



Provincial Palliative and End of Life Care

January 2016

Happy New Year!

The Palliative and End of Life Care (PEOLC) Innovations Steering Committee met on December 10, 2015 and endorsed the Health Care Provider infographic (*featured on the right*). Also at the December meeting, committee members recommended that an infographic targeted to patients and families should be developed. The provincial PEOLC team will be working with the patient and family representatives from the steering committee to draft this version in the coming months.

Over the last few months, the steering committee and working groups have been working on the following initiatives:

- Alberta PEOLC Website ([page 3](#))
- Community Support Initiative ([page 3](#))
- EMS PEOLC Assess, Treat and Refer 2.0 ([page 2](#))
- Provincial Bereavement Initiative ([page 3](#))
- Volunteer Network Support Plan ([page 4](#))

Also the steering committee will be partnering with the Clinical Knowledge Team to develop three Clinical Knowledge Topics for PEOLC. More information can be found on [page 4](#).

We are also pleased to announce that Aurora Leang has been chosen as the successful applicant for the Project Coordinator position within the PEOLC team. In the last two years, Aurora has worked with the Community, Seniors, Addictions and Mental Health portfolio within AHS providing admin and project support. Please join me in congratulating and supporting Aurora in her new role.

The provincial PEOLC team would like to express our thanks for the many hours of time, effort and commitment to those individuals who have participated on the steering committee, working groups and those who have contributed to the development and implementation of the Palliative and End of Life Care Alberta Provincial Framework Initiatives (<http://www.albertahealthservices.ca/about/Page10774.aspx>).

Thank you for a fantastic 2015. Looking forward to an incredible 2016.

PARTNERSHIPS

IN PALLIATIVE AND END OF LIFE CARE (PEOLC) IN ALBERTA

WHAT IS PEOLC ?



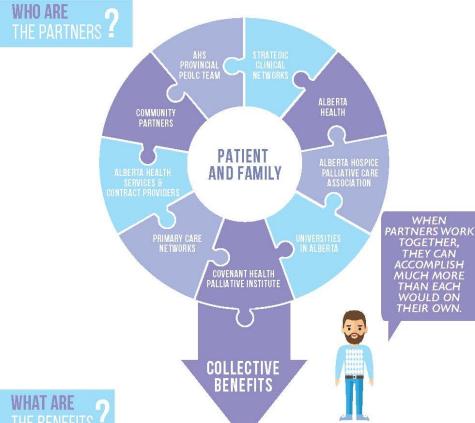
PEOLC PARTNERS ARE WORKING TOGETHER TO ENSURE ALL ALBERTANS RECEIVE THE BEST POSSIBLE PEOLC WHERE THEY LIVE.

9/10

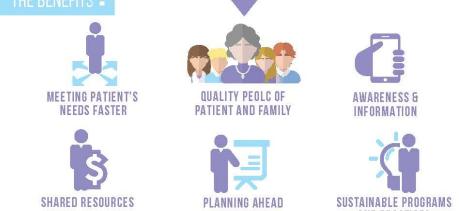
ALBERTANS WILL REQUIRE SOME DEGREE OF PEOLC IN THEIR LIFETIME.



WHO ARE THE PARTNERS ?



WHAT ARE THE BENEFITS ?

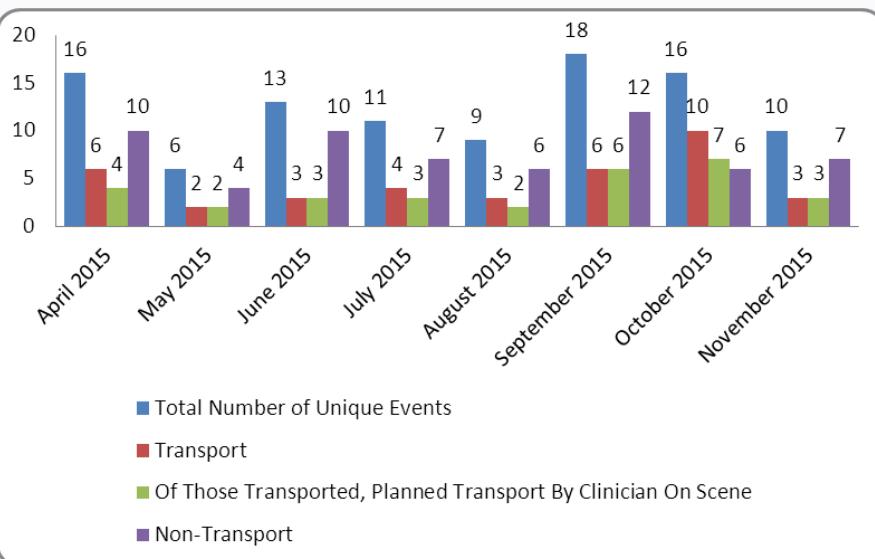


POSITIVE RESULTS !



EMS PEOLC Assess, Treat, and Refer

Phase I Implementation



Collaboration Across Zone Lines

In late November, the program was activated by a home care clinician on scene with a client in northwest Calgary Zone. Due to EMS's borderless response system, a crew out of Olds (Central Zone) was assigned to the event. Together home care and EMS provided support to the client to manage their pain crisis at home.

Meet Your ATR Program Reps!

North: Terri.Woytkiw@albertahealthservices.ca
Edmonton: Julia.Arsenault@albertahealthservices.ca
Central: Pansy.Angevine@albertahealthservices.ca
Calgary: Kristy.Schafer-Blood@albertahealthservices.ca
South: LeAnn.Esau@albertahealthservices.ca

Inquiries from EMS related to the Assess, Treat and Refer program may be directed to: Cheryl.L.Cameron@albertahealthservices.ca

Phase II Development

Phase 1 - (2014/15)

- Clinician activates by phoning 911 and requesting PEOLC EMS support
- Clinician & EMS collaboration on scene
- Tailored treatment plan in conjunction with online medical control
- Implemented within the 2014/2015 fiscal year

Phase 2 - (2015/16)

- Building from Phase I, EMS crews will now also identify PEOLC patients and phone community supports to maintain the patient in the community setting
- Remote access by clinician enroute to scene
- Follow up process if clinician cannot attend to scene
- Medical Control Protocols
- Physician specialist support
- Alternate transport destinations (hospice/ward)
- Inclusion of CCP programs
- Additional PEOLC education

Phase 3 - (2016/17)

- The working group continues to refine the protocol enhancements for Phase II including remote clinician access and EMS activation of the program.
- The program team continues to work closely with Pallium to evaluate the Learning Essential Approaches to Palliative and End of Life Care (LEAP) Paramedic pilot and investigate additional opportunities.

Got a Question? Contact us at
EMS.Palliative@albertahealthservices.ca

Palliative and End of Life Care Website

The screenshot shows the homepage of the MyHealth Alberta website for palliative and end-of-life care. It features three main sections: a top banner with a photo of a patient and a caregiver, a middle section with a photo of a child, and a bottom section with a photo of an elderly man. Each section contains text and links related to palliative care.

Palliative and End-of-Life Care (PEOLC)

The MyHealth Alberta website is for patients, their family and friends, doctors, nurses, health professionals, or anyone who wants to learn about palliative and end-of-life care.

Access online information and resources on:

- teams, programs and services
- who benefits from palliative and end-of-life care
- the importance of symptom management

MyHealthAlberta.ca

Having information can help you make choices. It can also reduce fear, uncertainty, and may help in regaining a sense of control.

People have different information needs at different times. Ongoing access to information is important. Visit myhealth.alberta.ca/palliative-care to find out more about palliative and end-of-life care.

MyHealthAlberta.ca has been created by the Alberta Government and Alberta Health Services (AHS). The information is relevant, up-to-date and readily available. Anyone with mobile or desktop access can use this website.

myhealth.alberta.ca/palliative-care

Alberta Health Services

PEOLC

rooms are getting a full makeover and will be amazing when done. A major new feature in 2015/16 will be “just in time” symptom management clinical content for health care providers.

To help drive more people to the website a new marketing post card for patients, families and health care providers is finalized and going to print.

The working group is leading the development of great improvements to both images and content on our site. Exciting new content for volunteer services and bereavement pages is in the planning phase.

Both of those

We are full steam ahead on developing both the online resource directory and our final report outlining recommendations. Our awesome large (22 member) working group has endorsed the use of a provincial bereavement package (What Do I Do Now?) to be given to families post death. Each Zone has the ability to customize this package to include bereavement information, resources and programs. We are also reviewing Zone specific grief care materials to see if we can “standardize provincially but implement locally”. Why re-invent the wheel?



Please contact Sharon.iversen@ahs.ca if you would like more information

Community Support Plan

A survey was distributed to hospice societies/PEOLC associations at the November 2015 Alberta Hospice Palliative Care Association's Imagine Conference. Feedback from the surveys has been collated and common themes have been identified as to what the needs are to enhance palliative and end of life care capacities in Alberta communities. To address these needs, a draft “toolkit” or guidelines document is in the process of being developed.

The working group plans to involve the societies and associations in the development of the document by requesting their feedback and input.



PEOLC Volunteer Network Support Plan

By March 31, 2016 the expected outcome of this initiative is to develop manual(s) with standardized best-practice recommendations to help guide volunteers, volunteer managers and healthcare providers to enhance and improve the effectiveness of PEOLC volunteer programs and services in Alberta, including recommendations for education. In addition a cost-analysis will be completed outlining what the funding requirements would be to implement the proposed recommendations as needed for PEOLC Volunteer services and education/training across Alberta.

Update of current progress:

- A description of the roles and training of volunteers involved in palliative and end of life care services in each zone across Alberta has been collated.
- A literature review has been completed by the working group.
- The final draft of the Provincial Volunteer Resource Training Manual has been completed and is currently at a English editor for review.
- The Rotary Flames Volunteer Resource Manual will be posted on the AHS Volunteer Resources webpage and a link will be provide on the Health Care Provider and Volunteer “room” on the Provincial PEOLC website.
- The working group is currently revising, enhancing, and updating the multi-zone AHS Volunteer Facilitator’s Manual and incorporating best practice guidelines.
- The working group is also brainstorming the final deliverable around cost analysis to implement PEOLC volunteer programs and services where there are gaps in Alberta.

For more information please contact michelle.petersonfraser@ahs.ca

Clinical Knowledge Topic Team



Goal is to create, maintain and disseminate best practice/evidence-informed clinical standards for defined diseases/conditions or specific patient populations



CKTs will include order set components, documentation tools, guidelines/protocols, patient teaching materials and more



CKTs will be built into CISs to provide front line workers access to provincial guidelines, with the goal of improving patient outcomes

The goal of the Clinical Knowledge Team is to create, maintain and disseminate provincially adjudicated best practice/evidence-informed clinical standards for defined diseases/conditions or specific patient populations.

Clinical Knowledge Topics (CKTs) will include order set components, documentation tools, guidelines/protocols, patient teaching materials, etc.

The clinical knowledge will be built into CISs to provide front line workers access to provincial guidelines, with the goal of improving patient outcomes.

The Provincial Palliative and End of Life Innovation steering committee has prioritized the following three CKTs to be developed by the Clinical Knowledge Team:

- Advance Care Planning and Goals of Care Designation;
- End of Life Care Guidelines; and
- Provincial Palliative Sedation Policy.

Email Katrina Simpson-Pineda at Katrina.Simpson-Pineda@ahs.ca, the Clinical Informatics Lead if you have any questions. We are also in the process of hiring a Palliative Clinical Knowledge Lead (F.T.E. 0.1).

It's About Life: Navigating the Reality of Hospice Palliative Care

On any given day in hospice palliative care, we're faced with the reality that the end of life is a complex journey. Family dynamics, spirituality, pain and suffering, physician assisted death, and even ethics are just some of the difficult issues we face. Learning to navigate these real life problems that come with living, working, and volunteering in hospice palliative care is the topic for the AHPCA 2016 Roadshow.

"It's About Life: Navigating the Reality of Hospice Palliative Care" is an interactive full-day workshop which will help you develop practical strategies through inspiring discussions, self-reflection, and thought-provoking case studies provided by our Roadshow communities.

REGISTER ONLINE at AHPCA.ca or call Theresa Bellows at 403-473-7845



Calgary Edmonton

Banff & Canmore

Wednesday May 4, 2016

The Fenlands Banff Recreation Centre
100 Mt Norquay Road, Banff, AB

Workshop 9:00-4:00 pm Registration and Coffee 8:30 am

Workshop Fees (Includes lunch)

\$10.00 for current AHPCA members
(register prior to March 31, 2016 for this rate)
\$65.00 for new members
(includes AHPCA/CHPCA membership to March 2017)

Host: Town of Banff/Town of Canmore FCSS



Calgary Edmonton

Grande Prairie

Wednesday June 1, 2016

Grande Prairie Regional College
10726 106 Avenue, Grande Prairie, AB

Workshop 9:00-4:00 pm Registration and Coffee 8:30 am

Workshop Fees (Includes lunch)

\$10.00 for current AHPCA members
(register prior to March 31, 2016 for this rate)
\$65.00 for new members
(includes AHPCA/CHPCA membership to March 2017)

Host: Grande Prairie Hospice Palliative Care Society



Calgary Edmonton

Red Deer

Wednesday June 14, 2016



Westerner Park
4847A 19 Street, Red Deer AB

Workshop 9:00-4:00 pm Registration and Coffee 8:30 am

Workshop Fees (Includes lunch)

\$10.00 for current AHPCA members
(register prior to March 31, 2016 for this rate)
\$65.00 for new members
(includes AHPCA/CHPCA membership to March 2017)

Host: Red Deer Hospice Society



Calgary Edmonton

Edson

Monday October 3, 2016

Seniors Pioneers Cabin
4836 - 7 Ave, Edson AB

Workshop 9:00-4:00 pm Registration and Coffee 8:30 am

Workshop Fees (Includes lunch)

\$10.00 for current AHPCA members
(register prior to March 31, 2016 for this rate)
\$35.00 for new members
(includes AHPCA/CHPCA membership to March 2017)

Host: Edson FCSS Program



Please register at www.ahpca.ca

This workshop can be used for Continuing Education credits

alberta hospice palliative care association
1245-70 Avenue SE Calgary, Alberta T2H 2X8
Ph: 403.206.9938

ahpca.ca



Palliative and End of Life Care

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

ADVANCE CARE PLANNING
CONVERSATIONS MATTER

GOALS OF CARE
DESIGNATIONS



Charting the Course: Legal Guidance in Preparing Advanced Care Plans

As our population ages, more and more people are giving serious thought to what their healthcare might look like should they develop a serious illness or condition. Personal beliefs, wishes and preferences have become critically important as patients take an active role in deciding what treatments they are willing to receive, at what point they no longer wish to receive treatment, and exactly how much medical intervention they want done on their behalf if they are no longer able to speak for themselves.

There can be difficult choices to be made, some of which can evolve into complex legal matters. The challenge for patients – and potential patients – can be finding a legal representative who is familiar not only with the laws around advanced care plans but who also has a clear understanding of the course of illnesses, institutional practice and documents, and the sorts of medical conversations that may be necessary to make important ‘in-the-moment’ decisions.

People often seek help from lawyers to plan for their future in various ways including writing wills and appointing a representative to manage their finances – it only makes sense, then, that they would wish to consult on future healthcare as well. What is needed, though, are a set of resources which provides members of the legal profession with the background that they need to ensure that the wishes of their clients are clearly understood when they are unable to speak for themselves.

Covenant Health’s Palliative Institute, the University of Calgary and the University of Alberta jointly received funding through Alberta Innovates – Health Solutions’ Collaborative Research and Innovation Opportunities (CARIO) to determine exactly what types of resources would be useful to the legal community to assist their clients with essential and binding Advanced Care Planning services. Starting in February 2015, inclusive consultation meetings were held in both Calgary and Edmonton to discuss the topic with lawyers in private practice; those who represented Alberta Health Services; Covenant Health; the Office of the Public Trustee and Guardian; Calgary Legal Assistance; Legal Education Society of Alberta; physicians with end-of-life care expertise; ethicists; members of the public; a social worker, and the Advanced Care Planning – CARIO team members.

The consensus from the first meeting and other consultations that followed is that a framework for a collaborative model needs to be created so that clients/patients receive optimal Advanced Care Planning support. Both lawyers and medical practitioners need to be better informed, engaged and involved in the process. The resulting team approach, where all of the client’s best interests would be fairly and clearly represented.

Workshops, focus groups and conversations are ongoing through the efforts of the ACP team. A survey was developed around ACP best practices and sent to practicing lawyers, and it may also be used in other locations in both Canada and Australia. Ultimately, the goal of the project is to develop an effective medical/legal framework for advanced care planning that will enhance the standards of end of life care for patients by ensuring that their wishes are heard, understood and respected.



Alberta Health
Services

Save the Date!

16th Annual Mary O'Connor Palliative and Hospice Care Conference

Through the Eyes of the Beholder: Multiple Perspectives on Palliative Care

Date: April 27, 2016

Location: MacEwan Hall
University of Calgary Campus

Registration will open February 2016.

Additional details will be forwarded at that time.



Call for Poster Abstracts

Alberta Health Services Palliative/End of Life Care – Calgary Zone invites you to submit an abstract for poster presentation at the 16th Annual Mary O'Connor Palliative and Hospice Care Conference being held **April 27, 2016** at MacEwan Hall, University of Calgary Campus in Calgary, Alberta. The deadline for abstract submission is **4:00 PM, January 29, 2016**.

The theme of the 2016 Conference is ***Through the Eyes of the Beholder: Multiple Perspectives in Palliative Care***. The overall goals of the conference are to understand new trends in palliative and hospice care, gain new information regarding palliative care, network with colleagues, and to celebrate, support and strengthen the future of palliative and hospice care. To achieve these goals we believe that showcasing the work that is taking place within our healthcare system will do just that.

Poster presentations associated with palliative and end of life care can be related to current or recent research studies, innovative practices, quality improvement projects, or program evaluations with related learning.

All abstracts selected for poster presentation will be published in the conference program which all delegates at the conference receive.

Submission Deadline: January 29, 2016 – 4:00 p.m.

For additional information, please contact: Pat Munro, Advisor, Conference Planning Services at (780) 644-8638 or pat.munro@ahs.ca



Rotary Flames House

When a child has a life-limiting or medically-complex illness, the stress of providing round-the-clock care can weigh heavily on parents and leave many feeling more like full-time nurses than moms and dads. Managing medications, therapies and appointments can be so physically and emotionally exhausting that there is little time left for other siblings, let alone parents themselves. Attending family gatherings, enjoying a relaxing dinner, even getting a good night's sleep are out of reach for many families whose children have medical needs too challenging to entrust to anyone but the specially-trained.

Thanks to community support, these families have access to respite care at Rotary Flames House, which allows them much-needed breaks for rest and renewal. Specialists at Rotary Flames House are well-equipped to care for children with very complex conditions so parents and siblings can have peace of mind knowing that their kids are in very kind and capable hands. In fact, community support has now helped expand services, making them available to children who have had tracheostomies – surgically implanted breathing tubes. Patients and families benefit from many resources including therapeutic day programming, a parent support group, a sibling support group and social events, activities and entertainment that provide new recreational, social and developmental opportunities for this special group of children.

In the 2014-15 year, families relied

on respite care at Rotary Flames House more than 250 times. The Okubos are one of those families. Little Eliina was born with Trisomy 18, a life-limiting genetic disorder that can claims the lives of children when they are just days or weeks old. "Eliina has an incredible fighting spirit," says her mom, Rhonda. "She's two years old now and we're so grateful for

the time we've been given to love and enjoy her." Rhonda attributes a large part of the family's ability to give Eliina the best life possible to the care provided through Rotary Flames House

– care for her daughter, herself, her husband and their two other children.

"When Eliina goes in for respite care, she is embraced with such love and compassion by her team of caregivers," says. Rhonda. "Respite is such a wonderful gift to us too. It allows us a short break from our daughter's round-the-clock care to spend time with our other kids and get a solid sleep.

"Though our time with Eliina is limited, the team at Rotary Flames House is helping us ensure it's very meaningful and special."

- Eliina's mom, Rhonda

We can rest easy, knowing Eliina is being cared for by a team with a combination of specialized skills and love. And though our time with her is limited, the team at Rotary Flames House is helping us ensure it's very meaningful and special."



Eliina Okubo and her mom, Rhonda benefit from donor-funded respite care at Rotary Flames House.

North Zone

Our North Zone Palliative Care Team is pleased to announce the hiring of LJ Gregory!! LJ will be based in the Peace River and will be the Palliative Care Resource Nurse for the Peace River, High Level, LaCrete and surrounding areas. We will provide more information as to her contact numbers once she has completed her orientation and is settled in her office. Please join us in welcoming LJ to the team

In October, the LEAP program went north to Ft. McMurray. In November, LEAP was taught in Bonnyville. Both sessions were very well attended. So to keep the ball rolling for 2016 (which is a Leap year!), plans are underway to present the LEAP program again in Bonnyville on February 5-6, 2016 and Fort McMurray in March. Please feel welcome to sign up through Pallium and join us!

A huge thanks to all those involved in arranging, planning and presenting the LEAP programs in the North Zone.

We were also invited to present "Final days and Hours" for the Lac La Biche nursing staff at their nursing skills day. Thank you for the opportunity to share our palliative care knowledge with your nursing staff. We look forward to seeing you in February 2016 for a new palliative care discussion.

The EMS Palliative End of Life Assess Treat and Refer program has been introduced into a number of communities in the North Zone, including Fort McMurray, Grande Prairie, St. Paul, Elk Point, Cold Lake and Onoway. We have had several activations, with positive feedback from staff involved. We were pleased to have staff from Onoway take part in two Patient Experience sessions at the Edmonton EMS Symposium, where one of the families shared how this experience supported their preference to keep a family member at home to the end of their life.

Contacts



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