

*First Nations
Palliative Knowledge Exchange*

March 20, 21, 2018

FINAL REPORT



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Message from the Project Committee

Sge:no, She:kon, Welcome

It is with great pleasure that we were able to welcome everyone to the Palliative Knowledge Exchange for the First Nations and Inuit Home and Community Care programs.

Invited guests, speakers, elders, Home and Community Care staff, and colleagues gathered together to share stories and information that will enhance the future of palliative care in First Nations communities.

Future opportunities and collaboration of our voices will give hope for future programming.

Working together in Health,

Lori Monture ~ Manager, Six Nations Long Term Care Home and Community Care

Edey Hobson ~ Nurse Advisor, Home and Community Care First Nations and Inuit Health Branch

Donna Loft ~ Health Program Advisor, Chiefs of Ontario

Robin Cano ~ Regional Coordinator, Ontario Region at FNIHB at the Department of Indigenous Services

Lori Davis Hill ~ Director, Six Nations Health Services

Vanessa L Follon ~ Jordan's Principle representative

Project Description

The objective of the project was to bring together content experts including: clinical providers, decision makers, funders, palliative researchers and community members to contribute to a KNOWLEDGE EXCHANGE on Palliative and End of Life Care in First Nation communities in Ontario.

Partners on this project are:



Chiefs of Ontario



Health Canada
Santé Canada



Home and Community Care



Special thank you to *Cancer Care Ontario* and their generous support in this event. Cancer Care Ontario supports health professionals, organizations and policy-makers with the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality patient care. Cancer Care Ontario actively engages people with cancer and their families in the design, delivery and evaluation of Ontario's cancer system, and works to improve the performance of Ontario's cancer system by driving quality, accountability, innovation and value. This event was supported in partnership with Cancer Care Ontario's Aboriginal Cancer Control Unity, whose work addresses cancer among First Nations, Inuit and Metis (FNIM) communities in Ontario.



Ontario
Cancer Care Ontario

Workplan ~ First Nations Palliative Knowledge Exchange

October 2017-March 2018

Objective	Activity	Responsibility
Knowledge Exchange in the field of Palliative and End of Life Care in First Nations communities	Bring together First Nation experts and contributors in the field of palliative and end of life care	FNIHB Regional Coordinator, Chiefs of Ontario, Six Nations of the Grand River, Director of Health and HCC Manager
<p>Outcome: First Nations presenters, physicians, elders, community representatives, care providers and youth all came together for two days to talk, sing, laugh, cry, teach and share stories about palliative care.</p>		
Objective	Activity	Responsibility
Identify gaps and needs to be able to set priorities for the future	Identify current and promising best practices. Do environmental scan of what is currently available in First Nation communities.	Participants and Knowledge Exchange event including stakeholders and First Nation communities.
<p>Outcome: The participants of the event were challenged to identify where they are in palliative care and reflect how or if they currently do palliative care in their community. The participants were able to review a model of care that could be considered in each First Nation's community. The participants were able to gather information on current best practices, palliative research outcomes and promising practices from other First Nation communities. Everyone had an opportunity to speak. Focus groups identified gaps in service, priorities, and most wanted to continue this work and have more gatherings of this type. There were numerous examples of traditional knowledge which included spiritual examples used during a palliative situation including songs, art, roles and responsibilities, and elders who practice journeying with a dying person.</p>		
Objective	Activity	Responsibility
Identify resources, tools, best practices in palliative care in First Nation communities.	To build collaborative relationships to support First Nation community members who wish to receive palliative and End of Life care within their home communities. To hear the stories and events occurring in First Nation communities as it relates to palliative care and end of life.	Participants and experts who participate in the Knowledge Exchange of event.
<p>Outcome: Participants were able to identify future linkages including champions in palliative care from a variety of communities, research in palliative care from Lakehead University, programs and service providers, as well as elders and physicians. Cancer Care Ontario, Federal and Provincial networks in palliative care were presented as opportunities for future linkages. The overall statement was "we all do it and we have a responsibility to carry on taking care of our people until they die."</p>		

Speaker Biographies

Dr. Michael Anderson ~ Striving for Equity in Hospice Palliative for Care for Indigenous Peoples



Dr. Michael Anderson is part of Toronto's urban Indigenous community. He is Mohawk (Bear clan) with family roots in Tyendinaga Mohawk Territory. While practicing surgical oncology in the Simcoe-Muskoka Regional Cancer Program, where he served as Cancer Care Ontario's (CCO) Regional Surgical Oncology Lead, he developed an interest in palliative care. Through participation in palliative care initiatives such as CCO/CPAC's *Integrate Project* and Anishnawbe Health Toronto's *Harmonized Indigenous and Western Palliative Care Model* development, he developed an appreciation for the challenges and opportunities Indigenous people experience in the final stages of life. Currently, he is a PhD candidate at the University of Toronto examining palliative and end-of-life care as it pertains to urban Indigenous people. He is a research team member at the Waakebiness-Bryce Institute of Indigenous Health at U of T and his research interests include Indigenous epistemologies and research methodologies, community engagement, and Indigenous conceptualizations of death and dying.

Pete Keshane ~ Traditional Healer Anishinawbe Health Team

Pete's teachings utilize a holistic approach covering the mind, body, spirit and emotions. He has spent many years helping those with physical ailments, battling addictions and mental health issues in a collaborative effort alongside western based practitioners.

Holly Prince ~ Developing Palliative Care Programs in First Nations

Communities

In 2010-2016, four First Nations communities in Ontario and Manitoba partnered with a research team based at Lakehead University with the goal of improving the end-of-life care of people living in First Nations communities. This research, funded by the Canadian Institutes of Health Research, focused on a community capacity development approach to developing local palliative care programs and teams. This project has demonstrated that First Nations communities can develop unique, culturally appropriate, community-based palliative care programs through undertaking local capacity development efforts, creating new partnerships with regional health services, and coordinating existing First Nations' community health and social support programs.



This workshop will provide an overview of the lessons learned from four First Nations communities involved in the project. First, it will present the five-phase community capacity development model that guided the research. This model includes local community development, regional partnerships, education and community empowerment. It will then present guidelines and resources for palliative care program development in the form of a workbook. This workbook was developed using literature on innovative practices and guidelines as well as research data indicating successes within four communities. Lastly, it will describe the experience of mentoring and supporting other First Nations communities in Ontario who are implementing the workbook.

Biography:

Holly Prince is an Anishinabekwe from the Red Rock Indian Band in Northwestern Ontario, Canada. She has a Master's degree in Social Work and is the Project Manager at the Centre for Education and Research on Aging & Health at Lakehead University in Thunder Bay, Ontario. Holly's research expertise is in Indigenous health and community-based and applied health services research using participatory methods. She has been working in the field of palliative care for the past 15 years with a focus on improving the end-of-life care in First Nations communities.

Dr. Amy Montour ~ Walking Beside you on the Palliative Care Journey



Amy Montour is an Oneida woman from the Six Nations of the Grand River Territory. She has completed Bachelor of Science in Nursing, Master of Science in Nursing and Doctor of Medicine degrees at McMaster University. Amy works clinically as a hospitalist, palliative care physician and family physician for the elderly. In addition, she currently sits as the Indigenous Health Consultant to the Department of Family Medicine, Michael G. DeGroote School of Medicine at McMaster University, the Regional Aboriginal Clinical Lead for Jurvanski Regional Cancer Program and Regional Palliative Care Clinical Co-lead for the Hamilton Niagara Haldimand Brant Local Health Integration Network.

Rodney Miller ~ Traditional Speaker

Oneida Nation, Bear Clan, He is a Faithkeeper, Chef and a Cayuga Language student. Rodney resides in Six Nations Grand River Territory with his wife and is a father to 7 children and has 4 grandchildren.

Lacey Lewis ~ Emcee

Lacey's personal and professional interests are one in the same: love, passion and commitment to her family and community. This is how she engages with the work she does in the social service sector, specializing in Indigenous children and youth matters. Lacey's personal achievements are reflective of her children's wellbeing; when they succeed, as a parent she achieves. Lacey is proud to be behind the creation, design and implementation of an Indigenous Dispute Resolution program. She is a designated Chartered Mediator, and Co-founder of Indigenous Child Service Management Ltd.; focusing on consulting, advocacy, training, education and Indigenous mediation.

Robin Cano ~ Regional Coordinator, Ontario Region at FNIHB at the Department of Indigenous

Services Canada (DISC, formerly Health Canada). She has been an RN for 25 years. Her background is a community nurse, general rehabilitation nurse working throughout care settings as a float at St. Joseph's hospital, Home Care Manager of Palliative Care and the Palliative Pain and Symptom Management Consultant at the NW LHIN. She remains a Hospice Unit RN since 2007 to the present. Robin's passion for providing access to high quality, high value palliative care stems from her work across care settings, with a realization that there is a need for strong front line voices to advocate for the palliative approach to care, regardless of care setting, and across the care continuum.

Peggy Dick ~ Registered Nurse, Algonquin's of Pikwanagan Community Presentation (Golden Lake)

In Health Services for the past 20 years – Minopimadiz-I Gamik. Currently works as Senior/Client Services Supervisor looking after all aging needs within the community and supervising Assisted Living. Active in numerous committees and involved in the Indigenous Health Circle Forum (Champlain LHIN) and Regional Palliative Care. Involved in nursing leadership and has assisted in developing numerous services and programs ranging from Home and Community Care, Mental Health, Aging at Home and recently Palliative Care.

Maxine Crow ~ Community Care Coordinator, Naotkamegwaning Community Presentation

“It's not about death and dying. It's about taking care of you the best that we can when there's nothing more the health care providers can do for you and your wish is to stay home for as long as possible.”

Hali Pitawanakwa ~ RN LTC/HCC Program, Wikwemikong Community Presentation

Currently enrolled in the Primary Health Care Nurse Practitioner program at Laurentian University. Attended St. Francis Xavier University in Antigonish, Nova Scotia the past summer. While there she was working on a project on Palliative Care in her community. She wanted to know what her community knew about Palliative Care. She conducted several community focus groups. Using graphic facilitation with participants, she developed a PATHway to Palliative Care – a visual, educational tool for community members and health care providers. This tool can be used to teach Palliative Care and can be adapted to a particular community, program or person.

Cathy Ferris ~ Wapekeka Community Presentation

Cathy is a Physiotherapist and Case Manager servicing the Sioux Lookout Zone communities for the past 20 years. She is currently working with Wunnumin Lake, Wapekeka and Sandy Lake First Nation through the Home and Community Care and Jordan's Principle Programs.

Donna Fiddler ~ Community Coordinator, Sandy Lake Community Presentation

Recording ~ Prime Focus Productions ~ Joel George



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Choose you Journey Logo ~ Kiana Sky

Kiana is a young artist from Six Nations of the Grand River Territory. She is Cayuga Nation, Bear Clan.

A natural born artist she enjoys different forms of medium including sketching, painting, henna, and photography.



Song ~ Life Blanket ~ Bear Fox

Theresa "Bear" Fox, Mohawk name is Kenkiohkoktha, of the Wolf Clan. Meaning I am "at the back of a crowd of people" or I am "the end of a long line of people". I am part of a woman's singing group called "Kontiwennenhawi" which means "Carriers of the Words".

Akwesasne Mohawk Nation Territory

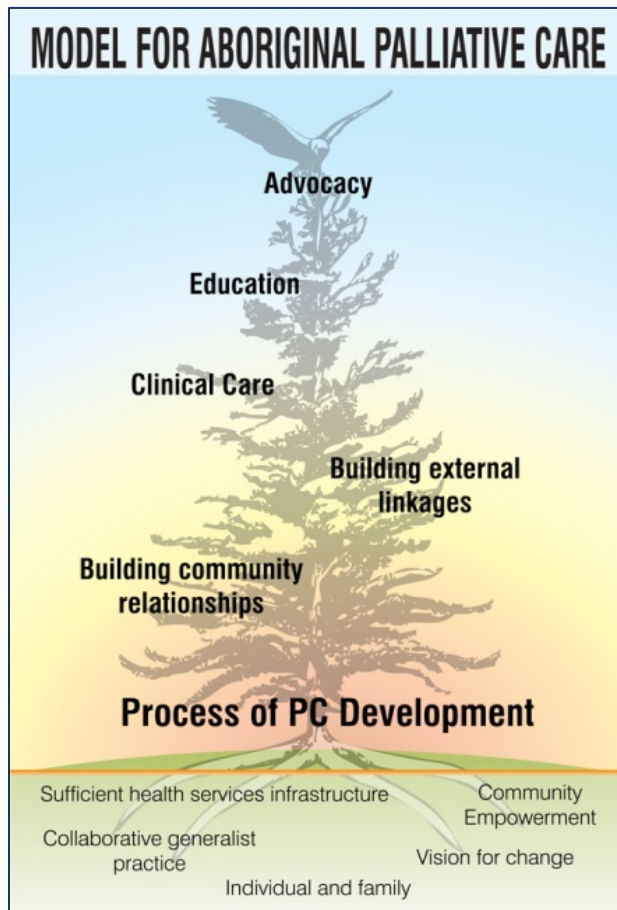
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Models of Palliative Care – Compilation

The *End of Life in First Nations* project created the Process of Palliative Care Program Development (tree diagram). The diagram uses the metaphor of a growing tree to represent developing a palliative program from the ground up. This diagram can be used to guide palliative care program development in any community since the process guides communities to adapt and customize the program to their unique needs at each phase of program development. This process is about building on local capacity, the strengths that already exist in individuals, organizations, and health services.

Participants were asked to circle where they felt their organization was in terms of delivering Palliative Care in their community.



Advocacy	7
Education	10
Clinical Care	6
Building External Linkages	11
Building community relationships	11
Process of PC Development	8
Sufficient health services infrastructure	2
Community empowerment	3
Collaboration generalist practice	0
Vision for change	5
Individual and family	2

Some (most) circled more than one area.

Comments:

1. No formal process
2. No formal process in place, only circumstance
3. Work in all areas is being done. (circled all)
4. Circled all. ..but growth needed and expansion as well
5. Go up and draw the tree like a squirrel...right now we are at the bottom trying to figure out how to help the young and dying

Communities Represented

Aamjiwnaang	Nippissing
Akwesasne	N'Mninoeyaa Ab Health Access Centre
Alderville	North Caribou First Nation-Weagamow Lake
Algonquins of Pikwakanagan (Golden Lake)	Oneida
Anishinawbe Health Toronto	Sagamok Anishnawbek
Batchewan FN	Sandy Lake
Cat Lake	Serpent River FN
Constance Lake FN	Six Nations
Delaware First Nation Moraviantown	St. Catherine's
Dokis	Thunder Bay
Hiawatha	Tyendinaga -Mohawks of the Bay of Quinte
Iskatewizaagegan #39 Shoal Lake	Waasegiizhig Nanaandawe'itewigamig
Kitchissippi Omaniwinini Anishinabeg	Wabun
KO tribal council	Wahgoshig First Nation
Marten Falls HS	Wapekeka First Nation
Mattagami	Wasauksing
Mississaugas of the New Credit	Webequie
Mnaanaadzawin HS	West Parry Sound
Moose Cree First Nation	Whitefish River First Nation
Naotkamegwanning Wilsonkotaatiwin Program	Wikwemikong
Neskantaga First Nation	Wikwemikong Unceded Territory
Nigigoonsiminikaaning First Nation (Red Gut)	Windigo

Participants registered: 106

Cancellations: 24

Total Attendees: 82

Vendors



Legacy Blanket Project ~ Thomas Anderson ~

Thomas Anderson's decision to go to school to study indigenous art is already paying dividends for his young artistic career. The 20-year-old has completed Six Nations Polytechnic's one-year Indigenous Visual Arts certificate, which can become a stepping stone to the Ontario College of Art and Design University (OCADU).

One of those projects is the Legacy Blanket Project, a collaboration between young artists and elders which involves creating textile works to tell Indigenous stories with a focus on historic events, resilience, wellness, and healing.

Richelle Miller ~ Curator & Project Facilitator, thelegacyblanket@gmail.com , 519-755-4258



Barbra Nahwegahbow

www.bluedawnjewellery.com

Blue Dawn Jewelry from Whitefish River First Nation. Bold and unique piece designs are influenced both by the urban environment and the more natural environment. In her designs, she uses semi-precious and precious gemstones and combines them with wood, nuts and seeds, or porcelain. She also sells a book by her friend, Kenn Pitawanakwat who is from Wikwemikong First Nation. His book is called, *When My Son Died* and it's about his grief and ongoing recovery process, his journey to find our traditional teachings about death and dying.



Brian Wright McLeod

www.brianwrightmcleod.com

Brian Wright-McLeod is a Toronto-based Native music journalist, radio host, and author

In 2011, Fifth House published his first graphic novel, *Red Power*, which he wrote and illustrated. Brian's works include original T-shirt designs, visual art cards, books he has written and illustrated, and "The Soundtrack of a People" 3-CD collection of 100 years of Native music



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First Nations Palliative Knowledge Exchange

Evaluation Summary Highlights

What is the most interesting or important thing you feel you learned about Palliative Care in First Nation communities?	
First Nations communities are very capable, interested and willing to take care of their own, in their own way. Come home and we will take care of you. This is very achievable for our communities.	
Relationship building and building trust is paramount in creating consistent palliative care programming. Initiating conversations about Advanced Care Planning.	
The development of workbook for other First Nations to utilize for their guidance in creating program within the community. The process of how to develop a palliative care program.	
That most First Nations are providing this care or doing what they can to provide this care without the resources and format processes but recognize it is what we do and do what we can to ensure it happens with or without the external supports. Decolonizing birth and death.	
Most if not all communities regardless the size felt that they could provide palliative care regardless how complex the care needs are. Docs on wards in hospitals are resistant to discharge pts home because they do not think the pts needs can be meet. However communities are saying they can meet the needs.	
Please list 3 Gaps or Challenges that create barriers for First Nation communities to accessing Palliative Care services:	
Funding	
Lack/denial of funds for FN people (6)	Perceived and actual jurisdictions/\$ received not equitable with the rest of Ontario. Cookie cutter monetary agreements that don't reflect the needs for travel and the chronic life changing diseases.
Resources (people and equipment) (funding)	
Family/Community	
Community and family involvement/support (5)	Lack of understanding /with families/other providers
Family boarding rooms	Relationship building within community and our allies
Workers	
Lacking social services worker and mental health counselling/support, PSWs, volunteers	Human services – Trained staff, Nursing, physician home visits, front line supports. NIHB –medical supplies.
Minimal staff/capacity in community – no physician/NPs.	Having more staff trained and able to service on weekends and evenings when needed.
Services	
Lack of Knowledge, Understanding, Communication of services available. LHIN/CCAC servicing the communities	Lack of outside services and lack of community support Barriers to accessing external services-too much red tape/protocol need better working relationships.
Hospital – not asking where they want to be or offering discharge planning choices	Client following up with Primary physician after a lengthy hospital stay-hospital bed.
Partnerships i.e. CCAC, pharmacies, primary care providers	No palliative services/housing. Starting care at early diagnosis
Silos in the health care team	Developing trust in a short period.

Resources/Supplies	
Lack Staff resources, PSW, nurses (3)	Specialized / Medical equipment. Access to assistive devices, equipment needed to deliver service.
Lack of supplies, resources equipment (5)	Communication and information sharing
Outdated HCC plans	Housing issues
Location/Transportation	
Geography, Remote areas-fly in, (often), isolated, small, transportation	Distance from medical facilities. Access to services.
Transportation for medical, specialty services	Jurisdiction issues-for accessing professional expertise and services, refusal of certain services
Education/Training	
Definition / Awareness of palliative care –what does it mean in the community.	Education for “Western” health providers. Being taken seriously by western thinkers
Education for providers.	No community support/no interest. (education)
Pain and symptom management	Respite for caregivers
Culture/Traditions	
Language/land/traditional practice	Cultural competency
List 3 possible linkages with existing Palliative Care initiatives, programs and service providers.	
AHAC, CCAA, HPCO, HCCP, Aboriginal Patient Navigators, Canadian cancer society CCO (5)	
LTC home in communities, Elders home, Chaplaincy/cultural services Traditional medicine services. Spiritual providers	
HCC (formerly CCAC) need to evolve. HCC local programs, nurse, program-provincial, coordinator/ (12)	
Hospital discharge planner. (2) Discharge model across Ontario.	
PSW's to have more workshops for palliative care. PSW/HSW	
LHIN HCC should NOT be able to decide not to provide care.	
LHINs need to reorganize and provide service to these areas/populations to provide palliative NP's and Palliative resources. fundamentals of palliative care, PICC team.	
Palliative care outreach team. Palliative care consult teams-indigenous. ON regional palliative care. More palliative workshops. Other palliative teams.	
Hospice. Hospice volunteers Local hospitals/VON/PCCT teams	
Support from existing practitioners-i.e. Providing northern opportunities for a coordinator; b) programs developer; c) care.	
Community nurses. Nurses Network with visiting nursing agencies,	
I think more work needs to be done with GP's to help them provide or advocate for our palliative people.	
FN band councils/elders circles. Community members.	
MD's/hospitals/nursing station (pain and symptom management) Pain and symptom management. Local physicians and ones with PC specialty NP's/physicians NP's new to umbrella of PC services	

What did you enjoy most about this event?
Stories (9): – inspiring, from various reserves/communities, awareness of the struggles, how communities’ have helped their community members have a full life in their last days.
It was good to have a range of FN (i.e. Isolated ones and those who are fully capable financially)
Interactive and we all got to speak or participate. Meeting grassroots workers who are all working towards the most wonderful expression of love in our communities.
Coming together with other communities who share cultural; spiritual and programming challenges but we all come together and provide for our people.
A lot of resources to take back and work with.
I liked being taken care of. Great hotel, not having to go outside to another location. Having food with no spices kind of normal. Liked it was Indigenous speakers. I liked the gifts and bag to carry my stuff.
Is there anything you would have liked to have seen done differently at this event?
I appreciate the direction on how to make a flowchart to work through. It would be great to meet up to follow-up and see how communities are working on Palliative Care. Take home points-roll-up report would be beneficial so that others can see what others are doing. Sharing best practices. Develop/share a best practices “Indigenous” tool kit for P.C.
More examples. See various stages of formalizing a process to establishing palliative care program in FN and specific roles external agencies.
I hope decision makers and funders are listening and are informed.
Provide a reference/attendance list of all participants. I heard often throughout 2 days that many traditional practices have been lost, or many area LTC’s had never experienced or never seen a cedar bath, other rituals. It would be ideal if someone could present or a video or story telling on these ritual/traditions for all to learn. Great conference. I was delighted to be a participant-Thank you!
Just look at other resources. The Workbook is great-just not being the only way. Making palliative program specific to each community.
More personal stories, struggles of providing palliative care alone as a family member.
Overview at beginning of size and location of reserves, communities, population.
More people to be allowed to exchange stories from the different areas. Workshop could have been an extra day. More stories, more days.
More information on emotional/spiritual care.
More question time with each speaker. (maybe 5-15 minutes) (there seemed to be none)
Continuing Capacity Building for sustainability. Next! Self care for the helpers. Be on the land and ceremony.