24/7 Access to Health Services and Medication

The provincial 24/7 Palliative Physician On-Call Service is designed to support physicians in all areas of the province, especially those in primary care and in rural settings who provide PEOLC^{xxv}. However, the need for additional 24/7 services and resources have been identified as an essential component to keeping patients in their community. Healthcare providers, both physicians and nurses (including Nurse Practitioners), must be available at night and on weekends. Patients also need extended access to hospice and community support beds if more care is needed than can be provided at home. Around-the-clock access to medication is required as well. For example, some review participants highlighted the importance of extended access to injectable medicines and remedies to treat pain, shortness of breath and agitation for dying patients at home. Rural Albertans, in particular, have difficulty accessing health services and medication outside of standard business hours.

Palliative Care Consult Services

The Palliative Care Consult service supports individuals with life-limiting illnesses and their families and care teams in managing complex symptoms that can be treated with PEOLC. This service is seen as providing beneficial support to frontline care providers, such as home care nurses, and acute and continuing care facilities. Some zones highlighted the success of a collaborative approach with integrated consultative teams. The teams keep patients on the caseload for the duration of PEOLC, with home care and allied health support, rather than immediate discharge after initial interactions. Many of the rural palliative care consult teams also support home care nurses working on reserves.

Primary Care Networks

Alberta's PCN model offers access to chronic disease prevention and management programs. However, many providers require additional training and support to ensure early access to PEOLC. Additionally, primary healthcare teams would benefit from increased awareness of available community resources that support providers and families. Significant opportunities exist to integrate the palliative approach to care by developing and piloting pathways for common chronic illnesses. However, physicians and other healthcare providers are often not sufficiently confident, skilled or have limited time to engage in detailed conversations about disease trajectory, ACP and palliative care; this, therefore delays access. Greater collaboration and resources can be considered to increase capacity within PCNs, to support Albertans with life-limiting illness.

System Navigation

Review participants described the abrupt transition from active treatment for advanced life-limiting illnesses to palliative care can cause significant distress to individuals and their families and caregivers. A delay in beginning palliative care can mean more inappropriately aggressive and expensive active treatment.

Information collected by AHS^{xxvi} on patients in Alberta with metastatic gastrointestinal cancers highlights that 60 per cent of individuals were referred late or not at all to palliative care. Half of these patients received inappropriately aggressive care, whereas only a quarter of those referred early to palliative care did. Other evidence cited by AHS indicates that integrating an early palliative approach to care with cancer care improves outcomes for patients.

Some pathways to support an individual's transition from chronic disease management to palliative care exist, but they are not always integrated into practice. Health care providers need the tools and skills to have wide-ranging conversations about palliative care and help individuals and allied care providers access the complex health care system. A dedicated approach to "palliative navigation", embedding system navigators into interdisciplinary services would be beneficial.

If non-specialist palliative care providers are to provide high-quality care in busy primary and specialty care settings, it is important for them to take the time to sit and listen to patients' hopes and concerns. This is key to patients feeling heard, understood and valued when living with a life-limiting illness. Building a rapport, trusting relationships and understanding how to navigate the system helps patients live comfortably in their preferred location for longer or die at home.

The physicians who participated in our review identified that workflows should be reconsidered to prioritize and enable time to be spent with patients. Healthcare aides, nurses, allied health and physicians all need the incentives and efficient workflows that enable home visits and double clinic appointment times to provide the time necessary to meet patients' emotional, physical, social or spiritual needs.

The Continuing Care System^{xxvii}

The medical and social needs of residents and clients of continuing care are becoming increasingly complex. This is illustrated by decreasing lengths of stay (LOS) within long-term care. The problem is exacerbated by a greater emphasis on discharging into the community following a shorter acute care stay. Many residents and clients within continuing care are living with complex conditions such as dementia and frailty. Frailty is an age-related syndrome due to an accumulation of deficits, loss of reserve, and increased vulnerability to stressors of all kinds. It is one of eight syndromes^{xxviii} within ageing that are potentially preventable and/or modifiable and can negatively contribute to worsening health status in Alberta's seniors. Undiagnosed frailty can contribute to delirium, chemotherapy intolerance, functional decline, increased disability, long term care admissions, hospitalization, mortality, and decreased quality of life.

Review participants also identified the opportunity to offer PEOLC to Albertans diagnosed with dementia.

In 2019-20, an estimated **69%** of Albertans in designated supportive living (DSL) and an estimated **79%** of Albertans in long-term care were living with dementia.

Source: Alberta Continuing Care Information System and Alberta Health Services

Through actively managing frailty and dementia within home care and facility-based continuing care, Alberta can divert individuals from acute care and promote effective ageing in place. This includes shifting the emphasis away from medical management of disease towards optimizing comfort and wellbeing, client goals and strengths, nutrition, sleep, rehabilitation, recreation and relational care. However, the implementation of PEOLC to manage frailty and dementia requires increased training/education, staff, and an overall shift towards this care philosophy -- this may be achieved through changes to the [Continuing Care Health Service Standards](#) and implementing recommendations in the [Facility-Based Continuing Care Review](#).

Initiatives focused on enhancing home and community care and the Facility-Based Continuing Care Review have identified the need to modernize Alberta's continuing care system. As such, several opportunities exist to incorporate PEOLC concepts into strategic policy foundations.

Specific PEOLC Approach for Indigenous Communities

Indigenous peoples have a lower life expectancy than other Albertans, due to historical and systemic health disparities, and have a high incidence of chronic disease-related deaths. The role of an integrated palliative care approach, tailored to cultural practices, is of particular interest to these populations. However, most Indigenous communities are in rural Alberta in areas that generally have small health centres that may not provide culturally informed palliative care services.

AHS recently established two Indigenous navigator roles to decrease barriers and increase access to vital services, and the impact is encouraging. There are also Indigenous representatives on AHS's provincial PEOLC innovations steering committee.

Review participants stated that Indigenous cultural end-of-life practices—referred to as Wise Practice—are not widely endorsed by the scientific community. Moreover, some traditions require the availability of space, which is seldom available in health centres. Consequently, there is a shortage of services, resource capacity, and facilities that can appropriately incorporate Indigenous cultural practices, leading to Indigenous individuals not being offered PEOLC and low uptake.

Specific PEOLC Approach for Underserved Communities

The population of Alberta is diverse and will increasingly become more so. Newcomers are predicted to form 54 per cent of Alberta's population in 25 years^{xxix}. PEOLC needs, access, and uptake vary across cultures. PEOLC services must be tailored to provide quality care to all Albertans, including people facing homelessness and individuals with language or cultural barriers. People facing homelessness should be given particular attention among the vulnerable groups. The Saint Elizabeth Research Centre has defined homelessness itself as a life-limiting and chronic health condition^{xxx}, but because of social stigma, discrimination and mistrust, individuals facing homelessness are often unable or unwilling to access health care. The Calgary Allied Mobile Palliative Program (CAMPP) and George's House in Edmonton are examples of programs that offer palliative care consultations and care navigation for people who are experiencing homelessness and other vulnerable populations. In addition, there are some dedicated palliative hospice beds in shelters serving homeless people in both Edmonton and Calgary.

There is a highlighted need for dedicated strategies for equitable PEOLC access for vulnerable populations across Alberta.

Vulnerable communities often build trusting relationships with social workers, shelter workers or addiction workers. These professionals have the potential to guide vulnerable individuals on how to access palliative care if they gain the appropriate knowledge.

Grief and Bereavement

PEOLC does not end when the patient dies. Grief and bereavement counselling for the family and caregiver is an integral part of the PEOLC continuum. Not all of the bereaved require professional services, but many do. However, existing mental health services do not always have the expertise and capacity to provide grief and bereavement counselling.

Everyone grieves differently, but the grief experience may be different when the loss occurs after a long illness rather than suddenly. When an individual has a chronic or life-limiting illness, their family, friends and even the individual themselves might start to grieve in the expectation of death. This normal response is referred to as anticipatory grief and can help people prepare themselves and their loved ones for the coming loss. However although death is expected, people may still not be prepared for the loss and shock. Unexpected feelings can arise after the loss of a loved one. Parents of children with a life-limiting illness have a significant need for grief services, but access is variable across the province.

The availability of specialized bereavement services is not consistent across Alberta. Many individuals requiring counselling do not have access to this integral part of PEOLC. Lack of access can be further exacerbated as grief and bereavement counselling services are often funded through one-time funding, through charitable donations, or a combination of both. This adds to the disparity. Albertans may or may not have access to specialized counselling depending on where they live and uncertain funding streams impact the viability of the service and make it difficult to sustain on a long-term basis.

To attempt to combat this gap, the Alberta Hospice Palliative Care Association was provided funding in September 2020, to establish in-person and online support groups, develop Alberta's first telephone peer-grief support line and expand workshops on PEOLC for Albertans.

“We walk along with patients and their families on this journey, wherever and however it will end.”

– Service Provider

RECOMMENDATIONS

Addressing chronic and life-limiting illnesses through the palliative approach to care allows individuals with life-limiting conditions to benefit from symptom management and psychological support early in their illness while pursuing therapy and treatment. The approach can further reduce an individual's suffering by managing pain and symptoms, supporting family and caregivers and reducing overall costs for health services as the illness progresses.

Integrating the palliative approach to care into chronic disease management recognizes three critical advancements within the health care system. Firstly, advances in treatment are changing illness trajectories, allowing people with chronic or life-limiting illnesses to live longer, albeit often with pain, loss of function or other symptoms. Secondly, palliative care is a holistic, person-centred approach that offers value to all people with serious illnesses. Finally, high-quality palliative care can enhance health and quality of life and reduce the utilization of more costly health services.

For the palliative approach to care to benefit Albertans, it needs to be fully integrated into the health system and become a part of health care thinking planning and delivery. To achieve this, additional investment is necessary, in four main areas, to achieve the following priority recommendations.

RECOMMENDATION 1 Earlier Access

Primary care (PCNs, physician offices, and community health centres) and continuing care (home care and facility-based continuing care) providers should adopt the palliative approach to care once an individual is diagnosed with a life-threatening or life-limiting condition, including age-related chronic conditions such as dementia. This includes establishing quality standards and standards of practice for these care settings.

To reinforce the critical importance of integrating palliative care into chronic and life-limiting illness management, PCNs should work to incorporate the palliative care standard for chronic disease clinics and programs. The focus should be primarily on access to essential services such as ACP, providing information on disease prognosis and trajectory, and regular discussions about goals of care at critical stages in the disease. Additionally, many clients and residents within continuing care would benefit greatly from this approach.

Specific quality standards should be developed for PEOLC, including mechanisms to register and monitor sites. Accreditation and quality improvement programs should also adopt standards for symptom management and the patient's knowledge of their illness and its implications. These standards should apply across the health sector and not just to specialized chronic disease management or cancer care clinics.

RECOMMENDATION 2

Education and Training

PEOLC competencies, the palliative approach to care and its benefits and serious illness conversations should be incorporated into health care and allied service provider entry-to-practice curricula and continuing professional development. Health service providers and/or community organizations should develop standardized training for families, caregivers and volunteers to increase their capacity to care for their loved ones at home and in their communities.

The competencies that health care workers need to provide PEOLC are identified and well understood in Alberta's health care system, although not wholly addressed in entry-to-practice education. To establish the palliative approach to care that is fully integrated into the health care system, health care and allied service providers must have an improved understanding of the interdisciplinary approach and training on serious illness conversations. This training needs to occur in entry-to-practice education and incorporated into continuing professional development. Additionally, families and caregivers would benefit from training to better support their loved ones in their homes. Volunteers also play a significant role in supporting Albertans and their families in the community and more training/education would amplify their impact.

RECOMMENDATION 3

Community Supports and Services

Government, AHS, and their partners, should grow and expand community-based PEOLC services via home and community care programs and facility-based continuing care. This includes establishing effective caregiver supports, such as respite, and offering high-quality grief and bereavement services.

Keeping more Albertans with life-limiting illnesses at home or in their communities requires increased home care capacity, with improved primary care integration. Leveraging current initiatives aimed at modernizing home care and facility-based continuing care can serve as a springboard for action.

While traditional capacity planning focuses on how many beds are required in facilities, Albertans, particularly in rural settings, can benefit from hospice-like services in their homes, thus optimizing hospice capacity. Enhanced caregiver support, including increased access to respite services, grief and bereavement programs, can help achieve this goal.

Additionally, stand-alone hospices face challenges in maintaining sustainable operational budgets and workforce. An economic analysis of adopting the palliative approach to care within acute and continuing care settings while identifying sustainable funding models for hospice is required. This analysis can account for access and use demographic growth projections for the coming 25 years in planning and mapping funding to meet Alberta's future palliative care needs.

RECOMMENDATION 4

Research and Innovation

Government should invest in establishing additional navigation and care pathways for the transition of chronic disease management to PEOLC while considering access and barriers to services and addressing social determinants of health.

Increased funding aimed at establishing navigation and care pathways for common chronic diseases would greatly benefit Albertans and further enhance access for underserved communities, Indigenous groups and vulnerable populations. Additionally, research programs and community organizations can collaborate to share information and integrate learnings creating seamless transitions between health and social services.

CONCLUSION

All Albertans will be touched by a life-limiting illness, whether their own or that of a loved one. The palliative approach to care can and should be integrated into care for every individual, starting as early as possible in the disease trajectory. Systemic shifts, through improving access, bolstering education and training, expanding community based services and improving system navigation and fostering innovation, will ensure that Albertans are effectively supported to meet PEOLC needs at home and in their communities.

PEOLC is centred on the individual, their expectations and cultural and spiritual beliefs. Albertans are diverse, so attention to diversity needs to be part of the palliative approach to care. We heard that access to services for rural populations, Indigenous people, immigrants and vulnerable populations such as the homeless must be prioritized when delivering PEOLC in Alberta. There are many reasons to have hope in the future. The people, providers and communities who deliver PEOLC in Alberta are committed, passionate and resilient – a solid foundation to meet, overcome, and surpass any challenges ahead.

APPENDIX 1 – PARTICIPANTS

NAME	ORGANIZATION OR TITLE
Dan Williams, MLA Peace River	Project Lead
Dion Penner & Samson Epp	Legislative Coordinators
Patients, Families and Caregivers	
John Cabral	(former) Assistant Deputy Minister, Health Service Delivery Division, Alberta Health
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Michelle Peterson Fraser	Director, PEOLC, Provincial Seniors Health and Continuing Care
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Dr. Bev Wilson	Physician, Pediatrics
Dr. Debbie McAllister	Section Chief, Palliative Medicine, Department of Pediatrics. Medical Director, (CHaPS)
Dr. Naomi Goloff	Physician, Pediatrics
Karen Butel	Manager, Pediatrics, Calgary Zone
Natalie Houseman	Patient Care Manager, Pediatric Oncology, Hematology and Palliative Care
Brenda Rehaluk	Director of Health for Bearspaw Nation, Eden Valley
Cherie Willier	Nurse in charge for Sucker Creek First Nation
Nicole Liboiron	Home and Community Care Regional Coordinator, First Nations and Inuit Health- Alberta Region
Pam Tailfeathers Buffalo	Home and Community Care Manager, First Nations and Inuit Health- Alberta Region
Tracy Lee	Lead, Indigenous Health, North Zone
Bev Berg	Director, PEOLC, Calgary Zone
Donna Rose	Project Manager, Person-Centred Care Integration, Provincial Practices, CancerCare Alberta
Dr. Sharon Watanabe	CancerCare Alberta
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Karen Fritz	Director - Integrated Home Care, South Zone, Seniors Health
Mary Sabbe	Central Zone Practice Lead, Palliative Care

Michelle Podmore	Director Palliative/End-of-life Care and Community Programs, Edmonton Zone
Terri Woytkiw	Lead, North Zone
Tracy Reberger	Acute Care Manager, Central Zone
Dr. Bev Wilson	Physician, Pediatrics
Dr. Naomi Goloff	Physician, Pediatrics
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Natalie Houseman	Patient Care Manager, Pediatric Oncology, Hematology and Palliative Care
Dr. Cara Robertson	Palliative Medical Director, North Zone
Dr. Charlie Chen	Medical Director, Palliative/End-of-life Care, Calgary Zone
Dr. Dionne Walsh	Palliative Medical Director
Dr. Eric Wasylenko	Medical Advisor, HQCA - Clinical Ethics
Dr. Ingrid DeKock	Section Chief, Palliative Care Program, Edmonton Zone
Dr. Josh Foley	Palliative Medical Director
Dr. Maureen McCall	Medical Director, Palliative Care, Central Zone
Dr. Peter Davis	Primary Care Physician
Andrew Kennedy	Senior Consultant, Strategic Coordinator
Aurora Leang	Lead, PEOLC, Provincial Seniors Health and Continuing Care
Emma Buzath	Lead, PEOLC, Provincial Seniors Health and Continuing Care
Carleen Brenneis	(former) Director, Palliative Institute, Covenant Health
Dr. Konrad Fassbender	Assistant Professor, Division of Palliative Care Medicine, Department of Oncology, University of Alberta, Scientific Director, Palliative Institute, Covenant Health
Karen Macmillian	Senior Operating Officer, Acute Services, Grey Nuns Community Hospital, Senior Lead for Palliative and End-of-Life Strategy, Covenant Health
Kristi Puchbauer	Chief Executive Officer, Alberta Hospice Palliative Care Association
Arrow Big Smoke	Indigenous Patient Navigator
Drs. Aynharan Sinnarajah and Jessica Simon	PaCES – Palliative Care Early and Systemic , University of Calgary
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Christene Gordon	Alzheimer Society of Alberta and Northwest Territories
Dr. Jose Pereira	Scientific Director, Pallium Canada
Jeffrey Moat	Chief Executive Officer, Pallium Canada
Janet Daghish, Tammy Whittaker, Daren Farnel, Sherry Hnatyshyn, Karl Frank	Bayshore HealthCare
Dr. Vincent Thai, Dr. Lawrence Lee and Dr. Ingrid DeKock	University of Alberta – Department of Oncology
Primary Care	Primary Care Network Governance Committee
Continuing Care Representatives	Alberta Continuing Care Association Christian Health Association of Alberta Alberta Seniors and Community Housing Association

Alberta Hospice and Palliative Care Society - North Zone	<ul style="list-style-type: none"> Peace Palliative Care Society Whitecourt Hospice Society Bonnyville Palliative Care Committee Catholic Women's League - St. Gabriel's Parish Central Peace Palliative Committee Cold Lake Palliative Care Society Elk Point Palliative Care Society Fairview and Area Palliative Care Society Grande Prairie Palliative Care Society High Prairie & District Holistic Palliative Care Society Lakeland Hospice Society Manning & District Palliative Care Society Peace Palliative Care Society Smoky River Palliative Care Society Westlock and District Palliative Care Society Whitecourt Cancer and Wellness Society
Alberta Hospice and Palliative Care Society - Edmonton Zone	<ul style="list-style-type: none"> Dr. Witharna and Pilgrims Hospice George's Hospice Heartland Community Hospice Light Up Your Life Tri-Community Palliative/Hospice Care Society St. Albert Sturgeon Hospice Association
Alberta Hospice and Palliative Care Society - Central Zone	<ul style="list-style-type: none"> Akasu Palliative Care Society Compassionate Care Hospice Society Hospice Society of Camrose & District Lacombe Palliative Care Society Stettler Hospice Society Olds and District Hospice Society Ponoka/Rimbey Palliative Care Council Red Deer Hospice Society Sundre Palliative Care Association
Alberta Hospice and Palliative Care Society - Calgary Zone	<ul style="list-style-type: none"> Airdrie and District Hospice Society Cochrane and Area Hospice Society Foothills Country Hospice Society Palliative Care Society of the Bow Valley Hospice Calgary Wheatland and Area Hospice Society Palliative Care Society of Bow Valley Dr. Colgan and Calgary Allied Mobile Palliative Program Sharp Foundation
Alberta Hospice and Palliative Care Society - South Zone	<ul style="list-style-type: none"> Prairie Rose Hospice Palliative Care Society

REFERENCES

- ⁱ Life Expectancy in Alberta, at Birth and Age 65. 2021; <https://open.alberta.ca/opendata/life-expectancy-in-alberta-at-birth-and-age-65>
- ⁱⁱ Branchard, B., Deb-Rinker, P., Dubois, A., Lapointe, P., O'Donnell, S., Pelletier, L., & Williams, G. 2018. At-a-glance - How Healthy are Canadians? A brief update. *Health promotion and chronic disease prevention in Canada: research, policy and practice*, 38(10), 385–387.
- ⁱⁱⁱ AHS Palliative and End-of-Life Care: Alberta Provincial Framework. 2014; <https://www.albertahealthservices.ca/assets/info/seniors/if-sen-provincial-palliative-end-of-life-care-framework.pdf>
- ^{iv} Ibid.
- ^v Ibid.
- ^{vi} Ibid.
- ^{vii} Ibid.
- ^{viii} Canadian Hospice Palliative Care Association. Milestones in Hospice Palliative Care. 2021; <https://www.chpca.ca/about-hpc/milestones-in-hospice-palliative-care/>.
- ^{ix} AHS Palliative and End-of-Life Care: Alberta Provincial Framework Addendum. 2021; <https://www.albertahealthservices.ca/assets/info/peolc/if-peolc-prov-framework-addendum.pdf>
- ^x Population Projects: Alberta and Census Divisions, 2020—2046. Treasury Board and Finance. 2020; <https://open.alberta.ca/dataset/90a09f08-c52c-43bd-b48a-fda5187273b9/resource/bb7c6ef6-ade5-4def-ae55-ef1fd5d4e563/download/2020-2046-alberta-population-projections.pdf>
- ^{xi} Ibid.
- ^{xii} For reference, in 2017, 54.7% of Albertans died in hospital while 17.4% died at home. This is compared to 48.7% dying in hospital in 2020 and 22.9% dying at home (Alberta Health Services, Tableau, PEOLC Vital Statistics Data on Death in Alberta Dashboard).
- ^{xiii} <https://public.tableau.com/app/profile/cancercontrol.ab/viz/The2021ReportonCancerStatisticsinAlberta/Highlights>
- ^{xiv} Alberta Health Services. Cancer in Alberta: A Regional Picture 2007. 2007; <https://www.albertahealthservices.ca/assets/healthinfo/poph/hi-poph-surv-cancer-regional-report-2007.pdf>
- ^{xv} Ibid.
- ^{xvi} Ibid.
- ^{xvii} Canadian Society of Palliative Care Physicians. Economics of Palliative Care. 2017; <http://www.cspcp.ca/wp-content/uploads/2017/02/Economics-of-Palliative-Care-Final-EN.pdf>
- ^{xviii} The Way Forward Initiative. Cost-effectiveness of Palliative Care: A Review of the Literature. <http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf>
- ^{xix} Canadian Society of Palliative Care Physicians. Economics of Palliative Care. 2017; <http://www.cspcp.ca/wp-content/uploads/2017/02/Economics-of-Palliative-Care-Final-EN.pdf>
- ^{xx} Canadians' Views on Palliative Care, Erin Roulston IPSOS Canada. 2016; <https://pubmed.ncbi.nlm.nih.gov/29283877/>
- ^{xxi} Camilla Zimmermann, Nadia Swami, Monika Krzyzanowska, Natasha Leighl, Anne Rydall, Gary Rodin, Ian Tannock, Breffni Hannon. Perceptions of palliative care among patients with advanced cancer and their caregivers. *CMAJ* Jul 2016, 188 (10) E217-E227.
- ^{xxii} Virtual Hospice. Serious Illness Conversation Guide. 2017; https://www.virtualhospice.ca/Assets/SI-CG-2017-04-21_FINAL_20190122135905.pdf
- ^{xxiii} Alberta Health. Advance Care Planning. <https://myhealth.alberta.ca/advance-care-planning/learn-about-the-goals-of-care-designation-order/general-approaches-to-care>
- ^{xxiv} Alberta Health Services. EMS PEOLC Assess, Treat and Refer Program. <https://www.albertahealthservices.ca/info/page14557.aspx>
- ^{xxv} Alberta Health Services. 24/7 Palliative Physician On-Call Services. <https://www.albertahealthservices.ca/info/Page14556.aspx>
- ^{xxvi} Alberta Health Services. Integrating an Early Palliative Approach into Advanced Colorectal Cancer Care. 2020; <https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-guide-metastatic-colorectal-early-palliative-cancer-care.pdf>
- ^{xxvii} The continuing care system includes homecare, supportive living, designated supportive living and long-term care.
- ^{xxviii} Litchford et al. Eight syndromes in older adults, associated with functional decline, disability, institutionalization and mortality, that can be modified using primary and secondary preventions. Counteracting the trajectory of frailty and sarcopenia in older adults. *Nutr Clin Pract* 2014;29(4):428-434.
- ^{xxix} Ibid.
- ^{xxx} Saint Elizabeth Health Care. A palliative approach to care for non-healthcare workers supporting people who are homeless. 2018; https://research.sehc.com/SEHCRResearch/media/Research_Centre/pdfs/DDG-285-2018_09_27_ROT-ROTR-Co-designing-curriculum.pdf