AHS brings palliative care home—Framework aims to deliver end-of-life care where patients want it.

Story by James Stevenson

Pam Cummer remembers clearly when her mom, Janet, was diagnosed with ovarian cancer.

She fought it head on with surgery, chemotherapy and radiation. And Janet lived two more happy years during which time she travelled with her husband, Ed, visiting family and friends and enjoying life.

In the third year, she began to get weaker and more frail. She received excellent care in hospital but just wanted to go home. So her family took her there.

“Dad, along with my brother Brian and I, cared for her with the help of the palliative home care team,” says Cummer. “Mom’s family doctor paid weekly house visits, often listening and acknowledging the care that we were providing. The pharmacist also made home deliveries, the home care nurses phoned frequently and visited whenever we asked them to. We had an on-call number, so we never felt alone.”

The day before Janet died, many of her grandchildren visited and spent private time with her. She died holding Ed’s hand, her husband of 57 years. She didn’t need anything else.

It's stories like Janet’s that bring home the importance of the new Palliative and End of Life Care Alberta Provincial Framework, which aims to strengthen the care provided and improve access for all Albertans.

“The goal is to ensure that patients and families have the end-of-life care that they require to help them stay in their communities and homes, if that's what they choose,” says Dr. James Silvius, Medical Director for Seniors Health at Alberta Health Services.

As part of the new framework, many supports and initiatives will be developed and implemented with the goals of strengthening services and options for Albertans within their communities.

One foundational initiative that has already begun provides access to palliative specialist physician support for primary health care providers no matter where they live in Alberta.

Additionally, there’ll be research and education for patients, families and care providers to increase confidence and provide tools in the delivery of quality care, and data will be gathered to help further hone the system in the future.

According to a recent public opinion survey from Harris/Decima, completed for the Canadian Hospice Palliative Care Association, 86 per cent of Albertans would prefer to die at home or in the community instead of in hospital. Currently, as few as 15 per cent of Albertans die in their homes or communities, and that's depending on location and disease.

“Along with a new palliative specific website built as part of the personal health portal for Albertans coming next year, this is going to help families better understand their situation, the choices they have and what resources are available to them,” says Silvius. “I encourage all Albertans to talk to their physician, caregivers, family and friends about their end-of-life choices for future health care.”

Palliative and end-of-life care for all Canadians is an important endeavour and especially timely with an aging population.

“The Canadian Hospice Palliative Care Association commends the Alberta government and Alberta Health Services for their leadership in developing a provincewide framework bringing and further enhancing the palliative approach and advance care planning to its citizens,” says Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association.

“This approach will lead to improved access and service options across all settings of care and benefit patients, their families and caregivers.”
PEOLC EMS – Assess, Treat, and Refer (ATR)

PEOLC EMS ATR Phase 1 Protocol and Dispatch Model was endorsed on October 31, 2014:

EMS Lead Change – Melanie Doiron recently accepted a position with Alberta Health and Cheryl Cameron stepped in to assume the EMS Lead role on this project as of November 3rd. Cheryl is a paramedic who historically hails from EMS Operations in Edmonton Zone and Central Zone, but has spent the last few years instructing EMT and Paramedic students in Lakeland College’s EMS Programs. Cheryl was able to shadow Melanie for a period of time to get brought up to speed on the current status of the project, and is excited to take on this new role and challenge.

Dispatch Engagement – Since endorsement of the dispatch protocol, discussions have continued with executive leadership in the dispatch center. Business rules have been created and a training package for dispatch personnel is currently being drafted.

ATR Form – A draft Assess, Treat and Refer Form has been created and is awaiting endorsement from the working group. As in other EMS ATR programs, the ATR Form is completed for any patient that fulfills the criteria for the program, is treated in place and is not transported to an acute care setting. This form serves a legal documentation to support the treat and refer process, and also as a record of the event for the patient to provide to their physician.

Communication Plan – A communications plan has been created in collaboration with EMS Provincial Communications. This plan was indorsed by the Innovations Steering Committee in December and work is moving forward to draft communications materials (brochures, etc.).

Education Plan – The project team has engaged EMS Learning & Development and created an education sub-working group. This group has been tasked with building an education package for EMS practitioners and community clinicians.

Evaluation Plan – In December the logic model for the project was endorsed by the Innovations Steering Committee, and the project team continues to meet regularly with Evaluation Services to build the evaluation component of the program.

Physician Engagement – Preliminary discussions between the EMS online medical control (OLMC) and PEOLC physician groups have occurred. The project team has identified the top 5 patient presentations EMS is likely to respond to under this initiative, and PEOLC physicians are currently reviewing the corresponding EMS Provincial Medical Control Protocols (MCPs). PEOLC physicians will be providing suggestions and recommendations to the EMS OLMC physician group on best practices for treatment of PEOLC patients in the community. Under the PEOLC ATR protocol, EMS practitioners on scene will be consulting with EMS OLMC physicians to provide the best care possible at the patient’s side. The patient’s family physician will be engaged by the on scene clinician either at the time of the PEOLC emergency or afterwards for follow-up.

Pathways and Guidelines

The working group has met several times over phone and emails to achieve a number of tasks over the past month:

- Met with PEOLC SCN Pathways/Guidelines Oversight committee to discuss the current state of PEOLC guideline development across the province and the future path of our initiative.
- The current state analysis has been completed and the following three areas of focus have been identified to help integrate PEOLC SCN Pathways/Guidelines plan moving forward:
  - Acute Care Transitions
  - Community Access
  - Enhanced Primary Care Capacity
- Sub-working groups with membership have been initialized based on these three areas.
- Within the next two months, a plan will be drafted outlining the deliverables coming out of the sub-working groups, on how to integrate various SCN guidelines into practice and identify the elements it will contain.
The ACP/GCD Policy and Procedure review process is well underway. Many of you will have had received the ACP/GCD Policy/Procedure Review Survey in your inbox during the first weeks in December; the surveys were extended to December 14, 2014. Together with Clinical Policy, the Provincial ACP/GCD team will be reviewing the survey feedback and will make appropriate changes to the Policy and or Procedure. The new Policy and Procedure will go live again April 1, 2015.

The ACP/GCD Provincial Team is also reviewing its provincial resources. Changes to existing resources and or developing new resources are being considered with the assistance of an ACP/GCD Resource Working Group. If you are interested in becoming involved in this Working Group, please email Claire Neeland: Claire.neeland@albertahealthservices.ca

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24/7 Palliative On-Call Support

Provincial Palliative Physician 24/7 On-Call Support for Adults and Pediatrics:
- Current state complete for adults and Pediatrics 24/7 Palliative Physician support provincially.
- Issues and Gaps identified (North Zone and Pediatrics have gaps in formalized 24/7 Palliative Physician support).
- Ongoing meetings and discussions with North Zone and Pediatrics group to brainstorm potential solutions.
- Have met with BC to learn about their Palliative Physician On-call program.
- Have met with Medical Affairs to identify and advocate for potential solutions to help with gaps in service with a further meeting to follow.
- Further meetings planned with Central Zone and Pediatrics, and with North Zone for further brainstorming and exploring potential solutions to help fill gaps in service.
- Meeting is planned with the working group to present recommendations for a plan for 24/7 coverage for Palliative Physicians and receive feedback.

PEOLC Website

The website initiative is planned to support clinicians, patients and families involved in the PEOLC program. A number of tasks and activities have been completed over the last month:
- PEOLC referral processes validated by zone representatives
- Inventor of AHS PEOLC patient information pamphlets begun
- Partnering with Pallium to secure mind map technology and symptom management content for Health Care Providers
- myHealth.Alberta.ca (MHA) content coordinator and project lead developing aggregation outline from current MHA pages.
- MHA content coordinator, user experience, web developer assigned and first meeting January 9, 2015.
- Project lead and project manager looking at possible Benefits Evaluation measures and the BE approach with University of Victoria researchers.

Capacity Planning

An update & expansion of the palliative aspects of the Continuing Care capacity planning will be incorporated into their 2035 needs assessment process, with plans to convene expert panels in 2015.
Business Casing

Business Case document updates include:

- The team took the remaining initiatives and over the course of two half-day sessions, grouped them into thematically similar clusters.
- The SCN Pathways/Guidelines initiatives was identified to be the first draft business case. This draft business case was completed and will now be used as a template for the following clusters.
- The team presented the SCN Pathways/Guidelines draft business case to the Research, Innovation, and Analytics group so that its analysts could be enlisted to develop the cost/benefit analysis for the SCN Pathways/Guidelines Cluster.
- The complexity of understanding the cluster has made it a challenge to quantify certain benefits; the team is now looking for additional support from a health economist in order to resolve some of these matters.
- A full business case draft document will be completed prior to the first working group meeting scheduled for December.

Dashboard

The Dashboard working group continues to meet on an ongoing basis to discuss and identify Alberta specific PEOLC quality indicators for the dashboard. As the work progresses, there has been a need to fill a role for a data analyst on this project. Updates on the Dashboard initiatives include:

- Identification of all PEOLC indicators have been confirmed.
- Procurement of data analyst to support with building of PEOLC dashboard.

Choosing Wisely Canada is a campaign to help physicians and patients engage in healthy conversations to make informed choices about tests, treatments and procedures.

In the second wave of Choosing Wisely Canada, the Canadian Society of Palliative Care Physicians (CSPCP) has noted advance care planning as a key component in these conversations. “Don’t delay advance care planning conversations” is one of the recommendations made by CSPCP in “Five Things Physicians and Patients Should Question.”

To read all five recommendations, and see the patient handout that CSPCP has developed to support it, go to the Choosing Wisely Canada website.


More information on Choosing Wisely Canada is also available on Canadian Hospice Palliative Care Association’s Advance Care Planning website.

http://www.advancecareplanning.ca/making-your-plan/choosing-wisely.aspx
We are pleased to announce that effective January 5, 2015, Cynthia Johnson will be the new Director of Palliative/End of Life Care & Community Programs with Edmonton Zone Continuing Care. Cynthia brings over 30 years of experience across a range of settings and roles, bringing both a local and a provincial perspective to the team. Her experiences include building and managing interprofessional teams within Continuing Care on her work.

The Central Zone Palliative Care Team has revamped our current courses and began presenting our new case-based education focused on caring for Palliative clients in their homes. The new course is presented via Lync and has received great feedback from participants thus far – we have had over 100 participants already! The team also continues to collaborate with our CZ Educator Team to present Palliative Care 101, after a successful launch last spring. The team is now busy working on a new presentation to help care providers understand the Palliative Care tools – how to use them, when to use them, and their impact on the client’s well-being.

The Central Zone team is also happy to report new growth! We are adding two more Nurse Consultants to our team (each working half time) and have readjusted our geographical boundaries for each nurse to rebalance our workload. It will be a new challenge to work with part-time nurses on our team but everyone is excited about the change.

One of the most exciting news items for us is the collaboration between AHS, Sunrise Encore Supportive Living and the Olds & District Hospice Society – the Society has rented two suites in the new facility for hospice palliative care clients in the service area to have another option for location of care within the Olds area. Care will be provided by LPN’s and HCA’s on-site at Sunrise and overseen by a designated Home Care Case Manager. We are working hard together to see these two suites be successful in serving the area in 2015.
Calgary Zone congratulates Dr. Leonie Herx who started as the new Medical Director for Intensive Palliative Care unit at Foothills Medical Centre in November.

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**Santuari Hospice Decommissioning—May 2015**

Santuari Hospice at the Peter Lougheed Centre was opened in 2010 as a temporary solution to address palliative care capacity issues in the Calgary Zone until community-based capacity could be secured. In May 2015, the Santuari Hospice will be decommissioned.

Thank you to all of the staff, volunteers and physicians at Santuari Hospice for their dedication to the nearly 900 residents and their families since the unit opened 4 years ago.

To maintain hospice capacity, and through due process, Alberta Health Services has awarded a contract to Covenant Care to open a new 26 bed community-based hospice at its St. Marguerite Manor site in 2015. This hospice will be adjacent to the Holy Cross Manor Supportive Living site at 70 Evanspark Manor N.W.

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**North Zone**

**Learning by Simulation: a new approach in North Zone**

*I sit at the bedside of my mother. Two months ago they said there was nothing more they could do. At first my mind wouldn’t recognize this, but as I watch her grow frailer each day, I have no choice but to accept the inevitable; soon my mom will be gone. 20 minutes ago someone came in to give her some pain medication. It hasn’t helped. Instead she has become agitated and confused. She moans and screams because her skin hurts. She forgets who I am. I ring the call bell. I ring it again. No one is coming! Where is everyone? Can’t they see that my mom needs help! “Who are you?” mom says to me. My eyes well up with tears. What is happening?*

Simulation is an experiential learning technique that allows health care staff the opportunity to practice various skills in context of a realistic scenario. The story above was written by Heather Cochrane, Medicine educator at the Queen Elizabeth II hospital in Grande Prairie. It is the premise of one such scenario, and is used as a fresh approach to mentoring staff on how to handle palliative emergencies. Heather plays the palliative patient, while Rhonda Shea, the simulation consultant for the North Zone, plays the distraught daughter. Staff practice interacting with Heather and Rhonda and learn to recognize the signs, symptoms and management of opiate toxicity. Once the scenario is complete the participants spend time discussing what happened in a debriefing session. This is the part of the training where the real nuggets of learning are discovered, as participants are free to discuss thoughts, emotions and strategies openly in a safe, non-punitive, non-evaluative setting. This initiative demonstrates how simulation is a powerful tool for highlighting the importance of family and patient-centered care.

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The Victoria Hospice Palliative Care: Medical Intensive Course was hosted in Victoria November 17-21/14 and was attended by the following participants from the North Zone: Dr. Francois Oosthuizen from Sexsmith, pharmacist Karen Hee from Peace River and Michael Wilson, Palliative Care Resource Nurse. Michael Wilson would like to thank the Manning Palliative Care Society, the Peace Palliative Care Society, the High Prairie & District Palliative Care Society and Alberta Health Services for sponsoring his attendance to this event.

For information about this biannual event go to victoriahospice.org and talk with your colleagues who attended as they will be able to share some of the pearls of knowledge gleamed from this program.
The Final Journey: Becoming a Compassionate Companion

The final journey of life offers an unparalleled opportunity for the dying and their companions to make meaning of this inevitable human experience we call death.

What do you really need to know when you’re with someone at the end of their life? How do you learn to become a compassionate companion - the kind that you want for your own final journey?

AHPCA’s 2015 Roadshow, “The Final Journey” is a dynamic full-day workshop which will lead to practical strategies that you’ll find invaluable whether you’re a health worker, caregiver, social worker, volunteer, or family member.

2015 Presenters
Blair Collins, BA, BTh, RSW
With his 30 plus years of experience in non-profits, Blair’s sense of humour, sensitivity, and passion significantly impacted volunteers and professionals during the AHPCA 2014 Roadshow.

Denise Renschler, MSW, RSW
Denise is an experienced social worker and a graduate of the Hadcn Institute (Canadian Program). Denise’s thoughtful and sensitive approach is welcomed by workshop participants throughout the province.

2015 Roadshow Schedule

<table>
<thead>
<tr>
<th>Location</th>
<th>Host</th>
<th>Date</th>
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<tr>
<td>Okotoks</td>
<td>Foothills Country Hospice</td>
<td>Thursday, March 26/15</td>
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<tr>
<td>Drumheller</td>
<td>Drumheller Palliative Care Committee</td>
<td>Monday, April 13/15</td>
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<tr>
<td>Bonnyville</td>
<td>Bonnyville Palliative Committee</td>
<td>Thursday, May 7/15</td>
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<tr>
<td>Stony Plain</td>
<td>Light up Your Life Society</td>
<td>Tuesday, May 26/15</td>
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Time: 8:30 A.M. to 4:00P.M.

Workshop Fees: Includes Lunch
$10.00 for current AHPCA members (register prior to March 31, 2015 for this rate)
$65.00 for new members (includes AHPCA/CHPCA membership to March 2016)

REGISTER ONLINE at www.ahpca.ca or contact Theresa Bellows at 403-473-7845

*AHPCA Roadshow hours may be submitted as Continuing Education Credits

ahpca.ca
HOSPICE PALLIATIVE CARE IN CANADA

96% of Canadians SUPPORT HOSPICE PALLIATIVE CARE

93% believe it REDUCES STRESS and family burden

94% believe it IMPROVES QUALITY OF LIFE

87% believe that a palliative approach to care should be AVAILABLE EARLY on in the course of a disease

94% believe it should INCLUDE ALL CARE PROVIDERS

93% believe palliative care services should be available in the SETTING OF THEIR CHOICE

49% are aware they CAN ACCESS these services outside of a hospital, hospice or facility

21% report having any PERSONAL EXPERIENCE with palliative care services

Those who believe it is important to have a CONVERSATION with loved ones about their wishes for care

96%

Have actually HAD A DISCUSSION

34%

Have COMPLETED AN ADVANCE CARE PLAN to communicate their wishes

13%

73% want more information from their doctors so that they can PLAN AND BEGIN these important conversations

80% feel these conversations should START WHEN THEY ARE HEALTHY or when they are diagnosed with a life-limiting disease

RESOURCES:
Canadian Hospice Palliative Care Association – www.chpca.net
Speak Up: Start the Conversation about End-of-life Care – www.advancecareplanning.ca

* A quantitative online research survey of 2,978 Canadian adults. Completed using Harris/Decima's proprietary online panel so is precluded from reporting a margin of error. Data were collected between July 5 and August 7, 2013. Survey data were weighted using the 2011 Census to reflect general population (gender, age and region).
Thank you for an amazing year. Looking forward to an exceptional 2015.

Have a wonderful holiday season.

From the Provincial Palliative and End of Life Care Team

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