Let’s make a resolution to talk about Palliative and End of Life Care!

It’s not the latest Hollywood blockbuster, a royal engagement, or a political headliner but Palliative and End of Life Care (PEOLC) impacts just as many people, if not more. Literature indicates that an estimated 75% - 90% of all deaths need PEOLC (Murtagh et al., 2013). This means that approximately 9 in 10 Albertans will need PEOLC in their lifetime.

PEOLC is provided in all care settings and has a proven ability to reduce inappropriate acute care utilization and costs while improving patients’ and families’ quality of life. Patients living with a serious life-limiting illness, their families and care providers, will receive the information needed to help them live the best life they can. Being able to access the right information or the right health-care provider at the right time will help people stay at home longer with better care.

In 2014, Alberta Health Services in collaboration with PEOLC experts across the province developed the PEOLC Alberta Provincial Framework to help ensure Albertans have access to quality PEOLC regardless of life limiting illness, age, or geography.

The PEOLC Alberta Provincial Framework defines PEOLC as both a philosophy and an approach to care. 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 aimed at comfort.

Over the past four years, under the guidance of the Provincial Palliative and End of Life Innovations Steering Committee (PPAL/EOL ISC), the provincial PEOLC team and many working group members have been actively implementing many of the 36 initiatives as recommended in the Framework. These initiatives have helped to enhance and improve existing PEOLC programs and services and have increased access to integrated PEOLC where gaps exist. In the last year, PPAL/EOL ISC and its working groups have worked on the following PEOLC initiatives and activities:

- Advance Care Planning and Goals of Care Designation (page 4)
- Clinical Knowledge Topics led by the Clinical Knowledge Content Management team (page 9)
- Community Support (page 3)
- EMS PEOLC Assess, Treat and Refer (page 2)
- Patient’s Death in the Home Care Setting (page 5)
- PEOLC Capacity Planning (page 4)
- PEOLC Clinical Documentation (page 5)
- PEOLC Dashboard (page 4)
- Provincial Bereavement Program—find out more about this program at https://www.albertahealthservices.ca/info/page15628.aspx
- Provincial PEOLC Website (page 3)

In 2018, the PPAL/EOL ISC will continue to prioritize, develop and implement initiatives from the PEOLC Alberta Provincial Framework. The provincial team would like to thank everyone who contributed to PEOLC work and initiatives in 2017. Without your support we would not be able to do all that we have accomplished so far.

Thank you. The provincial PEOLC team wishes everyone a very Happy New Year!
Within the Palliative and End of Life Care Alberta Provincial Framework 2014, standardizing and spreading palliative emergency symptom management support provided by clinicians and EMS within every zone was identified as a top priority. During the 2014/15 fiscal year, all the zones worked collaboratively to develop a provincial Emergency Medical Services Palliative and End of Life Care Assess, Treat and Refer (EMS PEOLC ATR) Program to support clients experiencing symptom crisis within the community setting. Over the last two fiscal years, the program was rolled out across the province and broadened to allow greater access to patients and families. Continuing to provide additional palliative care education for paramedics, expanding the program to the pediatric population, evaluation and sustainability planning are priorities in this fiscal year’s work (Phase III). The Provincial PEOLC team would like to acknowledge and thank Cheryl Cameron for her leadership on this initiative. Cheryl will be on a leave of absence for one year and recruitment for a new lead is in progress. Stay tuned for an announcement in the new year.

Recent Program Activity & Phase II Expansion

Since the launch of Phase II, program activations have significantly increased across the province. In the first 6 months of Phase II there were 221 events. This is a 56% increase from the number of events at the end of Phase I.

- There have been ~ 500 events in the last year (since Phase II launched in October 2016)
- This includes 221 events in the first 6 months and ~ 275 events in the last 6 months

Phase II Highlights (October 2016—March 2017)

Most patients (90%) continue to be treated at home and not transported to hospital. 2/3 of the events occurred through remote activation (clinician not on scene) or EMS identification of appropriate patients when they arrive in the home.

Benefit to Patients & Families

Overall, clinicians, EMS staff, and physicians believe that the program benefits patients and family members. In Phase I, the majority of clinicians and EMS staff felt that the ATR program benefitted patients and families. This trend continued in Phase II with the addition of physician data.

Key Evaluation Recommendations

- Encourage clinicians to activate the program on behalf of the patient/family
- Increase communication/awareness of program with physicians, EMS, patients, and families
- Communicate successes (reduced time on task) to help with culture shift/program acceptance with EMS staff
- Provide education in palliative care, grief and bereavement support for EMS staff

Next Steps and Phase III Development

- Phase III charter is now fully endorsed!
- Work has started on the inclusion of pediatrics and other Phase III deliverables
- Project team submitted a proposal for funding to support palliative care education for paramedics

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Inquiries from EMS related to the Assess, Treat and Refer program may be directed to: ems.palliative@ahs.ca.

For more information on EMS PEOLC ATR see EMS Initiative on https://myhealth.alberta.ca/palliative-care
The Resource Guide for Community Development of Palliative and End of Life Care within Alberta is a collection of resources and information to help communities across Alberta develop local PEOLC community services and support. Over the last few months, several presentations were given to showcase and promote the Resource Guide. These presentations include:

- Health Canada’s First Nations Inuit Health Branch in June and September.
- The 5th International Public Health & Palliative Care Conference in September.
- The Home Care Summit presentation in Toronto in October.
- The 18th Annual Mary O’Connor Palliative and Hospice Care Conference

Hard copies of the Resource Guide were given to the hospice societies and PEOLC organizations at the recent AHPCA Imagine Conference. These groups helped inform the Resource Guide and will be providing further feedback to improve this resource through an online survey.

For PEOLC education opportunities, review the Provincial PEOLC Education Bulletin attached to the email or visit [http://www.albertahealthservices.ca/info/page14438.aspx](http://www.albertahealthservices.ca/info/page14438.aspx)

The provincial PEOLC Website Content Review Committee (CRC) continues to update and enhance the provincial PEOLC website. We recently updated the pediatric Family Resources page as well as the EMS PEOLC ATR Program and Services and Health Care Provider pages. The CRC is currently reviewing PEOLC disease specific pages.

An evaluation of the website is in progress, including web analytics and an online feedback survey. Key results to date show:

- Our website had 30,053 unique pageviews from June 2016 – May 2017.
  - A unique pageview measures which pages were visited by the same user during a session. Repeat visits during a user’s session count as one unique pageview.
- 77 health care providers and patients/ caregivers/ members of the public completed an online feedback survey by October 5, 2017.
  - 89% reported increased awareness of PEOLC programs and services
  - 88% reported increased knowledge of PEOLC information

Work continues with the online learning modules. We are nearing the completion of the PEOLC Dyspnea e-learning module and have drafted an outline for the Grief and Bereavement e-learning module. The next step will be for the subject matter expert and the CRC to review the modules.
ACP GCD provincial work has been perking along at a good pace this fall, some of the highlights are:

- Health care providers Frequently Asked Questions (FAQ) are being refreshed. Target date for finalization is early February 2018.
- ACP GCD Tracking Record form is undergoing redesign to promote higher completion rates and to inform design for the new provincial Clinical Information System (CIS). We know the paper world of documenting ACP GCD conversations will continue for some time so it is important to design a user friendly form that promotes inter-setting communication.
- ACP GCD Community of Practice members have identified a need to develop a plain language, public facing, one page resource that health care clinicians can use to help differentiate between the seven GCDs. Work is beginning on this.
- 2017-18 provincial evaluation is well underway, with chart audits in North, Edmonton and Central Zones on target to be completed by the end of January. When auditors come across ACP GCD practice questions they are forwarding them to our provincial PEOLC team for response; involving the zone ACP GCD champions when needed. It is an excellent way to connect with clinicians who may have been wondering about a certain practice and providing education when needed.
- We have offered two virtual education sessions in the four-part ACP GCD Practice Improvement series. Attendance and feedback have been very positive. Stay tuned for a poster later in January advertising the remaining two sessions.
- Serious Illness Conversation Program training continues across the province. Soon, we will be adding a Serious Illness Conversation "tab" to the health professionals section of the ACP GCD website. AHS branded resources and information will be posted for health care providers to access and use.

PEOLC Dashboard

The ACP/ GCD Community of Practice reviewed a draft provincial PEOLC Tableau dashboard with provincial 2015/16 ACP/ GCD evaluation data in line with nine key indicators prioritized by ACP Collaborative Research & Innovation Opportunities (CARIO). Compilation of feedback is underway and will be followed by revision and publication of the dashboard on Tableau.

- The nine CARIO indicators have been built in to the current round of adult ACP/GCD evaluation.
- Vital Statistics data on the number of deaths per year, location of death and age of those that died (through 2014) continues to be available to AHS staff via Tableau.
- We are continuing to revise a draft provincial dashboard including additional PEOLC indicators before exploration and seeking validation from PEOLC programs across all zones.

Standardizing Hospice Data

- Provincially standardize hospice data tracking and reporting to support the evaluation of Enhancing Care in the Community.
- All five zones and Covenant Health came to consensus on a minimum data set for hospices. A minimum data set is the core data that all hospices need to track. This includes data related to hospice waitlist, admission, discharge and occupancy.
- We will start by leveraging data that already exists in electronic health records, and move towards ensuring all hospices collect and report on all of the data items.

PEOLC Capacity Planning

- Capacity planning was developed using an integrated approach, focusing on overall PEOLC capacity (combined across Hospice, Acute and Home Care) while accommodating differences in local context.
- The draft forecasting model was endorsed by Integrated Continuing Care Steering Committee (ICCSC) in October 2017. It proposes an increase in overall PEOLC service days utilization and shift towards community over the next 20 years including an increase in the percentage of days in community and a decrease in the percentage of days in acute care over the next 20 years. This aligns with the AHS and Alberta Health priority of Enhancing Care in the Community.
- Next steps:
  - The proposed PEOLC forecasting model and Briefing Note are with the broader Continuing Care Capacity Planning Committee for review and approval.
  - Zone specific data validation and implementation to follow.
The guideline and supporting documents were endorsed by ICCSC in October.

A final legal review has been completed.

We submitted the guideline for formal approval in December 2017. We are awaiting feedback from that final review and will incorporate requested changes before the guideline is formally approved.

After formal approval, there will be one month of education before a go live date for guideline implementation.

Once implemented, the guideline will be posted online and legacy documents will be rescinded.

Health care provider education will include:
- Online education sessions for health care providers
- A recorded Practice Wise education session that will be posted online including on the Continuing Care Desktop
- Frequently Asked Questions
- Checklists to support health care providers in following the guideline
- An online toolkit – a website with links to the guideline, education, and other helpful information related to the guideline

A brochure is being developed to support the education of patients and families.

The provincial PEOLC team is the first group out of the gate to work with Clinical Knowledge Content Management on clinical documentation. We are working to identify and decide on consistent clinical documentation data sets and processes in preparation for the provincial Clinical Information System.

A Working Group has been struck, with PEOLC representatives from the five zones and Covenant Health, as well as other AHS stakeholders that use or can inform PEOLC clinical documentation.

This Working Group will:
- Standardize PEOLC clinical documentation
- Harmonize data sets, practice and processes in Alberta

Two general orientation meetings occurred in October, and the inaugural Working Group meeting took place on November 6th.

We received ~500 items of clinical documentation in use by PEOLC programs. Current state analysis of PEOLC clinical documentation in the province is in progress.

Hear My Voice—Pediatric Resource

Hear My Voice is a deck of cards designed to stimulate important conversations within families who have a child or youth with a life-threatening illness or serious chronic condition. For instructions on how to order this resource, refer to Hear My Voice – Ordering Information found on the Pediatrics tab of the following webpage: http://www.albertahealthservices.ca/info/Page9099.aspx

Life is Where the Home Is

Patients with interstitial lung diseases (ILD) and their families suffer a heavy symptom burden and poor quality of life. Shortness of breath, a common symptom of ILD, is a leading cause of Emergency Room (ER) visits, multiple hospitalizations in the last year of life with most dying in hospitals. Patients express hopelessness, frustration with disease centric care, lack of attention to symptoms and advance care planning (ACP). In 2012, we reorganized our ILD clinic into a multidisciplinary team comprising two pulmonologists (ILD and palliative respiratory care experts), nurse, respiratory therapist and a dietitian. We adopted an early integrated palliative approach with a focus on early symptom management and ACP starting at the first clinic visit. We designed a Multidisciplinary Collaborative care model with emphasis on community-based care to manage patients in their homes, support caregivers and provide continuity. Our care model led to significant reduction in ER visits and hospitalizations at end of life (24 fold reduction in ER visits and 2 fold reduction in hospitalizations in the last year of life). Patients avoided hospital deaths; many passed away at home in keeping with their wishes (55% died at home and 85% died in the location of their choice i.e. home/hospice). Reducing time spent in hospitals allows patients to have a meaningful life at home, which is a patient centred goal. Our model aligns care with patient goals, improves symptom management by empowering patients and caregivers to address crisis at home and avoid unnecessary acute care visits. It allows patients to live at home where their life is. A qualitative study of the bereaved caregivers demonstrated value and impact of early and integrated ACP, use of self-management action plans and community based care and supports. Our innovative multidisciplinary collaborative model is in line with AHS Patient First Strategy that emphasizes patient and family centric care, enhanced communication, team based approach to care and better continuity. The Canadian Foundation for Healthcare Improvement (CFHI) recognized our model as an emerging innovation in palliative and end of life care.

Multidisciplinary ILD Collaborative Team
Dr. Meena Kalluri (Director)
Dr. Janice Richman-Eisenstat
University of Alberta
New team members were on board in early December. We were able to have almost all of our new team together in October for a team meeting and begin discussions of how to use the team’s expansion to have the most impact on the people we serve – the reason we are here.

We also added our first Nurse Practitioner, Marlee MacDonald, to the team and are busy getting all of our new members orientated and integrated into the team.

We are also continuing to move forward on setting up a collaborative pain and symptom clinic with the Red Deer Cancer Centre. We have held two more successful LEAP Core sessions and resumed our schedule of monthly Lync education for frontline staff in all sectors. We have been offered a new opportunity to adapt and share our Death, Dying and Dementia education program at the workshop series for primary care providers offered as part of the Seniors Health SCN Dementia Care Strategy in Central Zone – we are pleased to collaborate with that project in the area of education, as well as program development.

Finally, the Central Zone Palliative Care Team hopes that each and every one of you had a joyous holiday season that was filled with family, friends and fun! May 2018 bring all that you hope for!

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**KidsGrief.ca**

**NOW LIVE!**

Canadian Virtual Hospice and their pan-Canadian partners are pleased to launch KidsGrief.ca and DeuilDesEnfants.ca

**KidsGrief.ca** is a free, bilingual online resource for parents, guardians and caregivers who are supporting a grieving child. The modules were made possible through funding from the Canadian Internet Registration Authority (CIRA) and Hope & Cope.

When someone important to a child is diagnosed with a life-limiting illness, is dying or has died, families struggle with what to tell children, when to share information and how to address tough subjects like should children be at the bedside of someone who is dying and cremation. KidsGrief.ca is a series of three learning modules that help tackle these topics in a straightforward, practical way. They provide strategies, talking points and video clips of families sharing personal stories. KidsGrief.ca was developed by a national team of experts in children’s grief and family members who have “been there”.

KidsGrief.ca builds on MyGrief.ca, an online learning platform that helps adults with grieving launched by the Canadian Virtual Hospice in 2016, with funding by the Canadian Partnership Against Cancer.

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**Bill C-277 – Framework on Palliative Care in Canada Act**

Bill C-277 an Act providing for the development of a framework on palliative care in Canada became law December 12, 2017! The Palliative Care Matters Steering Committee is beginning work on supporting development of a national action plan utilizing the collaborative impact framework as a model to support palliative care in Canada.

Patient Family Centred Care is at the Heart of our Palliative Services

The Calgary Zone PEOLC portfolio Patient and Family Centred Care Committee (PFCC) is now established with membership from our programs and patient and family advisors. The committee’s purpose is to provide vision, leadership and direction to support sustainable PFCC initiatives. The committee will provide encouragement for a PFCC culture within our staff, volunteers, patients and families amongst their respective palliative and end of life care teams.

Our objectives for the 17-18 year are:

1. To develop a ‘What Matters to You’ initiative to better hear, and understand, what matters most to our patients as we provide care.
2. To research, develop and implement a methodology to solicit feedback from our patients and families regarding their experience of our services.
3. To further revise and develop program brochures and our website to improve how information on our palliative services are provided to patients and families.
4. To develop a greater awareness of the PEOLC services amongst all program areas so that clinicians can better inform patients and families about transitions of care.

What have we begun to do differently?

⇒ All our portfolio/program meetings now start with a patient story to ensure we are grounded in our planning and business discussions.
⇒ During AHS Leader Rounding Week, committee members participated in Leader Rounding on one of our units – a rich and rewarding learning experience for us all! Leader rounding is an intentional moment that leaders spend with patients and families. It is an excellent way to model behavior, reinforce culture and learn about opportunities for improvements.
⇒ During AHS PFCC week, we launched a campaign asking our teams:
  o How do we provide PFCC?
  o In what ways do we ask patients and families if our care is meeting their needs?
  o What are the best ways for patients and families to have input into how we provide care and services?

We are so pleased to have a very dynamic membership of clinicians, leaders and advisors who are passionate about patient and family centred care.

North Zone

The North Zone is very pleased to be proceeding with the roll out of the zone Palliative Care Team. Eight of 11 Palliative Care Resource Nurse positions have been filled, and we are pleased to have a team that brings a diversity of background and experience, including acute care, hospice, home care, chronic disease and pediatrics. Most staff have started work with the team and are completing orientation while beginning to work in their respective areas. Over the next few weeks, North Zone will be working to fill other positions on the team. In the meantime, consultation continues with stakeholders to make sure local concerns, strengths and challenges are reflected in the program. As well, practical operational processes are being developed and refined.

The staff have been active in meeting local clinicians. They have also offered face to face education in three communities with plans in place for several others for both Health Care Aides and professional staff. This is very exciting as North Zone has relied heavily on virtual delivery for palliative education in the past. Two communities have been preparing to implement the End of Life (last hours to days) Pathway developed by Covenant Health and AHS, with the support of the PCRNs, Edmonton Zone and Covenant Health. LEAP is in the planning phases in three communities over the coming weeks.

With support from Edmonton Zone Palliative Program, and Cheryl Cameron, formerly of the EMS PEOLC ATR Project, three LEAP sessions were held in Whitecourt and Hinton in September.

One of the North Zone team members, Loretta Manning, was able to attend Victoria Hospice’s Medical Intensive Course in November, and looks forward to sharing her knowledge with the new team.

We would like to thank the numerous leaders from other AHS Zones and Covenant Health who are supporting North Zone as we get our program in place!
Why PaCES? Currently, most Albertans with cancer only receive palliative care services in the final two months of life but evidence suggests that earlier palliative care supports enhanced quality of life and reduced costs.

What is PaCES? The Palliative Care Early and Systematic (PaCES) Program is a province-wide team working together to develop and deliver an early and systematic palliative care pathway for advanced colorectal cancer patients and their families. We are funded by grants from Alberta Health (2017-2019) and the Canadian Institutes of Health Research (CIHR) (2017-2021). This knowledge translation project will adapt and implement evidence-based practices for delivering early and systematic palliative care for patients with advanced colorectal cancer. We aim to improve patient outcomes and health system efficiencies, by increasing the number of patients receiving earlier palliative care.

What is early palliative care? It comprises of an early palliative care approach (delivered by general and oncology clinicians) as well as early access to specialist palliative care, soon after diagnosis of advanced cancer.

What are the objectives?

A. Measure current use of palliative, cancer, hospital and community care services across Alberta by patients with advanced colorectal cancer.
B. Assess barriers and facilitators to oncologists and family physicians providing palliative care concurrent with chemotherapy and radiotherapy.
C. Assess patient and caregiver preferences for early palliative care delivery in rural Alberta.
D. Develop an evidence-informed early and systematic palliative care colorectal cancer pathway.
E. Evaluate the proposed palliative care colorectal cancer pathway by implementing in Calgary (with Edmonton as the control site).

Who is involved? Our collaborative team includes oncology, palliative, primary and homecare researchers; administrative leaders; patient/family advisors; trainees; healthcare providers; health economics, health technology and policy, statistical, process improvement and knowledge translation experts. We welcome interested individuals to join our PaCES Collaborative!

How can I get involved? Visit www.pacesproject.ca.
The Clinical Knowledge and Content Management (CKCM) team, with help from the working groups, continues to work on the three prioritized Clinical Knowledge Topics from the PPAL/EOL ISC.

### Advance Care Planning & Goals of Care Designations (ACP/GCD)
**Topic Lead—Dr. Eric Wasylenko**
- Colleague Review Process (including a broader review by PPAL/EOL ISC) wrapped up on December 1, 2017.
- Feedback from Colleague and CSS review will be incorporated into the final draft which will then be distributed for final review and approval.

### End of Life / Care of the Imminently Dying
**Topic Lead—Lorelei Sawchuk**
- On-going process alignment with the End of Life Care Pathway Pilot and Roll-Out.
- Revised draft of the topic in progress with plans to review with the working group in January 2018.

### Palliative Sedation
**Topic Lead—Dr. Michael Slawnych**
- Consensus on definition of Palliative Sedation and scope of the knowledge topic achieved with Working Group.
- First draft of the topic in progress with plans to review with Working Group in January 2018.

The prioritized PEOLC Knowledge Topics for next year include Care of the Imminently Dying - Pediatrics, and Palliative Sedation - Pediatrics. Work will commence once current topic work has been completed.

We would like to introduce Leng My from the Clinical Knowledge Topic team, who will be working on the Palliative Knowledge Topics going forward as Katrina Simpson-Pineda transitions to a new role. For more information about Clinical Knowledge and Content Management (CKCM), AHS staff can visit our website on Insite. We encourage you to visit this page to learn more about CKCM’s three streams of work: Clinical Knowledge Topics, Foundational Knowledge and Clinical Documentation. From the CKCM website, you can also access the Clinical Knowledge Viewer, where the provincially adjudicated clinical content for Alberta’s Clinical Information System (CIS) will be published.

Please contact us at ckcm@ahs.ca or via the website to provide CKCM with any feedback or comments, or to express your interest. We value your input and opinion.

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