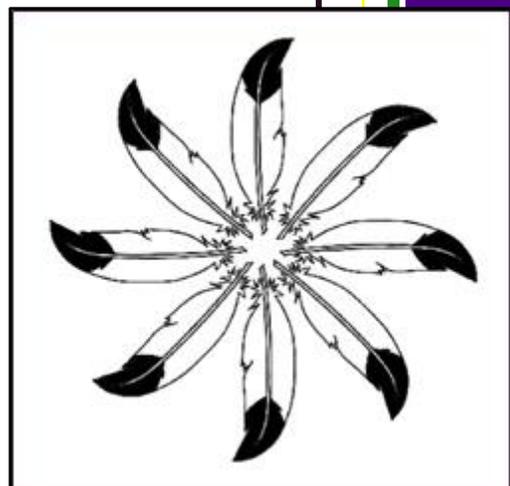


**A Framework to Guide Policy and
Program Development for
Palliative Care in First Nations
Communities**

Developed by the “Improving End-of-Life
Care in First Nations Communities”

Research Project

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POPULATION:

First Nations people across Canada who are living with advanced, progressive, chronic, and terminal illness wish to receive palliative care at home in a First Nations community. This population includes people of all ages with any diagnosis who would benefit from a palliative approach to care, especially in the last year of life, as well as the family and community caregivers of that person. When individuals wish to die at home, palliative care extends to include end-of-life care.

PROBLEM TO BE ADDRESSED:

People living in First Nations communities lack access to culturally appropriate, quality palliative care services at home. Palliative care is not a funded service under the First Nations and Inuit Health Branch (FNIHB) Home and Community Care program and provincial/territorial home care services do not consistently extend into First Nations communities. Due to lack of home care services, First Nations people lack the choice to die at home if that is their wish. Most First Nations people die in urban areas, in hospital or long-term care homes, separated from family, community, and culture.

Dying at home is not only the preferred option for most First Nations people; there is also a strong economic rationale for providing palliative care in First Nations communities. Today, First Nations people are dying in the hospital, which is the most expensive setting of care and not an efficient use of health services.

BACKGROUND:

This framework was developed out of original data and provides an integrated approach to addressing the gaps in palliative care services in First Nations communities. It is based on findings of a research project, funded by the Canadian Institutes of Health Research (2010-2015) and conducted by a research team based at Lakehead University, Thunder Bay, Ontario. This research is a partnership involving four First Nations communities from Ontario and Manitoba: Naotkamegwaning First Nation, Fort William First Nation, Six Nations of the Grand River Territory, and Peguis First Nation. The goal of this research is to improve the end-of-life care in First Nations communities by developing community-based palliative care programs and teams. Please visit www.eolfn.lakeheadu.ca for further information on the research.

PURPOSE OF THE FRAMEWORK:

This framework, for developing palliative care in First Nations communities, has 10 components. These components are based on the principles of equity, social justice, and are intended to improve quality of life for First Nations people who are dying and their families. Dying at home is not only the preferred option for most First Nations people, but there is a strong economic rationale for developing palliative care in First Nations communities. Today, First Nations people are dying in the hospital, which is the most expensive setting of care and not an efficient use of health services.

Overarching Policy Guidelines for Palliative Care Programs with First Nations Communities

1) The policy endorses a unique philosophy, definition, and, community-based process for providing palliative care in First Nations communities that is distinct from a westernized, medicalized or urban model of palliative care. The policy is:

- Based on Indigenous understandings of health, illness, birth, and death which differ across communities and linguistic groups.
- Based on local control and implementation of a community capacity development approach that emphasizes the engagement of community members, and incorporates community culture, strengths, and resources. One example is the theory of change titled “A Program Model for Developing Palliative Care in First Nations Communities” created by the Improving End-of-Life Care in First Nations research project (www.eolfn.lakeheadu.ca) at Lakehead University.
- Informed by the vision and goals of the “Way Forward National Framework” (Quality End-of-Life Care Coalition and the Canadian Hospice Palliative Care Association 2014) which promotes an integrated palliative approach to care for clients, their families, and community caregivers. This approach promotes autonomy and choice of setting of care (home, hospital, hospice, long-term care), meets the needs of an aging First Nations population with a high burden of chronic disease, and promotes the need for culturally safe care for First Nations people.

2) The policy needs to be founded on collaboration across federal, provincial, and territorial jurisdictions that will create equity of access to palliative care for people living in First Nations communities as compared to other citizens of the province or territory. The policy:

- Overcomes barriers to care that are embedded in jurisdictional issues and may prevent access and continuity of palliative care. One strategy to overcome barriers is to extend the implementation of Jordan’s Principle to people of all ages who require palliative care, not limit the principle to terminally ill children. Jordan’s Principle calls on the government of first contact to pay for required end-of-life home care services and to seek reimbursement later so the

person is not tragically caught in the middle of government red tape. (<https://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879>)

- Adopts the principle of “Two-Eyed Seeing,” which emphasizes integrating the best existing knowledge from traditional and western medicine to support people with serious illness and their families. (<http://www.integrativescience.ca/Principles/TwoEyedSeeing/>)

3) The policy allows for local customization of the eligibility criteria for palliative care services and customization of the funding and accountability processes. Customization of programs is needed in order to address diverse local client and community needs and to accommodate the inconsistency of other federal, provincial and territorial health and community services that are available in communities and regions. The policy promotes:

- Local control and customization; the opportunity to be creative and resourceful in service provision through the flexibility of roles and rules; and the ability to create partnerships within and outside of the community with relevant programs and services.
- Collaboration with the First Nations health care providers and communities to develop appropriate outcome measures and evaluation methods for delivering palliative care.
- Respectful and accountable relationships between First Nations palliative care programs, decision makers, and funders of services.

Program Development Guidelines

4) The palliative care program respects the integrity of the each First Nation community, its unique philosophy, and cultural traditions. The program:

- Builds on the First Nation community’s strengths and traditions of informal helping and providing support for people who are dying and their families.
- Provides First Nations people the choice to receive palliative care in the setting of their choice, including the choice to receive palliative home care services where they are surrounded by family, community, and culture.

5) The palliative care program is developed and implemented locally using a “bottom up” process of community capacity development. The program:

- Builds on local community infrastructure, community relationships and traditions, partnerships with regional and provincial/territorial health care providers, and responds to the unique realities and unique contexts of First Nations communities.
- Adopts a theory of change to guide local program development, such as the one created by Improving End of Life Care in First Nations (EOLFN) research project titled *“A Model for Developing Palliative Care Programs in First Nations Communities.”*

6) The palliative care program is built on teamwork/collaboration and partnerships across organizations and jurisdictions both within the First Nation community and between the First Nation community health care providers and external health service providers (hospital, home care, cancer care, etc.). The program:

- Empowers individual, family, First Nations health care providers, and external health care providers to collaborate actively in care planning and decision-making.
- Ensures effective and efficient protocols are in place across organizations and jurisdictions for communication, discharge planning, care planning, case conferencing, and sharing of important information in a timely way.
- Collaborates with cultural, traditional, and spiritual helpers/healers to ensure they are included in the Circle of Care.
- Provides training and support for all external health care providers (e.g. hospital, home care, palliative care) who provide direct care to people living in the First Nation community, including knowledge of community values and protocols (service, communication, advance care planning, and end of life conversations). This training is not standardized and must be guided by the communities served.
- Provides for client choice of where to receive their palliative and end-of-life care (home, hospital, long-term care, and hospice) that is equivalent to the services and options provided to all citizens of the region/province/territory.

7) The palliative care program provides access to local home care services at the level required to support First Nations health care providers, clients, and families. The program:

- Provides Home and Community Care services at the level sufficient to meet the needs of people with advanced chronic and terminal illness who choose to receive palliative care at home. This needs to extend to 7 days a week 24 hours a day at end of life to provide quality of life and avoid hospitalization or transfer to long-term care.
- Provides appropriate Non-Insured Health Benefits (NIHB) and timely access to the medication and equipment required to support palliative home care.
- Includes sufficient nursing, personal support worker services, volunteers, and respite care to support clients and family members in the community.
- Ensures palliative care assessments and care conferences are conducted within the First Nation community so that care appropriately meets clients' needs and unnecessary travel and hospitalization for this purpose can be avoided.

8) The palliative care program provides access to consultant and specialist services at the level required to support First Nations health care providers, clients, and families. The program:

- Provides access to provincial/territorial health services (home care, cancer care, respite care, etc.) and palliative care services for those people who require them in First Nations communities.
- Utilizes technology, such as Telehealth, which needs to be available in all First Nations communities (and currently is not generally available).
- Provides access to consultation, advice, and problem solving from palliative care experts on a 24 hour/7 day a week basis.

9) The palliative care program provides education related to palliative care and end-of-life experiences for family and community members (who provide the informal care) and for the First Nations health care professionals. The education:

- Includes knowledge, values, and skills of providing palliative and end-of-life care.
- Includes strategies to assess and plan care; and implement and modify care, depending on the needs and capacity of the family, community, and available supportive resources.

- Increases provider and family comfort to engage in end-of-life conversations.
- Builds team work and understanding within the palliative care team.
- Includes how to prepare advanced care plans and medical directives for western health care providers.

10) The palliative care program offers culturally appropriate holistic mental health and grief and bereavement support for community members, health care providers, and family, including culture-based support approaches where desired. The program:

- Provides grief and bereavement counselling to families and informal caregivers that incorporates cultural/traditional/spiritual practices as requested.
- Ensures all service providers' agencies have a debriefing protocol in order to honour the clients and their lives and promote self-care for their staff.
- Understands that mental health issues, addictions, historical trauma, the impact of unexpected and accidental deaths, and the high prevalence of death within the community impacts and may compound grief and bereavement, which means long-term counselling services may be required for community and family members.
- Develops educational materials for patients, families, and community members that are culturally and spiritually relevant and easy to understand, and includes managing grief and loss, and the resources available to them.