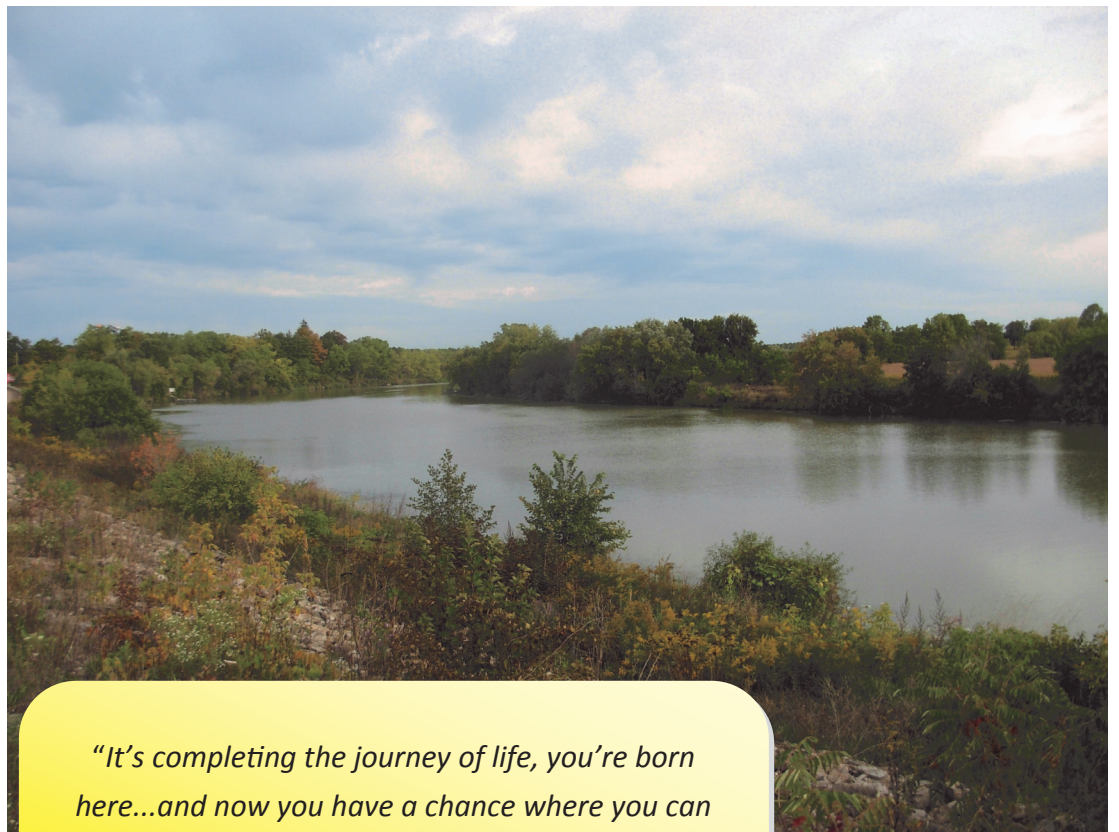


# Palliative Care Needs Assessment



*"It's completing the journey of life, you're born here...and now you have a chance where you can complete your life right on the territory and it's meaningful for a lot of folks, I've heard numbers say that they're coming home to die and they feel good."*



# Six Nations of the Grand River Territory



## 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, Naotkamegwaning 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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# Six Nations of the Grand River Territory

## Palliative Care Needs Assessment



### Purpose

This report presents the results from a community needs assessment conducted in Six Nations from April 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 Six Nations of the Grand River Territory 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 Ruby Miller, Director of Health Services and the members of the Advisory Committee: Lori Monture, Supervisor, Long-term Care/Home and Community Care; Verna Fruch, Case Manager, Long-term Care/Home and Community Care; and Lois Bomberry, Supervisor, Six Nations Family Health Team. 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 Audra Taillefer, who was hired as the Aboriginal Community Facilitator on the project and was 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.



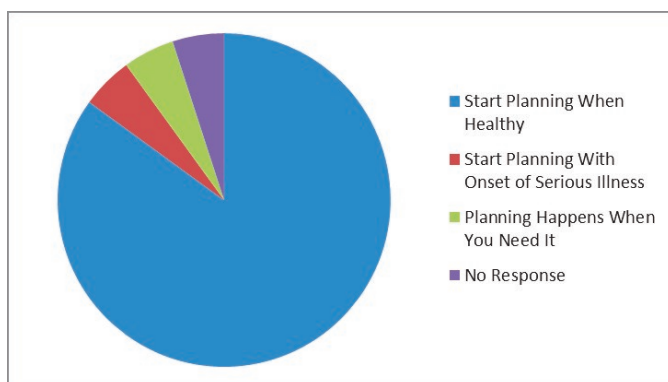
## Section 1:

### 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. 90% 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

- 75% of people surveyed felt that talking about death and dying was acceptable.
- 10% felt it was not acceptable due to cultural and traditional teachings and the idea that talking about death and dying will bring it about.



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

- being able to make your wishes known,
- being able to make informed decisions,
- being able to help to prepare family members,
- 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.

Community members felt that everyone handles death in their own way and that there can be a wide range of emotions involved including shock and denial. They feel some family members are not able to be around the dying and some also experience fear about being present near the end of a loved one's life.

Community members spoke of the grief and shame that can be experienced if one feels a sense of relief after the death of a loved one. This relief was associated with the huge responsibility associated with caregiving, which can often result in burnout.

Community members emphasized the importance of respecting the end-of-life wishes of the dying and also ensuring that the person's dignity is maintained throughout their illness until death.

Family support, awareness, and involvement are very important and that a lack of family involvement can impact care by not assisting in decision-making, which can result in confusion around the person's condition and treatment options.

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

90% 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.

*"You hear everyone say well they passed away at home in their bed, and that just makes you feel so good ... that was nice, it happened the way they wanted it, but some of us don't have that choice, we're taken away too soon."*

**(Six Nations Knowledge Carrier)**



## Section 2:

### Barriers and Supports



#### **BARRIERS:**

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

- a lack of knowledge: not knowing what services are available in the community and also regarding what all is involved in the provision of end-of-life care at home,
- lack of preparation for families prior to a loved one coming home,
- the health care system can be difficult to navigate
- caregiving is a 24/7 responsibility, however 24/7 care is not available in the community,
- access to doctors and proper pain management were also barriers mentioned by community members related to the current service system.

*“...when my brother-in-law was passing away, the nurse was only allowed so many visits in a twenty-four hour period and you can't expect her to get up and come back to the facility just to give the needle. So actually, my niece learned how to do some of the syringe stuff that needed to be done.”*

**(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,
- the high level of responsibility and pressure associated with caregiving can lead to fear of caring for someone at the end-of-life,
- lack of available resources, and
- financial implications, such as needing to rent/buy the necessary equipment.

Internal health care providers expressed that they are often not recognized as a family member, but rather need to remain in their 'worker' role.

*“It's very challenging because they might not see you as, that person's family...they only see you as their worker and expect you to you know, be the soldier and still do either both roles or be at work at, all the time.”* **(Internal Health Care Provider)**

#### **SUPPORTS:**

Six Nations 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.

Community members talked about how supportive and close-knit the community is despite being a large reserve geographically and the importance of volunteerism.



## 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,
- services available in the community, and
- grief and how to recognize when family members might be in need of support or care.

Education for Family Members:

- knowledge around palliative care, including being trained and prepared to assist in caregiving 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.

*“... what should we prepare for? You know, what are the signs and symptoms, how can we best take care of our parent, our relative, you know? But it’s like there’s not that prep and I think there should be something, you know.”*

**(Internal Health Care Provider)**

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,
- training around the different community beliefs and rituals, such as Longhouse, to be able to better serve their patients and family members.

#### PROGRAMS AND SERVICES:

- Increased access to support services is needed, including access to 24 hour/day care.
- More nurses are needed for respite services.
- 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.
- A palliative care team would be available 24 hours/day and provide education to family members about caring for a loved one at the end-of-life.
- 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.

#### RESOURCES AND EQUIPMENT:

- Hospice or centralized palliative care facility.
- Hospital/palliative beds for homecare.
- More respite beds.
- Pain control equipment and medication, and storage space.
- Transportation services

#### 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
- A process for making requests.



## Section 4:

### External Health Care Provider Input

#### ACCESSING CARE:

The main way for Six Nations 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 received care or if there is a lack of family support for clients, the only remaining option is for them to return to the 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 Six Nations 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.

A lack of funding for programs, 24 hour care, funds for hospice development in the community, cultural programming, and burial options is a major barrier. However, people remain hopeful that, as a result of the research project, options will open up and linkages will be created to give Six Nation community members more choices.

*"...it could be structural, they may have stairs to get in and out of their house and they can't manage, it may be that their bathroom isn't big enough to get a wheelchair into that type of structure ... their bedroom might be on a second floor or their bathroom might be on a second floor and they can't get up and down stairs."*

#### 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
- First Nations culture based programming.

*"...there is a fundamental need within Aboriginal communities to have something specifically relevant to the culture and the values, the heritage of Aboriginal peoples..."*

#### POTENTIAL PROGRAM CONTRIBUTIONS:

External health care providers are willing to:

- Facilitate education around end-of-life care,
- Help build confidence in those taking the training so that they may, in turn, train other staff members in the community and add community relevance to their training sessions,
- Bring training into the community,
- Share their experiences on how to assist and deal with families faced with crises,
- Expand and build upon community connections,
- Continue to strengthen and maintain relationships as there is already a strong connection in place between external health care providers and health care providers within Six Nations community.



## Section 5: Recommendations

Based on the data collected from community members, residents of the Six Nations of the Grand River Territory 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 Six Nations of the Grand River 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 Six Nations of the Grand River Territory.

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 Six Nations of the Grand River Territory 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 Six Nations of the Grand River Territory continues to support partnerships between their community health care providers, the Lakehead University End-of-Life Care in First Nations 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 Six Nations of the Grand River Territory 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 Six Nations of the Grand River 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 and 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 Six Nations of the Grand River.