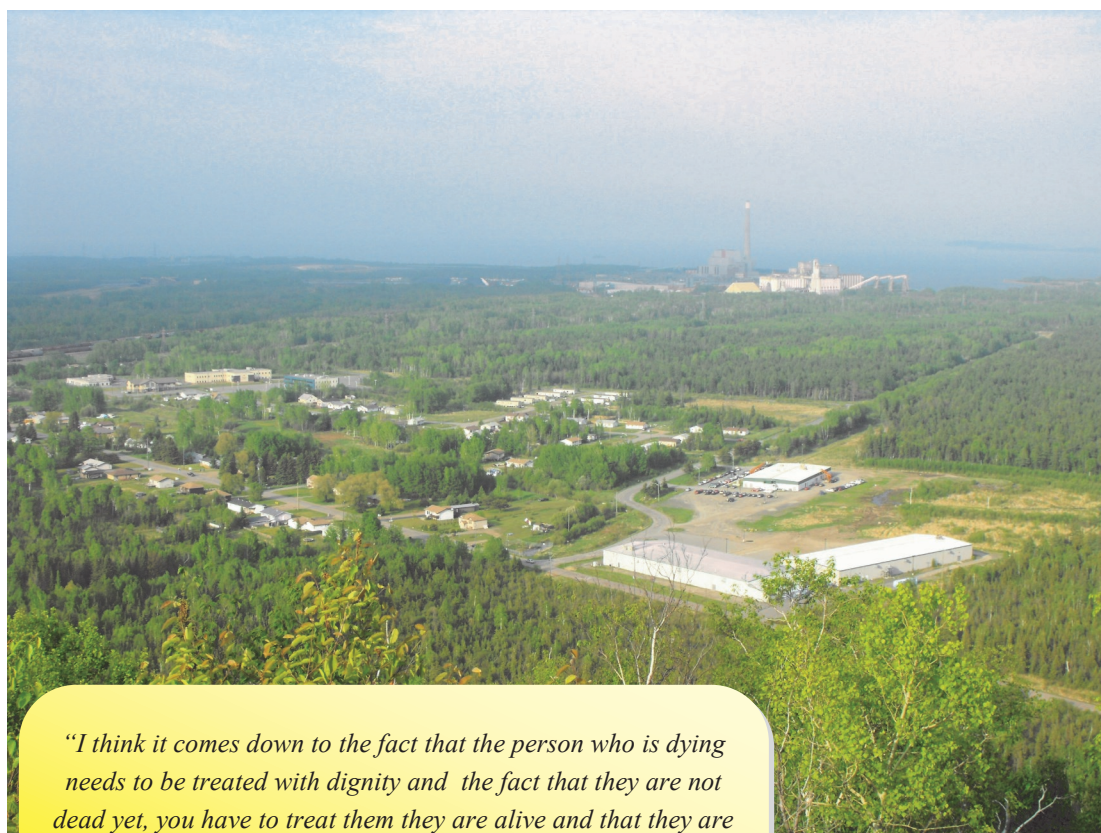


# Palliative Care Needs Assessment



*"I think it comes down to the fact that the person who is dying needs to be treated with dignity and the fact that they are not dead yet, you have to treat them they are alive and that they are going to live until they die. ... And you don't go in there with pity and you can't. You have to go in there with respect and recognize where they are at and what they need and offer but not rob them of their independence."*



# Fort William First Nation

## Palliative Care Needs Assessment



### Introduction

The need for palliative care services for First Nations people is increasing due to an aging population and the high burden of chronic and terminal disease. Many First Nations people want the opportunity to die in their home communities where they have lived all of their lives; however, First Nations communities have limited access to culturally relevant and formalized palliative care programs.

The research, funded by the Canadian Institutes of Health Research, is conducted with four First Nations community partners: Fort William First Nation, Nootkamegwanning First Nation, Peguis First Nation and Six Nations of the Grand River Territory.

A Project Advisory Committee was developed in each community to ensure local control and lead the implementation of the project. The committee also ensures that the research project addresses the needs of the community and is respectful of the culture. The Project Advisory Committees approved all of the instruments and interview guides that were used in the community assessment to ensure they were locally appropriate.

The research project follows the principles of OCAP (Ownership, Control, Access and Possession) which are sanctioned by the First Nations Information Governance Committee and the First Nations Regional Longitudinal Health Survey, to ensure self-determination in all research concerning First Nations.

The goal of this project is for each community is to develop a community based palliative care program and team within to support members who are sick. This will offer community members more culturally relevant choices at the end of life, provide better care for the Elders in the community, and help with training health care staff, community members and family caregivers.

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# Fort William First Nation

## Palliative Care Needs Assessment



### Purpose

This report presents the results from a community needs assessment conducted in Fort William from March 2011 – May 2012. An Aboriginal Community Facilitator interviewed and surveyed community members about understandings and experiences in providing palliative care; perceived barriers and supports; education and program needs; along with external health care providers input.

### Participants

Knowledge Carriers, identified by the Project Advisory Committees were invited to share their Indigenous understanding of end-of-life care through unstructured narrative interviews. In these interviews, participants would share stories and teachings of end-of-life care.

Community members were asked about their knowledge of palliative care and their previous experiences caring for a dying loved one. They were also asked about their perception of whether members in their community prefer to die at home or elsewhere, and what additional community programs, services and education would be required to support dying people and their families in their community. Existing attitudes and values surrounding death and dying were explored.

Health care professionals who serve the community, but are not locally based, were interviewed about services they currently provided in the First Nation community, their potential contribution to developing a palliative care program, and perceived barriers and opportunities to provide enhanced palliative care.

### Acknowledgements

This project has involved the hard work and determination of many people. First, we would like to thank the Knowledge Carriers, community members, health care providers and members of leadership who invited us into Fort William First Nation and participated in the data collection, as well as the external health care providers who supported the process and participated in interviews and focus groups. These individuals provided us with valuable insight, sharing their personal experiences, feelings and beliefs regarding end-of-life care. The level of understanding and knowledge gained in this project was only possible through the sharing of information from the grassroots of the community.

We would like thank the members of the Advisory Committee: Karen Bannon, Fort William First Nation Health Center Manager; Luanne Maki, Fort William First Nation Community Health Representative; Jean Pervais, Fort William First Nation Community Service Worker; Sherry Pelletier, Fort William First Nation Council Member; Marcella Kudaka, Dilico Home and Community Care Services Manager; and Lorraine Bannon, Fort William First Nation Elder. The organizational support and guidance received from their programs facilitated in the success of the project, and the expertise and experience of these individuals provided the project with a foundation to build upon. We would also like to acknowledge Tom Grinnell and Natalia Collins, who were hired as the Aboriginal Community Facilitators on the project and who were responsible for the data collection.

Finally, we would like to acknowledge and thank the Canadian Institutes of Health Research for their financial contribution and support of the research.

## Section 1:

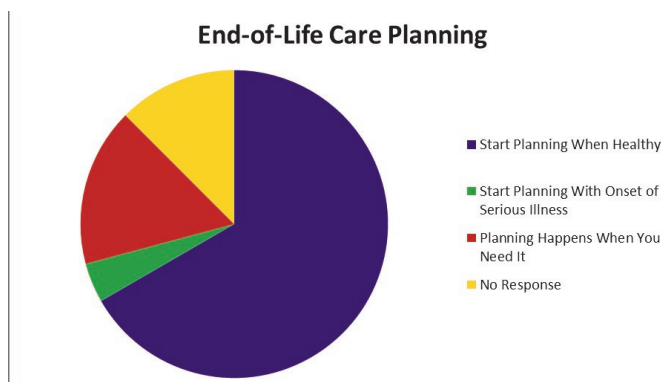
### Understanding and Experiences in Providing Palliative Care



Community members who completed a survey had a good awareness and understanding of palliative care. The majority of them felt that palliative care was intended for people who were at the end of their lives, regardless of their illness. 71% of them had either personally cared for or knew of a family member who had provided care for someone who was dying. The majority of this care was provided in the home.

#### End-of-Life Care Planning

- Over 80% of people surveyed felt that talking about death and dying was acceptable.
- 5% felt it was not acceptable as it has become a much more medicalized event rather than the more personal experience it had been in the past.



Benefits of discussing and planning for end-of-life care given include:

- being able to make your wishes known,
- can prevent family stress and conflict,
- family members can be better prepared emotionally for the loss of a loved one,
- family is better prepared for dealing with the practical matters associated with death,
- people can make informed choices regarding their care and are able to make other important decisions while still cognitively able to.

While talking about death and dying is difficult, it was expressed by participants that older people may be more willing to talk about it because it is more expected and accepted that older people are inevitably approaching their end of life. Therefore, the circumstances of a death, or who is dying, can impact the acceptability or willingness of community members to talk about it.

Community members highlighted the importance of empathy and respecting the choices and wishes of the person who is dying. Participants believe that community members who are dying need to be treated with dignity and respect, while ensuring their needs are recognized and met.

Community members spoke of the need to make do with what resources they had and to 'just keep going'. It was expressed that family caregivers exemplify great strength and often put aside their own emotions to support the dying, as well as other family members. Community members also stressed that caring for a family member is a 24/7 responsibility which can be very stressful and lead to caregiver burnout.

#### Preferred Place for Receiving End-of-life Care

75% of people surveyed and the majority of focus group/interview participants felt that if services were available and adequate, more community members would choose to die at home.

*"If that was me, what would I do? ... I wouldn't want to be alone. When my grandmother was passing, I stayed there right around the clock because I did not want her to die alone, And that's most important. That they don't go by themselves." (Community Member)*



## Section 2:

### Barriers and Supports



#### BARRIERS:

Fort William community members identified many barriers to being able to die at home:

- lack of a formalized palliative care program and associated services,
- lack of funding and facilities,
- lack of trained community members to provide care (members may not want strangers in their home),
- lack of case management and confidentiality restraints, and non-streamlined process of different consents for different programs to initiate care,
- lack of education: prevents members, specifically the elderly, from making informed decisions,
- the limited amount of time a PSW can spend with a client, and
- proper pain management and safe narcotic medication storage.

*"I mean, just because we are close to town, doesn't mean that we're a part of, we're not a part of that community, in town, we're across the bridge here and we have our own ways and our own you know. It's not the same."*

**(Elder)**

Respondents reported that barriers to being able to commit to providing care included:

- work and family-related responsibilities,
- lack of additional support,
- personal physical and emotional limitations,
- lack of knowledge in the type of care required.

Community members felt that even though an individual may want to die at home, fear can take over and the individual may decide to go to hospital/hospice for pain management, or out of concern for family members.

*"I have had my first death in the facility and I thought, oh my god, what if it was my mom? I did not deal with it at first ... Because it was my first and all sudden my tears came down and I kind of got scared ... I learned to love them and let them go because you don't want them to suffer any more."* **(Internal Health Care Provider)**

#### SUPPORTS:

Fort William community members identified many advantages of remaining in the community:

- familiarity and comfort,
- access to culturally appropriate services, including Traditional Healers,
- care could be provided by people you know,
- transportation would not be an issue,
- dying at home can help to retain one's dignity until the end-of-life, and
- having frequent access to family, friends and community members. Visitation can occur at all hours, enabling the person to remain supported,

The community is very important when someone is dying and can be described as providing support, both to the individual who is dying and to their family.

A key strength highlighted by participants is the ability of community members to put aside differences and past conflicts and come together to support families in times of death.

## Section 3:

### Community Identified Needs



#### EDUCATIONAL NEEDS:

Education for Community Members:

- traditional teachings and greater cultural awareness to alleviate some of the fear associated with death,
- available resources both off and on-reserve, and
- Palliative care training for volunteers.

Education for Family Members:

- knowledge around palliative care, including being trained and prepared to assist in care giving for a loved one dying at home,
- services available for their loved one and the options besides the hospital or nursing home for end-of-life or palliative care, and
- helping to assure them that they have done all that they can in caring for their loved one.

*"I would like to see a home right on the reserve ... that they would have a place to go if they choose or if you know, they're unable to remain at home, you know? So, I would like to see a place where our own people would be all together, you know? Close to home and close to family, you know, in the community."*

**(Community Member)**

Education for Health Care Providers:

- training of local people to provide care in the community,
- more training in palliative care,
- doctors in need to be knowledgeable about the process of initiating a palliative care approach.
- more nursing staff needs to be trained to use CAD machine pumps, and
- training around the different community beliefs

#### PROGRAMS AND SERVICES:

- Increased access to support services is needed, including access to 24 hour/day care;
- On call nurse and doctor, including doctor home visits;
- A palliative care program within the community that would be inclusive of all health care and social service providers, spiritual and cultural resources, and volunteers;
- Culturally sensitive programs, the use of traditional medicine.;
- Grief support services are needed in the community, both for family members and for health care providers;
- Meals on Wheels program.

#### RESOURCES AND EQUIPMENT:

- Elders centre or nursing/seniors home, designated as a smoke-free facility,
- Home renovations for accessibility purposes, such as ramps, and
- Accessible transportation services (especially for those with mobility restrictions), including escort.

#### POLICIES AND PROCEDURES:

- Policy and procedures related to palliative care amongst health care providers, would decrease service fragmentation and provide more timely access to care for community members.
- Bereavement and compassionate leave policy

## Section 4:

### External Health Care Provider Input



#### ACCESSING CARE:

The main way for Fort William community members to access care, either in the community or at health care facilities outside the community, is through a referral process. For the most part, referrals are handled through health care providers, between professionals or through the medical facility one is receiving care at.

If there are no options within the community to receive care or if there is a lack of family support for clients, the only remaining option is for them to return to hospital to receive care.

#### BARRIERS TO PROVIDING CARE:

Fiscal restraints and what they are able to do with their budget limits the ability to provide enhanced care within the Fort William community.

A lack of staff can cause issues as there ends up being an overload on files limiting ability to see clients in a timely manner.

Dilico is the main provider of Home and Community Care; however, the stigma of Dilico as a Child Welfare agency has resulted in community members either denying Dilico home care services when offered or not accessing services at all.

*"I think there's a bit of that 'Oh, Dilico wants to come', Dilico they think right away child welfare ... you have to make it very clear that we're a health program and we're very separate and have nothing to do with child welfare."*

#### OPPORTUNITIES:

Participants highlighted many opportunities to further develop or enhance palliative care programming, which include:

- building on preexisting programming,
- collaboration with community partners,
- community designed and driven programming,
- the de-medicalization of programming,
- education and training, and
- expanding services, and
- a volunteer program.

*"First Nations communities, there are a lot of different diseases that have no cure and that do impact and so would benefit from the palliative approach earlier on, things like diabetes and those kinds of things, so, doing education around that to build capacity within the First Nations communities is key."*

#### POTENTIAL PROGRAM CONTRIBUTIONS:

External health care providers could offer of themselves, or on behalf of health care agency they work for, the following areas for program contribution:

- Education and training, especially for families;
- Human resources: to assess in program development, collaboration, capacity building within the community, and information sharing;
- Advocacy on behalf of their clients; and
- Program accessibility: available programs and services, including ensuring program visibility within the community.

## Section 5:

### Recommendations



Based on the data collected from community members, residents of the Fort William First Nation would prefer to die at home if services and community supports were available and adequate. The advantage of dying at home is access to family and friends as well as to cultural and spiritual resources. Our recommendations have been formulated with the intent to provide people a choice to die at home on the First Nation through improving their access to high quality palliative care services at home. At present, many residents of Fort William First Nation do not feel that having the choice to die at home currently exists.

Based on the results of the needs assessment, we offer a series of recommendations to advance palliative care program development and expand the palliative care program in the Fort William First Nation.

We begin by offering four overarching general recommendations for community leaders. These are followed by specific recommendations that can serve to guide future actions related to developing palliative care practice, policy, and education. These specific recommendations can be located in the larger, comprehensive palliative care needs assessment.



#### OVERARCHING GENERAL RECOMMENDATIONS FOR COMMUNITY LEADERS

- That the leadership of the Fort William First Nation identifies ongoing development of their local community palliative care program and teams as a priority within their strategic planning process for the next three years.
- That the leadership of the Fort William First Nation continues to support partnerships between their community health care providers, the Lakehead University End-of-Life Care in First Nations Communities project, and regional palliative care service providers to improve access and quality of palliative care for residents of the First Nation.
- That the leadership of the Fort William First Nation commit to supporting a program of culturally appropriate education for residents of the community about palliative care, the services that are available, eligibility requirements, and how to access them.
- That the leadership of the Fort William First Nation commit to supporting the community palliative care program and team in their efforts to 1) continue to identify and address unmet community palliative care needs, 2) to advocate for required resources and solutions within the community and externally, and 3) to educate non-Aboriginal external health care providers who provide cross cultural health care to residents of Fort William First Nation.
- That the leadership of Fort William First Nation and Dilico Anishinabek Family Care commit to working collaboratively to proactively market Dilico's role as a health service provider and differentiate this role from Dilico's historical role in child welfare. This is needed in order to address the stigma associated with accepting home and community care services from Dilico, which is a barrier to providing palliative and end-of-life care in the home.