

A Resource Guide for Community Development of Palliative and End-of-Life Care within Alberta

An initiative led by Alberta Health Services

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All links provided in this guide are current as of February 1, 2024. Please e-mail palliative.care@ahs.ca if you note any broken links and/or you have information that would contribute to this guide.



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Background

Communities across Alberta are seeking information about developing local Palliative and End-of-Life Care (PEOLC) community services and support. Alberta Health Services (AHS) realized communities were working in isolation, each starting from scratch without access to a common source of basic information. To address this need a Working Group was formed to develop a Resource Guide to assist communities to build their local PEOLC capacity. To achieve this goal it was necessary to identify common information needs of Alberta communities. The Working Group developed a survey that was distributed to participants of the Alberta Hospice Palliative Care Association Imagine Conference in November 2015. From the survey results several common themes were identified to form the basis of this resource guide.

From the broad range of survey responses it was evident that each local situation is different. Therefore, each community needs to assess and address its own local needs in collaboration with health and other community supports. The resource guide is not a route map, but rather a guide to help with the needs of communities across Alberta.

The current landscape of PEOLC is emphasizing a need for the involvement of the whole community to address the needs of those suffering from life-limiting illnesses. Most of the survey responses referred to the need for programs and services and how to develop them. To make this whole-community concept a focus in the resource guide an additional theme called the “compassionate community” has been included.

It is also important to remember that PEOLC does not end with the death of the patient, but extends beyond death into bereavement. Families can often benefit from companionship and support for a long time after the death of a loved one.

The Resource Guide cannot include all possible sources of information relevant to PEOLC, nor can it cover all scenarios that may arise within a community. In this resource guide, the focus is on identifying core sources of information under each theme.



Definitions

For the purpose of the resource guide we are using the following definitions:

- 1) Community: Any group of people who share common ideas and values, in this case in relation to the promotion and support of palliative and end-of-life care. A community in this context does not refer to a specific geographical identity, but could include a city, a region, or even a whole province.
- 2) Community support: Any service or resource provided in or available to, a community to support programs enabling people to live well until they die without leaving their locality.
- 3) Palliative and End-of-Life Care (PEOLC):
 - Palliative Care aims to improve the quality of life of patients and 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.
 - End of Life Care is care provided to an individual and their family when they are approaching a period of time closer to death, which may be exemplified by an intensification of services and assessments.
<http://www.albertahealthservices.ca/assets/info/seniors/if-sen-provincial-palliative-end-of-life-care-framework.pdf>

Format

Many of the referenced links contain information on a wide range of PEOLC topics. Such links have been listed in the resource guide under each of the themes. The resource guide provides a focus on available information for local community PEOLC groups. Some links to general information on PEOLC are included in Appendix A. These resources will be reviewed annually to ensure all links are up to date and current.

Methodology

This Resource Guide is a collection of information from a number of sources and consulted stakeholders (appendix C). A survey was distributed to Alberta hospice societies and PEOLC organizations in attendance at the 2015 Alberta Hospice Palliative Care Association Imagine Conference. The goal was to understand issues and needs from communities in Alberta around the development of PEOLC supports and/or community services.



The survey (appendix B) contained seven open-ended questions asking respondents to provide feedback on:

- best source of information / encouragement that has supported their goals to date and would be helpful for PEOLC in other communities;
- raising public awareness on their activities;
- type of information that would have been helpful when they started; and
- barriers they encountered in developing community supported palliative and hospice care in their region.

Each of the representatives from the Alberta hospice societies and PEOLC organizations who attended the Imagine Conference completed a survey and brought additional copies to their boards and organizations to gather further responses. The responses received were combined and a list of key themes were developed.

In order to obtain additional feedback on the Resource Guide, a draft was circulated to a wide variety of stakeholders for review and feedback. During this process Alberta Health Services PEOLC leaders also received a copy of the draft to review.

Any general questions regarding local PEOLC development issues not covered in this guide can be e-mailed to palliative.care@ahs.ca



Compassionate Communities

When there is a life limiting illness, health services on their own can never meet all the needs of patients and families. We are all relational, with social, spiritual, emotional, and physical needs, and it is within compassionate communities that these needs can best be met. Compassionate communities are communities where people, motivated by compassion, take responsibility for and care for each other (refer to appendix D). An example of how a compassionate community supports a person with a serious life limiting illness is to provide a delivery of scheduled meals by volunteers within the community.

Resources and sharing capacity-building experiences among communities are needed for Alberta communities. Across Alberta, PEOLC is provided for patients and families in many different settings, with a variety of programs and services. While there are some exceptional service delivery models and programs, they are not available everywhere, creating inequity of services for Albertans. Smaller communities that have limited health services have seen their members leave the community when care needs exceed what can be provided locally. Members of communities who are overlooked through poverty, homelessness, mental illness and addictions encounter significant barriers to health services access and therefore receive limited support for advancing, life-limiting illness.

In order to provide access and high quality integrated PEOLC services to all Albertans, a [PEOLC Alberta Provincial Framework](#) was developed in 2014. The Framework recommended 36 initiatives to be developed to address the existing PEOLC program and service gaps in Alberta. A number of initiatives have been completed with a focus on increasing community capacity and avoiding PEOLC acute care admissions. A few examples include:

- the PEOLC EMS Assess, Treat and Refer program,
- 24/7 Palliative Physician On-Call support to primary care physicians,
- a centralized access to resources and information on PEOLC through a provincial PEOLC website <https://myhealth.alberta.ca/palliative-care>

In addition, academic programs in palliative medicine and advance practice palliative nursing are available through both the University of Calgary and the University of Alberta. Knowledge transfer initiatives such as training, research, and community engagement have led to improvement in PEOLC service availability in many communities.

It is clear that in Alberta we are just beginning to build community capacity. Capacity is only beginning to be developed worldwide, and because of our unique circumstance in having a regional health authority, we find ourselves in a position of providing leadership in developing a truly collaborative approach to PEOLC that responds to local needs. We hope there will be increased interest and investment in the evolution of community



capacity for PEOLC in a collaborative relationship with health service providers, which will enrich communities and help ensure sustainable health care capacity (appendix D).

Please refer to the following links and documents that support compassionate communities:

- The concept of a compassionate community is expanded upon in the Milford website in the videos, “Bill’s story” and “Did you hear about Bill?” [Bill's Story](#)
- Information on Advance Care Planning and Goals of Care Designation is available at www.conversationsmatter.ca
- A venue that promotes talking about death and dying is found on deathcafe.com



Getting Started

The development of a compassionate community as described on pages 8-9 does not just happen. The community is initiated by the calling together of a group of individuals committed to the promotion and support of PEOLC activities in their area. Each community is unique and will have differing needs and goals in relation to PEOLC. There is no one pathway for communities to follow. Each community will need to determine its own goals and objectives, and work out its own way of achieving them. There are certain features that are common to most, if not all, PEOLC supports and services. The following list is not exhaustive or in chronological order. It is provided to give some guidance to be considered by each local group as it begins to develop their own compassionate community.

Initial considerations for community initiatives addressing PEOLC:

- 1) Inform yourselves on what PEOLC includes:
 - a. Start with 'Bill's story' video [Bill's Story](#)
 - b. Attend an AHPCA Roadshow - <https://ahpca.ca/programs-services/alberta-hospice-palliative-care-association-roadshow/>.
 - c. Look around on the internet at sites like the Canadian Virtual Hospice which includes a broad variety of PEOLC topics including the indigenous people's approach to death and dying: www.virtualhospice.ca. For Indigenous Perspectives on Death and Dying inclusive of the Cree: <http://www.cpd.utoronto.ca/endoflife/Slides/PPT%20Indigenous%20Perspectives.pdf>
 - d. Informally talk to everyone you know about your interest in starting something in PEOLC in your community.

Outcomes:

- You will find out who else is interested in being involved – it will surprise you!
- Word will spread in the community.
- Community gains an understanding and when people hear things are moving forward, they could more likely be on board.
- People will know who to talk to when they, or people they know, have PEOLC needs.
- Your understanding of palliative care will grow and you will receive ideas from others about how to proceed.



- People will tell you their own stories and you will be better able to answer the questions below.
- 2) When you have a group of interested people, ask yourself:
- 1) What is currently being offered in our community to support a person or family who may need PEOLC? (Think broadly, including publicly funded services, businesses and volunteer organizations.)
 - 2) Are there any organizations that have formal PEOLC programs that support the community?
 - 3) Who are those community organizations and formal health systems that already exist in your community? e.g. Alberta Health Services (AHS), Covenant Health, private care facilities, church groups, Family Community Support Services (FCSS)?
 - 4) Are there any gaps in the current provision of PEOLC in our community?
 - Who did people call to make connections?
 - Who is available to support caregivers on evenings and weekends?
 - What are the education and potential training resources?
 - 5) What funding resources are available locally, provincially and nationally to support the development of PEOLC? (For example, are there any community philanthropic groups?)
 - 6) What could be done to improve what is already being offered without duplicating services?
 - 7) What could be done to improve our community's involvement in, and knowledge and awareness for programs and services for PEOLC?
 - 8) What unique informal and formal resources do exist in our community that could be harnessed to develop and promote PEOLC (including for fund-raising)? (For example, bereavement programs, seniors advisory groups, activity of daily living support programs, volunteer drivers, hospice society and/ residential hospice beds, the resources of a community college, or a particularly active youth group; the participation of service clubs and faith-based organizations; promotion - and fund-raising - through and with local shows, festivals and key businesses).

Some examples of activities communities in Alberta use to raise awareness and promote engagement that can be replicated include:

Education and Awareness

Some Alberta community-driven volunteer organizations in the past have truly lived and exemplified what this Resource Guide hopes to engender, can serve as exemplars and mentors for aspects of the journey that communities and groups



may wish to embark on. If your community or organization would like to connect with other successful PEOLC groups this can be fulfilled through the following link in the Alberta Hospice Palliative Care Association website

<https://ahpca.ca/resource-directory>

- Learn information from other community-based programs such as: how to incorporate, building communication strategies, and offering sessions to public to educate and prepare them to deal with friends and loved ones who are or will be in need of PEOLC.
- Circulate a needs assessment for the community,
- Host a Speakers Services based on the needs of the community and an expression of interest.
- Use social media, radio advertising, and newspaper articles.
- Involve students from a local college to develop a communication strategy.
- Provide awareness training for potential volunteers and community members about end of life issues with a focus on communications, grieving and family dynamics.
- Host fundraising events by partnering with local restaurant establishments, local artists for art shows, or nationally with the Canadian Hospice Palliative Care Association for <https://www.chpca.ca/campaigns/hike-for-hospice-palliative-care/>
- Create a user-friendly website for your community.

Facility Ideas

- Develop a data base of volunteers to support PEOLC in your community.
- Develop in home support for caregivers including home visiting companion programs and time off/away for caregivers.
- Work with hospital administrators to allocate and furnish a palliative care room (or two).
- Make a kit to give to new members of the group with information regarding the community including clergy names, lawyers etc.

Bereavement Support

- Provincial Bereavement directory <https://myhealth.alberta.ca/palliative-care/resources/grief-bereavement>
- Canadian Virtual Hospice Living My Culture <http://livingmyculture.ca/culture/>
- Canadian Virtual Hospice MyGrief.ca <http://www.mygrief.ca/>
- Hospice Calgary Child + Family Grief Services | Support Groups | Calgary <https://www.hospicecalgary.ca/childrensgriefcentre/>



- Develop a Bereavement Support program for children and families in collaboration with formal organizations such as churches, Covenant Health, and AHS.
 - Provide lunch and assistance to the annual "Blue Christmas" service for grieving family and friends of recently deceased.
 - Establish a compassionate fund for the use of home care patients who need additional funding.
 - Make legacy videos with palliative patients to be left with families.
 - Host a Day of Remembrance close to Christmas for families who have lost a loved one.
- 3) Start doing something. The 'something' will differ depending on how you answered the above questions. It may involve organizing volunteer training, disseminating information by involving clubs and/or faith based groups. It may involve forming an organization, fundraising, getting charitable status, or building a place for community palliative care purposes, or organizing support groups.

Organizational Resources / Links

At some point you may decide to incorporate as a society or a non-profit company, there is information about regulations around fund raising through the Canada Revenue Agency.

- The Service Alberta website gives parameters for each type of organization, responsibilities and requirements, phone numbers, forms, and the necessary steps for incorporation. <https://www.alberta.ca/service-alberta>
- For charitable status under the Federal Income Tax Acts, the Charities and Giving section of the Canada Revenue Agency website has extensive information on charitable activities and defining charitable objects, as well as on their rules and regulations and how to apply for charitable status. www.cra-arc.gc.ca/chrts-gvng/menu-eng.html
- Government of Alberta has a number of resources available to support not-for-profit groups on organizing, developing their role in the community and facilitating their operations (things like writing bylaws, defining roles and job plans, etc.). <https://www.alberta.ca/charitable-and-non-profit-organizations>
 - Board Development Program <https://www.alberta.ca/non-profit-learning-webinars>
- A public legal education website with information on requirements for fundraising, receipting, and record keeping for charities. <http://charitycentral.ca>.

- 
- <http://nonprofitally.com/start-a-nonprofit>. (An American website)

The following links provide additional information on a wide range of organizational development and activities.

Alberta First Nations Cancer Prevention and Screening Practice Project

- [Alberta First Nation Information Governance Center](#)

Muttart Foundation: Board Development Workbooks

- <https://www.muttart.org/publications/board-development-workbooks/>.

Community Tool Box: an American website, but with a very wide range of topics relevant to PEOLC organizations

- <http://ctb.ku.edu/en/table-of-contents>

Family and Community Support Services (FCSS)

- Check with local **Family and Community Support Services (FCSS)**. They may be able to help with matters of incorporation, bylaw preparation, and strategic planning. Find your local FCSS office –

<https://www.alberta.ca/family-and-community-support-services-fcss-program>



Training and education

Developing a compassionate community will require mentors and champions as well as a dedicated volunteer group. For sustainability of PEOLC in the community, training, education and self-care for volunteers and caregivers is essential. The following resources have been developed and are available for use:

- AHS Provincial Volunteer Resource Training Manual
- AHS Provincial Volunteer Resource Facilitator Manual
- Bereavement package information
- Bereavement directory of programs and services

The training materials are available for use by community educators. When you e-mail the Provincial PEOLC team for access to these documents they will connect you with a designated volunteer manager/coordinator in your zone to assist you with the blended learning approach that may be done in conjunction with these resources for optimal learning. Email the Provincial PEOLC team at Palliative.care@ahs.ca for more information.

PEOLC Alberta Provincial Framework 2014 and the companion patient and family document

- <http://www.albertahealthservices.ca/about/Page10774.aspx>

Provincial PEOLC website for patients and families and health care providers in Alberta

- <https://myhealth.alberta.ca/palliative-care>

Advance Care Planning and Goal of Care Designation

- www.conversationsmatter.ca

AHS volunteer resources webpage

- <http://www.albertahealthservices.ca/info/Page12616.aspx>

Alberta Hospice Palliative Care Association where you will find information about the “road show” education, informative articles, research and blogs

- www.ahpca.ca



Fundraising Resources

The following resources can be helpful for training and education for health care providers, patients and families:

- www.chpca.net
- www.palliative.org
- <http://palliative.org/grief-and-bereavement.html>
- http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- <https://www.alberta.ca/family-social-caregiver-supports>
- <http://www.health.alberta.ca/services/primary-care-networks.html>
- A Caregiver's Guide: A Handbook About End-of-life Care
[Caregivers Guide](#)
- Learning Essential Approaches to Palliative and End of Life Care (LEAP)
www.pallium.ca

It is difficult to provide specific resources relating to fundraising as communities will differ in available resources and needs. See below for possible options:

Municipal/Regional

Community and Hospital Foundations – a directory of foundations in Alberta

- <http://www.albertahealthservices.ca/give/Page255.aspx>

Private Foundations and Faith-Based Charities

- A list of Canadian charities and funders.
<https://www.canadahelps.org/en/explore/charities/region/AB/>
- (<https://www.canadahelps.org/en/>)
These organizations will often donate money or help other organizations fundraise.

Propellus - Volunteer and Capacity Building Centre of Calgary

- <https://www.volunteerconnector.org/>
Propellus exists to serve non-profit organizations to achieve their missions and build their organizations, while they focus on the cause.



Calgary Chamber of Voluntary Organizations (CCVO)

- www.calgarycvo.org
CCVO promotes and strengthens the non-profit and voluntary sector by developing and sharing resources and knowledge, building connections, leading collaborative work, and giving voice to critical issues affecting the sector.

The City of Edmonton Grants and Funding

- https://www.edmonton.ca/programs_services/funding-grants A list of City of Edmonton grants.

Provincial

The Government of Alberta Municipal Grants Web Portal

- <http://www.seniors-housing.alberta.ca/seniors/age-friendly-funding.html#nfp>
Provides local government with a way to find information on all provincially and federally administered programs that provide grants to municipalities and Métis Settlements in Alberta.

Fundraising in Alberta, the Charitable Fundraising Act, the Charitable Fundraising Regulations, and Donations Consumer Tips

- <https://www.alberta.ca/fundraising-solicitation-responsibilities>
Provides legal information about fundraising.

Community Facility Enhancement Program

- <https://www.alberta.ca/community-facility-enhancement-program>
Assists with fostering the unique characteristics of Alberta's many communities

Alberta Gaming and Liquor Commission

- aglc.ca
Information on licensing on charitable fundraising.

Alberta Hospice Palliative Care Association - Successful Fundraising Tips

- <http://www.ahpca.ca/category/fundraising/>
Tips in fundraising specifically for hospice palliative care.



Volunteer Alberta

- www.volunteeralberta.ab.ca

Collects resources, including funding sources and fundraising information, for Alberta non-profits.

Additional Resources

Special Fundraising Events

Hike for Hospice:

- <http://www.chpca.net/news-and-events/hike/directory-of-hike-sites/alberta.aspx>

These could include runs, gala dinners, and raffles.

What is Planned Giving and Bequests?

A planned gift, and a gift in a Will through a bequest, is a charitable donation which can be arranged during an individual's lifetime, but is not available until sometime in the future.

Remember that fundraising activities are governed by the Canada Income Tax Act and under the direction of the Canada Revenue Agency (CRA). Their website is: <https://www.canada.ca/en/services/taxes/charities.html> It has extensive information on the regulations governing charities and how to set up a charitable organization.

In addition to specific fundraising it is also essential to be able to promote ongoing awareness of PEOLC at all levels of the community:

- General advertising including local newspapers
- Websites
- Other forms of social media such as Facebook, Twitter, Instagram
- Community media outlets
- Maintaining contact with provincial and local government officials
- Community faith-based organizations



Logistics

Introduction

The full spectrum of PEOLC includes a lot more than bricks and mortar. Communities can plan with a very broad perspective and recognize that even if a hospice or other facility doesn't make sense in their community there is still a lot that can be done to meet the needs of PEOLC patients and their families.

It is very important for communities thinking about building a facility to be in communication with AHS prior to beginning their planning process. The first contact is the Provincial PEOLC team at palliative.care@ahs.ca who will help connect you to the zone PEOLC operational leaders. Collaborating with AHS operations will help you understand hospice capacity needs, determinations and funding models. There are required organizational processes with awarding AHS funding for hospice beds.

A 2013 Hospice Capacity Planning Expert Panel made up of Palliative and End-of-Life Care and data experts across the province helped inform what AHS currently considers the ideal number of hospice beds is 7.7 beds per 100,000 population adjusted for a variety of demographic considerations. In addition to this, AHS will be proceeding with capacity planning and forecasting for PEOLC beds within hospitals and palliative home care throughout Alberta. There is a department in AHS Continuing Care that will work collaboratively with the PEOLC provincial team and PEOLC experts across the province inclusive of Alberta Health, Data Analysts, and Researchers who will be developing a forecasting plan for a 20 year period.

If a community is thinking about building a hospice there are many logistical issues to consider. Those relating to finances have already been covered in section 4 – Funding Resources. Those relating to the legalities of founding a formal organization have already been covered in Section 2.2 – Getting Started.



The following is a list of logistical considerations if planning to build/modify a facility for dedicated hospice beds:

Medications (management, access, and storage), Supplies and Transport:

Alberta Formularies

- <https://www.ab.bluecross.ca/dbl/publications.php>

Alberta Palliative Blue Cross

- <https://www.alberta.ca/palliative-care-health-benefits>

The Alberta Drug Benefit List defines the prescription drugs and drug products covered by the ministry's supplemental health plans

- <https://www.ab.bluecross.ca/dbl/publications.html>

Equipment and Supplies (based on AHS contract)

Facility considerations

Questions that may be asked:

- Contract provider common requirements/standards and basic information
- Tubs
- Sprinkler systems
- Backup generator
- Occupancy expectations
- What is definitely not funded?
- Dietician consult for menus specific for population
- Food inspector
- Building requirements/security for Narcotics
- Room size
- Consideration for a designated bed(s) for First Nations people
- Fire walls
- Building standards
- Guest suite for out of province visitors as well as to accommodate the large numbers of extended family coming in to see family from First Nation Reserves



Building requirements

- Please refer to Infection Prevention and Control (IPC): Health Care Facility Design Guidelines and Preventive Measures for Construction, Renovation and Maintenance Activities document for information on design specifications, building requirements, and infection prevention and control guidelines.

Design Guidelines for Continuing Care Facilities in Alberta

- https://www.alberta.ca/system/files/custom_downloaded_images/infrastructure-technical-design-requirements.pdf

Technical Design Requirements for Health Care Facilities

- <http://www.infrastructure.alberta.ca/Content/docType486/Production/BlueBook-2005.pdf>

Infection Prevention and Control: Health Care Facility Design Guidelines and Preventive Measures for Construction, Renovation and Maintenance Activities

- <http://www.infrastructure.alberta.ca/Content/docType486/Production/IPCMarch2016.pdf>

- **Continuing Care Health Service Standards.**
 - [Continuing Care Health Service Standards 2018 \(alberta.ca\)](#)
- **AHS Multi-Year Facility Infrastructure Capital Submission**
[Lots of helpful information. See, for example, pages 9-11 and page 19]
 - <http://www.albertahealthservices.ca/Blogs/BTH/Posting274.aspx#.V0nQgcArLIV>
- **Cost Estimates, Institute of Health Economics, Alberta**
 - <https://obrieniph.ucalgary.ca/groups/health-economics/he-costing-resources>
- **Development of a Rural Palliative Care Program in the Calgary Zone of Alberta Health Services**
[Lots of helpful information about working together with rural communities]
 - [http://www.jpsmjournal.com/article/S0885-3924\(12\)00015-2/abstract?cc=y=](http://www.jpsmjournal.com/article/S0885-3924(12)00015-2/abstract?cc=y=)

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- **CHPCA: A Model to Guide Hospice Palliative Care Based on National Principles and Norms of Practice**
 - <https://www.chpca.ca/wp-content/uploads/2019/12/norms-of-practice-eng-web.pdf>
 - **King's Fund: Principles of Hospice Design**
 - <http://www.kingsfund.org.uk/projects/enhancing-healing-environment/hospice-design>

Inspections prior to occupation are (in sequence):

- Fire (inspection and occupancy load certificate)
- Municipal Safety Codes (inspection)
- AHS Environmental Public Health (inspection and licensing for Food Handling permit)
- Municipal Accommodation Licensing

Operational requirements:

- Need to comply with Infection Prevention Control requirements, <https://open.alberta.ca/publications/accommodation-standards-and-licensing-information-guide-revision-5> and <https://www.alberta.ca/continuing-care-accommodation-and-health-service-standards>
- Evidence is required as part of the commissioning process. See below Standards of Practice for IPC guidelines.

Standards of Practice:

- Accreditation Canada (hospice and PEOLC specific standards). There are other accreditation options available for privately owned or contracted palliative and end-of-life care service providers.
<https://accreditation.ca/standards/>
- Data collection required (based on AHS contract)
- Continuing Care Health Service Standards [Continuing care health service standards : information guide \[2018\] - Open Government \(alberta.ca\)](#)
- Infection control requirements
- Pandemic plan
- Accommodation Standards - Accommodation Standards do not apply to palliative and end-of-life spaces as these are not considered permanent accommodation. They can be referred to as a resource, but compliance is not mandated by



Alberta Health. [Continuing care accommodation and health service standards | Alberta.ca](#)



Factors that may affect sustainability in a stand-alone facility because they are not a shared resource within long term care or supportive living:

- Linen/laundry service
- Housekeeping service
- Security
- Food service

For more information:

AHS Provincial PEOLC team Palliative.care@ahs.ca



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Alberta Health Services (2014). *Palliative and End-of-Life Care Alberta Provincial Framework*. Retrieved October 10, 2016, from Alberta Health Services: [Palliative and End of Life Care Alberta Provincial Framework | Alberta Health Services](#)

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Appendix A: General PEOLC Resources in Alberta

The following links are helpful resources for patients, families, and communities seeking to promote and in need of PEOLC.

- Palliative and End-of-Life Care Alberta Provincial Framework 2014 and companion document for patients and families
<http://www.albertahealthservices.ca/about/Page10774.aspx>.
- Provincial Palliative and End-of-Life Care website
<https://myhealth.alberta.ca/palliative-care>.
- Alberta Hospice and Palliative Care Association
www.ahpca.ca.
- Grief and Bereavement page on palliative.org website
[Palliative Care - Grief and Bereavement](#)
- Advance Care Planning and Goals of Care Designation website
www.conversationsmatter.ca.
- Office of the Public Guardian and Trustee – Alberta Health
[OPGT Forms | Alberta.ca](#)
- PEOLC EMS Assess Treat and Refer (ATR) Program [Emergency Medical Services Program | Alberta Health Services](#)
- Inform Alberta - A directory that contains information about community, health, social, and government services across the province
www.informalberta.ca.
- Improving End-of-Life Care in First Nations Communities Research Team, Lakehead University (2015), Developing Palliative Care Programs in First Nations Communities: A workbook, Version 1, retrieved from [Improving End-of-Life Care in First Nations Communities | \(lakeheadu.ca\)](#)
- Canadian Cancer Society Resource Tote bags – can be obtained free of charge by calling Tel: 1-888-939-3333.



Resources relating to PEOLC outside of Alberta

- Canadian Virtual Hospice – Information and support on palliative end-of-life care, loss and grief
<http://www.virtualhospice.ca/>
- Canadian Hospice Palliative Care Association website
www.chpca.net
- Resources for cultural diversity found on Canadian Virtual Hospice - Quality palliative care helps you honour your culture, spirituality and traditions. At www.LivingMyCulture.ca, people from various cultures share their stories and wisdom about living with serious illness, end of life and grief to support others.



Appendix B: Community Support Working Group Survey

This survey is in response to the community members who were in attendance at the June 2014 Alberta Hospice Palliative Care Association (AHPCA) Imagine conference where by we heard *“that Alberta Health Services (AHS) needs a way to participate and partner with communities to help address the needs of communities and address the sustainability of palliative and end- of- life care (PEOLC) in rural areas...immediately.”* One region reported that a mere fraction of people who died in their area were able to die at home; and many are transferred away from family and friends. We heard you then and now we need your input.

Here is how your voice can be heard

Why are we asking you to complete this survey?

Recently, a working group has been assembled to engage with organizations that provide PEOLC and other supports within their communities across Alberta. This group, the Community Support Working Group, has members from AHS, Alberta Government, AHPCA, palliative care physicians, other professionals and community representatives from both urban and rural geography’s in Alberta. The Community Support Working Group is asking you to complete this survey to understand and gain more insight into the issues within communities around developing PEOLC programs or services from your perspective and present the results to AHS. The group intends to use the information gathered in this survey to help develop recommendations for community groups that want to improve PEOLC resources in their communities. The recommendations will not be a recipe for every circumstance, but they will be used as building blocks to strengthen and improve how together we can build capacity.

Survey Questions:

1. Can you tell us what you think has been your best source of information/encouragement that has supported your goals thus far and would be helpful to improve PEOLC in other communities? (An example might be “key contacts” for AHPCA and who to call within AHS for questions around operational issues.)
2. What are some things that your group has done that you are proud of and think other groups could learn from?
3. What do you do to raise awareness of your services or programs, to both support your program and reach people in need of PEOLC? (What mechanisms do you use to advertise or connect with individuals or families/ municipal leaders?)



4. What other information/resources would you like to be available to help you to reach all those who can benefit from these services as early as possible in their palliative care journey?
5. What do you know now that you wished someone had told you at the onset of your endeavors to get PEOLC enhanced in your community?
6. What are the barriers to developing community supported palliative and hospice care in your region?
7. Please add any other comments below that you think would be helpful for us to know as we try to put together useful information for groups who want to offer PEOLC in their communities. Thank you for completing this survey. Would you be willing to provide us with your contact information in the space below so that we may share the results of the survey and the resulting recommendations from the working group with your organization or board?

Please contact: michelle.petersonfraser@ahs.ca for any questions or concerns.



Appendix C: Key Stakeholders and Contact Information

This section provides basic information on who to connect with in AHS, AH and local stakeholders.

This infographic shows all the partners that work together in Alberta PEOLC

PEOLC Palliative & End-of-Life Care
Working together for Albertans

WHAT IS PEOLC ? PEOLC is a range of care from the time of diagnosis of a life-limiting illness until the time of death and into bereavement.

Diagnosis of life-limiting illness. Palliative Care starts at the time of diagnosis.

Palliative Care

End-of-Life Care focuses on helping the patient be comfortable, with the best quality of life possible.

Death

Bereavement Care

9/10 Albertans will need some PEOLC in their lifetime.

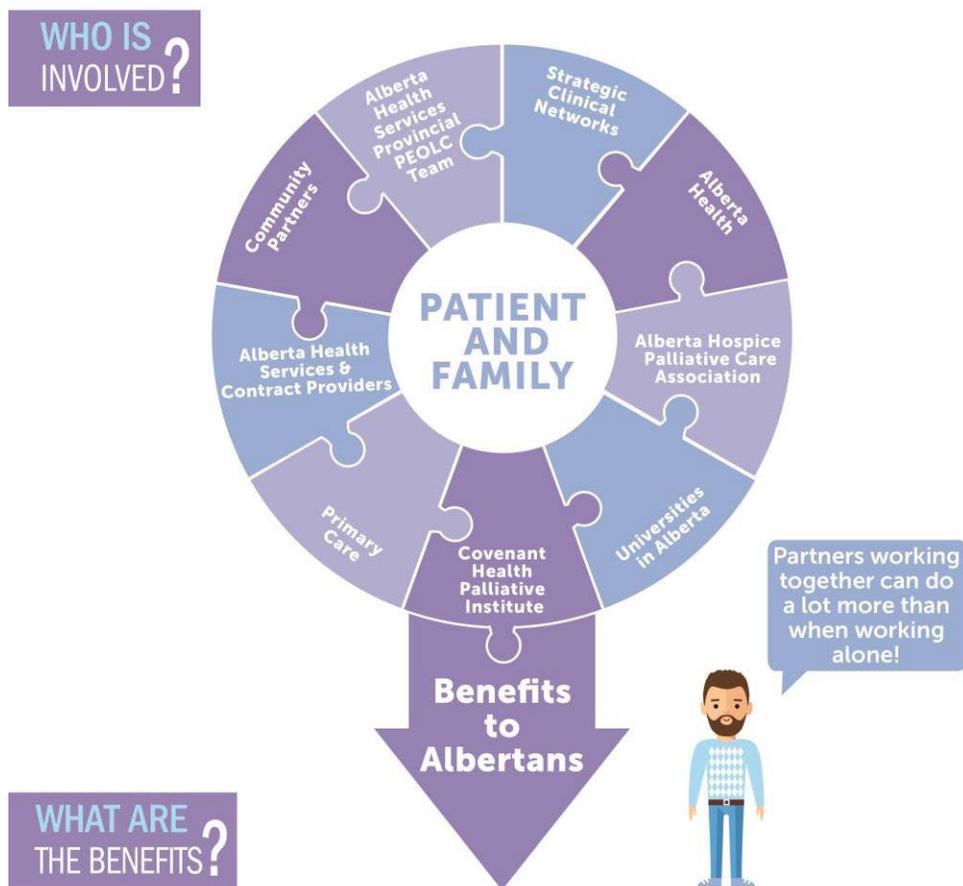
PEOLC partners work together so all Albertans receive the best possible care from wherever they choose to live.

HOSPITAL HOSPICE

(Continued over)



(Infographic continued)



Meeting Patients & Families Needs Faster

Quality Care to Patient & Family

Better Access to Programs & Services

Awareness & Information

Planning Ahead Together

Better Use of Provincial Resources

To learn more about PEOLC in Alberta, go to: myhealth.alberta.ca/palliative-care OR conversationsmatter.ca

ADVANCE CARE PLANNING | GOALS OF CARE
CONVERSATIONS MATTER
 A GUIDE FOR MAKING HEALTHCARE DECISIONS



Key Stakeholders

1) AHS Provincial PEOLC team Palliative.care@ahs.ca

Key roles

- Advocates for quality PEOLC for patients and their families in Alberta regardless of geography.
- Facilitates the implementation of provincial initiatives as recommended in the PEOLC Alberta Framework document and under the direction of the Provincial Palliative and End of Life Innovations Steering Committee (PPAL/EOL ISC).
- Facilitates connections between Hospice organizations, PEOLC organizations and AHS PEOLC operations.
- Participates in strategic capacity planning for PEOLC across Alberta.
- Facilitates provincial policy development.
- Maintains and enhances the AHS Provincial Palliative and End- of- Life Care Website <https://myhealth.alberta.ca/palliative-care>
- AHS Patient Concerns and Continuing Care Concerns Resolution Link <http://www.albertahealthservices.ca/about/patientfeedback.aspx>.

2) Alberta Health

Key roles

- “Alberta Health is the provincial government ministry responsible for setting, monitoring and enforcing provincial health policy and standards; some health and seniors programs; and managing health capital planning, procurement and outcome measures.” <https://www.alberta.ca/health>



3) Alberta Hospice Palliative Care Association

Key roles

- Engages in education, advocacy, and provision of resources to achieve comprehensive quality hospice palliative and end-of-life care for all Albertans.
- Provides individuals and families with information about local programs and services specific to hospice palliative care in Alberta through its online Resource Directory with an interactive map, community listing and type of service category.
- Has day-long roadshows which are travelling workshops that facilitate vital networking and meaningful education in hospice palliative care for volunteer, caregivers, families and professionals each year in Alberta's smaller centers and rural communities.
- Supports the various hospice palliative care groups and societies with education and networking opportunities at events such as the Imagine Conferences.
- AHPCA www.ahpca.ca.
- Helps your organization connect with PEOLC groups in other Alberta communities through this link: <https://ahpca.ca/resource-directory/>

4) Other Key Stakeholders in local communities include:

- | | |
|--|--|
| • Primary care network | • MLA |
| • Community hospital | • Local government officials |
| • Continuing Care operators | • Private contractors / Supportive Living builds |
| • Family physician with an interest in PEOLC | • Community pharmacy |
| • PEOLC Nurse Consultant | • Volunteer groups |
| • Palliative Care Physicians | • Community Social Worker |
| • EMS ATR program members | • Strategic Clinical Networks |
| • Family Community Support Services | • Home Living / Home Care services |
| • Faith-based community groups | <i>Home Care receives palliative referrals for the Reserve</i> |
| • Municipal boards | |

General PEOLC inquires about programs and services:

Alberta Health Services
Provincial Palliative and End-of-Life Care team
Palliative.care@ahs.ca



Appendix D: Compassionate Communities: Working to Develop Community-Engaged Palliative and End-of-Life Care in Alberta

Contributed by Dr. Martin LaBrie

Over the last two decades, Alberta has demonstrated leadership in the development of palliative and end-of-life care (PEOLC) services, awareness and education. Across the province there are excellent examples of quality PEOLC services that provide care to Albertans in a highly integrated manner. In Calgary and Edmonton, these integrated services are supported by academic training, research, and community engagement. In many urban and rural communities, there are strong innovative service delivery programs that strive to address the unique needs of those communities.

As in most jurisdictions in developed countries, however, there is considerable variation in access to PEOLC services among the various communities and segments of the population within Alberta. Since PEOLC services have been provided primarily through health services, all of the barriers that impair health service access have affected the accessibility of PEOLC support. Smaller communities that have limited health services have seen their members leaving the community when care needs exceed what can be provided locally. Members of our communities who are marginalized through poverty, homelessness, mental illness and addictions encounter significant impediments to health services access and consequently receive limited support for the management of suffering that result from advancing, life-limiting illness.

Along with the professionalization of PEOLC delivery, there have been other social changes (for example, the loss of the support traditionally provided through extended families), that has resulted in a dramatic decline of knowledge within communities regarding the care of individuals approaching end-of-life. As the caregiver, financial and emotional burdens increase for family members, those individuals who would prefer to remain in their homes and communities at the end-of-life are obliged to obtain care in institutional settings. For many individuals, it is their care needs rather than their symptom burden that forces them in to facilities.

Over the last twenty years, a significant body of research has developed in an effort to understand and address this dilemma, and many grass roots initiatives have been undertaken throughout the world, especially in resource-limited settings, that focus on the engagement of communities in addressing the quality of living for their members approaching the end-of-life. These initiatives have identified benefits not only for the individual and family affected by illness, but for the community at large, demonstrating



the gain in social capital that the communities acquire as they develops the capacity for care at end-of-life.

There has been considerable variation in the development of the concept of community engagement for PEOLC over the last several years. Community-engaged palliative care defined by Sallnow and Paul¹ is as follows:

Community engagement in end-of-life care is an umbrella term for a process which enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related wellbeing. It exists on a spectrum of engagement that extends from informing through to empowering, depending on a range of factors such as the degree of participation from the local community and the intention of the work. Community engagement activities by end-of-life care services go beyond working in the community to working with the community to improve its experience of end-of-life care (emphasis added).

(Sallnow and Paul, 2015, pp 231-238)

Access to information regarding resources and the sharing of experiences among communities regarding capacity-building are essential needs for Alberta communities. It is hoped that this Resource Guide will be helpful in obtaining information that can assist in achieving this goal. It is clear, however, that we in Alberta are just beginning to build community capacity, as the above definition illustrates. This capacity is only beginning to be developed worldwide, and because of our unique circumstance in having a regional health authority for the entire province, we find ourselves again in a position of providing leadership in developing a truly collaborative approach to PEOLC that brings strength to communities and promotes effective integration of health care services that is responsive to local needs. It is our sincere hope and a core recommendation of the working group that there will be increased interest and investment in the evolution of community capacity for PEOLC in a truly collaborative relationship with health service providers, which will enrich communities and help ensure sustainable health care capacity.

Reference:

¹Sallnow, L., & Paul, S. (2015). Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health*, 25(2), 231-238. doi:[10.1080/09581596.2014.909582](https://doi.org/10.1080/09581596.2014.909582)



Notes



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