

# Palliative Care Needs Assessment



*“More traditional teaching and include the elders with the knowledge. First Nations need to open the door between traditional knowledge and conventional methods. We need what is across the road...”. (Survey Participant)*



Centre for Education  
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Peguis First Nation: Palliative Care Needs Assessment

  
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# Peguis 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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## Purpose

This report presents a summary of results from a community needs assessment conducted in Peguis First Nation from January 2011 – June 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 and Elders, 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 and Elders, community members, health care providers and members of leadership who invited us into Peguis 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: Jeroline Smith, Sharol Kohoko, Maurice Bear, Doris Bear, Judy Stevenson, Donna Spence, and Melissa Manningway. 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 Mavis Stevenson, Tracy Sinclair, and Edie Thomas, 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

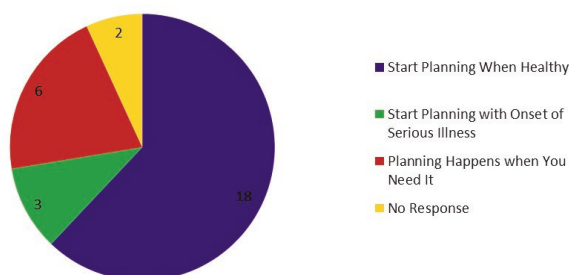


Community members who completed a survey had a good awareness and understanding of palliative care. The majority of them felt that palliative care was intended for people who were at the end of their lives, regardless of their illness. Over 70% of them had either personally cared for or knew of a family 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

- 69% of people surveyed felt that talking about death and dying was acceptable in the community.
- 14% felt it was not acceptable. Respondents listed lack of palliative care knowledge, no prior experience dealing with death, and unresolved grief as reasons talking about death and dying is not acceptable.

End of Life Care Planning



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

- Prevents family stress,
- Allows people to make informed decisions, and
- Makes wishes known.

Participants expressed that there is no one singular belief or value around death and dying in the community: every family is different in what they believe and want, and such values and beliefs are dependent upon family upbringing and may be Christian or Traditional-based. It was expressed that what is important is to respect and participate with the dying and the family whatever spiritual path they may follow because having and sharing beliefs is very important at end-of-life.

In terms of some more general community practices around death and dying, it was expressed that community involvement in care is a traditional way of caring that is continued today. For instance, supporting families is a community practice at end-of-life and has traditionally been so. Lighting and keeping fires going until the person is buried also seemed to be a general community practice, as were the holding of feasts after a loss. Other general community practices related to death and dying were the holding of wake services, cedar baths, and offering tobacco. Standing by the person as they pass away, and not leaving the person or body alone, were also practices mentioned.

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

93% 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.

*"But for myself, I wouldn't want to die at home because I wouldn't want to put my family in that [position] ... but I would like to have a facility on my home reserve where family was free to come and go as they please kind of thing, more like a home setting but not in a home that's my personal..." (Elder)*

## Section 2:

### Barriers and Supports



#### BARRIERS:

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

- Lack of access to adequate care provision and palliative care services in the community,
- Care responsibilities place a great amount of stress on family,
- Care is seen as 24/7, families and community services cannot meet this need,
- Inadequate housing to provide safe and appropriate care (e.g. door widths, grab bars),
- proper pain management and safe narcotic medication storage, and
- Lack of palliative care training for staff and a lack of resources

*“we have a senior centre that does not have the capacity or capabilities of caring for terminally ill patients, taking people within that. Putting them in their homes I guess is also another issue because again you’re looking at family and capacity to care for somebody at home that is terminally ill, we just don’t have that, we don’t have the nurses that have that capacity or capability to go out and do it, so a lot of the times the diagnosis is not good” (Community Member)*

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, and
- Lack of knowledge in the type of care required.

#### SUPPORTS:

Peguis community members identified many advantages of remaining in the community:

- Familiarity and comfort,
- Less stressful on families,
- Less exposure to communicable diseases,
- Transportation would not be an issue,
- Access to culturally appropriate services and care, and
- Having frequent access to family, friends and community members. Visitation can occur at all hours, enabling the person to remain supported.

Participants felt that the whole community provides support in various ways and is often an intergenerational effort. It was expressed by participants that support is provided purely out of care for one another, not for praise or recognition. Thus, often no words are even spoken, but rather community members take it upon themselves to see what a person or family needs and will provide that for them. Community members shared that it is often the little things that people do to help that are the most meaningful and that one person’s personal loss can make them a good support resource for others going through a similar experience.

*“I had one patient we were taking home ... he kept saying are we there yet, are we there yet. He was just getting more and more excited, just to get home and he didn’t have long, he was, you could just feel the excitement in him, and it progressed to his son and when we got home it was just like a big relief and got him into bed ... you could see the peacefulness on the face, the anxiety was gone”.*  
*(Internal health care provider)*



## Section 3:

### Community Identified Needs



#### EDUCATIONAL NEEDS:

Education for Community Members:

- Information and knowledge about what services are available in the community,
- Seek out volunteers and train them in palliative care,
- Community experts should pass knowledge on to others at a grass-roots level, and
- Education on death, dying, and palliative care targeted to the younger generations

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. Specific cares should focus on pain medication and management, using oxygen, personal care techniques (turning, lifting), and
- Awareness of training opportunities available in the community.

*“One of the things, that there is such a great need in the community for end of life care, and it brings a community together, and not being able to have that loved one at home because of barriers can really ah, pull a family, not only the family, the community apart. That’s why it’s so important to ah, to bring them home, where they belong”.*  
(Community Member)

Education for Health Care Providers:

- Training of local people to provide care in the community,
- More training in palliative care and mental health disorders,
- Communication training on death and dying, and
- Culturally appropriate and safe care training for health care staff on and off reserve.

#### PROGRAMS AND SERVICES:

- Increased access to support services is needed, including access to 24 hour/day care;
- Palliative and end-of-life care, including advanced care planning
- Mental health services
- Grief support services and resources, including emotional supports for families, and
- Community clinic with access to doctors.

#### RESOURCES AND EQUIPMENT:

- Community palliative care centre,
- Palliative care rooms at Percy E. Moore Hospital,
- Community buildings and home renovations for accessibility purposes, such as ramps,
- Equipment such as beds and wheelchairs, including storage space for current equipment, and
- Accessible transportation services (especially for those with mobility restrictions).

#### POLICIES AND PROCEDURES:

- Increased funding and resources, specifically funds be earmarked for palliative care. Participants feel that this is an inherent treaty right under the Medicine Chest treaty clause,
- Revisit current policies in Peguis regarding palliative care, and create forms and resources for families,
- Gaps in policies and procedures as it pertains to pain medication and management need to be addressed, and
- Hospitals need to revisit policies, including staff cultural sensitivity training.

## Section 4:

### External Health Care Provider Input



#### ACCESSING CARE:

The main way for Peguis 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:

- Advanced care planning (talking about death & dying),
- Funding—programming, resources & support
- Infrastructure—human resources & infrastructure,
- Location, and
- Palliative care trained staff.

*“one of the barriers in First Nations communities that I’ve encountered has to do with what I eluded to earlier that are kind of, the supportive agencies whether its FNIH or whether it’s a the local regional health care, or even the band, it seems like people kinda tend to wait for someone to take first ownership of that. It’s like when you watch baseball and you got three outfielders that watch the ball hit the ground, because each one thought the other one was going to catch it. It feels like that and that’s what happens sometimes when it comes to, especially kinda cost issues around supporting somebody and it, the challenge of palliative care is that it is often not a lot of time to sort that stuff out.” (external health care provider)*

#### OPPORTUNITIES:

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

- collaboration with community partners and non-palliative care focused programs, including program and resource development,
- Building on preexisting guidelines already set out by other programs,
- Community designed and driven,
- the de-medicalization of programming, and
- education and training.

*“And First Nation people are, they need to think through how can we develop, culturally appropriate ways to deal with the death, the ways that our people are dying recently, they didn’t die this way in the old days.” (external health care provider)*

#### 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 for Peguis health care providers and community members.
- Human resources: collaboration, capacity building within the community, and information sharing; and
- Program accessibility and community connections: available programs and services, including ensuring program visibility within the community.

## Section 5:

### Recommendations



Based on the data collected from community members, residents of Peguis 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 Peguis 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 Peguis 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 Peguis 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. Any programming that is developed must incorporate cultural practices, traditions and teachings.
- That the leadership of Peguis 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 Peguis 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 Peguis 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 Peguis First Nation.