



Palliative Care Gaps and Challenges – Summary of Themes

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November 2018

This document was created to explain how the gaps and challenges that were identified in the *First Nations Palliative Knowledge Exchange Event, Final Report (Six Nations of the Grand River Territory, 2018)* were validated by the following reports:

Recommendations to Improve Quality and Access to End-of-Life Care in First Nations Communities: Policy Implications from the “Improving End-of-Life Care in First Nations Communities” Research Project (Lakehead University/CERAH, 2014)

The Provision of Palliative End-of-Life Care Services in First Nations and Inuit Communities (FAV COM, 2016)

First Nations Advisory Committee, Home and Community Care in First Nations Communities in Ontario, Final Report (Chiefs of Ontario, 2017)



Theme	FNPKE Event	EOLFN Recommendations	PEOLC Services	First Nations Advisory Committee
Funding	<ul style="list-style-type: none"> - Lack/denial of funds for FN people. - Resources, people and equipment. - Perceived or actual jurisdictions \$ received is not equitable with the rest of ON. - Cookie cutter monetary agreements that don't reflect the needs for travel and the chronic life changing diseases. 	<ul style="list-style-type: none"> - Review the current approval process within the Non Insured Health Benefit (NIHB) program to ensure there are "fast track" approval processes for clients in the last year of life, and implement Jordan's principle in any cases of funding disputes across jurisdictions. <p>https://www.aadncaandc.gc.ca/en/g/1334329827982/1334329861879</p>	<ul style="list-style-type: none"> - The NIHB Program will not provide the equipment and supplies needed to provide IV therapy as part of caring for persons at the end-of-life. Hydration is an extremely important comfort measure. Note: some communities may have agreements with RHAs for these costs, so that care can continue in the home. - The limit assigned by the NIHB Program regarding the amount of oxygen that a person can receive is tailored to home use, and may not be sufficient for persons with multiple health needs who are traveling distances from their community to access specialists or therapies -Persons cannot obtain nutritional supplements from the NIHB Program, unless they have been designated as palliative and not expected to live longer than six months. This designation must come from the family physician who may be reluctant to make that diagnosis. 	<ul style="list-style-type: none"> - Many patients often require palliative care services prior to being determined eligible given the definition of palliative care is linked to being in the last stages of life. - Determine how First Nations patients should be assessed and when they receive palliative care. - Noted that supports for patients and families who must leave their communities to access palliative and/or respite care should be considered. These supports include funding of caregiver/provider travel through non-insured benefits when accompanying patients.



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Family/ Community	<ul style="list-style-type: none"> - Community and family involvement/support. - Family boarding rooms. - Lack of understanding amongst families and other providers (re: palliative approaches to care). - Relationship building with community and our allies. 	<p>-2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home.</p>	<ul style="list-style-type: none"> - A significant burden of care is lovingly assumed by family members or friends who may be older themselves and/or facing their own disabilities and health concerns. - Taking patients out of the community to receive PEOLC disrupts family life and creates emotional, social, spiritual and economic burden. The disruption in the grieving process caused by this dislocation has negative effects on overall community, social and economic wellbeing. - Fear of stigmatization if HIV/AIDS status is disclosed is not an issue only with indigenous populations, but may have a greater impact in First Nations and Inuit populations as the small community populations mean that the health system may not be able to provide a cloak of anonymity. Persons who have HIV/AIDS (and could benefit from home care) may disclose their health status to their community's social service so that they qualify for food, however paradoxically may not make a similar disclosure to the health system. Social services are prevented from sharing this information with health providers due to confidentiality. - Many communities may have a lack of quality housing, including issues of overcrowding, potable water, adequate sewage systems, and require modification of homes in order to accommodate palliative services and equipment (hospital beds, electrical requirements etc.). - Overcrowded homes can also have an impact on the safety and health risks of home care workers. - Leadership support for the development of a palliative care program must be secured to increase the acceptance and success of the program. Among other benefits, these leaders can provide guidance on how to approach end-of-life practices within the community 	<ul style="list-style-type: none"> - Members also recognized that providing palliative care at home requires flexibility and consideration of housing needs, including long-term care homes or congregate living. - An early emphasis on caregiver support and education, health care planning and care coordination, followed by an increased focus on medical interventions as death approaches.



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<p>Workers</p>	<ul style="list-style-type: none"> - Lacking social services worker and mental health counselling/support, PSW's, volunteers. -Minimal staff/capacity in community-no physician/NP's -Human services- trained staff, Nursing, physician home visits, front line supports. -NIHB- Medical supplies 	<ul style="list-style-type: none"> - 2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home. - 3) Ensure telemedicine is available in every First Nation community so that people with complex and high intensity needs, especially people who are dying, and their families can receive expert consultation from regional palliative care teams and consultants at home; and First Nations' health care providers can receive palliative care education, consultation, and support in their day to day work in the community. 	<ul style="list-style-type: none"> - Recognition of the personal support worker/home health aide role as integral to supporting PEOLC clients in the home, and investment into additional personal care and home making services. - Strategic utilization of nursing resources by instituting an on call system where after hours nursing care can be accessed at critical points in the client trajectory, via either telephone, or if the medical need cannot be met by a phone consultation, by in person visits. - There is a need for resident physicians (particularly in Inuit communities) and critical shortage of nurses and other specialized resources such as allied health professionals in the north. - Consistency in case management to be provided by the home care nurse or other community health provider who can monitor the client's needs, be ready to make changes in services as required (which can include contacting a regional/provincial palliative care team), and de-escalate crises. - Diseconomies of scale associated with the small size of many First Nations and Inuit communities in practical terms means that some health provider positions are funded at a small fraction of a full time equivalent (FTE) and cannot be filled. 	<ul style="list-style-type: none"> -The committee suggested providing health human resources for 24/7 care from nurses and personal support workers, including e-shift. The committee also suggested providing more training opportunities in local First Nations communities to reach more health care providers and support broader community involvement. -There is a need for resident physicians (particularly in Inuit communities) and critical shortage of nurses and other specialized resources such as allied health professionals in the north -Committee members acknowledged the important role that culturally safe Patient Navigators have in connecting patients and their families to culturally appropriate care, including palliative services. Patient Navigators provide a broad range of patient supports including support at clinic visits and hospital discharge planning; helping patients and families find services and communicate with doctors and nurses; arranging language and cultural translation services; and connecting with traditional healers.



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<p>Services</p>	<ul style="list-style-type: none"> -lack of knowledge, understanding, communication of services available LHIN/CCAC servicing the communities -Hospital_ not asking where people want to be at end of life, or offering discharge planning choices -Partnerships i/e/ CCAC, pharmacies, primary care providers -Silos in the healthcare team -lack of outside services and lack of community support -Barriers to accessing external services-too much red tape/protocol needed to better working relationships -Client following up with Primary physician after a lengthy hospital stay-hospital bed. -No palliative services/housing. Starting care at early diagnosis -Developing trust in a short period. 	<ol style="list-style-type: none"> 1) Review the current service and equipment levels (essential and supportive services) for federally funded Home and Community Care programs in First Nations and adjust them to reflect the aging of the population, the increased burden of chronic and terminal disease and frailty, and the increased number of people with high intensity and complex care needs who require home care and intensive case management, especially in the last year of life. 2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home. 3) Ensure telemedicine is available in every First Nation community so that people with complex and high intensity needs, especially people who are dying, and their families can receive expert consultation from regional palliative care teams and consultants at home; and First Nations' health care providers can receive palliative care education, consultation, and support in their day to day work in the community. 	<ul style="list-style-type: none"> - For persons entering the final phase of their lives, as a result of chronic disease or cancer or other life-threatening conditions, a missing part of the Program's care continuum concerns the end-of-life. - Persons with chronic and life-limiting diseases populate home care programs, and in First Nations and Inuit communities, exert the greatest pressure on resources. Currently the FNIHCC Program does not fund PEOLC services which would allow persons to remain in their home in this final segment of their life. - There is often lack of in-home support from RHAs as services stop at the reserve borders. There may not be formal or even informal discharge protocols in place to alert the home care program as to a community member returning who needs care Cross jurisdictional linkages must be established with provincial and territorial funded health professionals (e.g. physicians specializing in pain management) to support community-based services. - Gaps or delays in local access to health care providers and services such as diagnostic tests and procedures is compounded in the northern areas of Canada due to the high cost of living and the deficiency of health infrastructure. 	<ul style="list-style-type: none"> - The need for more respite care services to support families and community members who provide 24/7 care for patients who are receiving palliative care at home. - The development of protocols with the police and coroner are encouraged. - Access to advanced pain and symptom management from provincial specialists facilitated through linkages and partnerships and use of telecommunications/telemedicine technology.



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Resources/ Supplies	<ul style="list-style-type: none"> - Lack Staff resources, PSW, nurses. - Lack of supplies, resources equipment. - Out-dated HCC plans. - Specialized / Medical equipment. Access to assistive devices, equipment needed to deliver service. - Communication and information sharing. - Housing issues 	<ul style="list-style-type: none"> - 1) Review the current service and equipment levels (essential and supportive services) for federally funded Home and Community Care programs in First Nations and adjust them to reflect the aging of the population, the increased burden of chronic and terminal disease and frailty, and the increased number of people with high intensity and complex care needs who require home care and intensive case management, especially in the last year of life. - 4) Review the current approval process within the Non Insured Health Benefit (NIHB) program to ensure there are “fast track” approval processes for clients in the last year of life, and implement Jordan’s principle in any cases of funding disputes across jurisdictions. <p>https://www.aadncaandc.gc.ca/eng/1334329827982/1334329861879</p>	<ul style="list-style-type: none"> - The NIHB Program will not provide the equipment and supplies needed to provide IV therapy as part of caring for persons at the end-of-life. Hydration is an extremely important comfort measure. Note: some communities may have agreements with RHAs for these costs, so that care can continue in the home. - The limit assigned by the NIHB Program regarding the amount of oxygen that a person can receive is tailored to home use, and may not be sufficient for persons with multiple health needs who are traveling distances from their community to access specialists or therapies. - Persons cannot obtain nutritional supplements from the NIHB Program, unless they have been designated as palliative and not expected to live longer than six months. This designation must come from the family physician who may be reluctant to make that diagnosis. 	<ul style="list-style-type: none"> - The importance of ensuring that specialized services, equipment, training and supports are made available on short notice in the patient’s home.



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Location/ Transportation	<ul style="list-style-type: none"> - Geography, Remote areas-fly in, (often), isolated, small, transportation. - Distance from medical facilities. Access to services. - Jurisdiction issues-for accessing professional expertise and services, refusal of certain services. - Transportation for medical, specialty services. 	<ul style="list-style-type: none"> - 2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home. - 3) Ensure telemedicine is available in every First Nation community so that people with complex and high intensity needs, especially people who are dying, and their families can receive expert consultation from regional palliative care teams and consultants at home; and First Nations' health care providers can receive palliative care education, consultation, and support in their day to day work in the community. - 4) Review the current approval process within the Non Insured Health Benefit (NIHB) program to ensure there are "fast track" approval processes for clients in the last year of life, and implement Jordan's principle in any cases of funding disputes across jurisdictions. <p>https://www.aadncaandc.gc.ca/eng/1334329827982/1334329861879</p>	<p>Gaps or delays in local access to health care providers and services such as diagnostic tests and procedures is compounded in the northern areas of Canada due to the high cost of living and the deficiency of health infrastructure;</p> <ul style="list-style-type: none"> <input type="checkbox"/> The allocation of resources for "northern" costs unrelated to actual care must include, not only weather conditions and impact on transportation costs, but also acknowledge transportation service monopolies, language translation requirements, staff turnover related to burnout and isolation, lack of experience of staff affecting the number of medical evacuations, non-continuity in care plans, and nomadic existence of some communities. <input type="checkbox"/> There is a need for resident physicians (particularly in Inuit communities) and critical shortage of nurses and other specialized resources such as allied health professionals in the north. <input type="checkbox"/> Diseconomies of scale associated with the small size of many First Nations and Inuit communities in practical terms means that some health provider positions are funded at a small fraction of a full time equivalent (FTE) and cannot be filled. 	<ul style="list-style-type: none"> - The remoteness and isolation of many First Nations and Inuit communities increase costs, present challenges in recruitment and retention of health care providers, and demand innovative ways to support community-based professionals professionally and clinically (teleconference, telemedicine, site visit, workshops etc.). -The committee suggested providing health human resources for 24/7 care from nurses and personal support workers, including e-shift. -The committee also suggested providing more training opportunities in local First Nations communities to reach more health care providers and support broader community involvement. -The committee also noted that supports for patients and families who must leave their communities to access palliative and/or respite care should be considered. These supports include funding of caregiver/provider travel through non-insured benefits when accompanying patients, enabling cultural ceremonies related to end-of-life and building on existing best practices in palliative care. -A residential hospice is a home-like environment where adults and children with life-threatening illnesses receive end-of-life care services¹¹. Currently, many patients and their families must travel a distance from First Nations communities to access Residential Hospice services. The committee discussed the need for more First Nations hospice models in northern and southern communities and that decisions about where these should be located should be made with input from First Nations.



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Education/ Training	<ul style="list-style-type: none"> - Definition/awareness of palliative care –what does it mean in the community. - Education for providers. - Pain and symptom management. - Education for “Western” health providers. Being taken seriously by western thinkers. - No community support/no interest (education). - Respite for caregivers. 	<ul style="list-style-type: none"> - 2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home. 	<ul style="list-style-type: none"> - FNIHCC palliative care training to nurses, PSWs and HHAs is variable across the regions. Educational strategies are required, both to culturally sensitize non-Aboriginal health professionals and to provide palliative care training and education to all health care providers, including volunteers and family care givers. 	<ul style="list-style-type: none"> - Palliative and end-of-life training for First Nations health care providers should focus on building capacity and understanding the specific cultural context and terminology associated with palliative care. - Advance Care Planning to support end-of-life care wishes is a complex concept that is governed by different laws regarding informed consent and substitute decision making. - It is important to increase understanding of legal systems and roles and responsibilities in preparing for end-of-life (e.g., who can legally be a substitute decision maker and when informed consent is needed for end-of-life care wishes). - The approach to palliative and end-of-life care in First Nations communities includes aftercare, bereavement and spiritual care. Training and services available to First Nations communities should reflect these important components, including allowing for adaptations to First Nations traditions and models of aftercare. - Attention to the continuing education needs of health care providers within the community, through the provision of palliative care-specific education opportunities.



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Culture/ Traditions	<ul style="list-style-type: none"> - Language/land/traditional practice. - Cultural competency. 	<p>- 2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home.</p>	<ul style="list-style-type: none"> - There is a shortage of Aboriginal health service providers to provide culturally appropriate care. - Cultural and spiritual considerations include access to traditional caregivers and acceptance of traditional practices by western health care providers. - Find common ways of appropriately discussing concepts about end-of-life care planning and agreed upon vocabulary in relevant languages. - Enabling cultural ceremonies related to end-of-life and building on existing best practices in palliative care. - Inclusion of a traditional healing and spiritual role to nurture and support the client and family with traditional approaches to care, attention to spiritual needs, advanced care planning, and participation in bereavement care. - An indigenous person may look at impending loss from a different world perspective. 	<ul style="list-style-type: none"> - Communities have different cultural and spiritual beliefs that are important considerations in discussions about end-of-life care. - Find common ways of appropriately discussing concepts about end-of-life care planning and agreed upon vocabulary in relevant languages. - Enabling cultural ceremonies related to end-of-life and building on existing best practices in palliative care. - Inclusion of a traditional healing and spiritual role to nurture and support the client and family with traditional approaches to care, attention to spiritual needs, advanced care planning, and participation in bereavement care.