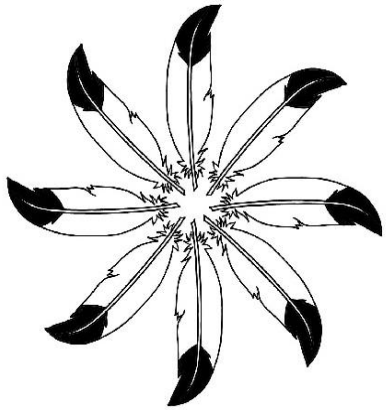
Improving End-of-Life Care in First Nations Communities



Development Guidelines and Resources for Developing Palliative Care Programs in First Nations Communities

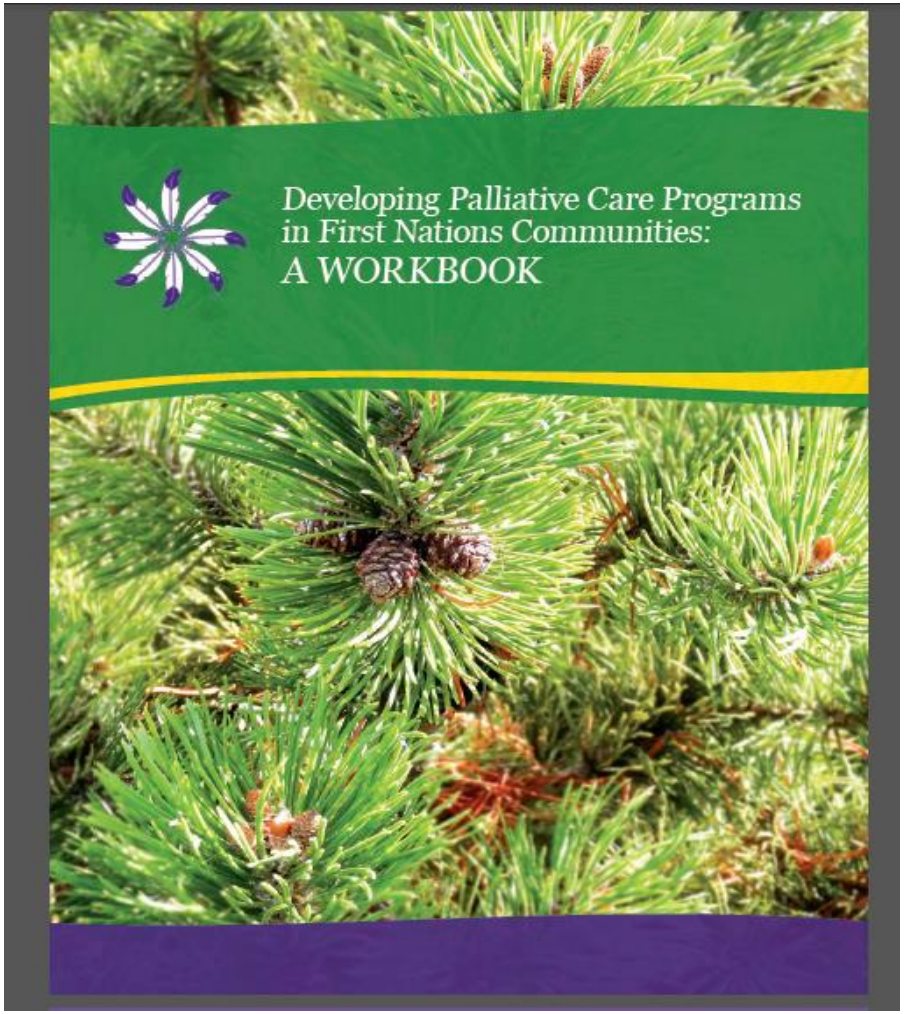
CHPCA, October 2015

Ottawa, Ontario

CIHR IRSC
Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Centre for Education and Research on Aging & Health | Lakehead UNIVERSITY

Workbook Cover



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This document was created by the Improving *End-of-life Care in First Nations Communities (EOLFN)* project team, Dr. Mary Lou Kelley, Principal Investigator.

The research team included four First Nations Communities: Peguis First Nation, Naotkamegwanning First Nation, Fort William First Nation and Six Nations of the Grand River Territory.

FORT WILLIAM FIRST NATION

All First Nations communities are free to copy and share any part of this Workbook and use the tools and resource materials that accompany the Workbook in any way that is helpful to them.

The tools and resources may be adapted and combined with other resources to better fit the needs of a community. We only ask that you acknowledge the source of these materials when you use them.

We ask that you reference this document as follows:

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For more information about this workbook, the *End of Life Care in First Nations Communities* project resources or overall research please visit our project website at www.eolfn.lakeheadu.ca or contact us by email at eolfn@lakeheadu.ca

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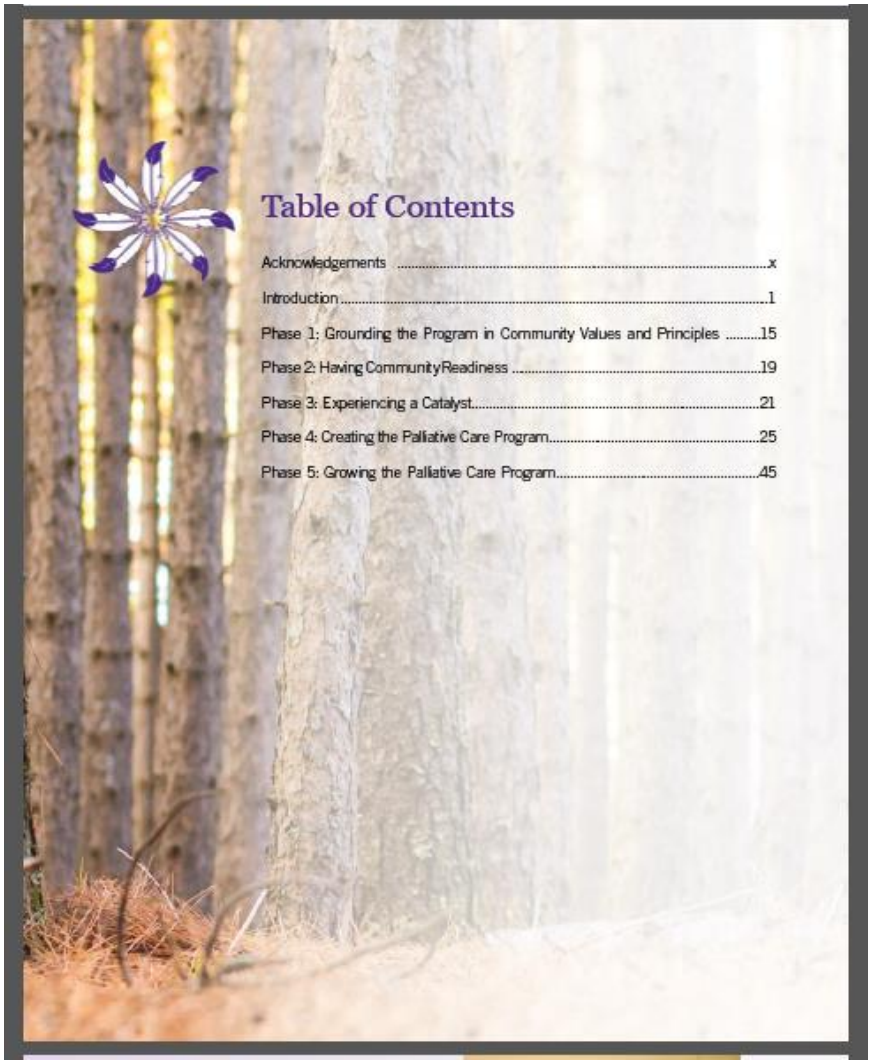
What's inside …



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Acknowledgements

Acknowledgements

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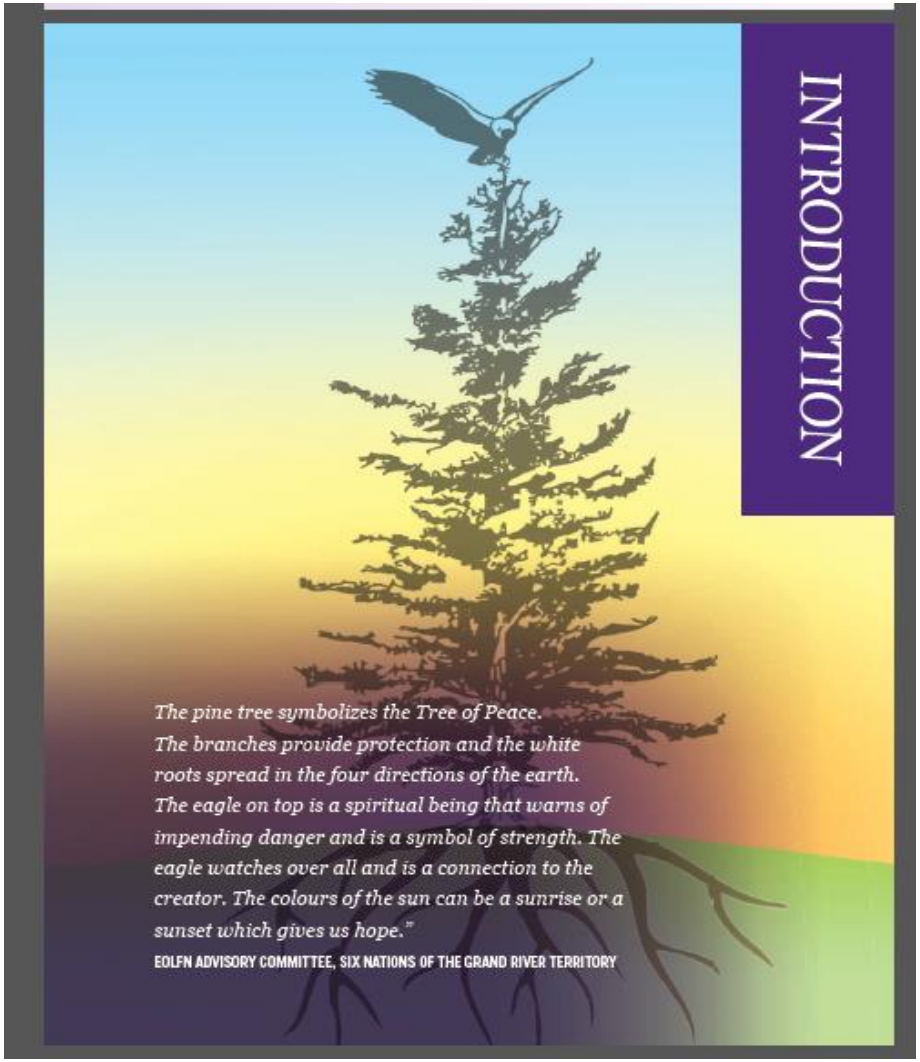
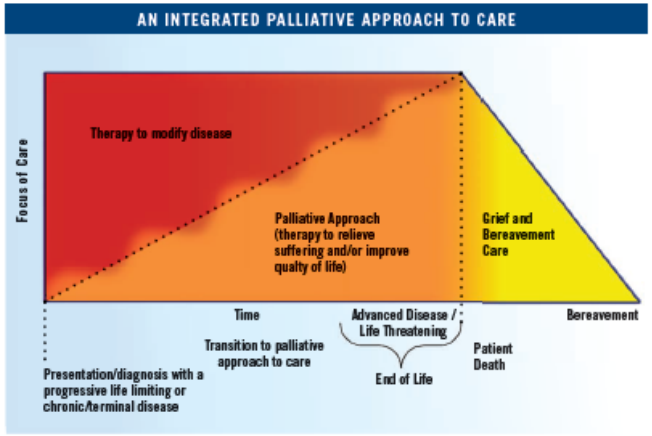
Introduction



Palliative Approach to Care

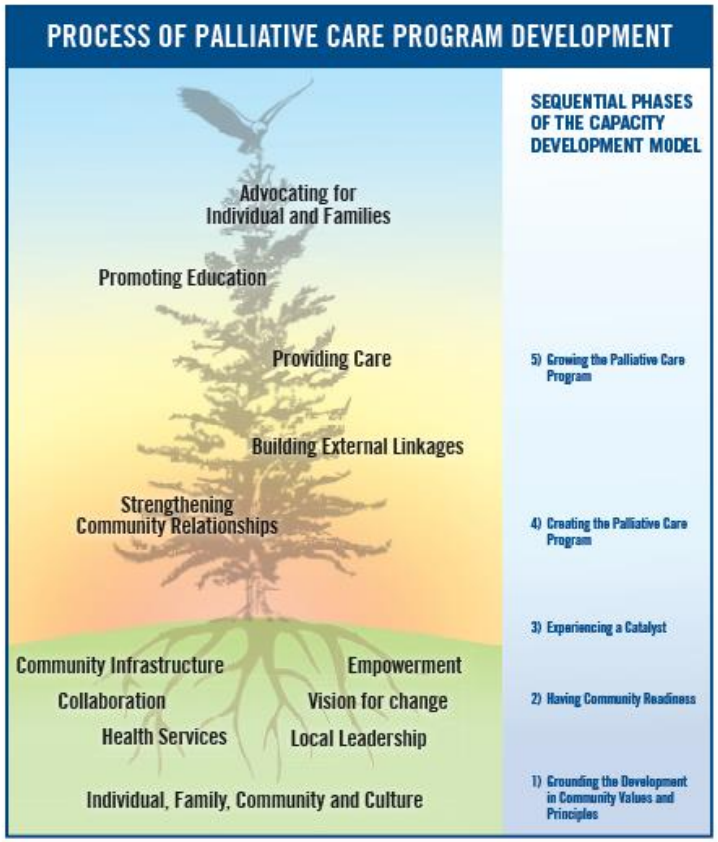
The following diagram, An Integrated Palliative Approach to Care for First Nations Communiies, illustrates how a palliative approach to care can be incorporated at different stages of a person's chronic illness. This diagram was developed by the EOLFN project and adapted from the Canadian Hospice Palliative Care Association model of care.



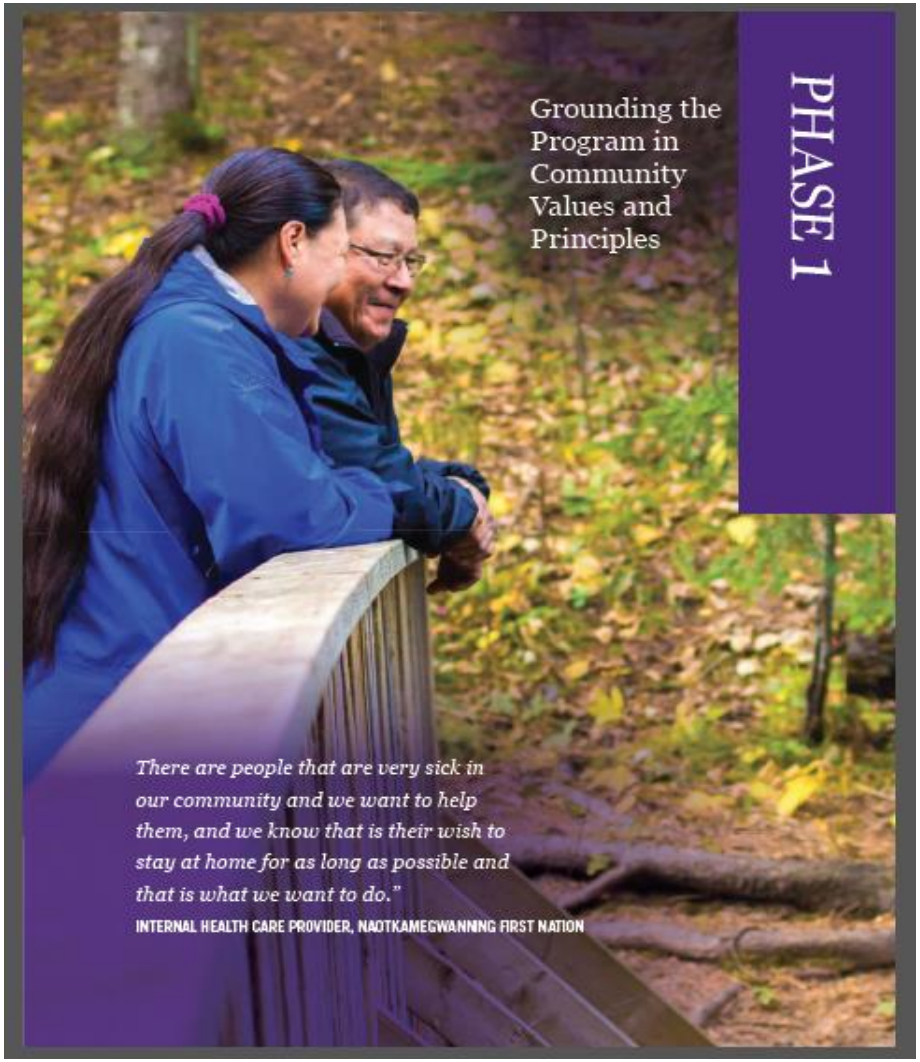
An Integrated Palliative Approach to Care for First Nations Communities

In relation to the diagram, the palliative approach (which is depicted in the lower right hand section) is implemented at diagnosis and extends to end-of-life and through bereavement. Over time, there is a gradual transition in the focus of a person's care from diagnosis to end-of-life. As the individual's disease progresses, the focus of care gradually shifts. The primary care team of health care providers in the community provide the majority of the palliative care; however, occasional consultation and support from palliative care experts may be beneficial.

Initially, there is a greater focus on therapies to modify the disease. Later, the focus shifts to the palliative approach, relieving suffering and improving quality of life. Treatment for the disease and the palliative approach occur at the same time throughout the course of the illness. In the last year of life there is particular emphasis on the palliative approach to care.


PROCESS OF PALLIATIVE CARE PROGRAM DEVELOPMENT
SEQUENTIAL PHASES OF THE CAPACITY DEVELOPMENT MODEL
Advocating for Individual and Families
Promoting Education
Providing Care
Building External Linkages
Strengthening Community Relationships
Community Infrastructure
Empowerment
Collaboration
Vision for change
Health Services
Local Leadership
Individual, Family, Community and Culture
5) Growing the Palliative Care Program
4) Creating the Palliative Care Program
3) Experiencing a Catalyst
2) Having Community Readiness
1) Grounding the Development in Community Values and Principles

Phase 1


PHASE 1
Grounding the Program in Community Values and Principles
There are people that are very sick in our community and we want to help them, and we know that is their wish to stay at home for as long as possible and that is what we want to do."
INTERNAL HEALTH CARE PROVIDER, NAOTKAMEGWANNING FIRST NATION

Grounding the Program in Community Values and Principles

"...when a person would pass on, they [the community] celebrated, they weren't sad. They were happy for that person, because they knew that, you know, it wasn't the end of life, like there was life after, kind of thing in a spirit world. They knew that's where they, the spirit, came from. How we went home. So instead of being sad they were happy for that person going to the spirit world. So people weren't sad when someone passed on, they were happy for them, they envied them kind of thing."

Traditional Knowledge Carrier, Naotkamegwanning First Nation

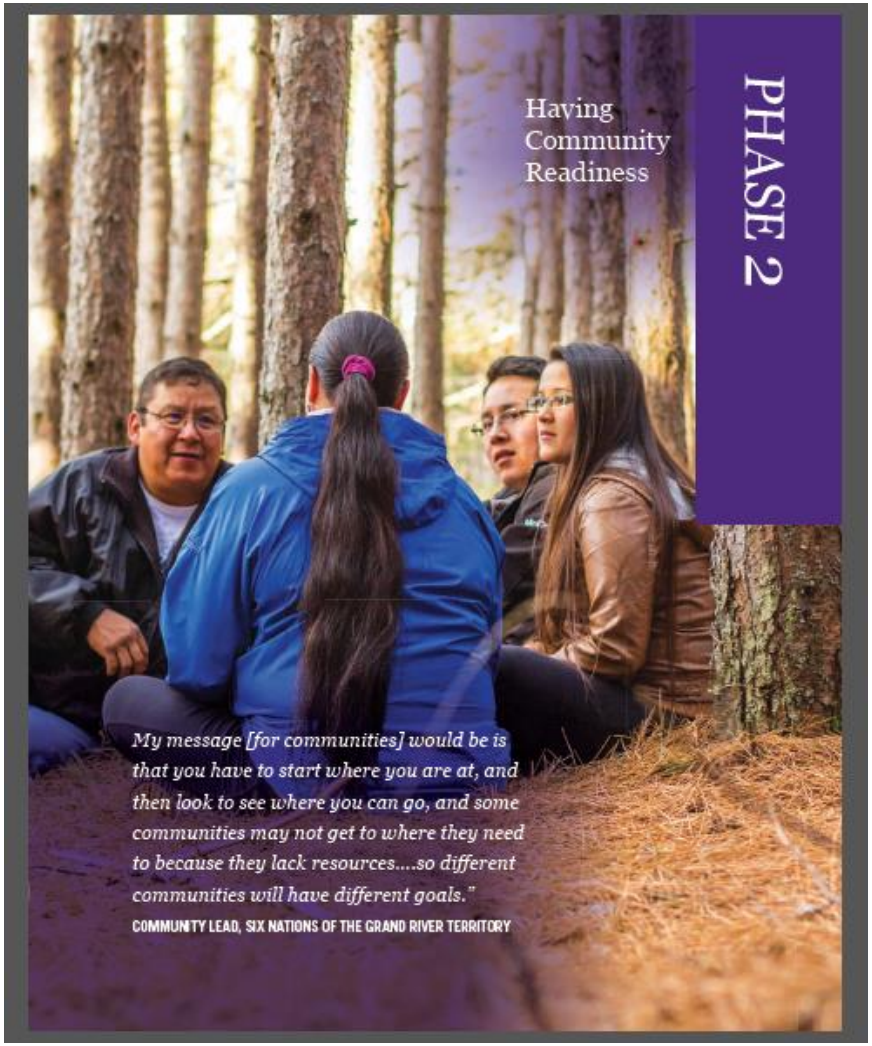
PHASE 1: Grounding the Program in Community Values and Principles

In developing a palliative care program in a First Nations community, the first phase of the process Grounding the Program in Community Values and Principles acknowledges and respects that the program needs to grow out of the roots of individual, family, community and culture. What this means is that each community has unique values, beliefs, and philosophy which are based on Indigenous understandings of health, illness, birth, and death. These differ across communities and linguistic groups and they need to be recognized, honoured, and valued.

The following principles need to be understood and respected when developing a palliative care program in a First Nations community:

- Palliative care delivery in a First Nations community may be different than westernized, medicalized or urban models of palliative care;
- The program needs to be based on local control and engage community members;

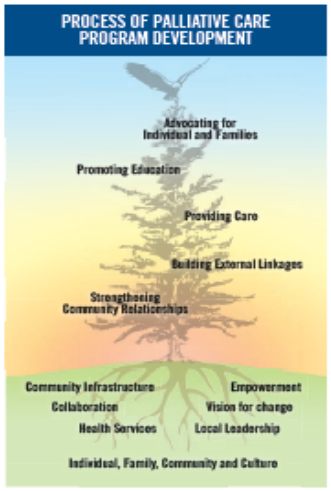
Phase 2


PHASE 2
Having Community Readiness
My message [for communities] would be is that you have to start where you are at, and then look to see where you can go, and some communities may not get to where they need to because they lack resources....so different communities will have different goals."
COMMUNITY LEAD, SIX NATIONS OF THE GRAND RIVER TERRITORY

Community Readiness

Characteristics that Influence Community Readiness:

1. **Community Infrastructure** - having enough community infrastructure (e.g. housing, clean water, transportation, good communication technology). These community factors impact how challenging it will be to provide home care for people who are very sick.
2. **Health Services** - having enough local community health services and health care providers (e.g. health centre, Elders centre, doctors, nurses, home and community care program). The total number of services and providers available is less important than whether or not that number is sufficient to provide community members with palliative care at home when it is required.
3. **Collaboration** - having health care providers who are able to work well together and are committed to collaborate in order to meet new and important community needs. Clients in the palliative care program will require services from more than one program or organization, and good quality care will require many people within the community and outside the community to work well together.
4. **Empowerment** - having a sense of community empowerment to take action and responsibility to solve local problems by drawing on family and community support networks. The palliative care program must be initiated by local people and developed by community members who are willing to work hard to achieve their vision.
5. **Vision for Change** - having a vision to provide better home care for people who are seriously ill and/or Elderly so that they can receive quality palliative care in the community to the end of their lives. It is the vision of the community that will guide the work of the leaders and community members.

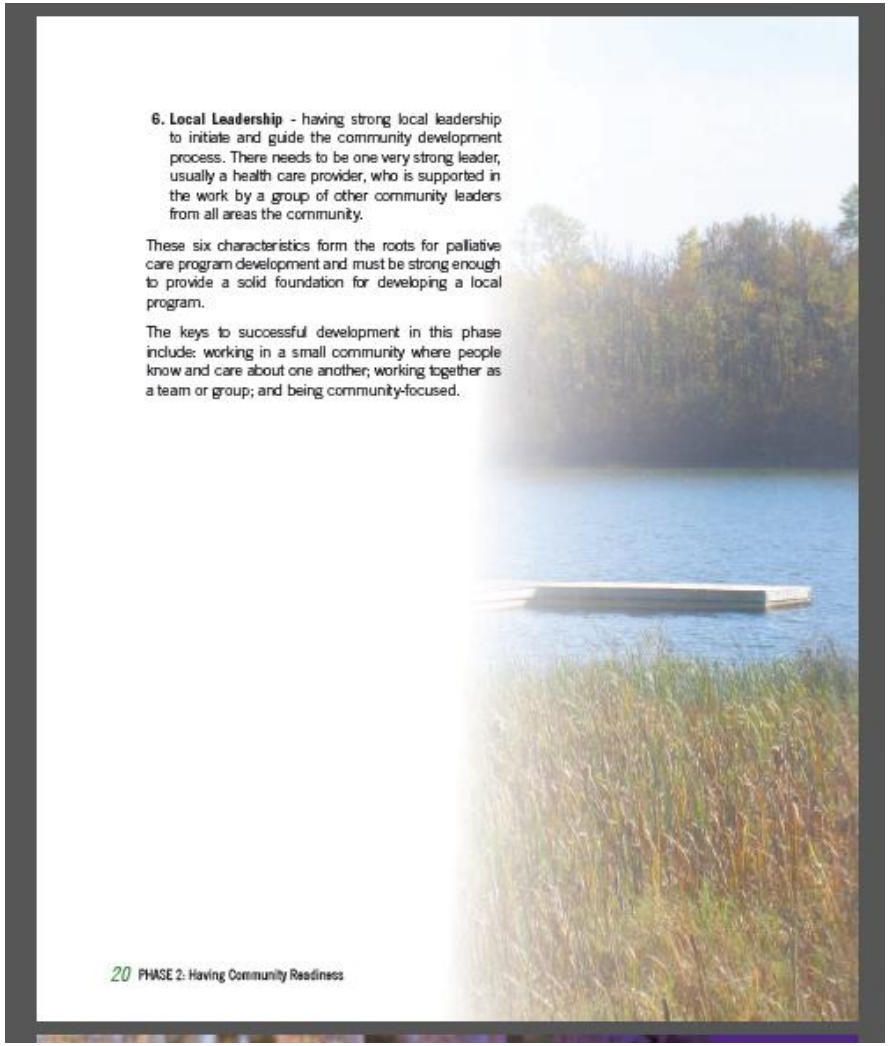


The six characteristics are shown in the diagram as the roots of the tree.

"....what I'd like to see...is for everybody to be on board with a shared ... vision, like a goal. Then once that's in place, when you know someone is coming home, just make a call and everybody ... has a role and knows their role."

Community Member, Naotkamegwanning First Nation

Community Readiness cont…

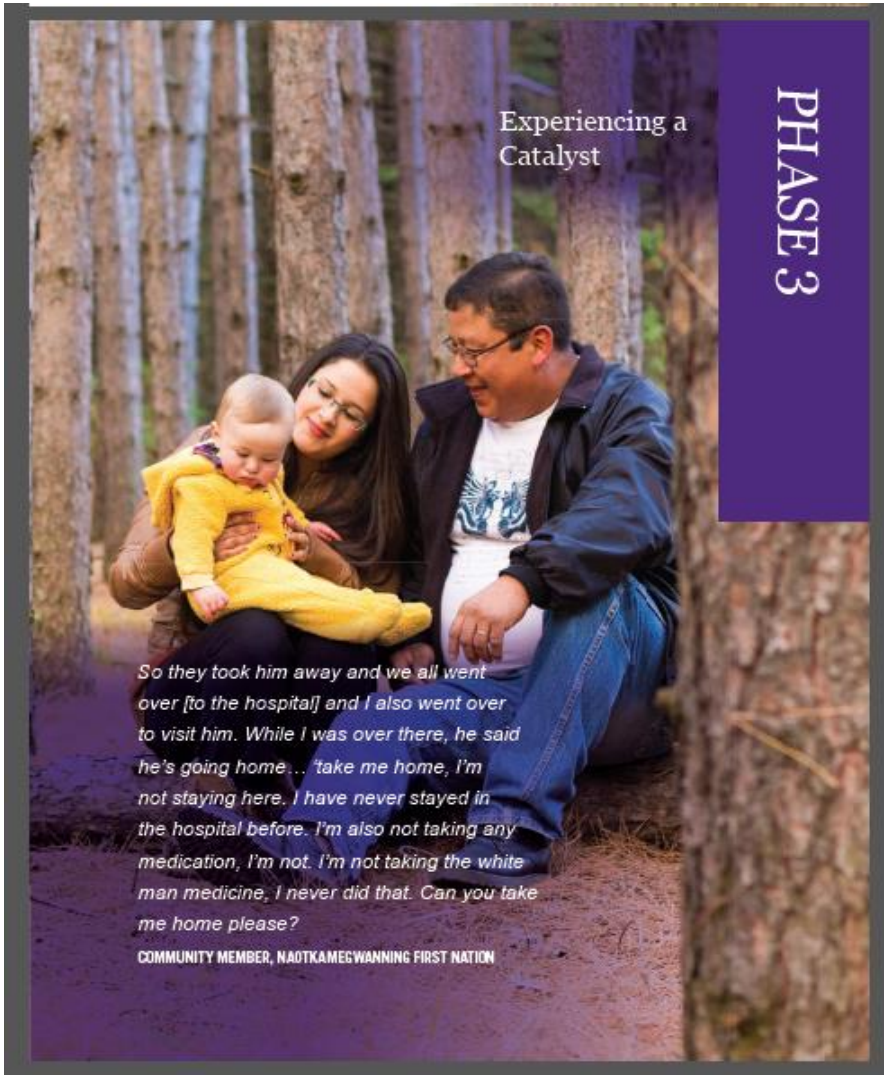


6. **Local Leadership** - having strong local leadership to initiate and guide the community development process. There needs to be one very strong leader, usually a health care provider, who is supported in the work by a group of other community leaders from all areas the community.

These six characteristics form the roots for palliative care program development and must be strong enough to provide a solid foundation for developing a local program.

The keys to successful development in this phase include: working in a small community where people know and care about one another; working together as a team or group; and being community-focused.

Phase 3


PHASE 3
Experiencing a Catalyst
So they took him away and we all went over [to the hospital] and I also went over to visit him. While I was over there, he said he's going home… 'take me home, I'm not staying here. I have never stayed in the hospital before. I'm also not taking any medication, I'm not. I'm not taking the white man medicine, I never did that. Can you take me home please?
COMMUNITY MEMBER, NAOTKAMEGWANNING FIRST NATION

Catalyst

The description of the Community Lead role is included in the tools; please see the folder **Phase 3 – Experiencing a Catalyst**. The folder includes the following templates as editable Microsoft Word documents that can be adapted and customized to your First Nation community:

1. **Community Lead Description Template**
2. **Example EOLFN Community Lead Description PDF**

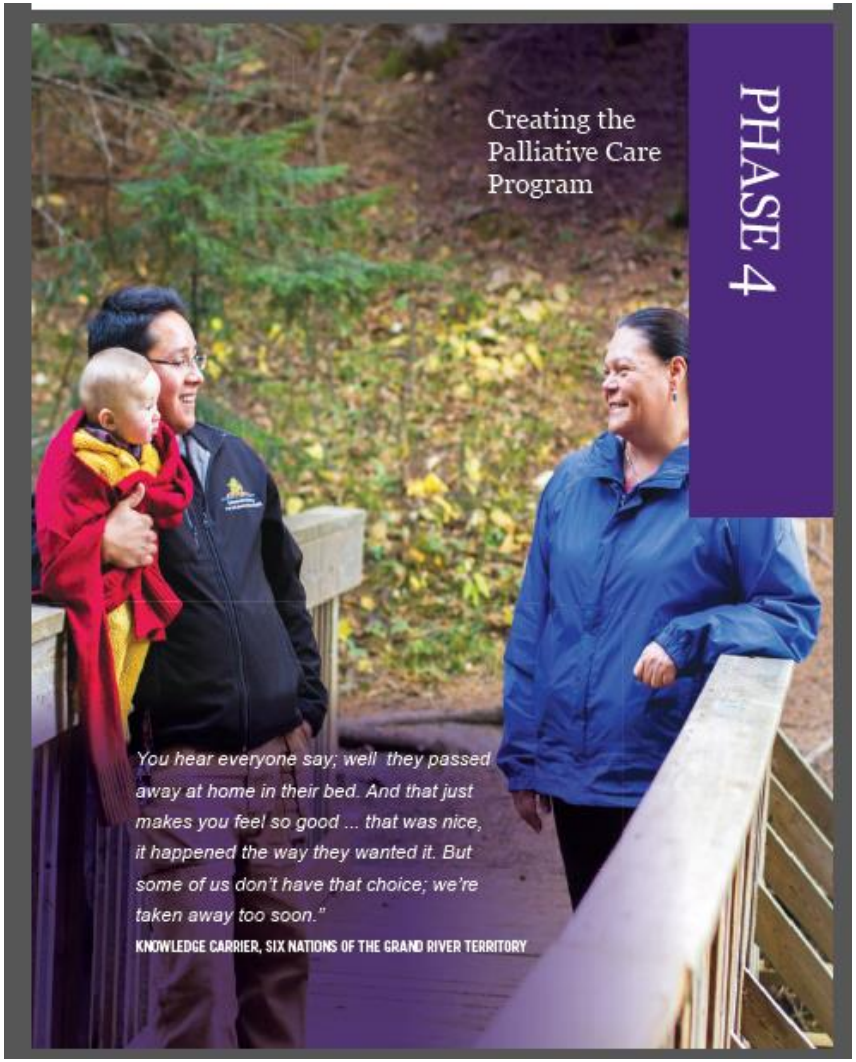
Once identified, the Community Lead engaged with other community members to form an Advisory Committee that would guide the remainder of the community development process. This Advisory Committee consisted of a small group of individuals who worked together to start the process of developing palliative care. They were key people in the community who could create community change. Having the Advisory Committee also demonstrated the community's involvement and commitment to change, which is why it is recommended that this committee be established.

The specific membership of the Advisory Committee is at the discretion of the Community Lead. Advisory Committee members should be individuals who are highly respected, knows how to get things done, and have a commitment to improving end-of-life care for community members. Within the EOLFN project, Advisory Committee members included: the health director, home and community care coordinator, Elders' worker, Elders/Knowledge Carriers, representatives of community leadership, managers of health programs, community health educators, home care/ support workers, and administrative staff. The Community Lead invited the appropriate people to a meeting, introduced them to palliative care, gave them some background information, and obtained their commitment to work together to develop a palliative care program.

At this stage in the program development, it is highly recommended that the Advisory Committee be small in number, for example 5-10 people. A smaller group is easier to organize and create manageable plans. At a later date, after some initial work is done, a larger committee called the Leadership Team will be developed. The Leadership Team will include a much broader scope of people from both within and outside the community. Forming the Leadership Team is explained later in the workbook.

The Advisory Committee members are fundamental to getting the palliative care program off the ground. The committee will meet as frequently as needed and may be formal or somewhat informal. They will work on getting someone to become their Community Facilitator and focus on community engagement. They will also start to look at community needs and identify key people to be interviewed and surveyed. They will develop the community recommendations and work plan. These activities are described later in the workbook.

Phase 4


Creating the Palliative Care Program
PHASE 4
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."
KNOWLEDGE CARRIER, SIX NATIONS OF THE GRAND RIVER TERRITORY

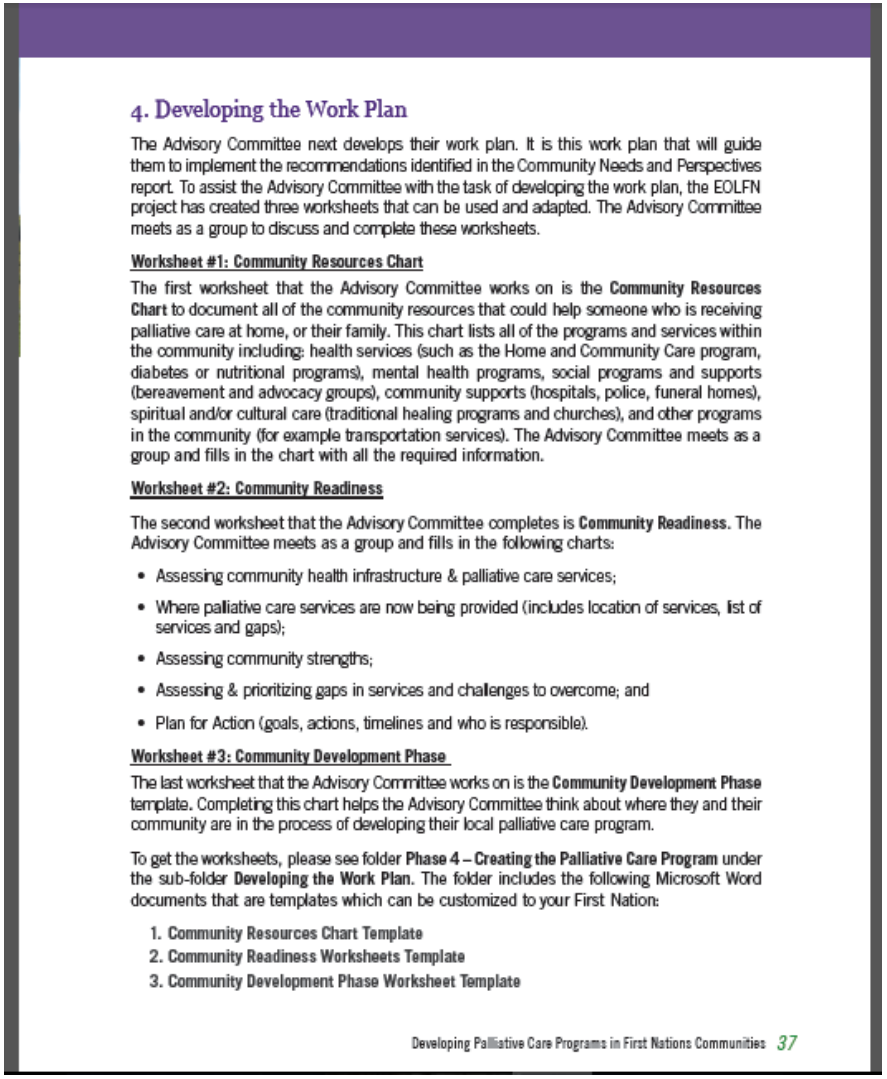
Creating PC Program

PHASE 4: Creating the Palliative Care Program

In developing a palliative care program in First Nations communities, the fourth phase of the process is called **Creating the Palliative Care Program**. In this phase, community members begin to formalize the process of creating a palliative care program. This phase pulls together all the preparatory work the community has done to get organized and get community members on board with the goal.
This phase comes after, and emerges out of the catalyst phase.
In the previous phase, the Community Lead was identified and the Advisory Committee was put in place. In this phase, the Community Lead and Advisory Committee turn their attention to completing the following seven steps we recommend to create a local palliative care program:

1. **Hire a Community Facilitator**
2. **Create a Timeline**
3. **Understand Community Needs and Perspectives**
4. **Develop the Work Plan**
5. **Form the Leadership Team**
6. **Create Palliative Care Guidelines**
7. **Address Outcomes**

Developing the Workplan



4. Developing the Work Plan

The Advisory Committee next develops their work plan. It is this work plan that will guide them to implement the recommendations identified in the Community Needs and Perspectives report. To assist the Advisory Committee with the task of developing the work plan, the EOLFN project has created three worksheets that can be used and adapted. The Advisory Committee meets as a group to discuss and complete these worksheets.

Worksheet #1: Community Resources Chart

The first worksheet that the Advisory Committee works on is the **Community Resources Chart** to document all of the community resources that could help someone who is receiving palliative care at home, or their family. This chart lists all of the programs and services within the community including: health services (such as the Home and Community Care program, diabetes or nutritional programs), mental health programs, social programs and supports (bereavement and advocacy groups), community supports (hospitals, police, funeral homes), spiritual and/or cultural care (traditional healing programs and churches), and other programs in the community (for example transportation services). The Advisory Committee meets as a group and fills in the chart with all the required information.

Worksheet #2: Community Readiness

The second worksheet that the Advisory Committee completes is **Community Readiness.** The Advisory Committee meets as a group and fills in the following charts:

- Assessing community health infrastructure & palliative care services;
- Where palliative care services are now being provided (includes location of services, list of services and gaps);
- Assessing community strengths;
- Assessing & prioritizing gaps in services and challenges to overcome; and
- Plan for Action (goals, actions, timelines and who is responsible).

Worksheet #3: Community Development Phase

The last worksheet that the Advisory Committee works on is the **Community Development Phase** template. Completing this chart helps the Advisory Committee think about where they and their community are in the process of developing their local palliative care program.

To get the worksheets, please see folder **Phase 4 – Creating the Palliative Care Program** under the sub-folder **Developing the Work Plan.** The folder includes the following Microsoft Word documents that are templates which can be customized to your First Nation:

1. **Community Resources Chart Template**
2. **Community Readiness Worksheets Template**
3. **Community Development Phase Worksheet Template**

Creating Palliative Program Guidelines

6. Creating Palliative Care Program Guidelines

The Leadership Team starts working on the development of **Palliative Care Program Guidelines.** These guidelines describe the palliative care program in detail and how it works in the community.

The Leadership Team creates a working group, referred to as the Clinical Team, of internal and external health care providers. The Clinical Team creates the Care pathway (or Path of Care) and the required consent or treatment documents.

The EOLFN project created a template for a First Nation Palliative Care Program that the Leadership Team can use as a tool to help create local program guidelines. The Palliative Care Program template outlines the following components of a successful palliative care program:

- Mission Statement and Vision
- Specific Services
- Screening and Training of Staff/Volunteers
- Care pathway (or Path of Care)
- Consent or Treatment documents

Mission Statement and Vision

The palliative care program has a mission statement and a vision. The mission is the program's reason for existence, and vision is what it wants to be.

A **mission statement** is a statement of the purpose of the program. The mission statement should guide the actions of the program, clearly outline its overall goal, provide a path, and guide decision-making. It provides the framework or context within which the program's strategies are formulated.

A **vision statement** defines the way a program will look in the future. Vision is a long-term view, sometimes describing how the program would like the world to be in which it operates.

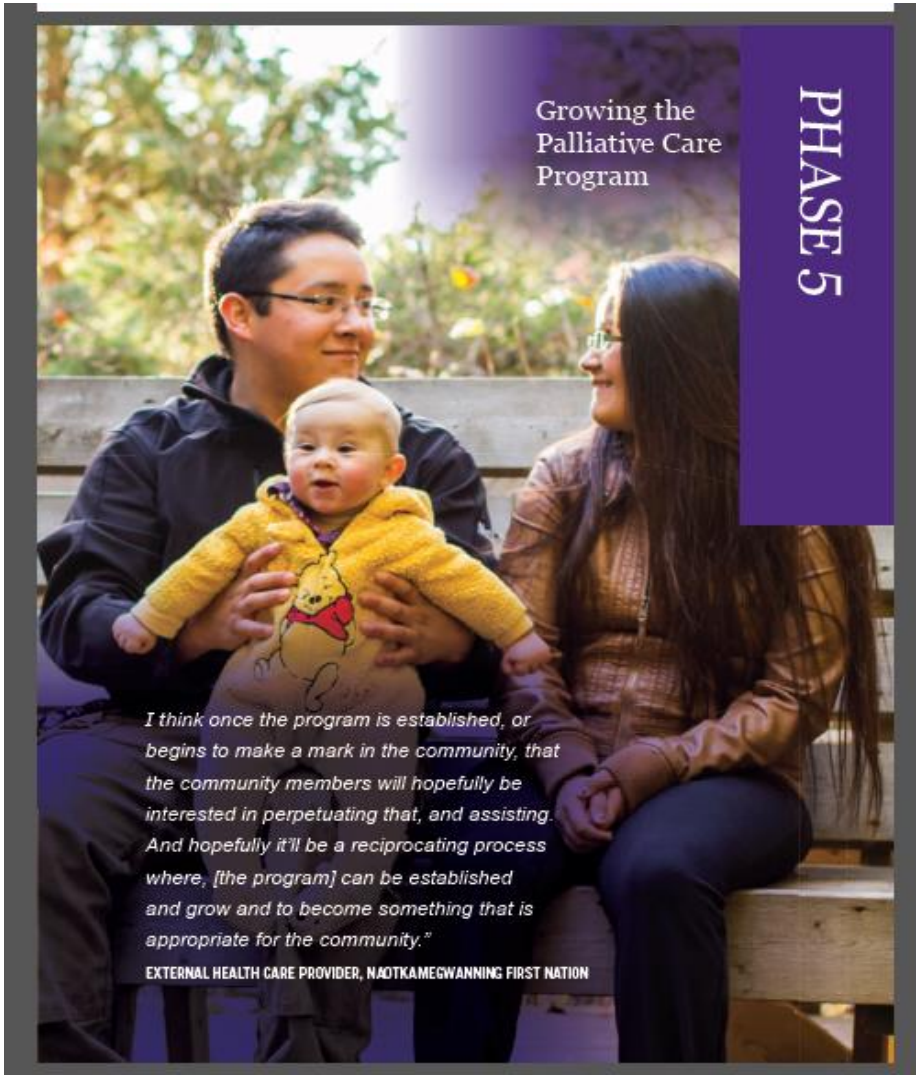
List of Specific Services

The specific services that are offered within the program need to be clearly defined and articulated. This is a **written description of the services**, including: goals, objectives, and relevant policies, procedures, and protocols. It also includes methods to reduce risk and monitor outcomes and eligibility requirements.

"Having a palliative care program allows for that community to bring their loved ones home, to die where they were born...Certainly in an Aboriginal community that is one thing that is key, to be born on the territory and to pass away on the territory. Having a palliative care program helps them to feel comfortable leaving the hospital."

Community Facilitator, Six Nations of the Grand River Territory

Phase 5 – Growing the Program



Growing the Program

PHASE 5: Growing the Palliative Care Program

In developing a Palliative Care Program in First Nations communities, the fifth and final phase of the process is called **Growing the Palliative Care Program.**

The Palliative Care Program was created by the Leadership Team during Phase 4. Now the Leadership Team is ready to extend palliative care out into the community and put the program into practice.

Extending the Palliative Care Program into the community involves working on five strategies that are listed below:

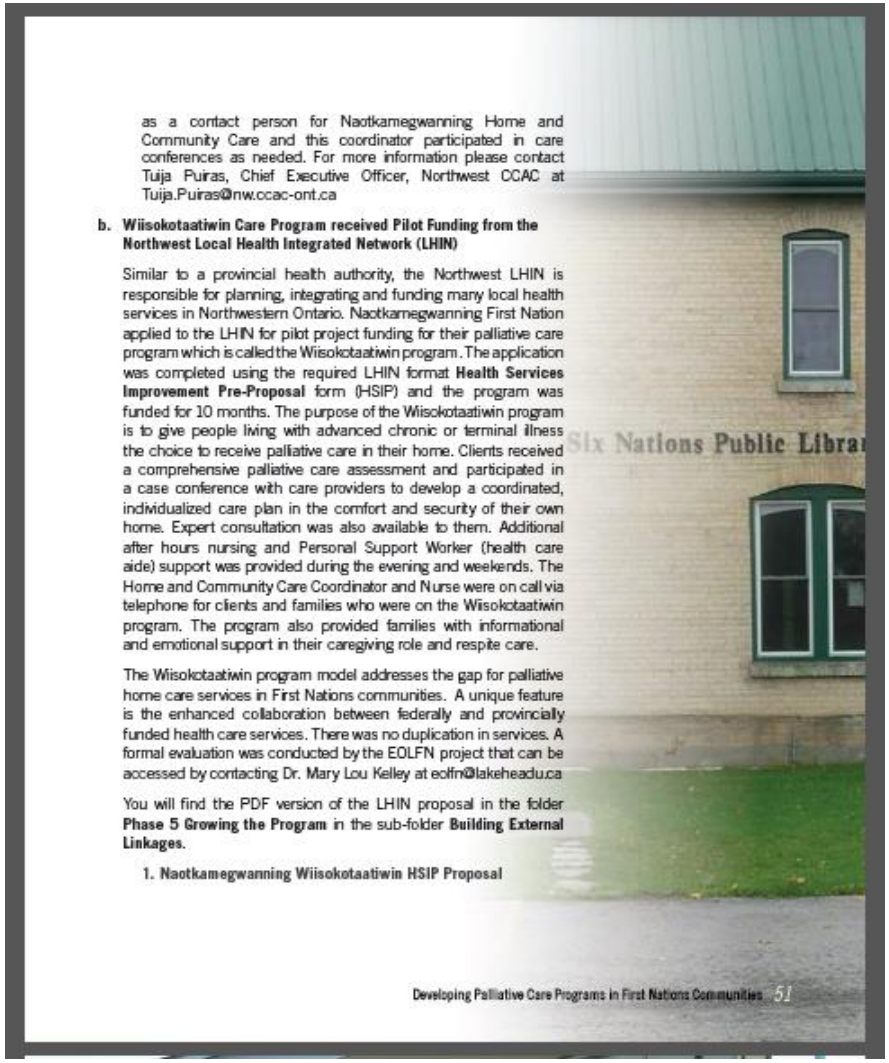
- Strengthening Community Relationships
- Building External Linkages
- Promoting Education
- Providing Care
- Advocating for Individuals and Families

The diagram illustrates that the Growing the Palliative Care Program phase emerges out of the previous phase. The five strategies in the phase are seen among the branches of the tree. All strategies are important and they need to be worked on at the same time.

The major goals in this phase are: strengthening the local resources; engaging the regional health care providers; engaging regional palliative care experts; and sustaining the program by integrating the palliative approach to care into existing community services.

The keys to success in this phase are: remaining community-focused; educating community providers; working together/teamwork; having local leadership; and feeling pride in the community's accomplishments.

Wiisokotaatiwin Program (NFN)



as a contact person for Naotkamegwanning Home and Community Care and this coordinator participated in care conferences as needed. For more information please contact Tuija Puiras, Chief Executive Officer, Northwest CCAC at Tuija.Puiras@nw.ccac-ont.ca

b. Wiisokotaatiwin Care Program received Pilot Funding from the Northwest Local Health Integrated Network (LHIN)

Similar to a provincial health authority, the Northwest LHIN is responsible for planning, integrating and funding many local health services in Northwestern Ontario. Naotkamegwanning First Nation applied to the LHIN for pilot project funding for their palliative care program which is called the Wiisokotaatiwin program. The application was completed using the required LHIN format **Health Services Improvement Pre-Proposal** form (HSIP) and the program was funded for 10 months. The purpose of the Wiisokotaatiwin program is to give people living with advanced chronic or terminal illness the choice to receive palliative care in their home. Clients received a comprehensive palliative care assessment and participated in a case conference with care providers to develop a coordinated, individualized care plan in the comfort and security of their own home. Expert consultation was also available to them. Additional after hours nursing and Personal Support Worker (health care aide) support was provided during the evening and weekends. The Home and Community Care Coordinator and Nurse were on call via telephone for clients and families who were on the Wiisokotaatiwin program. The program also provided families with informational and emotional support in their caregiving role and respite care.

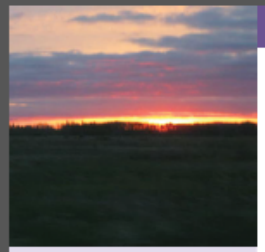
The Wiisokotaatiwin program model addresses the gap for palliative home care services in First Nations communities. A unique feature is the enhanced collaboration between federally and provincially funded health care services. There was no duplication in services. A formal evaluation was conducted by the EOLFN project that can be accessed by contacting Dr. Mary Lou Kelley at eolfn@lakeheadu.ca

You will find the PDF version of the LHIN proposal in the folder **Phase 5 Growing the Program** in the sub-folder **Building External Linkages**.

1. **Naotkamegwanning Wiisokotaatiwin HSIP Proposal**

Six Nations Public Libra

Education for Health Care Providers



"I think when you're dealing with palliative care, I think it's so important that caregivers, health care aides, nursing, get the proper training on compassionate care you know for that individual, it's not a job, it's, giving that care, the best quality care, end-of-life care, it's so important, you know."

Internal Health Care Provider, Peguis First Nation

Education for Health Care Providers

- Palliative Care for Front-Line Workers in First Nations Communities

This workshop is based on the curriculum *Palliative Care for Front-line Workers in First Nations Communities* developed by the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University in partnership with First Nations Communities. The purpose of this curriculum is to provide an introduction to the philosophy and principles of palliative care for front-line care providers in First Nations communities. The education presented in this curriculum is a support to the development of palliative care services in First Nations communities. The curriculum uses the holistic teaching concepts of the medicine wheel combined with the holistic focus of palliative care. The curriculum utilizes a manual called *Caring for the Terminally Ill: Honouring the Choices of the People* to enhance the material covered in this program. This manual can be found on the CERAH website at www.cerah.lakeheadu.ca

Naotkamegwanning First Nation, with permission from CERAH, adapted the curriculum content (Microsoft Power Point slide decks) to be more culturally and community appropriate. These slide decks are included in the workbook as a sample of palliative care education. The curriculum includes the following 7 modules:

Module 1: Creating Context

Module 2: Working with Families

Module 3: Pain and Symptom Management

Module 4: When the Time is Near

Module 5: Grief and Bereavement

Module 6: Helping Relationships

Module 7: Community Care Teams

You will find the editable Microsoft Power Point templates for *Palliative Care for Front Line Workers in First Nations Communities* in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education, section 1 – Palliative Care for Front Line Workers in First Nations Communities.**

1. **PCFN Module 1 Creating Context Template**
2. **PCFN Module 2 Working With Families Template**
3. **PCFN Module 3 Pain and Symptom Management Template**
4. **PCFN Module 4 When the Time is Near Template**

Community & Family Education

"I think family involvement is a big thing, I think family involvement means anything from how to toilet someone, how to change a depends, to what to cook, if it has to be pureed, how to give out medications, you know, if someone in lots of lots of pain at two in the morning, well odds are there's not gonna be a staff member available. I mean unless there is someone on call. But family it kind of all falls on family, in a community like this..."

Community Member, Naotkamegwanning First Nation

You will find the EOLFN PDF example facilitator guide and power point presentation for the Grief and Loss workshop in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education, section 2 – Finding our Way Through: Navigating Loss and Grief in First Nation Life.**

1. **Grief and Loss Facilitator Manual**
2. **EOLFN Grief and Loss Power Point**

Education for Family and Community Members

Education for family and community members is important to increase understanding and acceptance of the palliative care program. Tools and resources that were developed and used in the First Nation communities are described below:

- Palliative Care in First Nations Communities Brochures

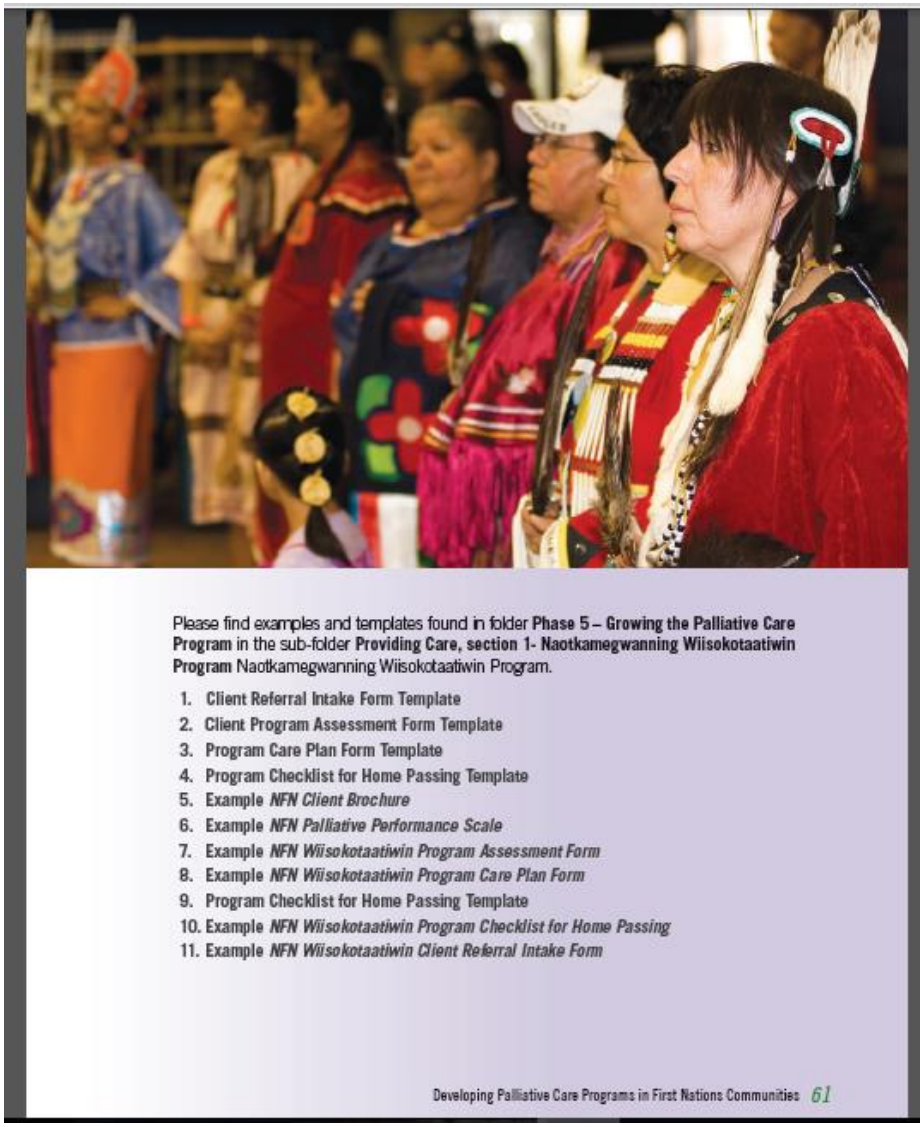
Six brochures were developed in collaboration with First Nations community members. They use clear and simple language for the general public.

- *What is Palliative Care*
- *Living with a Terminal Illness*
- *Caring for Someone with a Terminal Illness: Care for the Caregiver*
- *Caring for Someone with a Terminal Illness: What to Expect*
- *Supporting the Caregiver and the Family*

You will find the EOLFN PDF brochures series Palliative Care in First Nations Communities along with the Microsoft Word templates of the text in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education, section 3-Palliative Care in First Nations Community Brochures.**

1. **What is Palliative Care Template**
2. **Example EOLFN *What is Palliative Care***
3. **Living with a Terminal Illness Template**
4. **Example EOLFN *Living with a Terminal Illness***
5. **Caring for Someone with a Terminal Illness Care for the Caregiver Template**
6. **Example EOLFN *Caring for Someone with a Terminal Illness Care for the Caregiver***
7. **Caring for Someone with a Terminal Illness What to Expect Template**

Program Forms – Examples & Tools



Please find examples and templates found in folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Providing Care, section 1- Naotkamegwanning Wiisokotaatiwin Program** Naotkamegwanning Wiisokotaatiwin Program.

1. **Client Referral Intake Form Template**
2. **Client Program Assessment Form Template**
3. **Program Care Plan Form Template**
4. **Program Checklist for Home Passing Template**
5. **Example *NFN Client Brochure***
6. **Example *NFN Palliative Performance Scale***
7. **Example *NFN Wiisokotaatiwin Program Assessment Form***
8. **Example *NFN Wiisokotaatiwin Program Care Plan Form***
9. **Program Checklist for Home Passing Template**
10. **Example *NFN Wiisokotaatiwin Program Checklist for Home Passing***
11. **Example *NFN Wiisokotaatiwin Client Referral Intake Form***

Shared Care Outreach Team (SNGRT)

Shared Care Palliative Outreach Team in partnership with Stedman Hospice and HNHB LHIN

Shared care teams are a group of health care providers who work together to provide unified, multi-disciplinary, quality palliative care to patients in their homes. The teams are available 24/7 and usually include a palliative care physician, nurse, and social worker. The main goals of the shared care team are to provide education, symptom management, and organize care and support services for patients.

The Six Nations of the Grand River Territory Shared Care Palliative Outreach Team was developed by the Advisory Committee and Leadership Team with support from the regional health care providers. It included an Aboriginal physician, Clinical Nurse Specialist, and Psychosocial/Spiritual/Bereavement Counsellor who provided care to people living in the community. The team was funded by the provincial health system and worked as part of the Regional Palliative Care Program that was based at Stedman Hospice. (See Building External Linkages for related information about the MOU)

Community members of Six Nations of the Grand River Territory have benefited greatly from the Shared Care Palliative Outreach team. These benefits include:

- A detailed care pathway for clients who need palliative care.
- Care is provided in client's homes by a team that includes a First Nation physician, nurse and psychosocial/spiritual/bereavement counsellor who are community members.
- There are more home deaths, as compared to hospital or hospice deaths.
- There is improved access to palliative care education and mentorship for local health care providers.
- Haudenosaunee Philosophy is incorporated in supporting clients and staff around death, dying, grief and loss.

For more information, please contact Lori Monture, Manager of Six Nations Long-term Care/Home and Community Care, Six Nations Health Services at lmonture@sixnations.ca.

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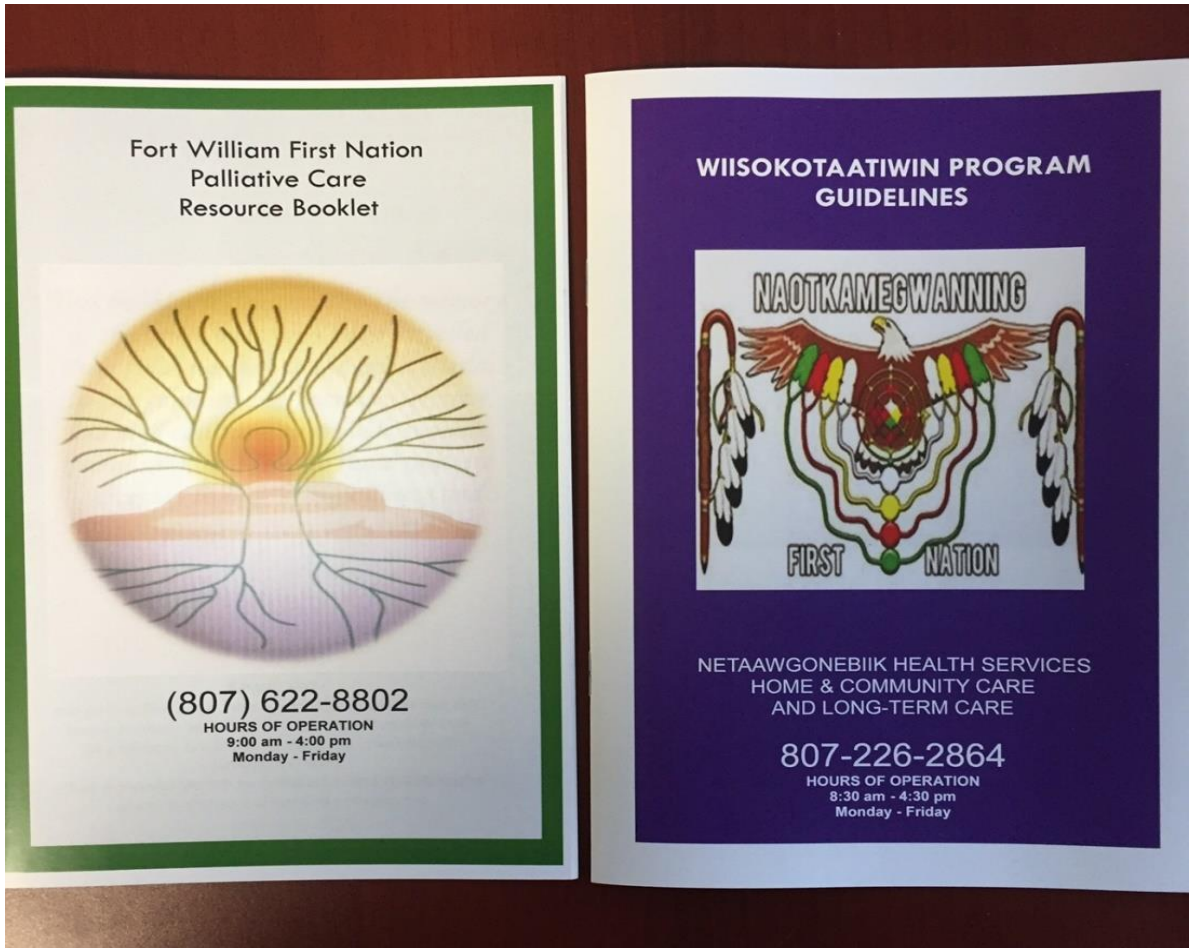
Tools & Resources

First Nations Palliative Care Brochures

Palliative Care Program Guideline Booklets



First Nations Advanced Care Planning Resources

Acknowledgements

Fort William First Nation

Peguis First Nation

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