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HIGHLIGHTS OF THE COVENANT HEALTH PALLIATIVE INSTITUTE 2012-2017

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MESSAGE FROM KAREN MACMILLAN

Senior Operating Officer, Acute Services,  
Grey Nuns Community Hospital & Executive Lead, Palliative Care  
Covenant Health, Alberta, Canada

I am pleased to present to you, the highlights of our work by the Covenant Health Palliative Institute. Since the Institute’s launch in October 2012 we have made significant progress in achieving our goals. We will continue our work on improving and advocating for palliative and end-of-life care, a high priority for Covenant Health. Covenant Health is a key partner in Alberta’s integrated healthcare system and it is Covenant Health’s mission to care for vulnerable populations. With more people living longer with life-threatening illnesses, there is a great need for better palliative care.

Over the last five years and before the Institute was formed, our researchers and clinicians have made steps forward in pain assessment, pain classification, clinical care pathways, and advance care planning. Furthermore, the Institute hosts an annual gathering of the palliative care community to review research and educate practitioners, and has facilitated and held major conferences that focused nationally and internationally on palliative care research and advocacy, and advance care planning research and education.

Some of the factors that have contributed to our success have been our strong links to our partners and our ability to pilot projects and see results in the Covenant Health environment. We have acquired a deep network, academic expertise, and esteem for our work on an international level, and we have the capacity to build on the work that is currently being done. We invite you to contact us to discuss the work we have already completed and work that we may undertake on your behalf or in collaboration with you. For contact information please see the outside back cover of this report.

Sincerely,

Karen Macmillan
ABOUT THE PALLIATIVE INSTITUTE

The Institute supports the Covenant Health strategic objective “We will be leaders in robust palliative and end-of-life care and advocate for it as an essential part of the health system.”

Our Five Pillars

The Institute focuses on supporting excellence in palliative care through clinical support, education, research, policy, and community engagement.

Our Current Goals

1. **Increase palliative care capacity to address gaps in service within Canada**
   - Supporting clinical tools, development and implementation of care pathways, knowledge translation, and public awareness

2. **Increase the use of Advance Care Planning (ACP) and Goals of Care Designation (GCD)**
   - Partnering with ACP CRIO (Collaborative Research & Innovation Opportunities Program) in identification of barriers, facilitators and performance indicators, supporting change management projects, and developing tools for the legal community. The Institute supports policy and education for ACP.

3. **Advocate for a national robust palliative and end-of-life care system**
   - The Palliative Care Matters Initiative, hosted by Covenant Health and collaborative national partners, continues to advocate and support quality palliative care for all Canadians. The Institute, with its collaborators, is working to translate research into practice by publishing and undertaking various knowledge translation approaches.

OUR NETWORK: SUPPORTERS, PARTNERS, COLLABORATORS & CLIENTS

Covenant Foundation
Covenant Health Palliative Care Services
University of Alberta
University of Calgary
Provincial Palliative and End-of-Life Care Steering Committee (Alberta, Canada)
Alberta Hospice Palliative Care Association
Alberta Health
Alberta Health Services
Alberta Innovates – Health Solutions (AIHS)
   - Collaborative Research and Innovation Opportunities (CRIO) program
   - Partnerships for Research and Innovation in the Health System (PRIHS) program
Palliative Care Matters Initiative (Canada):
   - 13 national health organizations, 9 experts
Catholic Health Alliance of Canada
Canadian Hospice Palliative Care Association
Canadian Virtual Hospice
End-of-Life (Last Hours to Days) Care Pathway

In response to criticisms of the 1997 Liverpool Care Pathway and in order to improve on a 2011 Albertan version of a pathway, the Palliative Institute, and Edmonton Zone Continuing Care revised and re-released the Palliative Care Pathway as the Care of the Imminently Dying Pathway. The 2017 Care of the Imminently Dying Pathway will be the provincial framework for supporting care in all patients’ last hours to days of life.

The pathway is a set of tools that enhances the quality of care and provides comfort for a person in their last few hours or days of life. It provides guidance for any member of the health care team in any care setting and offers a coordinated approach to care and communication. It can improve outcomes, promote safety, increase satisfaction with care, and optimize the use of resources.

Renal End-Stage Pathway

Conservative Kidney Management (CKM) is a treatment option for managing advanced chronic kidney disease. This clinical care pathway is a resource for patients and healthcare professionals that focuses on quality of life, symptom management, and living well without dialysis. The online pathway is publicly available to patients, families, and health professionals at www.CKMcare.com.

As a Collaborative Member of the Kidney Supportive Care Research Group, the Palliative Institute has supported the development of this pathway. The pathway is currently moving from research to implementation in collaboration with Alberta’s Kidney Strategic Clinical Network.

The Edmonton Symptom Assessment System - Revised

The Edmonton Symptom Assessment System - Revised (ESAS-r) is an internationally recognized nine-item self-report symptom intensity tool developed for palliative care patients, with the option of adding a 10th patient-specific symptom. Three studies that gathered validation evidence of the ESAS were completed, which resulted in a revised version: the ESAS-r. A French translation study of the ESAS-r, including patients’ perspectives, has recently been published. Future research directions include examining the role of the ESAS-r in the symptom assessment of psychosocial and spiritual distress screening including aging, cognitively impaired, and non-cancer palliative care patients.

Edmonton Classification System for Cancer Pain (ECS-CP)

A classification system for cancer pain identifies patients who may require more complex management. This system allows for improved assessment and management and facilitates appropriate comparisons of clinical and research experience. The classification system was created in Edmonton with multiple collaborators. A series of validation studies have been conducted in Edmonton and international sites. Findings from this program of research have been presented and published internationally. Work is underway on translations into French, Spanish, and Catalan.

Family Caregiver Satisfaction

In response to Accreditation Canada’s recommendation, the Edmonton zone palliative care program and provincial Covenant Health palliative care has adopted the FAMCARE-2 tool as a measure of family caregiver satisfaction with palliative care services. A process evaluation study of the FAMCARE-2 was conducted in Edmonton hospices and the Grey Nuns Community Hospital Tertiary Palliative Care Unit. It was also piloted at the St Michael’s palliative unit in Lethbridge to test the appropriateness of the tool in obtaining family satisfaction feedback. The tool is now utilized by all Edmonton and Covenant Health palliative units in Alberta, with regular reporting and posting of family caregiver comments for the staff.

Paying Attention to Patient Dignity

The maintenance of dignity is an inherent component of the palliative care philosophy, frameworks, and clinical care. The Patient Dignity Question (PDQ) is a novel, brief approach for obtaining information about personhood. Patients and their families are asked to respond to the question: “What should your health care providers know about you (your family member) as a person to give you (them) the best care possible?” The primary objective of this pilot study was to prospectively evaluate the quality of using the PDQ on the Tertiary Palliative Care Unit (TPCU) at the Grey Nuns Community Hospital and two acute care hospitals as part of an ongoing Division of Palliative Care Medicine Residency project.
The Palliative Institute has hosted and continues to host conferences in the local, national and international spheres in order to share and further the knowledge and practice of palliative care:

**Annual Palliative Education & Research Days Conference**

This conference held in Edmonton, Alberta has become well known as a centre of excellence to discuss and further the practice of palliative care. It has been held for 28 years and brings together people interested in palliative care to network, educate health professionals and share research.

**European Association for Palliative Care Research Network**

This international seminar was held in December 2016 in Banff, Alberta.

The seminar lead and organized by the Palliative Institute in cooperation with the European Palliative Care Research Centre and EAPC Research Network. Researchers shared their experiences of conducting collaborative research within Canada and in both North America and Europe. The conference provided great opportunities to connect, share experiences, and discuss approaches to palliative care research.

**Environmental Scan of Canadian Catholic Palliative Care Services and Innovations**

The environmental scan describes the scope of palliative care service delivery and innovation in Canadian Catholic healthcare. Catholic facilities identified 22 palliative care innovations. Catholic healthcare organizations completed a self-assessment on their readiness to promote change. The project was completed in collaboration with the Catholic Health Alliance of Canada.

**Knowledge Translation Activities**

The Palliative Institute utilizes a variety of methods to support turning research into clinical practice. Infographics, on-line learning modules, world cafés, and change management are some of the techniques beyond publishing that encourages utilizing best practice. The Institute commonly uses Canadian Institutes for Health Research’s Knowledge to Action approach to improving best practice.

See also ACPEL on pg.6 and Palliative Care Matters on pg.7
The Palliative Institute has undertaken projects to increase the use of Advance Care Planning (ACP) and Goals of Care Designation (GCD) in partnership with the Advance Care Planning Collaborative Research and Innovation Opportunities (ACP CRIO) research program:

**Integrating performance indicators in Alberta for putting ACP & GCD into practice**

The Palliative Institute chaired a collaborative study to identify ACP best practice indicators and distributed a report to provincial stakeholders last year. Currently, the province is auditing the use of many indicators for implementation into the provincial ACP dashboard. A series of reports and academic articles will be published and presented nationally.

Performance indicators provide information about progress and shortcomings in the adoption and practice of ACP. Both ACP and GCD have been shown to lead medical care according to patients’ desires when they cannot speak for themselves. This utilizes healthcare resources in an effective way.

**Barriers and facilitators to the implementation of ACP & GCD – application of learnings in two change management projects: vascular surgery & fractured hip surgical populations**

The Palliative Institute is co-leading ACP & GCD change management projects in the fractured hip and vascular surgical populations at two Covenant Health hospitals. For each project, a team of key health care provider and administrative stakeholders, educators, process improvement specialists and researchers have reviewed barriers and facilitators (at the patient, health care provider and system levels) and developed a plan to implement ACP & GCD into regular surgical practice.

**International Society of Advance Care Planning & End-of-Life Care Conference**

The Palliative Institute hosted the 6th International Society of Advance Care Planning and End-of-Life Care conference (ACPEL 2017) in Banff, Alberta with the support of the Covenant Foundation and other sponsors. 200 people from 16 countries attended. More than 220 research abstracts provided the international scientific committee with ample material to devise a strong conference program that included poster walks and awards. Part of the conference outreach included a national webinar presented by a lay person and physician. Delegates at the conference said that seeing the webinar and being able to interact with ACP leaders was very helpful in understanding where ACP is at internationally.

**ACP in lawyers’ practice**

In collaboration with the Canadian Bar Association, Legal Education Society of Alberta and Office of the Public Guardian/Trustee and ACP CRIO, the Palliative Institute undertook a research study to assess barriers and facilitators to the lawyers’ role in ACP. Through numerous focus groups and a survey of 133 Alberta lawyers who practice in Wills and Estates, Elder and Health Law, the study identified critical gaps in lawyers’ knowledge of health care practices and documents, and means of equipping lawyers and clients with ACP tools while fostering conversations between lawyers and physicians.
The Palliative Care Matters (PCM) initiative is intended to develop a consensus of Canadians on the future of palliative care and catalyze change in healthcare policy and practice. The Palliative Institute initiated, and hosted Palliative Care Matters (PCM) in collaboration with 13 national organizations.

PCM included an Ipsos survey of 1540 Canadians in the summer of 2016, a consensus development conference in Ottawa in November 2016 (touching 1.2 million Canadians), and a Conference Board of Canada report released in June 2017 (providing recommendations for action and implementation).

At the conference, a lay panel of Canadians considered the Ipsos public opinion research, heard the presentations, and questioned experts on how quality palliative care could be delivered. The lay panel made 20 specific recommendations addressing national frameworks, palliative home care, integration of care, education and training, indicators, and public awareness.

Ensuring that the suffering of our fellow citizens is alleviated is at the heart of a civil society…. It isn’t enough to care; Canada must turn its caring into commitment that ensures palliative care is a part of the Canadian health system and receives the attention and resources it needs.

Consensus Statement of the Lay Panel, Palliative Care Matters Conference, November, 2016

Following the conference, The Conference Board of Canada reviewed the consensus statement and the work to date. The report, “Palliative Care Matters: Fostering Change in Canadian Health Care,” provided the following insights on how to move forward implementing the recommendations:

- **Acknowledge Patients and the Public as Experts** in their own care.
- **Develop a Better Understanding of the Landscape** - Palliative and end-of-life care is evolving. More people are dying outside of hospital settings than in the past, and this has implications for care provided in homes, communities, and long-term care settings.
- **Move from Organic to Strategic to Implementation** - Access to quality care is uneven within and across jurisdictions, with some populations significantly underserved. Strategic frameworks and plans can be effective in addressing quality and access.
- **Recognize that Workforce Planning Is Essential** - The future demand for palliative and end-of-life care services means governments and other stakeholders must develop workforce capacity.
- **Foster Current Opportunities in Home and Community Care** - Canada needs to immediately develop enhanced palliative and end-of-life capacity in home, community, and long-term care settings.

**Going Forward**

The private member’s Bill C-277, “An Act providing for the development of a framework on palliative care in Canada” was enacted in November, 2017. This bill provides further impetus to move forward on an integrated palliative care strategy. PCM is committed to action, organizing a meeting in February 2018, and utilizing the collaborative impact framework to bring palliative care leaders together in developing a national action plan. The Palliative Institute continues to chair and support PCM.
As a society, we need to place as much emphasis on this critical part of the life journey as we do on bringing life into the world.

Don Newman, Chair of the Lay Panel
Palliative Care Matters
RESEARCH & ACADEMIC PUBLICATIONS

Book Chapters


Edited Volumes


Academic Publications


Duggleby, W., Cooper, D., Nekolaichuk, C., Cottrell, L., Swindle, J., & Barkway, K. (2016). The psychosocial experiences of older palliative patients while participating in a Living with Hope program. Palliative and Supportive Care, 14: 672-679.


**RESEARCH & ACADEMIC PUBLICATIONS**


