



Provincial Palliative and End-of-Life Care Innovations Steering Committee

Winter seems to have taken over autumn in Alberta rather quickly. The Provincial Palliative and End-of-Life Care (PEOLC) team hopes that you and your family are staying warm and well despite the cold weather outside.

The Palliative and End-of-Life Care Innovations Steering Committee (PPAL/EOL ISC) met in September and endorsed the PEOLC Alberta Provincial Framework Addendum. This document will continue moving through the approval process in the upcoming months. The addendum will be published soon, so stay tuned for more updates!

The Provincial Minister of Health assigned MLA Dan Williams from Peace River to complete a stakeholder review regarding PEOLC in Alberta. MLA Williams and his team have been meeting with small groups within PPAL/EOL ISC. This has included the following representatives within the steering committee: the Provincial PEOLC team, operational leadership, physicians, indigenous groups, pediatrics, and Provincial programs. MLA Williams will be providing a summary report with recommendations on how to spend the remaining \$14 million from their \$20 million platform commitment to improve PEOLC supports for Albertans. This report is expected by the New Year.

“I’m so pleased to be part of this important work. As we continue to face the challenges of the COVID-19 pandemic, now is an important time to discuss end-of-life matters with our families and friends so that we can face the future with strength and dignity.”

Dan Williams, MLA for Peace River and government engagement lead on palliative care

Changes to PEOLC Team

Welcome to Emma Buzath, she will be filling in the vacant provincial Lead position with the PEOLC team for a two year term. Emma has a background in Public Health and Bioethics. Over the last five years Emma’s work has focused on palliative care, mental health, and substance use disorders. Her work has included collaborations with rural hospice societies, the Cumming School of Medicine, AHS, and non-profits such as the Calgary Homeless Foundation. We are excited to welcome her to our team!

Provincial Palliative End-of-Life Care Updates:

Evaluating the impact of COVID-19 on PEOLC ([Page 2](#))
The provincial PEOLC website ([Page 3](#))

For PEOLC education opportunities, review the Provincial PEOLC Education Bulletin link.
www.albertahealthservices.ca/info/page14438.aspx



Canadian Hospice Palliative Care Association (CHPCA) Presents the: National Hospice Palliative Care Day for Children



October 13 celebrated the first National Hospice Palliative Care Day for Children, with support from the Canadian Hospice Palliative Care Association. A webinar was held and broadcasted across the country featuring Dr. Dave Lysecki, the Medical Director of the QofA (“Koala”) team at McMaster Children’s Hospital. His webinar was titled “Children’s Hospice Palliative Care: It Takes a Village.” Alberta is mainly serviced by two pediatric palliative care teams, known as ASSIST in both North and South. One team is based out of Calgary and runs out of the Rotary Flames House – a freestanding pediatric hospice; the other team is

based out of Edmonton and runs out of the Stollery Children’s Hospital. Both teams provide palliative care in urban and rural locations and support families in hospital and community settings. This includes family and bereavement supports for child and infant loss.

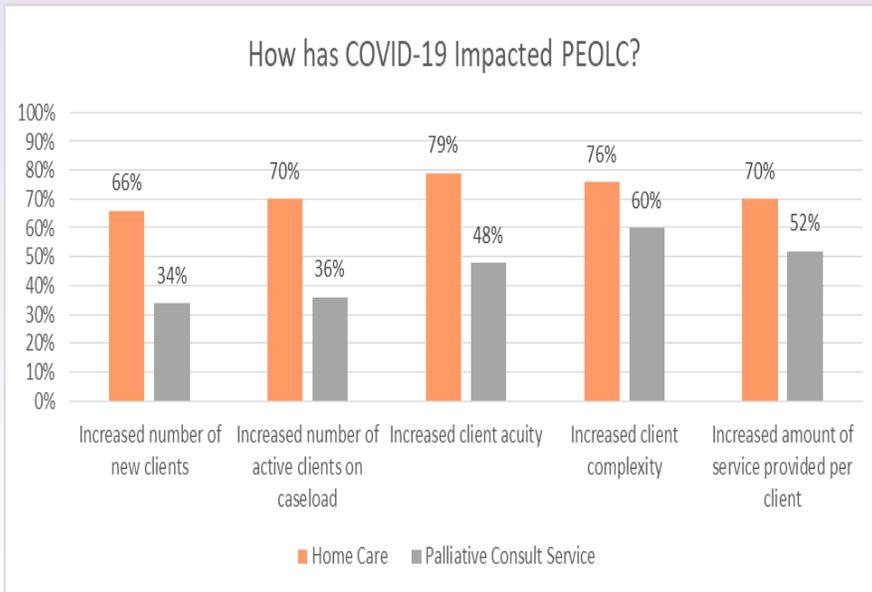
Over the last 30 years, pediatric palliative care has evolved greatly as a multidisciplinary specialty in Canada. October 13 provided an opportunity to create awareness of this important area of specialized care. Many articles and news clips were shared on social media that highlighted the celebrations that occurred on this special day. More information can be found here: <https://www.chpca.ca/wp-content/uploads/2020/09/FIANL-faq2.pdf#page=1>

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Evaluating The Impact of COVID-19 on PEOLC

As mentioned in the previous newsletter, an online qualitative survey was completed with hospice, home care, and palliative consult healthcare providers provincially. Responses were collected between June 30 and July 31, 2020. The results from the qualitative survey have been compiled into a draft report. One of the findings highlighted in this report was the increased number of new clients and the number of clients on the home care and consult service caseloads. Both the acuity and complexity of clients has increased during this pandemic, as has the amount of service provided per client within home care and consult services. The results from this survey will be used to inform current work, as well as planning for a potential COVID-19 surge. Additional data is being sought to better understand the impact of COVID-19 on palliative home care.



The Provincial PEOLC team and the PPAL/ EOL ISC would like to thank frontline clinicians and staff for caring for PEOLC patients and their families during this critical time. Thank you to those of you supporting PEOLC in other ways as well such as providing direction, revising guidelines, and creating documents to support patients, families, and frontline healthcare providers.

The Provincial PEOLC Website Concurrent Session at the 31st Annual Palliative Education & Research Day

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

On October 19th Covenant Health hosted an extremely successful online Zoom conference. The 31st Annual Palliative Education & Research Day, Kaleidoscope of Diversity: Honoring individuality in palliative care. Over 650 individuals registered, an amazing attendance. In one of the concurrent sessions Sharon Iversen presented The Web of Palliative and End-of-Life Care (PEOLC) Resources Online: Tips to Help Navigate a Trusted Resource for Alberta Health Care Providers, Patients, and Their Families. Over 280 online participants joined this session virtually, asking questions in the chat feature and learning about the diverse suite of content AHS has posted on palliative and end of life care and advance care planning. Congratulations to the event planners for organizing such a dynamic and accessible end-of-life conference.

Palliative Care, Early and Systematic (PaCES) Update

PaCES

Emerging Results

Jan 2018-May 2020

PALLIATIVE CARE EARLY AND SYSTEMATIC

The PaCES project seeks to improve the lives of Albertans with advanced cancer by providing timely palliative care, as an added layer of support during cancer treatment.

The early, integrated palliative care pathway for advanced colorectal cancer was co-developed with patients and healthcare providers and introduced into Calgary's Cancer Centre in Jan 2019, with 6 months of facilitated implementation support.

We are tracking patient outcomes and health systems use from Jan 2018-Dec 2020.

Process Outcomes

20% Shared Care Letter Use

for patients on second-line chemotherapy and 50% responded to by family doctors

8% increase in referral to "early" Palliative Care Services

Patient Outcomes

"The sooner we understood what was happening and what services were available, it gave us a **peace of mind** and it didn't diminish the hope for best quality of life and what's ahead."

System Outcomes

Patients are accessing Palliative Care sooner

Fewer patients died in hospital with early palliative care

Median 5 months before death in 2019 compared to 3 months before the pathway was implemented

29% died in hospital in 2019 with early palliative care Vs. 42% without

These emerging results suggest the early palliative care pathway is working. Please keep using it!

Covenant Health Palliative Institute

Alberta Health has announced a commitment of over \$5 million for the Covenant Health Palliative Institute, located in Edmonton Alberta, as part of the \$20 million they have dedicated to improving access to palliative care for Albertans and their families. These funds will support public- and patient-focused initiatives, and continue to promote awareness, understanding, and access to advanced care planning and palliative care in Alberta. Covenant Health is searching for a knowledgeable and talented project manager, communications advisors, project coordinators, and assistants. If interested, please contact palliative.institute@covenanthealth.ca

knowledge, skills, behaviors, and attitudes toward palliative care. These documents can be used to inform and guide academic curricula, professional development, professional regulatory bodies, continuing education programs, and employers. The competency frameworks can be found at <https://www.covenanthealth.ca/innovations/palliative-institute> and will soon be available at <https://albertahealthservices.ca/info/Page14559.aspx>



The Covenant Health Palliative Institute is pleased to announce the completion of **15 discipline-specific competency frameworks**. These documents provide an opportunity for clinical staff and volunteers to engage in self-assessment of

Rotary Flames House

Patients and families have been incredibly gracious, understanding and accepting as the many phone calls were made by the bedside Registered Nurses (RNs), Aid for Symptoms & Serious Illness Support Team (ASSIST) RNs and Clinical Nurse Specialists (CNS) to cancel all pre-booked respite stays at Rotary Flames House (RFH) initially through mid-June and subsequently through December. Initial cancellation phone calls have been followed by phone calls to touch base, coach families as needed, and to identify patients and families in need of urgent respite or symptom management stays. The team has made hundreds of such phone calls. The result: in this 4 month period we have been able to provide 65 urgent respite stays of 5 or more days to children and families most in need and, we have provided 5 urgent symptom management stays. We have also had 32 new consults to the program for respite, symptom management and end-of-life support. In addition we have had two new antenatal referrals to the program.

Many on the team have learned the magic of the ZOOM platform during this time and how to work and contribute effectively via virtual platforms. Child Life, the Therapeutic Arts team, and the RFH Summer Virtual Student Intern (Callum) have been collaborating since April to offer the families followed by Children's Hospice and Palliative Care Services (CHaPS) a variety of virtual programming, local resources, and activity ideas. With 1-3 Zoom programs a week currently offered, the RFH outpatient families have enjoyed music therapy, stories, sound bingo, tactile play, cookie baking, and creative arts. Along with these programs, the team also offered a virtual safari facilitated by the Calgary Zoo as well as Motivational Magic & Laughter Yoga from the Alberta Children's Hospital Therapeutic Clown. To date, RFH has been able to facilitate **38 Outpatient Zoom sessions** with a total of **292 participants** local to Calgary and throughout Alberta. Outpatient families are emailed each week with the current program information, Zoom login, as well as new resources to explore on their own. There has been very positive feedback from the families about the fun experienced and the wonderful connections felt with others that this programming has provided. The team has been very grateful to have the opportunity to continue connecting with outpatient families in this unique way.

The RFH is also very excited to be offering a 4-week virtual sibling grief group for children aged 7-12 years. This will be a unique opportunity for bereaved siblings to connect with each other and the Child Life Specialist through a structured program aimed at emotions, coping, legacy, and creative outlets for grief. Currently there are 11 children participating in this program that we are hoping to continue to offer in the future.



Child Life has continued to support individual inpatients with the aid of appropriate Personal Protective Equipment in order to provide sensory play, creative arts, outdoor exploration and infant development. The absence of volunteer team members has been a loss for all during this time and the RFH is so pleased to see the volunteer members returning to the team as Phase 2 has allowed.

The RFH have been directly involved in the end-of-life care of 21 children during this pandemic. The team has supported these children, their families and their primary teams at many locations including Alberta Children's Hospital Neonatal Intensive Care Unit (NICU), Pediatric Intensive Care Unit (PICU), RFH, patients' homes and patients' home community hospitals. The loss of each of these exceptional children during this time of physical distancing and absence of traditional family supports has felt even more profound. The entire team has been involved in these children's care in different and important ways. Thank you to the healthcare providers who served the patients and families so well. During this time, the grief and bereavement support team, remarkably, has initiated ZOOM platform group therapy along with, a suicide loss support group, a first in program history. In June and July via ZOOM platform, two mixed loss groups and two suicide loss groups were offered. The Grief and Bereavement support team received thirty five new pediatric death referrals from the Calgary Zone and provided bereavement follow up from RFH. Additionally, about 170 phone and ZOOM counselling sessions were provided and, once Phase 2 relaunch allowed, in person Eye Movement Desensitization and Reprocessing (EMDR) sessions for trauma were held. This team has also supported in person care reviews with bereaved families and involved the medical team.

All of the above activity represents a small snapshot of team contributions for our patients and families during a very challenging time. Thank you.



North Zone

For Dan*, a client in North Zone, it was important to remain in his home as long as possible. He had brain cancer and lived with his wife and dependent daughter. Since his wife and daughter were his care providers, they struggled to have meaningful interactions with him. To support the family, a Recreation Therapist was able to provide Dan's wife and daughter with activity ideas that could bring meaning to Dan's life and provide special moments that they could share during this difficult time.

Dan and his wife traveled throughout their lives; with guided support, they enjoyed looking at pictures of their travels.

This experience was enhanced by connecting Dan's TV to an iPad and enlarging the pictures on the TV. This allowed Dan and his wife to reconnect and reminisce. They found pleasure in reflecting on their memories which helped Dan with his feelings of loneliness, isolation, and depression. After Dan's passing his wife commented, "some of the greatest moments we shared was when we looked at those pictures and reminisced about those great times".

Dan's daughter offered her dad a simple hand or foot massage which aided with maintaining meaningful conversations between them.



Recreation Therapy plays an important role in supporting clients and their families during end-of-life care. Pet visits, music, art, and socialization are methods that can reduce pain and provide comfort, along with improving the client's quality of life. Recreation Therapists are an integral part of Palliative Care teams, providing purposeful engagement in leisure interests which can foster a continued sense of self-worth, reduce boredom, foster a sense of accomplishment, enhance social supports, and increase quality of life at a difficult time.

**names were changed to protect client confidentiality*

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