# Developing Palliative Care Programs in First Nations Communities:
A WORKBOOK

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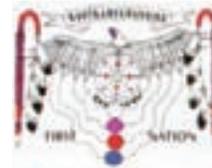
All First Nations communities are free to copy and share any part of this Workbook and use the tools and resource materials that accompany the Workbook in any way that is helpful to them.

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 *Improving 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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GLOSSARY

Care Pathway: In this workbook, care pathway, or path of care, refers to a diagram or map that outlines the expected care for clients who would benefit by receiving palliative care, including the appropriate timeframes for different phases of palliative care. The care pathway is created by a group of involved care providers during a series of journey mapping workshops in order to become a resource that will guide care for individuals progressing through their care and treatment. The care pathway focuses on providing clients the best palliative care and most positive outcomes as they move between different health care providers and organizations. See developing the care pathway using journey mapping as discussed in Phase 5 of the workbook.

Case Conference: In this workbook, case conference refers to a meeting at which all parties involved in a client's care meet to discuss and create an individualized care plan for a client and family. Ideally, the client and family will be present at the care conference. The care pathway (above) is used as a resource for this case conference that results in an individual care plan for a client. The case conference and care plan is discussed in Phase 5 of the workbook.

Catalyst: In this workbook, a catalyst refers to someone or something that stimulates and mobilizes change within the First Nation community. It can be a person, such as a passionate local leader, or a community event, such as a community member dying in hospital when they wanted to die at home. The community catalyst causes community members to begin to work together to achieve a shared vision for developing a palliative care program and brings the idea for the program into concrete action. The catalyst cannot come from outside the community, however, outside people and events can be important to support and facilitate local work. The catalyst is discussed in Phase 3 of the workbook.

Collaboration: In this workbook, collaboration refers to people working together in order to achieve or do something that cannot be done by any one person or organization alone. In the First Nations community, developing the local palliative care program requires collaboration amongst the Band Council and many community programs such as Home and Community Care, mental health, transportation, housing, community health, Elders' programs and other support services such as meals on wheels. Collaboration is discussed throughout the workbook.

Community Capacity: In this workbook, community capacity refers to all of the assets and strengths that exist in a First Nations community that can be mobilized and applied to developing the local palliative care program. Community capacity includes things such as knowledge, skills, attitudes, motivation, leadership, and relationships amongst the people. It also includes the existing programs, resources, and infrastructure (such as roads, housing and water) within the community. Building on their existing capacity is the starting point for each community to create and sustain their new palliative care program. Community capacity influences readiness to move ahead. Where significant gaps in community capacity exist, communities may need to address these gaps prior to beginning to create their local palliative care program. Community capacity is discussed throughout the workbook and is the main concept in the tree model used in every phase.

Community Capacity Development: In this workbook, capacity development is the process of growth and change that occurs inside the First Nation's community as members work together towards their goal of creating the local palliative care program. Development builds on the existing community capacity (defined above) and follows the four stage process that is depicted in the *Process of Palliative Care Program Development* diagram (tree diagram) in the workbook. Capacity development is ongoing (never ends) and each phase builds on the work

of the earlier phases. However, progress is not always linear. Events internal and external to the community can facilitate or become barriers to progress. Barriers must be overcome along the way and communities may find themselves moving forward and backward in their capacity development journey. Despite this, our research has shown that sustained community efforts will move development ahead over time. It does take a number of years to develop a sustainable palliative care program. Community capacity development is discussed throughout the workbook and is the main concept in the tree model used in every phase.

Cultural Competency: In this workbook, cultural competency refers to a person's ability to understand, appreciate, and interact respectfully with Indigenous peoples and their cultural teachings and traditions. Creating workshops as a strategy to promote the cultural competency of external health care providers is described in Phase 5 of the workbook.

End-of-Life Care: In this workbook, end-of-life care refers to care for people and their families when a person is imminently dying. End-of-Life care involves providing social and spiritual support as well as care measures to promote comfort, dignity and prevent suffering. It is the last hours, days, or weeks of life, which is depicted at the lower right section of the diagram *An Integrated Palliative Approach to Care* that can be found in the Introduction of the workbook.

External Health Care Provider: In this workbook, external health care provider refers to a person of any discipline (doctor, nurse, physiotherapist etc.) that provides health services in the community but who lives outside the community. For example, external health care providers work for a hospital or home care agency and may not be culturally competent (see above) in the First Nation's traditions and values. The role of external health care providers is discussed in Phase 4 of the workbook.

Frailty: In this workbook, frailty refers to a clinical syndrome commonly found in older adults and describes a range of conditions including general weakness and cognitive impairment. Frailty carries an increased risk for poor health outcomes including falls, incident disability, hospitalization, and mortality. Frailty is often associated with Alzheimer's disease and dementia. Older people with frailty can benefit from a palliative approach to care as discussed throughout this workbook.

Grief & Bereavement Care: In this workbook, grief and bereavement care refers to care and support for people dealing with the loss of a loved one. Grief and bereavement care is often provided by social workers, mental health workers, nurses, cultural Knowledge Carriers, priests or pastors, or Elders. Strategies to provide grief and bereavement care are provided in Phase 5 of the workbook.

Internal Health Care Provider: In this workbook, internal health care providers refers to health care providers of any discipline who provide health care services to member of the First Nations community and also live in the community. Leadership and involvement by the internal health care providers is key to the development of local palliative care programs and this is discussed throughout the workbook.

Journey Mapping: In this workbook, journey mapping refers to a process to improve the coordination and integration of care for clients as they access services from multiple programs and health care providers. It is done using a workshop format that brings together internal and external health care providers, Elders, and community leadership. It involves in-depth discussion of how First Nation community members transition through the health care system as they approach end of life, and identifies obstacles and solutions to improve service integration. Journey mapping is a useful tool to help create the Care Pathway that is an important component of the Palliative Care Program guidelines. Resources to guide communities in journey mapping are included in Phase 5 of the workbook.

Life-Limiting Illness: In this workbook, life-limiting illness refers to any medical condition, caused by injury or disease that cannot be cured – a condition that one would be expected to die from eventually. It includes any progressive illness including cancer, chronic diseases such as diabetes, heart or renal disease, frailty, and dementia. People can live with a life-limiting illness for many years and benefit by a palliative approach to care along with treatment of their illness or disease. Access to palliative care is especially important in the last year of life as discussed throughout the workbook and depicted in the diagram *An Integrated Palliative Approach to Care* in the Introduction to the workbook.

Pain & Symptom Management: In this workbook, pain and symptom management refers to providing medical care that alleviates or reduces pain and other common symptoms experienced by people with advanced chronic or terminal illness. Strategies for pain and symptom management are offered in Phase 5 of the workbook.

Palliative Care: In this workbook, palliative care refers to an approach that improves the quality of life of patients and their families facing the problem associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. It begins when a person has been identified as having a progressive, life-limiting or terminal disease that cannot be cured and is particularly important in the last year of life. The disease can be cancer, diabetes, heart disease, liver disease, dementia, frailty, or any disease. It includes medical, psychosocial, and spiritual care of the person and family. Receiving palliative care does not mean the person is dying or that people are giving up treatment. Rather, people continue to get treatment of their disease for purposes of disease management, comfort, and quality of life.

Conversations about the person's future wishes for their end-of-life care are important. The diagram *An Integrated Palliative Approach to Care* depicts the way that the palliative approach combines therapy to treat disease and therapy to relieve suffering and improve quality of life. This diagram is found in the Introduction to the workbook.

Primary Care Provider: In this workbook, primary care provider refers to a health care practitioner who sees people that have common medical problems. This person is usually a doctor, but may be a physician assistant, a nurse practitioner, or a nurse. While they are not specialists in palliative care, they care for people in the last year of life that would benefit by receiving a palliative approach to care. Many are people with a chronic disease. Primary care providers may ask palliative care specialists for a consultation or make referrals to palliative care specialists if required. Primary care providers are key participants in providing palliative care especially in the home and community setting. This is discussed throughout the workbook.

Psychosocial & Spiritual Care: In this workbook, psychosocial and spiritual care refers to emotional and spiritual care for individuals dealing with a life-limiting illness and their families. It includes support for grief, loss and bereavement. It is commonly provided by social workers, mental health workers, nurses, cultural knowledge keepers, priests or pastors or elders. Strategies for providing psychosocial and spiritual care are provided in Phase 5 of the workbook.
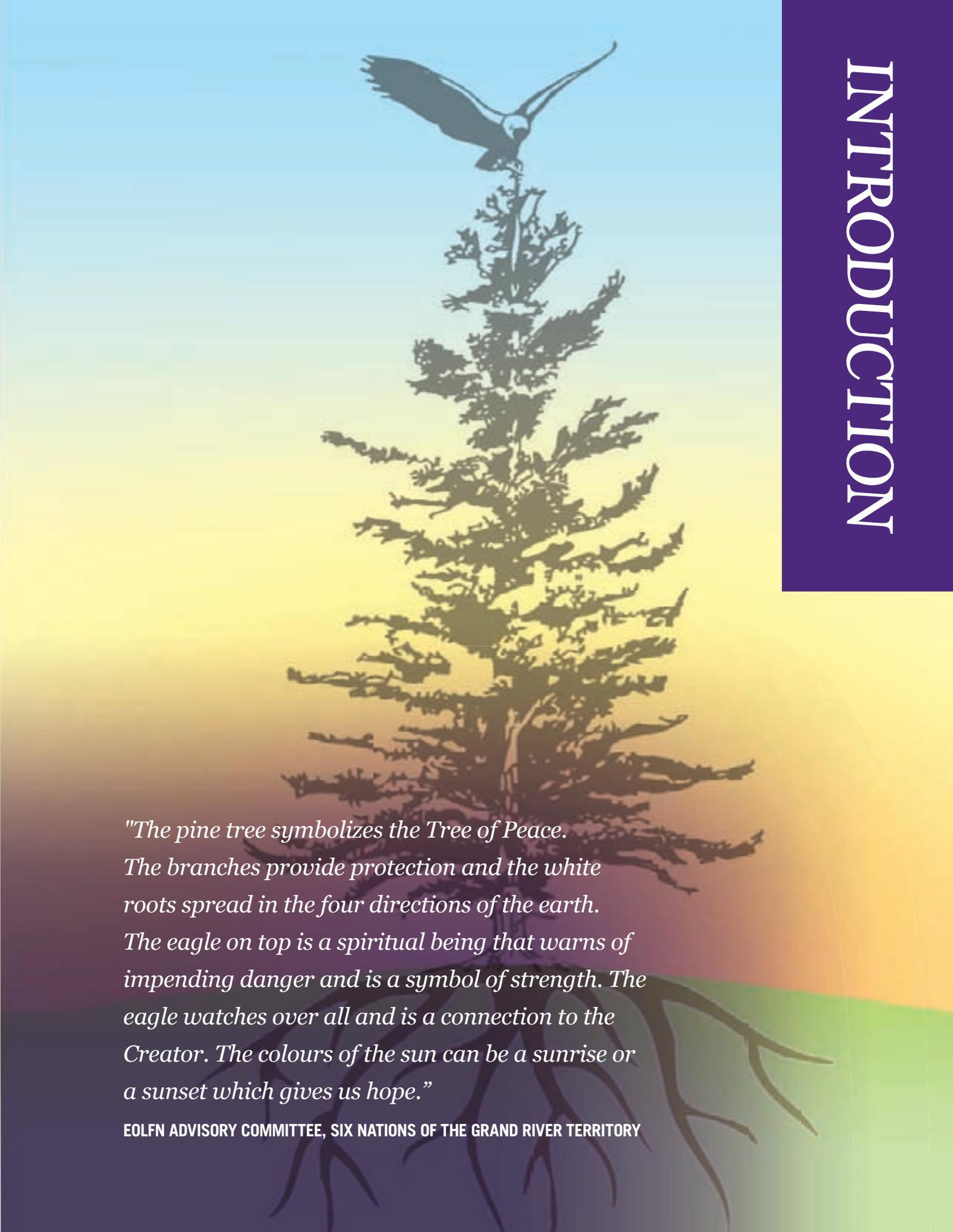
"The pine tree symbolizes the Tree of Peace. The branches provide protection and the white roots spread in the four directions of the earth. The eagle on top is a spiritual being that warns of impending danger and is a symbol of strength. The eagle watches over all and is a connection to the Creator. The colours of the sun can be a sunrise or a sunset which gives us hope."

EOLFN ADVISORY COMMITTEE, SIX NATIONS OF THE GRAND RIVER TERRITORY

Introduction

The First Nations population is aging and the burden of chronic and terminal disease is increasing. The home and community care needs of Elders and chronically ill community members have significantly increased in the last ten years. Our research project, *"Improving End-of-Life Care in First Nations Communities"* (EOLFN), was funded by the Canadian Institutes of Health Research and conducted in partnership with four First Nations communities in Ontario and Manitoba. The communities wanted to learn how they could provide better care for this population at home until the end of their lives. This workbook shares their experience and learnings for the benefit of other First Nations communities.

Our findings indicated that if services were available and adequate, the majority of First Nations people would prefer to receive their palliative and end-of-life care at home in familiar settings, where they are surrounded by family, friends, and culture. However, most First Nations people currently die in distant regional and urban hospitals and long-term care homes. First Nations communities lack the health services and other supportive community resources to meet the growing demand for home care services for people with complex and high intensity care needs, in particular the elderly, frail, and people at the end-of-life.

Our research developed a community-focused approach to addressing these gaps at the local level. The goal was to improve the end-of-life care in the four First Nations communities by developing community-based palliative care programs and teams; as well as to create a *Workbook* of research informed strategies for developing palliative care programs in other First Nations communities. The *Workbook* offers a resource that can guide other First Nations communities who choose to undertake similar work.

Building on and reclaiming their historical and cultural traditions of family and community caregiving, the four First Nations communities involved in our research have demonstrated

that they can mobilize their own capacity to provide palliative and end-of-life care. First Nations communities are willing and able to support community members and their families to receive a palliative approach to care and to die at home if that is their choice.

However, to be successful, communities needed strong, dedicated local leadership and a facilitator from within the community. This facilitator helped the community leaders to organize and mobilize local community capacity and create new collaborations with palliative care experts and services in their provincial health care system.

The communities also required enhanced resources such as home care services and intensive case management for clients with complex care needs, including timely access to equipment and medication when life expectancy is short. The First Nations communities in the project advocated for additional resources from federal and provincial health funders based on their local needs assessment findings and community action.

What is in the Workbook?

This workbook is a major outcome of the EOLFN project and is intended for use by First Nations communities. It was developed by the research team that included the four First Nations community partners and is intended as a guide and a resource for other communities.

This workbook provides an outline for creating local palliative care programs in First Nations communities. The hope is that this workbook will

support other First Nations communities interested in developing a palliative care program. It offers a process for community development and change, practical guides, ideas, and lessons learned.

During the five year project, each community developed their own local palliative care program. In doing so, they created many resources and tools for use by internal and external health care providers and community members. Overall, the workbook offers an approach to assess palliative care capacity in a community and, based on what already exists, to develop or enhance the programs and resources to better support people to live at home until the end of their lives.

The research team documented the community development process that the four communities went through while creating their palliative care program, and used this information to create an outline of the steps required. All of these resources and learnings are shared in this workbook for use by all First Nations communities across Canada to develop similar programs.

First Nations communities are free to copy and share any part of this workbook and use these materials in any way that is helpful to them. The tools and resources can be found on the USB flash drive that accompanies the workbook, or they can be downloaded from the EOLFN website. The resources may be adapted and combined with other resources to better fit the needs of a community. We only ask that you acknowledge the workbook and EOLFN project as a resource where you use it.

For more information about this workbook, the EOLFN resources or overall research please visit our project website at www.eolfn.lakeheadu.ca or contact us by email at eolfn@lakeheadu.ca

Palliative Care In First Nations Communities

Our project has demonstrated that First Nations communities can develop unique, culturally appropriate, community-based palliative care programs through undertaking local capacity development efforts, creating new partnerships with regional health services, and coordinating existing First Nations' community health and social support programs. This section describes the philosophy and approach used in the EOLFN project and our thinking about palliative care.

The Palliative Approach to Care

There has been a shift in thinking about palliative care over the last ten years. In the past, it was only viewed as a specialty team or program that occurred in a hospital or hospice. Palliative care was only offered in the last few days or weeks of life, and usually only to cancer patients. Many people have not had access to this care, especially those living in First Nations communities.

Today, national groups such as the Canadian Hospice Palliative Care Association and the Canadian Medical Association think of palliative care more as a philosophy and an approach to care. It can benefit people with any progressive and life limiting illness, not only cancer. Experts now think the palliative approach to care should be integrated into all settings where people receive their health care. Further, the palliative approach should be offered by all health care providers who provide primary care, including doctors, nurses, social workers, therapists, and personal support workers. These primary care providers are accessible and know their patients the best. However, primary care providers need support from palliative care experts, if required, especially for complex pain and symptom management.

The EOLFN project team adopted the Canadian Hospice Palliative Care Association model of care and the palliative approach to care. The EOLFN team thinks of the palliative approach to care as benefiting people of all ages who are living with any progressive chronic or terminal illness, including frailty. This would include people with diabetes, heart disease, stroke, respiratory or Alzheimer's disease, and cancer. Care extends throughout the entire last year of life and can be offered anywhere that there are primary care services.

Thus, people living in First Nations communities would benefit by having access to a palliative approach to care at home in the last year of their lives. It can be integrated into their existing Home and Community Care program and provided by the primary care providers who work in the community. These health care providers need to be supported by partnerships with external services and health care experts. This thinking is embedded throughout this workbook.
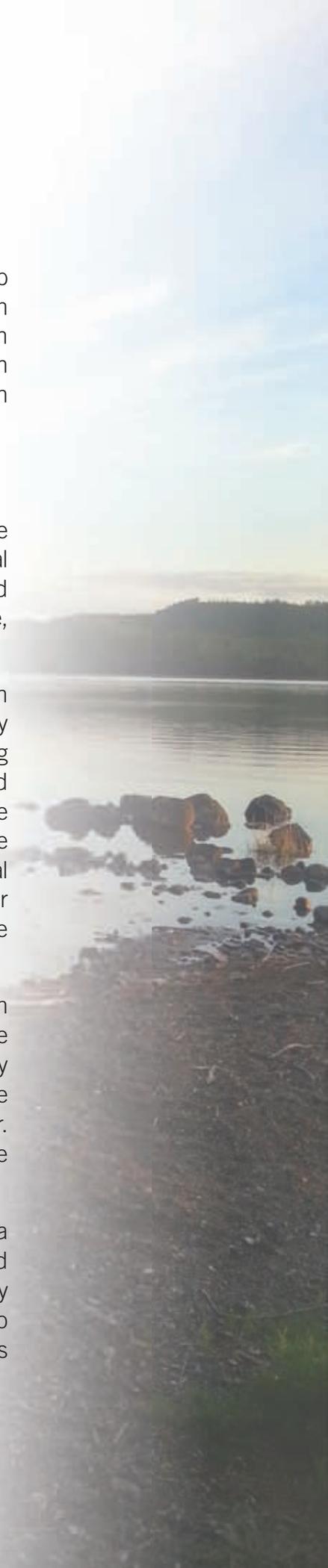
Integrating The Palliative Approach To Care With Chronic Disease Management

The palliative approach to care can be integrated with care that focuses on therapy to modify disease. According to the Canadian Hospice Palliative Care Association, an integrated palliative approach to care:

> "focuses on meeting a person and family's full range of needs-- physical, psychosocial and spiritual--at all stages of frailty or chronic disease, not just at the end of life. It sees hospice palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of a simultaneous or integrated approach to care that can enhance their quality of life throughout the course of their illness or the process of aging." [1]

Using the palliative approach, the following describes the components of a person's care plan.

After diagnosis and in the early stages of the illness, the palliative approach would focus primarily on:

- Open and sensitive communication about the person's prognosis and illness trajectory, including any changes he or she may have to make in their lives, such as limiting certain activities;

- Advance care planning, including discussing the range of treatments available and setting the person's goals of care;

- Psychosocial and spiritual support to help individuals and families struggling with any issues related to the illness; and

- Provide any pain or symptom management that may be required.

In later stages of the illness, a palliative approach would focus on:

- Reviewing the person's goals of care and adjusting care strategies to reflect any changes in those goals;

- Ongoing psychosocial support for individuals and families;

- Ongoing pain and symptom management; and

- Discussions of if and when there is a need to engage specialized palliative care providers (e.g., for people and families with challenging physical, psychosocial or spiritual symptoms, conflicts over goals of care or decision making, family distress).

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[1] Canadian Hospice Palliative Care Association, The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care, The Way Forward Initiative, March 2015, page 2. www.hpcintegration.ca

The following diagram 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

FOCUS OF CARE

Therapy to Treat Disease

Palliative Approach

(therapy to relieve suffering and/or improve qualty of life)

Grief and Bereavement Care

TIME

Advanced Disease / Life Threatening

Presentation/diagnosis with a progressive life limiting or chronic/ terminal disease

Transition to palliative approach to care

End of Life

Patient Death

Bereavement
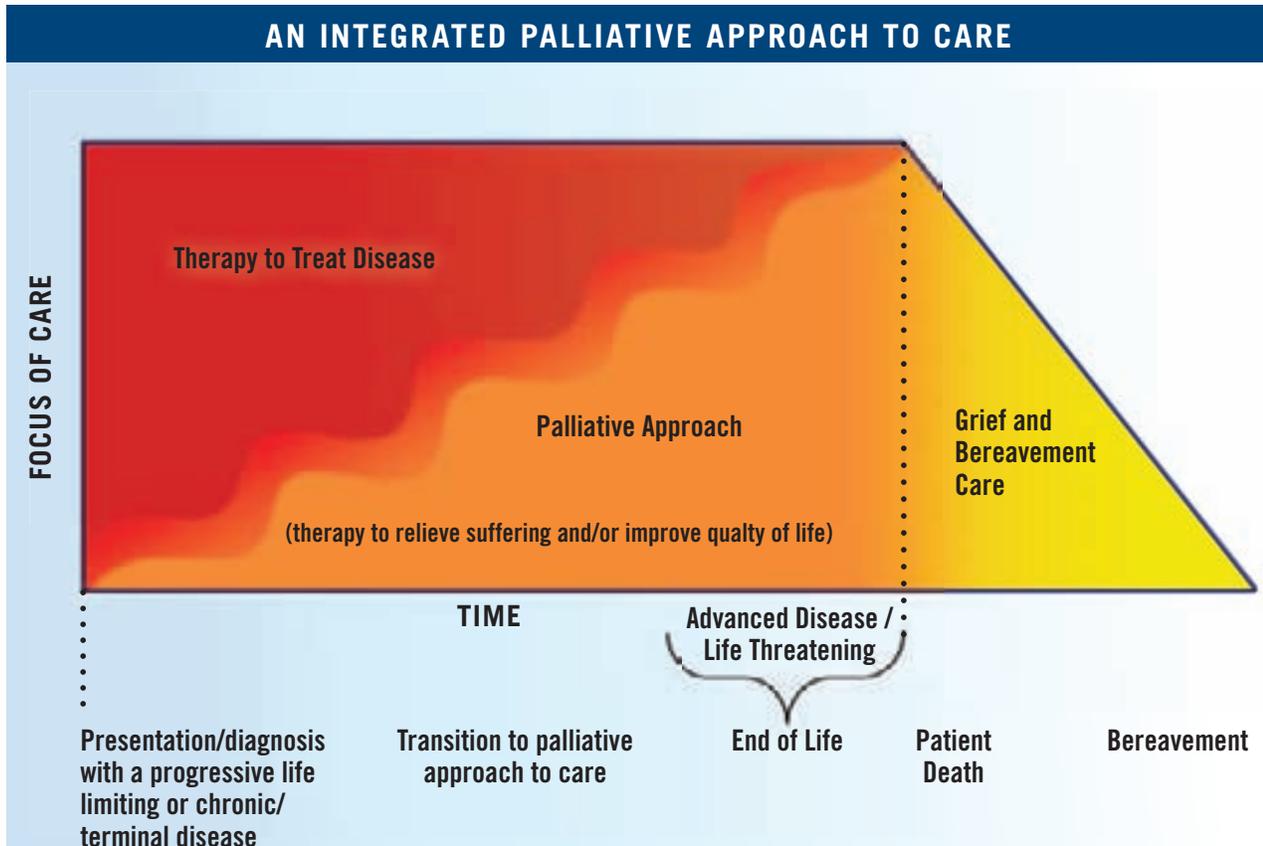
An Integrated Palliative Approach to Care for First Nations Communities

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.

Care in the end-of-life phase (the last days and hours of life) is facilitated when the palliative approach begins earlier rather than later in the illness. People may live longer and have better quality of life when they receive palliative care early. That is because health care providers, patients, and families are better prepared and supported.

First Nations communities would benefit by implementing a palliative approach in home care at all stages of frailty or chronic illness, including but not limited to the end-of-life.

The Process of Developing Palliative Care Programs in First Nations Communities: An Overview

The project's overall approach to palliative care program development in each community is described below. The process is illustrated using the diagram of a growing tree and outlines several phases of growing community capacity. This diagram can be used to guide palliative care program development in any community since the process guides communities to adapt and customize the program to their unique needs at each phase of program development. This process is about building on local capacity, the strengths that already exist in individuals, organizations, and health services.

The *Process of Palliative Care Program Development in First Nations Communities* diagram is based on earlier research (2000-2005) by Dr. Mary Lou Kelley to describe how local palliative care programs developed in rural and remote communities. Throughout the research with the First Nations communities, the learnings from this earlier research were built upon and adapted to the unique First Nations community context.

The overarching keys to success in community capacity development are local collaboration and teamwork, and customizing the palliative approach to the unique community. Other keys to success are educating front line care providers, having strong local leadership, and feeling pride in supporting people at home. The principles of local control and community empowerment are fundamental to success.

The EOLFN project created the *Process of Palliative Care Program Development* (also known as the tree diagram), on the experience of the four First Nations communities. The diagram uses the metaphor of

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

Collaboration

Health Services

Empowerment

Vision for change

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

a growing tree to represent developing a local palliative care program from the bottom up. The pine tree symbolizes the **Tree of Peace.** The branches provide protection and the white roots spread in the four directions of the earth. The eagle on top is a spiritual being that warns of impending danger and is a symbol of strength. The eagle watches over all and is a connection to the creator. The colours of the sun can be a sunrise or a sunset which gives us hope.

The tree diagram outlines **five phases** of developing a palliative care program in a First Nation community. Beginning at the bottom, each phase needs to build on the phase below; however, work in each phase is continuous and ongoing. The rate of progress varies. Communities can move forward or backward in the phases depending on unique circumstances within each community. For example, if local leadership changes or there is a crisis such as a flood, the progress of program development may be affected.

Palliative care program development is ongoing and takes time [months to years]. The palliative care program ultimately becomes part of existing programs, such as Home and Community Care, and is not a separate specialty program. While developing the palliative care program may be led by the health care providers, to be accepted and sustainable it needs to involve the whole community such as Elders, families, and volunteers.

The diagram, *Process of Palliative Care Program Development in First Nations Communities*, and the related explanation are based on the findings and promising practices developed in the EOLFN project across all the community study sites.

Phase 1: Grounding the Program in Community Values and Principles

In the diagram, the palliative care program has its roots in **individual, family, community and culture**. This phase is the foundation for developing a local palliative care program. It recognizes that each community has a unique philosophy, values, and beliefs based on their Indigenous understandings of health, illness, birth, and death, and these beliefs will differ across communities and linguistic groups. The local palliative care program can accommodate these differences. The keys to successful development in this phase include working in a small and clearly defined community, working together, and being community-focused.

Phase 2: Having Community Readiness

In the diagram, six characteristics influence community readiness to develop local palliative care programs. Together, the characteristics form the roots for palliative care program development and must be strong enough to provide a foundation for a local program. Examples of each characteristic are provided, however it is understood that not every community will have every example. When they want to create their palliative care program, the community members will need to make an overall assessment of their own readiness based on their unique characteristics. These are the required characteristics:

- Having enough **community infrastructure** (e.g. housing, clean water, transportation, good communication technology).

- Having enough local **health services** and health care providers (e.g. health centre, Elders centre, doctors, nurses, home and community care program).

- Having health care providers who are committed to **collaboration** and able to work well together to meet new and important community needs.

- Having a **vision for change** to provide better home care for people who are seriously ill and/or elderly
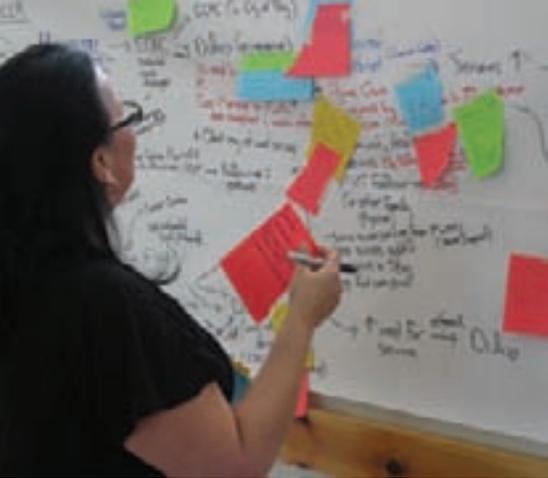
so that they can receive care in the community to the end of their lives.

- Having a sense of community **empowerment** to take action and responsibility to solve local problems.
- Having strong **local leadership** to initiate and guide the community development process.

Phase 3: Experiencing a Catalyst

Experiencing a catalyst begins the process of community change that will create the palliative care program. Change is initiated in the community by a person (a local leader) or local event (such as a person dying in pain or having to go to the hospital when they really wanted to die at home). The catalyst takes the community vision and moves it from being an idea or wish, to being a commitment to create and formalize a new palliative care program.

While events external to the community, such as new funding, policy or education, can create an opportunity and help facilitate developing a palliative care program, events outside the community cannot by themselves be catalysts. External events can only be real catalysts when they are combined with the local leadership and commitment. The local conditions of community readiness are essential.

In our research, the catalyst was a local health care provider who was passionate about improving palliative care. She engaged other community members to form an Advisory Committee to guide the remainder of the community development process. Forming an Advisory Committee demonstrates the community's commitment to change.

Phase 4: Creating the Palliative Care Program

The palliative care program is created by a local Advisory Committee, with the support of a community facilitator wherever possible. The Advisory Committee is composed of the right people in the community to begin the process of change, for example health care providers, leadership, and Elders. The Advisory Committee begins by conducting a community needs assessment. Based on the recommendations from this needs assessment, a work plan is developed that includes forming a Leadership Team of health care providers and local leaders. This Leadership Team is comprised

of the members of the Advisory Committee along with others who are dedicated and committed to forming the palliative care program. Each community needs to choose dedicated people and ensure that the **right people** are involved, that is, people who are respected and have influence in getting things done within the community.

The Leadership Team then becomes responsible for the planning, education, and evaluation related to the palliative care program. This team guides the work of growing the palliative care program. This work includes developing detailed program guidelines and program pamphlets for community members. These program guidelines continue to evolve throughout phase 5 on the diagram, the phase of growing the program.

Keys to success in this phase include working together (strong relationships, communication, support), dedication, and physician/nurse practitioner support and involvement. The team creatively builds on local strengths in the community and identifies who can support their efforts, which is part of the capacity development process. The team can ensure that the program is developed in accordance with cultural values and beliefs and customize it for the specifics of the local community.

Phase 5: Growing the Palliative Care Program

The Leadership Team is now ready to extend into the community and begin to grow the program. The major focus in growing the program includes strengthening the local resources, engaging the regional health care providers, engaging regional palliative care experts, and sustaining the new palliative approach to care by integrating it into existing services. The keys to success for growing the program are: remaining community focused; educating community providers; working together/teamwork; having strong local leadership; and feeling pride in their accomplishments. The five components of Growing the Palliative Care Program can be seen amongst the tree branches on the diagram. Each component, with the related activities, are described next.

Strengthening community relationships

- Identifying all of the people that currently work in the community that could contribute to the palliative care program and engaging them to work together to improve service delivery (e.g. Elder's workers, Home and Community Care, mental health workers, community health providers, cultural and spiritual care providers, Elders and Knowledge Carriers, members of leadership, and volunteers).

- Increasing public awareness of the meaning of the palliative care, of the services offered, and how to access them.

Building external linkages

- Creating linkages with palliative care experts and external health care resources outside of the community in order to support the local health care providers in delivering palliative home care. This includes: hospitals, hospices/hospice units, regional home care programs, cancer centres, telemedicine, Aboriginal Health Access Centres, etc.

- Engaging internal and external health care providers to meet together in a journey mapping process. The purpose is to collaboratively develop a palliative care pathway and other protocols for communication and consent in order to enhance continuity of care for clients.

Promoting education

- Offering local health care providers education on the principles and practices of the palliative approach to care. This includes grief and bereavement, care for the caregiver, pain and symptom management, and family support. These providers then mentor and support other local health care providers.

- Offering external health care providers education focused on cultural competency, local community protocol and practices, and about local health care services in the First Nation community.

Providing care

- Local health care providers begin providing the palliative approach to care to community members who wish to receive it. Normally these are clients of the Home and Community Care program who are in the last year of life and are identified as needing a palliative approach.

- Local health care providers begin changing their clinical practice to implement the palliative approach to care.

- Building local health care providers' confidence through supporting one another and sharing their knowledge and skills amongst themselves.

Advocating for individuals and families

- Continually advocating for individuals and families to have access to quality palliative care in the community. This can include managing challenges, getting additional resources, and developing new policies needed to sustain the palliative care program.

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

PHASE 1: Grounding the Program in Community Values and Principles

In developing a palliative care program in First Nations communities, 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;

PROCESS OF PALLIATIVE CARE PROGRAM DEVELOPMENT

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Individual and Families

Promoting Education

Providing Care

5) Growing the Palliative Care Program

Building External Linkages

Strengthening
Community Relationships

4) Creating the Palliative Care Program

3) Experiencing a Catalyst

Community Infrastructure   Empowerment

Collaboration   Vision for change

2) Having Community Readiness

Health Services   Local Leadership

Individual, Family, Community and Culture

1) Grounding the Development in Community Values and Principles

- The program builds on each individual First Nations community's strengths, resources, culture and traditions of informal helping, and providing support for people who are dying and their families;

- The program provides First Nations people the choice to receive palliative care in the setting of their choice, including the choice to receive palliative care at home where they are surrounded by family, community, and culture; and

- The program builds on local community partnerships with regional and provincial/ territorial health care providers.

In addition to recognizing and honouring First Nations community values and principles, the development of this workbook was informed by the vision and goals of *The Way Forward: A National Framework* that provides a Roadmap for An Integrated Approach to Palliative Care in Canada. The *National Framework* was created by the Quality End of Life Care Coalition and the Canadian Hospice Palliative Care Association in 2014. This *Framework* promotes an integrated palliative approach to care for clients, their families, and community caregivers.

> "There is such a great need in the community for end-of-life care, and it brings a community together. Not being able to have that loved one at home because of barriers can really pull a family, not only the family, but the community apart. That's why it's so important to bring them home, where they belong."

Community Member, Peguis First Nation

The *National Framework* also promotes individual autonomy and choice of the setting where people wish to receive palliative care (home, hospital, hospice, long-term care). Providing the palliative approach to care is integrated into the work of primary health care providers who work in the community, such as doctors, nurse practitioners, and nurses. Thus, *The Way Forward*'s vision and goals meet the needs of an aging First Nations population with a high burden of chronic disease and addresses the need for culturally safe care for First Nations people.

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

PHASE 2: Having Community Readiness

In developing a palliative care program in First Nations communities, the second phase of the process is called **Having Community Readiness.** This phase highlights the importance of six characteristics that influence community readiness to develop a local palliative care program. Examples of each characteristic are provided, however it is understood that not every community will have every example.

Each community is unique in its local environment. The palliative care program will need to build on these six characteristics. Members of the First Nation community need to discuss whether or not they have what they need to begin the process of creating their local palliative care program.

Characteristics that influence Having 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.

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

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.

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.

"....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**

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.

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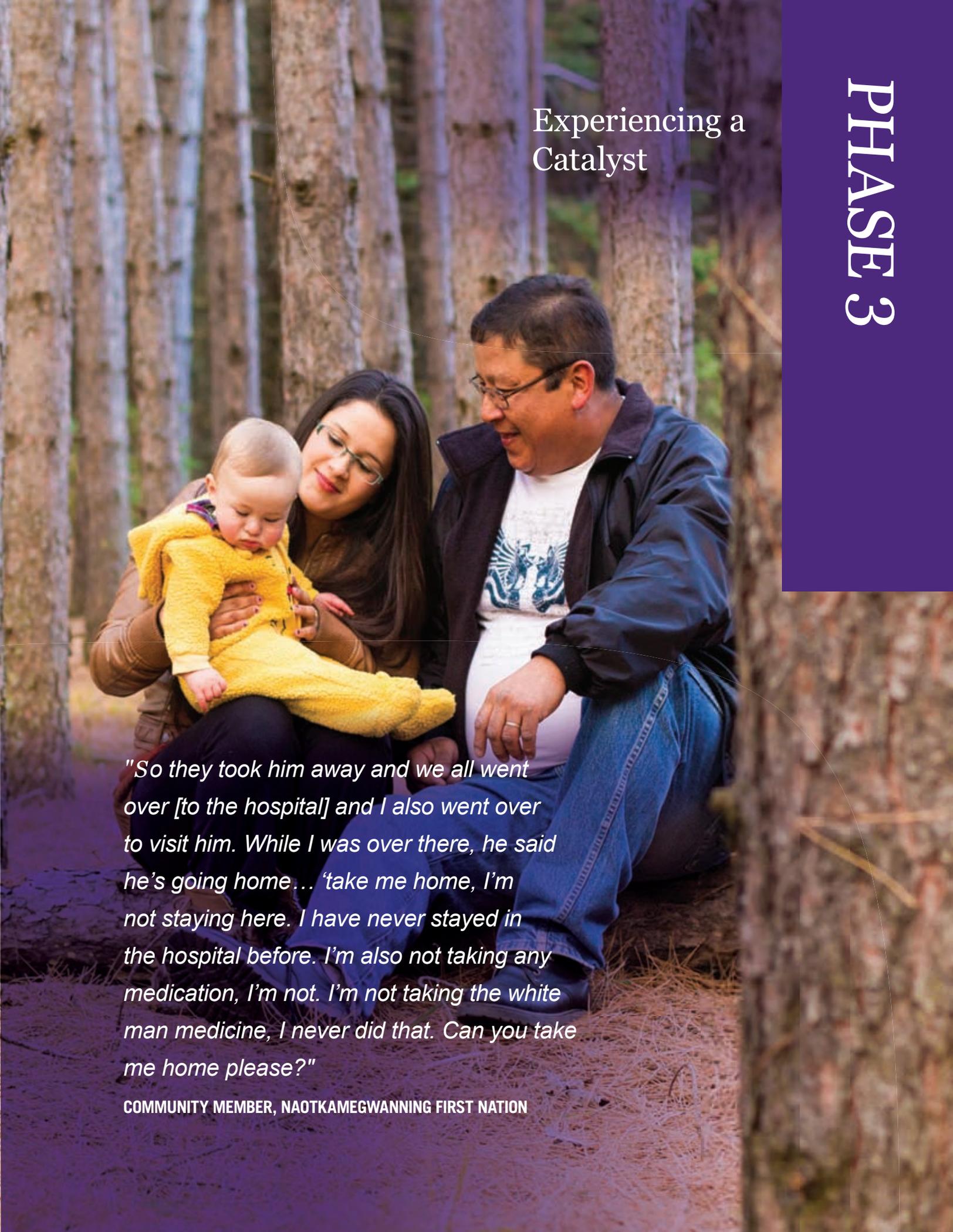
"So they took him away and we all went over [to the hospital] and I also went over to visit him. While I was over there, he said he's going home… 'take me home, I'm not staying here. I have never stayed in the hospital before. I'm also not taking any medication, I'm not. I'm not taking the white man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

COMMUNITY MEMBER, NAOTKAMEGWANNING FIRST NATION

PHASE 3: Experiencing a Catalyst

In developing a palliative care program in First Nations communities, the third phase of the process is **Experiencing a Catalyst**. This catalyst begins the process of community change and mobilizes community members to work towards their vision.

The community catalyst might be a person, such as a passionate local leader. Or the catalyst might be an event such as a community member dying in pain or having to go to hospital for care when they wished to die at home. Regardless, the catalyst is something in the community that moves the vision for change from being an idea to becoming concrete action.

While events outside the community such as new funding, a new policy, or palliative care education can create an opportunity and support the community's work, these outside events cannot be a catalyst. The change process must always be initiated from within the community and requires local leadership and commitment.

In our project, the catalyst in each community was a local health care provider who was passionate about improving palliative care. These individuals were inspired to become a Community Lead because they had experienced a good or bad death, had attended palliative care education, or wanted to make a difference in the community. The Community Lead assisted in growing and promoting the palliative care program, and ensured that the program was designed to meet the unique needs of their community.

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"...they went into the hospice, so that takes away from the dying at home. They didn't die at home; they died in the hospice. So where are we lacking to keep them at home? The care became so great. There wasn't enough to go around. Because now they need around the clock care and there is not enough services in the community that give round the clock care."

Community Member, Fort William First Nation
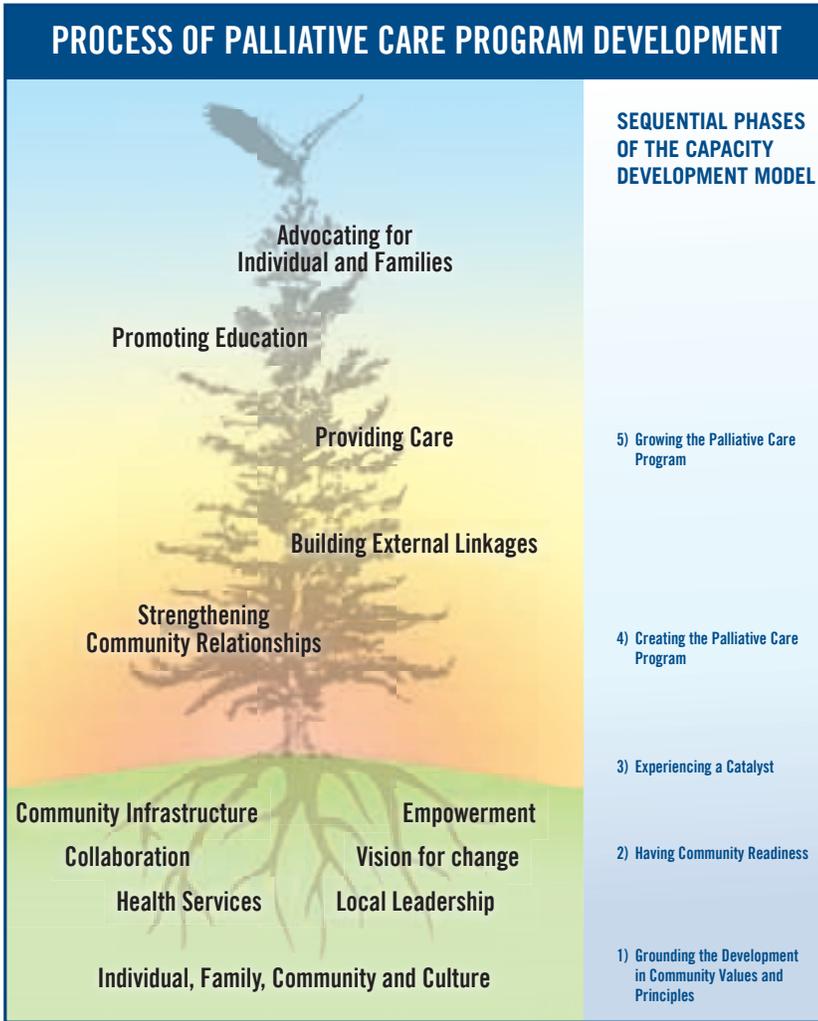
Community Leads stepped forward within each community as opposed to being chosen. They each had a vision to improve the care of community members who were very sick and wanted to receive their end-of-life care at home. They had passion and a commitment to achieving community change, and the necessary skills to achieve their goals. Within the EOLFN project, three of the Community Leads were a Coordinator/Manager of the local Home and Community Care program. In the fourth community, the Community Lead was a Health Director who shared this responsibility with the Community Health Representative.

The job title of the Community Lead is less important than the qualities and skills of that person.

The Community Lead inspired and helped organize other health care workers and community members to achieve their goals. The Community Lead worked towards improving existing health care policies and practices, welcomed new challenges, and had the confidence to advocate for what was in the best interest of the community members.

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

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 programs. 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, know 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.

Creating the
Palliative Care
Program

"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

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.

It 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**

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1. Hiring a Community Facilitator

The first step in developing the community's palliative care program is for someone to take on the role of a Community Facilitator. The Community Facilitator takes direction from, and is accountable to, the Community Lead and Advisory Committee. They are the person on the ground that is responsible for helping the Advisory Committee to develop the palliative care program. They do the leg-work.

The role of the Community Facilitator can be:

- A part-time position or full-time position depending on the community's needs (within our EOLFN project, all the Community Facilitators worked part-time);

- A new paid position (if funding is available) to do this work; and/or

- Taken on by an individual who already holds a paid position in the community but who agrees to add these additional tasks to their job description.

The Facilitator is chosen by the Advisory Committee. It is a temporary role until the palliative care program is developed. The person chosen should be someone that the Advisory Committee and community members are confident has the skills and qualifications to perform the tasks described below.

The main tasks of the Community Facilitator include:

- Meeting with Chief and Council, health care providers, community members, and the Advisory Committee;

- Collecting information by doing focus groups, interviews, and helping people do surveys;

- Organizing events, education sessions, and workshops;

- Facilitating community presentations about the work being done to develop the palliative care program;

- Creating resources such as posters and pamphlets;

- Organizing information and writing reports for the Advisory Committee and community;

- Supporting local health care providers and helping them to connect with regional service providers and palliative care resources; and

- Providing updates on progress to the Advisory Committee, attending and organizing meetings, and preparing meeting minutes for the Advisory Committee.

The skills and qualifications needed by the Community Facilitator include:

- Knowledge of the community protocols, services, and informal/formal leadership;

- An understanding of palliative care and end-of-life care;

- Excellent time management and organizational skills;

- Demonstrated leadership and problem-solving abilities;

- Excellent communication and team-building skills;

- Ability to create written reports; and

- Ability to maintain confidential and sensitive information in an appropriate manner.

For helpful information to choose your Community Facilitator, please see the folder, **Phase 4 – Creating the Palliative Care Program**, under the sub-folder **Hiring the Community Facilitator**. The folder includes the following Microsoft Word document templates that can be adapted and customized to your First Nation community:

1. **Community Facilitator Job Description Template**
2. **Community Facilitator Interview Questions Template**

2. Creating a Timeline: The Evolution of Palliative Care in the Community

Once in place, the Community Facilitator begins to gather information about how and where palliative care services are provided now in the community and by what people, organizations, and/or programs. The Community Facilitator also gathers information about current funding and policies that impact providing palliative care in the community. When the information gathering is complete, the Community Facilitator writes a report that summarizes the present situation for people living in the community who require palliative care and describes how this care has evolved.

To gather information for the report, the local Community Facilitator will work with the Community Lead and Advisory Committee. They need to identify a small number of people to interview. They also need to identify reports, documents, and policies that they can read to gather information.

Based on the interviews, reports, and documents, the Community Facilitator can write a short report using the

template provided in the folder. The report will provide the Advisory Committee with the following information:

1. The historical development of palliative care programming:
   a. Identify how end-of-life care historically has been provided.
   b. Detail the development of the Home and Community Care program.
   c. Identify key stakeholders (leaders and partnerships).

2. The current status of palliative care programming:
   a. The current availability of palliative services and programs within the community.
   b. Outline the funding and administrative structure of palliative services.
   c. Identify key stakeholders currently advancing the palliative care agenda.
   d. Examine community knowledge of palliative care.
   e. Identify the administrative structure of palliative services.
   f. Identify current partnerships in providing palliative services.

3. Future considerations for palliative care programming:
   a. Examine current vision for palliative care in the community.

For helpful information to complete the baseline report, please see the folder **Phase 4 – Creating the Palliative Care Program.** Look under the sub-folder, **Creating a Timeline,** and you will find the following resources: Timeline reports in a PDF format as examples from the EOLFN project; and a Microsoft Word document template which can be adapted and customized for use by any community.

1. **Example EOLFN Creating a Timeline Report**
2. **Creating a Timeline Template**
3. **Example FWFN Detailing the Evolution of Palliative Care**
4. **Example NFN Detailing the Evolution of Palliative Care**
5. **Example PFN Detailing the Evolution of Palliative Care**
6. **Example SNGRT Detailing the Evolution of Palliative Care**

3. Understanding Community Needs and Perspectives

Following the direction and guidance of the Advisory Committee, the Community Facilitator next begins to find out about the community's needs and perspectives about palliative care.

What information will the Community Facilitator collect?

- Community members' knowledge about palliative and end-of-life care.
- Previous experiences people had in caring for a dying loved one.

- Perceptions of whether members in their community prefer to die at home or elsewhere.

- Perceived barriers and supports in the community.

- Current palliative care practices and policies.

- Educational needs of formal and informal community caregivers.

- Resources available inside and outside the community.

From whom will the Community Facilitator collect this information?

- Community members who have provided care to someone at end-of-life.

- Health care providers both internal and external to the community.

- Knowledge Carriers and Elders, including all of the traditional/spiritual/religious leaders in the community.

- Members of Chief and Council.

How will the Community Facilitator collect this information?

Within our project, each of the four communities followed the same steps to find out about their community members' needs and perspectives. For each step, we have included a sample of an information gathering tool that we used.

We encourage you to use some or all of these tools and adapt them to your own community's needs. This may mean changing the wording, taking out or adding questions and personalizing it for your community (i.e. adding your First Nation's logo, community contact information, etc.).

For the resources to help you collect information, please see folder **Phase 4 – Creating the Palliative Care Program** under the sub-folder **Understanding Community Needs and Perspectives**. This folder includes the following templates in the form of Microsoft Word documents that can be customized for your First Nation community:

1. **Survey Template**
2. **Survey Participant List Template**
3. **Interview Guide for Community Members Template**
4. **Interview Guide for Elders and Knowledge Carriers Template**
5. **Interview Guide for Internal Health Care Providers Template**
6. **Interview Guide for External Health Care Providers Template**
7. **Invitation Poster Template**

Step 1: Information Letter

When getting ready to collect information from people, the Community Facilitator should prepare a one-page information letter to give each person. The letter should describe what the community is doing and why people are being asked for information. The Advisory Committee should guide the Community Facilitator in what to put in this letter, and may want to include the following:

- The purpose for the survey (for example, we are trying to develop a local palliative care program or improve care for community members who are very sick);

- Who is in involved and leading the project (that is, the names of the Community Lead and individuals on the Advisory Committee);

- How and why they were selected to do a survey, interview or focus group; and

- What will happen with the information that is provided.

If the Advisory Committee prefers, the Community Facilitator can describe this information verbally when he or she approaches people. However, it is ethical to inform people.

Step 2: Surveys

The Community Facilitator will collect some of the information by doing surveys in the community.

- The Advisory Committee and Community Facilitator meet as a group and they review the **survey template** provided in this workbook. Before using the survey, it is important to ensure that the language is easy to understand and user-friendly in the community. The Advisory Committee could add questions if they want additional information collected, or they could delete certain questions. Reasons they might delete certain questions include: the questions are not culturally appropriate to ask, or the information is already known.

- The Advisory Committee then selects 20 community members to complete the survey. We recommend these 20 people include:
    - 5 community members who have provided care to someone at end-of-life;
    - 5 health care providers who are located in the community;
    - 5 Elders and Knowledge Carriers (includes traditional/spiritual/religious leaders in the community); and
    - 5 Members of Chief and Council.

        Additional people can be added if the Advisory Committee wishes.

        The people who are selected for the survey should be those people that the Advisory Committee thinks can provide the best information. They are selected because they have knowledge and experience about palliative care and the needs and perspectives of the community. The names of the 20 selected individuals are documented on the **survey participant list template** provided.

"And even to celebrate the person's life. I think that when they do die, people come together, that there's a lot of community support in this community."

**Knowledge Carrier,
Fort William First Nation**

- The Community Facilitator then goes around the community and invites these 20 individuals to fill out the survey. The Community Facilitator would provide these individuals with the one page information letter.

- After people agree, the Community Facilitator can have them complete the survey in two different ways: 1) the Community Facilitator can give the person a survey to complete on their own and collect it at a later time; or 2) the Community Facilitator may sit with the individual, go through the questions with them, and record their answers on the survey.

- If translation is going to be an issue, the Advisory Committee will need to make arrangements for translation to be provided. If the Community Facilitator is not fluent in the language, the Advisory Committee should arrange for a translator to accompany the Community Facilitator to complete the surveys.

Step 3: Interviews

Once the surveys are complete, the Community Facilitator will need to do some interviews. The interviews will gather additional information and stories from Knowledge Carriers and Elders, community members, health care providers (both internal and external to the community), and members of leadership.

The interviews can be done either one-on-one or in a group format. One-on-one interviews can be 30 minutes to 1 hour in length, depending on how much the person has to share. The group format allows you to collect information from 4-8 people at one time. Groups will take approximately 1-1½ hours, depending on the experience and comfort level of the participants. Normally, people in a group are similar to each other; for example, a group of Elders or a group of health care providers. As much as possible, all interviews/groups should be completed in an area that is private, quiet, and free of distractions.

The Advisory Committee can determine whether individual or group interviews would be the better and more appropriate way to gather information. The Community Facilitator will use the **interview guide** (questions) provided in the workbook to lead a conversation with an individual or focus group discussion. It is not necessary to ask all the questions exactly as they are written; however, the questions are there to help the Community Facilitator make sure the important topics are covered. The questions are a guide.

If individuals agree (give their permission), the Community Facilitator may want to audiotape the interviews and/or group discussions. Audiotaping allows the Community Facilitator to listen to the interview later and summarize the key information. If the interview/group is not taped, the Community Facilitator can take hand written notes during, or make summary notes following, the interview. However, it is important that the Community Facilitator record the ideas in some way. Each tape (or the notes) should also be labelled with the date and who is being interviewed or who attended the group discussion.

The Community Facilitator's audiotapes or notes should be treated as confidential (private). The Community Facilitator can use their tapes or notes to help them prepare a summary for the Advisory Committee and a report. After the report is completed and approved, the tapes and notes are no longer needed and can be destroyed by the Facilitator.

Elders and Knowledge Carriers (includes traditional/spiritual/religious leaders in the community)

- The Advisory Committee and Community Facilitator meet together and select Knowledge Carriers and Elders within the community. They will be asked to share their knowledge and experiences about health and wellness, end-of-life care, the needs of the community, and the future direction of the palliative care program.

- At this meeting, the Advisory Committee determines which format will be the most appropriate to capture information from Elders and Knowledge Carriers (either a one-on-one interview or group interview). The Advisory Committee also reviews the **interview guide template** (questions) and adapts it to be more culturally and community relevant if needed.

- Once the individuals have been selected and the format decided upon, the Community Facilitator invites these individuals to do an interview. The Community Facilitator follows any cultural protocols in asking the Knowledge Carriers and Elders to participate (i.e. providing a gift, honorarium, tobacco, etc.).

- At the time of the invitation, the Community Facilitator also provides each person with the one page information letter and answers any questions that the individual might have about it.

- The Community Facilitator then organizes the location and time for the individual or group interviews to occur. The Advisory Committee
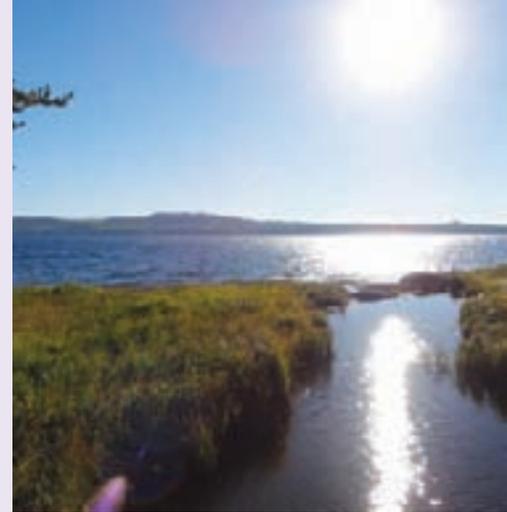
"In the Hospital, you got to get out at a certain time, certain number of people, but when you're at home, people can go in and out. People can sit there and sit with you for hours on end. That is one of the reasons people like being in their household."

Knowledge Carrier, Naotkamegwanning First Nation

"When a person becomes ill they lose control and power. They walk the line of being determined to be incompetent. They become totally dependent on their family who need to fight for their best interests. When I am near death wheel me outside let me smoke my pipe outside the long-term facility. Don't worry about the cold, I am dying. My physical being needs to hold the pipe (its last chance). Don't maul my body! Give my family time. It doesn't matter if you know the exact time of my death."

Survey Participant, Fort William First Nation

may also choose to provide a lunch as an incentive for people to attend, and the Community Facilitator will organize the food.

- The Community Facilitator leads the interview or group discussion using the interview guide and records the ideas using an audio recorder (if people give their permission) or by taking notes during or after the session.

Community Members

- The Advisory Committee and Community Facilitator meet as a group and determine how to gather information from the community members, including local health care providers and members of Chief and Council. Information needed includes their perceptions and experiences in providing palliative care, the perceived barriers and supports for palliative care in their community, and their educational needs. The easiest way to capture this information would be through focus group interviews; however, individual interviews may also be done. There are two interview guides provided, one for community members and one for internal health care providers. The Advisory Committee would also review the **interview guide templates** provided in this workbook and adapt them to be more culturally and community relevant, if required.

- At this meeting, the Advisory Committee will decide how many focus groups are needed, which people to target, and when to hold the interviews in order to capture the most information. For example, there may need to be a group held during the lunch hour on a weekday to capture health care providers' information, one held in the evening on a weekday to capture community members' experiences, and one held on the weekend to capture a local church group's experience. The Advisory Committee may also want to hold one focus group just for health care providers or one just for members of leadership (Chief and Council, Manager/Directors).

- The Community Facilitator then organizes the locations and times that the focus groups will occur. The Advisory Committee may also provide a lunch as an incentive for people to attend.

- The Community Facilitator then starts inviting people to attend the different groups. The Community Facilitator can place invitation posters around the community, submit invitations in the local newsletter, request health care managers to send invitations out via email to their staff, or send personal invitations to members of Chief and Council.

- At each focus group or interview, the Community Facilitator provides individuals with the one page information letter. The Community Facilitator uses the adapted interview guide to lead the discussion to gather the information. Depending on permission given by individuals, the Community Facilitator will audiotape the interview/group, take hand written notes during the interview, or make summary notes following the interview.

External Health Care Professionals

- The Advisory Committee and Community Facilitator will meet and develop a list of individuals who provide health services in the community, but are not locally based. These service providers, and in some cases a representative of the organization they work for, will be interviewed by the Community Facilitator in person or by telephone. The people interviewed are asked about the services they currently provide in the First Nation community, their potential contribution to developing a palliative care program, and the perceived barriers and opportunities to provide enhanced palliative care in the First Nation community. The Advisory Committee would also review the **interview guide template** (questions) for external health care professionals provided in the workbook, and adapt it to make it more culturally and community relevant, if required.

- Once the list of people the Advisory Committee wish to interview is compiled, the Community Facilitator contacts each person by phone or in person and invites him or her to do an interview either in person or on the phone. The Community Facilitator also provides each person with a copy of the one-page information letter and explains the purpose of the requested interview.

- The Community Facilitator then uses the interview guide to lead a conversation and gather the information required. Depending on permission given by individuals, the Community Facilitator may want to audiotape the interview, take hand written notes during the interview or may make summary notes following the interview.

"I think a big part of it is talking to them, the families, and educating them ahead of time what to expect as well. Because it can be scary, frightening for families, especially when we see them dying … or in pain or struggling. And, just providing that knowledge and support ahead of time, instead of in the moment when they're stressed, or anxious about what's going on. And just preparing them gradually before it gets to that point is very important."

Internal Health Care Provider, Naotkamegwanning First Nation

Step 4: Compiling the Information into a Report

Once all the information is gathered, the Community Facilitator, with help from the Advisory Committee, summarizes all the information from all surveys and interviews/groups about community needs and perspectives. They use the information to create a short community report that also includes some recommendations that the Advisory Committee wishes to make. This report may be shared with the community and all the people who participated in the surveys and interviews/focus groups.

To assist Community Facilitators in creating a community report, we have included the final community reports completed by the EOLFN First Nations communities. These community reports may be helpful to organize the information and create recommendations. To find these reports, please see folder **Phase 4 – Creating the Palliative Care Program** under the sub-folder **Understanding Community Needs and Perspectives.** The four First Nations community reports are in a PDF format as examples from the EOLFN project; and a Microsoft Word document template which can be adapted and customized for use by any community.

8. **Example FWFN Community Report**
9. **Example NFN Community Report**
10. **Example PFN Community Report**
11. **Example SNGRT Community Report**
12. **EOLFN Community Report Template**

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 template** 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 works on is the **Community Readiness template**. 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**

5. Forming the Leadership Team

Once the work plan is developed, the next step is for the Advisory Committee to gather people together to carry out the work plan. More people will be required to carry out the work plan. The EOLFN project recommends forming a Leadership Team to carry out the work plan.

What will the Leadership Team do?

The Leadership Team is responsible for the overall planning, education, and evaluation of the community palliative care program. The work of the Leadership Team focuses on four areas:

- Identifying common issues/concerns and determining solutions;

- Promoting educational opportunities for care providers and community members;

- Increasing public awareness of the availability of palliative care in the community; and

- Developing a care pathway for palliative care and protocols to guide the health care providers who are caring for clients and their families. This is done by a task group of health care providers who are involved in providing care in the community. This task group is also known as the Clinical Team.

The care pathway is developed by conducting journey mapping workshops that involve internal and external care providers. Journey mapping is explained in the next section of the workbook.

Palliative care protocols need to be developed in three areas: communicating via the common chart; arranging for and attending case conferences; and coordinating post-death follow-up with families.

Once the care pathway and protocols are developed, the internal and external health care providers can work more effectively together as members of the Clinical Team to provide palliative care for community members. The health care providers may be different for each client depending on his or her needs; therefore, having the protocols written down and formalized is important.

Who is on the Leadership Team?

The Leadership Team is comprised of the members of the Advisory Committee, the Community Facilitator, and several people from inside or outside the community who are dedicated and committed to forming the palliative care program.
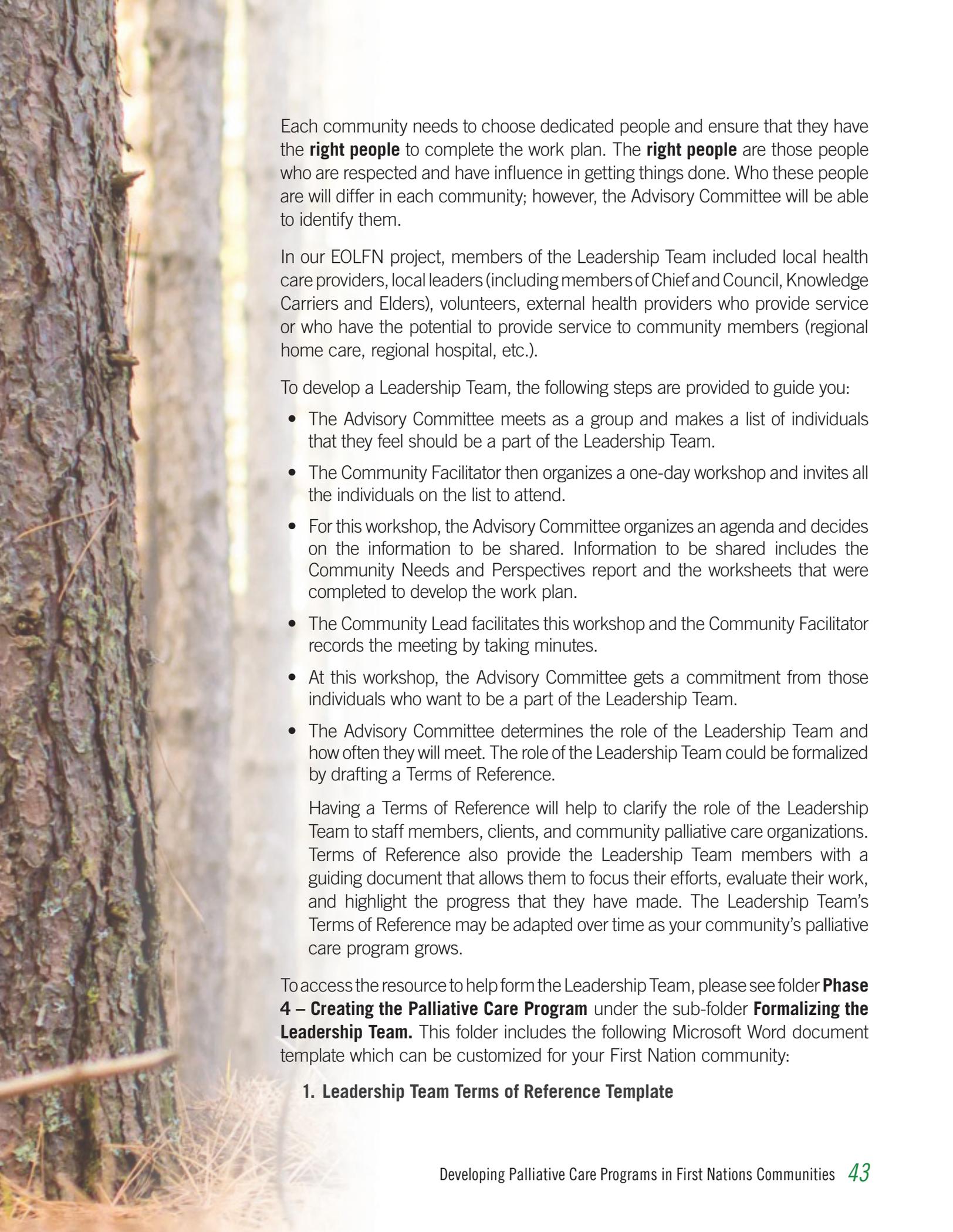
Each community needs to choose dedicated people and ensure that they have the **right people** to complete the work plan. The **right people** are those people who are respected and have influence in getting things done. Who these people are will differ in each community; however, the Advisory Committee will be able to identify them.

In our EOLFN project, members of the Leadership Team included local health care providers, local leaders (including members of Chief and Council, Knowledge Carriers and Elders), volunteers, external health providers who provide service or who have the potential to provide service to community members (regional home care, regional hospital, etc.).

To develop a Leadership Team, the following steps are provided to guide you:

- The Advisory Committee meets as a group and makes a list of individuals that they feel should be a part of the Leadership Team.

- The Community Facilitator then organizes a one-day workshop and invites all the individuals on the list to attend.

- For this workshop, the Advisory Committee organizes an agenda and decides on the information to be shared. Information to be shared includes the Community Needs and Perspectives report and the worksheets that were completed to develop the work plan.

- The Community Lead facilitates this workshop and the Community Facilitator records the meeting by taking minutes.

- At this workshop, the Advisory Committee gets a commitment from those individuals who want to be a part of the Leadership Team.

- The Advisory Committee determines the role of the Leadership Team and how often they will meet. The role of the Leadership Team could be formalized by drafting a Terms of Reference.

  Having a Terms of Reference will help to clarify the role of the Leadership Team to staff members, clients, and community palliative care organizations. Terms of Reference also provide the Leadership Team members with a guiding document that allows them to focus their efforts, evaluate their work, and highlight the progress that they have made. The Leadership Team's Terms of Reference may be adapted over time as your community's palliative care program grows.

To access the resource to help form the Leadership Team, please see folder **Phase 4 – Creating the Palliative Care Program** under the sub-folder **Formalizing the Leadership Team.** This folder includes the following Microsoft Word document template which can be customized for your First Nation community:

1. **Leadership Team Terms of Reference Template**

How does the Leadership Team do its work?

Once the Leadership Team is formalized, the Advisory Committee no longer needs to meet as a separate group. The members of the Advisory Committee have become members of the Leadership Team. The Community Lead is the Chair of the Leadership Team, and the Community Facilitator takes on the role of the organizer and recorder of Leadership Team meetings.

In the EOLFN project, the Leadership Teams met monthly. Monthly meetings were helpful and worked well in all four communities. These meetings provided an opportunity for everyone to come together to discuss how to best accomplish the work plan.

At the meetings, the Chair of the Leadership Team assigned tasks to several small working groups. These working groups completed assigned tasks during the next month. The working group came back to the Leadership Team meeting the next month and reported what they had accomplished. The Leadership Team provided feedback. The working group would then revise, edit, or add to the task as needed over the next month. Each working group continued until their task was complete.

One of the important working groups of the Leadership Team is the Clinical Team. This working group is made up of the internal and external health care providers who provide palliative care in the community. The Clinical Team working group creates the path of care and consent documents. This is described more in the next section.

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 Nations Palliative Care Program that the Leadership Team can use as a tool to help create local program guidelines. This 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

The Palliative Care Program Services may include the following:

- Nursing and personal support services (foot & nail care, bathing, oral care, transferring and positioning techniques, nursing assessment and nursing care to help clients to remain at home).

- Dietary services (dietary counselling, Meals on Wheels).

- Medical services (doctor on site/in community, appropriate transportation services to medical centres/doctors for appointments).

- Organized programs to ensure reasonable opportunity to pursue religious and spiritual practices (list of Pastors/Priests/Clergy and traditional medicine (wo)men according to spiritual preference of client).

- Homemaking services (including housekeeping, laundry, and maintenance).

- Grief and bereavement support.

- Volunteer programs.

Screening and Training of Staff/Volunteers

Volunteers and staff should be screened, including a criminal reference check (unless under the age of 18). Orientation and training should take place before starting to work with clients. Orientation should include promotion of zero tolerance of abuse and neglect, and infection prevention and control.

Training required for palliative care includes:

- Review the Palliative Care Program policy & procedures, mission statement and palliative care program vision, and services;

- Review the philosophy and principles of the palliative approach to care, including care in the last days and hours, and grief support;

- Falls prevention and management;

- Skin and wound care;

- Continence care and bowel management; and

- Pain and symptom management, including recognition of specific and non-specific signs of pain.

Plan of Care

Each client must have a written plan of care (or care plan) that includes his/her planned care, the proposed goals of care, and clear directions to staff and others who will be providing the care. Every individual client's care plan is unique to their needs.

Creating the plan of care requires the involvement of the client, their substitute decision maker (if any), and any other person they wish to assist them. Ideally, the plan of care is created in a care conference that is attended by the client, family, and involved health care providers. Care must be based on an assessment of the client and his/her needs and preferences. The plan of care must be assessed for effectiveness, and revised when required, at least every six months.

Consent or Treatment Documents

Any document that contains a consent or directive with respect to client's treatment (such as plans of care, level of care forms, and advance care plans) must meet the requirements of the applicable *Health Care Consent legislation*.

The rules about providing consent are governed by laws that are slightly different in each province or territory. The Leadership Team needs to become aware of the legal requirements for consent and treatment that impact them. These laws include the requirement for informed consent.

Once all areas of the Palliative Care Program guidelines are complete, the Leadership Team compiles them in the form of a booklet. This booklet can be shared with community members, external health care providers, etc.

For resources to assist in creating the Palliative Care Program Guidelines, please see folder **Phase 4 – Creating the Palliative Care Program** under the sub-folder **Creating Palliative Care Program Guidelines**. This folder includes the following: PDF versions of the EOLFN Palliative Care Program Guidelines, a Microsoft Publisher document that offers a template which can be customized to your First Nation, along with non-editable PDF examples of guideline booklets created by the First Nations communities:

1. **Example EOLFN Palliative Care Program Guidelines**
2. **Palliative Care Program Guidelines Booklet Template**
3. **Example FWFN Palliative Care Program Guidelines Booklet**
4. **Example NFN Wiisokotaatiwin Program Guidelines Booklet**
5. **Example SNGRT Palliative Care Program Guidelines Booklet**
6. **PDF Poster: Integrated Palliative Approach to Care**
7. **PDF Poster: Process of Palliative Care Program Development**

"I got this thing in my mind about a booklet. To me a booklet is a reference for yourself that you may need when you feel you need it. Because, the access to information is not always there ... when you have a question come up ... especially as things progress more intensely. But right at the beginning, I am a believer, if you understand, you cope better. So, if you understand the whole process, you are going to cope better with it and you will recognize and identify your needs better. Whether you are the caregiver or whether you are the person who has got the terminal illness."

**Community Member,
Fort William First Nation**

"I told the [hospital] nurse he's [the Elder] not going to take the medication. The nurse says, 'he needs to take the medication. That is what the doctor gave to him. If not he will end up with blood clots.' The Elder says 'I am not, I am going home. I'll take Native medicine.' I told him [the Elder] that 'I believe the white man, I believe the doctors.' I even talked him [the Elder] into it. The Elder said 'it won't work' and that's when he never came home. That's where he passed away. It hit all of us when he passed away, why didn't I listen to him?"

Knowledge Carrier, Naotkamegwanning First Nation

7. Address Outcomes

The Leadership Team continues to meet monthly. They focus on monitoring their progress and addressing the issues and barriers they encounter while creating the palliative care program. The Leadership Team can organize and promote educational opportunities for health care providers and community members and find ways to increase public awareness of palliative care in the community.

Ongoing discussion helps the Leadership Team to identify their new tasks. They can also review the worksheets previously developed by the Advisory Committee (see Step 4) to identify new goals or tasks. The work plan is a living document that needs to be reviewed and updated continuously.

Growing the
Palliative Care
Program

PHASE 5

"I think once the program is established, or begins to make a mark in the community, that the community members will hopefully be interested in perpetuating that, and assisting. And hopefully it'll be a reciprocating process where, [the program] can be established and grow and to become something that is appropriate for the community."

EXTERNAL HEALTH CARE PROVIDER, NAOTKAMEGWANNING FIRST NATION

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.

PROCESS OF PALLIATIVE CARE PROGRAM DEVELOPMENT

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

SEQUENTIAL PHASES OF THE CAPACITY DEVELOPMENT MODEL

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

Each of the five strategies is described below, with examples and resources.

1. Strengthening community relationships

Strengthening community relationships is about engaging community members to work together to improve palliative care services (e.g. Elder's workers, Home and Community Care staff, mental health workers, community health providers, cultural and spiritual care providers, Elders and Knowledge Carriers, members of leadership, and volunteers).

In addition, it focuses on increasing public awareness of the meaning of palliative care, the services offered, and how to access them.

There were a number of tools that the four EOLFN First Nations communities used to strengthen community relationships and create awareness of the palliative care program.

To access these resources, please see the folder, **Phase 5 – Strengthening Community Relationships**. All of the tools are Microsoft Word documents that can be customized to your First Nation community. There are also examples created by our EOLFN First Nations communities that are PDF files and cannot be altered.

a. **Client Brochure and Program Information Poster**

In addition to the program guidelines booklet developed in the previous phase, Phase 4: Creating the Palliative Care Program, the Leadership Team can develop pamphlets and posters. These pamphlets and posters can describe the palliative care program, the eligibility criteria, who the program is for, where the care is provided, what services are provided, and who is involved in providing care. All of these resources can then be distributed at local health fairs, community meetings, and feasts.

Please find a template of a client brochure in **Phase 5 – Growing the Palliative Care Program** under the sub-folder **Strengthening Community Relationships**. The folder includes a Microsoft Word adaptable template that can be edited and customized to your First Nation community. There is also an example created by an EOLFN First Nation community in PDF format and cannot be altered:

1. **Client Brochure Template**
2. **Example NFN Wiisokotaatiwin Information Poster**

b. Logo Contest

The Leadership Team can encourage community members to become more involved and interested in the Palliative Care Program by holding a Logo Contest. This contest can target local artists from the community, of any level of skill, to develop a logo that could be used in the program materials. The logo can be included on educational and/or promotional materials directly related to the Palliative Care Program and on correspondence.

Please find a Microsoft Word editable template for a logo contest poster which also includes some rules, regulations, and a consent form in **Phase 5 – Growing the Palliative Care Program** under the sub-folder **Strengthening Community Relationships**.

3. Logo Contest Poster and Rules Template

c. Community Launch

The community can hold a **Community Launch** of their program. The Leadership Team can organize a public meeting and a feast to talk about the program, discuss the work plan, and get some feedback on the program development process. This is also a great opportunity to introduce some of the external health care providers involved in the program.

Please find a Microsoft Word editable template for a poster for a community launch in **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Strengthening Community Relationships**.

4. Community Launch Poster Template

Other tools to use when creating community awareness:

- Media: radio, social media such as Facebook and Twitter, websites, and E-blasts sent to email lists (a short description about the project or current project happenings).
- Print: local and area newspapers, program newsletters, promotional items such as pamphlets, brochures to be distributed at various events and locations throughout and external to the community.
- Presentations: information booths, workshops, and conference attendances.

2. Building external linkages

Building external linkages means the community is getting connected with palliative care experts, and external health care providers and resources that are based outside of the community. This includes organizations such as hospitals, hospices/hospice units, regional home care programs, cancer centres, telemedicine, and Aboriginal Health Access Centres. These are the resources that can support the local health care providers in delivering palliative home care.

One very effective activity that brought the internal and external health care providers together was the Journey Mapping process. Journey mapping was introduced in Phase 4 and continues to be relevant in Phase 5. Journey mapping workshops are described in more detail later in this section of the document.

There are a number of resources and tools that the four First Nations communities involved in the EOLFN project developed or used to build external linkages and they can be found in folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Building External Linkages**. Examples of building external linkages can be found below.

a. **Memorandums of Understanding (MOU's) with External Health Care Providers**

Several Memorandums of Understanding were created between the communities and external health care providers, including provincially funded health care services. The following are some examples of MOU's that were developed:

- Six Nations of the Grand River Territory and the Hamilton Niagara Haldimand Brant (HNHB) Community Care Access Centre, that provides home care services, developed an MOU. They mutually agreed to a framework which provides a platform for collaborative partnerships, education/training opportunities, and information sharing. The MOU assisted in outlining expectations and accountabilities for community in-home services to the clients of Six Nations of the Grand River Territory, Ohsweken. 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

- Six Nations of the Grand River Territory and Stedman Hospice, located in Brantford, Ontario, committed to collaborate to train, develop, and mentor a Shared Care Palliative Care Outreach Team. The Shared Care Team consists of an Indigenous

"We need that linkage; we need stronger linkages with the doctors and the staff, the people off reserve and on reserve. So they can understand, you know. They always talk about the communities, but they've never been here, they've never experienced it. So, how do they know … they're just starting to learn, I think. And understanding what the wants are in First Nation communities, what the needs are in First Nation communities." And you know, years ago, we took care of our own. And that is coming to pass again; it's slowly, getting stronger and stronger. It's what the people want."

Community Member, Peguis First Nation

physician, Psychosocial/Spiritual/Bereavement Counsellor and a Clinical Nurse Specialist who all provide palliative care to clients living in Six Nations of the Grand River Territory. This MOU clearly defined the roles and responsibilities of the partnership regarding the training, development, and preceptorship of the Shared Care Team. The MOU is reviewed and signed annually, and has evolved to include working relationships, funding, service provision, charting, and reporting. 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. An example MOU PDF can be found in folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Building External Linkages, section 1 - MOU**.

    1. **Example SNGRT MOU**

- The EOLFN project and Thunder Bay Regional Health Sciences Centre/Regional Cancer Centre developed an MOU to support Naotkamegwanning First Nation and Fort William First Nation to develop their local palliative care program. The MOU was developed to explore, document, and evaluate several initiatives including improving discharge planning for First Nations people returning home for care, delivering community education in Fort William First Nation, and providing telemedicine consultation using a tablet in Naotkamegwanning First Nation. A set of guidelines, checklists and a presentation on discharge planning for people returning home to a First Nation community, was developed by Dr. Mike Harlos from Winnipeg, Manitoba. These resources to improve discharge planning were provided to the hospital and are included in our toolkit so that they can be promoted nationally. For more information, please contact Chisholm Pothier, VP Communications & Engagement, Aboriginal Affairs and Government Relations, Thunder Bay Regional Health Sciences Centre at pothierc@tbh.net or Trina Diner, Manager of Palliative Care and Telemedicine, Thunder Bay Regional Health Sciences Centre at dinert@tbh.net.

Please find both PDF and Microsoft Word editable templates for Dr. Harlos's hospital discharge planning resources in the folder **Phase 5 – Growing the Palliative Care Program**, in the sub-folder **Building External Linkages**, **section 2 – Hospital Discharge Planning**

    1. **Care Plan Template**

    2. **Checklist Template**

    3. **Hospital Discharge Planning Description Template**

    4. **Example Hospital Discharge Planning Remote Communities Power Point Presentation**

- The EOLFN project with Waasegiizhig Nanaandawe'iyewigamig Health Access Centre (WNHAC) developed an MOU to support Naotkamegwanning First Nation to develop their local palliative care program. This included discussing what WNHAC services are needed, how the community would access WNHAC services, and the benefits to clients, community, and service providers. A WNHAC nurse practitioner, who had training and experience in palliative care, did home visits and assessments for clients receiving palliative care and participated in community care conferences. For more information please contact Anita Cameron, Executive Director, Waasegiizhig Nanaandawe'iyewigamig Health Access Centre at ACameron@wnhac.org

- The EOLFN project with the North West Community Care Access Centre (CCAC) provincial home care program, developed an MOU that would help support Naotkamegwanning First Nation to develop a local palliative care program. This included discussing what CCAC services are needed, how the community would access CCAC services, and the benefits to clients, community, and service providers. A CCAC Care Coordinator was identified 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 North West 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 **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 were provided during the evening and weekends where needed.. 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 Palliative Care Program** in the sub-folder **Building External Linkages**, **section 3 - HSIP Proposal**.

1. **NFN Wiisokotaatiwin HSIP Proposal**

c. Journey Mapping Workshop

The goal of journey mapping is to improve the coordination and integration of care for clients as they access services from multiple programs and health care providers. It is done using a workshop format that brings together internal and external health care providers, Elders, and community leadership. It involves in-depth discussion of how First Nation community members transition through the health care system as they approach end-of-life, and identifies obstacles and solutions to improve service integration. Journey mapping is a useful tool to help create the Care Pathway that is an important component of the Palliative Care Program guidelines.

A completed Care Pathway looks like a process flow chart or diagram, and it is accompanied by a narrative that describes a typical client's progression through the health care system. The Care Pathway encompasses medical and psychosocial services and supports, and highlights care options in various settings such as home, hospital, and long-term care. It illustrates the current state interaction with services and providers and the desired future state of care.

In the resources, you will find a journey mapping tool that is based on Naotkamegwanning First Nation's experience. The Leadership Team used journey mapping to create their new integrated Care Pathway for clients to receive palliative care at home. The tool describes the step-by-step process used to develop the Care Pathway, including engaging with external partners, identifying barriers and capacities, and compiling the information to create the

Care Pathway diagram. The tool also describes the implementation of the Care Pathway, including creating new policies, and recommendations.

We have provided a PDF version of the Step by Step Guide for conducting the journey mapping process. The complete process includes 3 workshops and 3 Leadership Team meetings. The appendices include editable agendas, worksheet templates and a diagram of the care pathway. These resources are all located in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Building External Linkages**, **section 4 - Journey Mapping**.

1. **Conducting Journey Mapping to Create a Palliative Care Pathway for First Nations Communities: A Step by Step Guide**
2. **Leadership Team Meeting 1 Sample Agenda Template**
3. **Nine Stage Palliative Care Pathway Diagram Template**
4. **Journey Mapping Workshop 1 Sample Agenda Template**
5. **Documenting the Current State Worksheet Template**
6. **Leadership Team Meeting 2 Sample Agenda Template**
7. **Implementing the Palliative Care Pathway Worksheet Template**
8. **Journey Mapping Workshop 2 Sample Agenda Template**
9. **Leadership Team Meeting 3 Sample Agenda Template**
10. **Implementing the Palliative Care Pathway Action Plan Worksheet Template**
11. **Journey Mapping Workshop 3 Sample Agenda Template**
12. **Evaluating the Palliative Care Pathway Worksheet Template**

3. Promoting education

Promoting education involves providing local health care providers with education about the principles and practices of the palliative approach to care. This education includes grief and bereavement; care for the caregiver; pain and symptom management; and family support. These providers then mentor and support other local health care providers.

External health care providers who provide palliative care in the First Nations community also received education on cultural competency, local community protocols and practices, and the local health care services available in the First Nation community.

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

External Health Care Provider, Fort William First Nation

There were a number of strategies and tools that the four First Nations communities involved in the EOLFN project used for education. These tools are divided into three categories based on which group the education targeted.

All of the tool and resource templates in our workbook can be customized to your First Nation. The EOLFN First Nation PDF files are provided as examples and cannot be altered. These resources can be found in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education**.

a. 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**
5. **PCFN Module 5 Grief and Bereavement Template**
6. **PCFN Module 6 Helping Relationships Template**
7. **PCFN Module 7 Community Care Teams Template**

For further information on the *Palliative Care for Front Line Workers in First Nations Communities* curriculum, including facilitator guidelines, facilitator and participant resources, or to inquire about hosting a workshop in your First Nation community, please contact Stephanie Hendrickson, Education Planner at CERAH at shendric@lakeheadu.ca

- Grief & Bereavement Workshop

First Nation individuals, families, and communities deal with many unique challenges related to loss and grief. The Centre for Education and Research on Aging & Health (CERAH) was asked by First Nation partners to create a Grief and Loss curriculum to support community healing and well-being. The curriculum, *Finding Our Way Through: Navigating Loss and Grief in First Nations Life*, was developed by an Indigenous educator and has been used and evaluated in First Nations communities.

The purpose of the curriculum is to provide an introduction to First Nations peoples' experience of loss, grief, and grieving. It is intended for use with the front-line care providers who serve First Nations individuals and families. This educational workshop is offered as a support to capacity building at the community and organizational level.

This experiential workshop involves participants in developing a circle of trust and feeling a sense of safety and trust in a group of people. The group is used as a foundation for learning about sensitive topics such as grief and loss. The workshop requires a skilled facilitator and involvement of Elders and cultural guides. It is designed for adults age 18 and over.

Objectives of the Two Day Workshop:
- To provide an opportunity to develop further awareness, knowledge, and skills in reflective practice and processing of personal loss, grief and trauma;
- To develop options for helpful responses drawing on the strengths and capacities of First Nation communities;

> *"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**

– To provide a culturally relevant and supportive environment for health care providers and others providing family support to explore First Nations' loss, grief, and bereavement;

– To further understand the unique characteristics of First Nations' loss and grief; and

– To increase capacity to provide care with First Nations individuals, families, and communities in their loss, grief, mourning, and bereavement work.

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. **Example EOLFN Grief and Loss Manual**
2. **Example EOLFN Grief and Loss Power Point**

b. **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**

8. **Example EOLFN Caring for Someone with a Terminal Illness What to Expect**

9. **Supporting the Caregiver and the Family Template**

10. **Example EOLFN Supporting the Caregiver and the Family**

- Community Palliative Care Awareness Sessions

  Fort William First Nation organized a series of awareness sessions for community members. The needs assessment conducted in the EOLFN project indicated that most First Nations community members found it difficult to talk about issues of death and dying. Awareness sessions such as these helped to normalize death as part of the cycle of life.

  External health care providers, experts in palliative care, volunteered to come to Fort William First Nation and make presentations on a variety of topics which included the following:

  – Introduction to Palliative Care

  – Supporting the Family

  – Managing Pain & Symptoms

  – Care for the Caregiver

  – Providing Care at Home

  You will find a PDF poster from Fort William First Nations' Community Palliative Care Awareness Sessions in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education, section 4 – Palliative Care Community Awareness Sessions**.

  1. **Example FWFN Palliative Care Community Awareness Sessions Poster**

- Advance Care Planning Sessions & Resource Development

  Two of the communities created Advance Care Planning resources for their communities. Six Nations of the Grand River Territory created a

"This woman knew that she was passing on, and she was preparing her husband. She was talking to him, letting him know she did have cancer. And she wrote in her journal daily or weekly, whenever she had to describe how she was feeling, and things she wanted her husband to remember when she passed on. She gave it to a family member, told the family member where this journal was, but not to give it to her husband until after she was buried. It was such a beautiful experience."

Community Member, Peguis First Nation

power point presentation, video, and a brochure. Fort William First Nation created a power point presentation for community members.

In addition to these community resources, the EOLFN project, in partnership with the Canadian Hospice Palliative Care Association (CHPCA) and The Way Forward, created and evaluated culturally appropriate advance care planning resources which included the following:

– *Advance Care Planning Brochure*
– *Substitute Decision Maker Brochure*
– *Advance Care Planning Poster*
– *Advance Care Planning Facilitator's Guide and PowerPoint Presentation*
– *Advance Care Planning Video*

You will find the adaptable Microsoft Publisher and Word files, and PDF examples on the Advance Care Planning resources in folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education, section 5 – Advance Care Planning**.

1. **Advance Care Planning Pamphlet Publisher Template**
2. **Advance Care Planning Pamphlet Word Template**
3. **Example EOLFN Advance Care Planning Pamphlet**
4. **Substitute Decision Maker Pamphlet Publisher Template**
5. **Substitute Decision Maker Pamphlet Word Template**
6. **Example EOLFN Substitute Decision Maker Pamphlet**
7. **Advance Care Planning Poster Word Template**
8. **Example EOLFN Advance Care Planning Poster**
9. **Example EOLFN Advance Care Planning Presentation Facilitators Guide**
10. **Example EOLFN Advance Care Planning Power Point Presentation**
11. **Advance Care Planning Power Point Presentation Template**
12. **Example FWFN Advance Care Planning Presentation**
13. **Example SNGRT Advance Care Planning Brochure**
14. **Example SNGRT Advance Care Planning Presentation**

c. **Education for External Health Care Providers**

• Cultural Sensitivity Workshop

The Wiisokotaatiwin Program Leadership Team felt that engaging in dialogue with their external health care providers was very important in establishing mutual trust and understanding of Naotkamegwanning First Nation cultural ways and customs.

Based on the recommendations from their community needs assessment, and with direction from their Leadership Team, Naotkamegwanning First Nation developed a one-day cultural sensitivity

workshop. The workshop engaged community members and health care providers, along with external health care providers who provide home care to very ill community members.

After discussion with the Leadership Team and with guidance from the Elders, the Leadership Team decided to proceed with a narrative style of workshop that focused on storytelling and providing opportunities for questions and answers regarding customs and traditions.

Invitations were sent to all of the external health care providers asking them to attend the workshop, stressing the importance of effective cross-cultural communication. The invitation also let the participants know that the workshop would be presented by some of the highly respected Elders from the community. The external health care providers were invited to submit questions regarding the community's customs and traditions that would be discussed in the workshop.

Following the workshop, all participants, community members, and Elders feasted together on a traditional shore lunch. Participants completed a workshop evaluation. The results indicated external health care providers found it very beneficial and they requested more workshops be offered.

You will find a copy of a PDF evaluation form used in the workshop in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Promoting Education, section 6 – Cultural Sensitivity Resources**.

1. **Example NFN Cultural Sensitivity Workshop Participant Evaluation Survey**

"Being respectful of a culture that is very wise, and really knows how it should be going and making it work. That's our biggest challenge, or the western society's biggest challenge ... For a system to sort that through is going to be major. I don't think it's impossible, I think it definitely can be done. But there has to be a recognition ...and respect. There has to be dialogue around it, and a lot of times the First Nations communities are really reluctant to enter into that dialogue, for a lot of reasons and good historic reasons."

External Health Care Provider, Fort William First Nation

4. Providing care

Providing care begins when local health care providers are ready to offer the palliative approach to care for community members who wish to receive it. The palliative care program is organized, the guidelines are created, and the health care providers have received education. Following education, the health care providers begin changing their clinical practice. They build their confidence through supporting one another and sharing their knowledge and skills amongst themselves.

There were a number of resources that the four First Nations communities involved in the EOLFN project used to provide palliative care. Some of these were created and some were adapted to their needs from existing resources. These resources are described below.

All of the tools and resource templates can be located in the folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Providing Care**.

Wiisokotaatiwin Program Forms

The Naotkamegwanning First Nation Home and Community Care Coordinator worked with the Leadership Team, the EOLFN project consultant, and the Home and Community Care nursing provider agency to create a series of forms that would guide them when providing care to clients on the Wiisokotaatiwin Program. These included:

- A Referral or Intake Form to help them gather initial information when a person was referred to the program.

- A Program Assessment Form which includes detailed information on the client's care needs and issues related to pain and symptom management. This information helps create the care plan.

- Adopted the PPS (Palliative Performance Scale) as part of the assessment. This tool provides a score that helps health care providers to describe and communicate the functional status of clients to other members of the care team. It is helpful to track changes in client needs from month to month or week to week. People who score 50% or less on this scale would normally benefit from a palliative approach to care. People who score 30% or less on this scale are normally considered in need of end-of-life care. This tool was developed by Victoria Hospice and is commonly used in Canada.

- A Care Plan Form that was completed in the care conference that included the client, family, and health care providers.

- Protocol for passing at home (an expected death in the home protocol) that guides the health care providers through all the steps required to support the family, pronounce the death, and notify the police and funeral home.
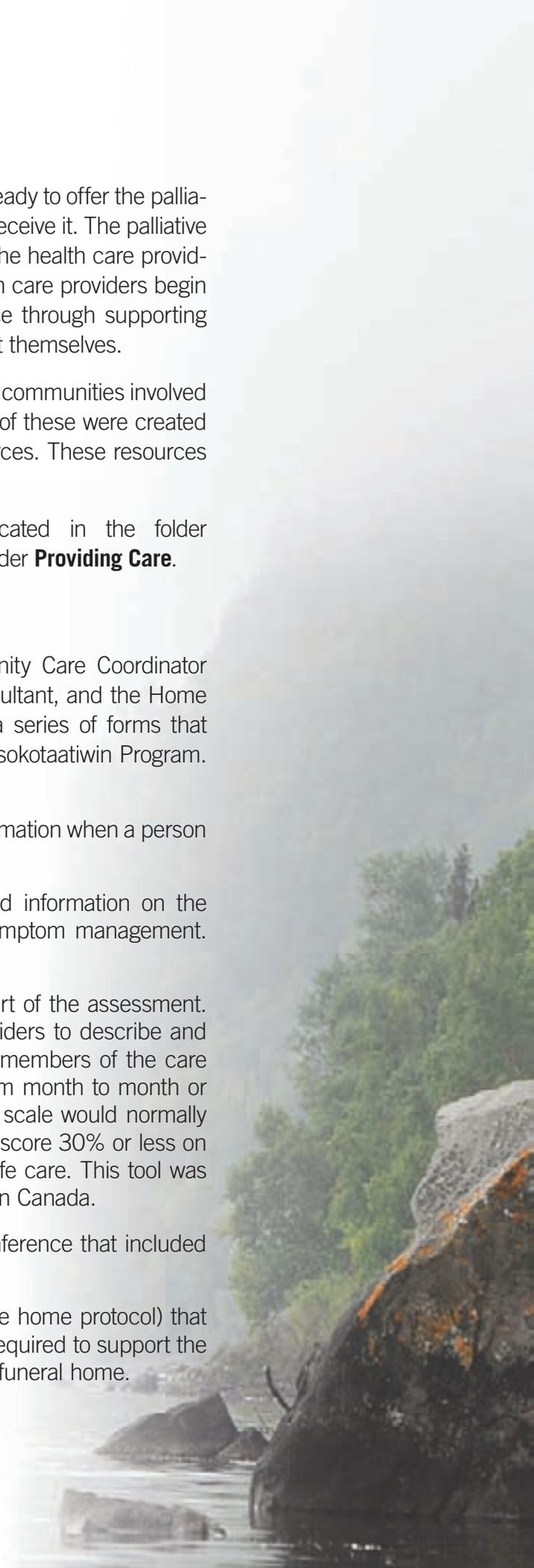
For more information, please contact Maxine Crow, Home and Community Care Coordinator, Naotkamegwanning Health Services at maxineranville@gmail.com.

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**.

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 Palliative Performance Scale**
7. **Example NFN Wiisokotaatiwin Program Assessment Form**
8. **Example NFN Wiisokotaatiwin Program Care Plan Form**
9. **Example NFN Wiisokotaatiwin Program Checklist for Home Passing**
10. **Example NFN Wiisokotaatiwin Client Referral Intake Form**

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 Indigenous 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.

Please find PDF examples from Six Nations on the Shared Care Outreach Team, which includes a care pathway and work plan in folder **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Providing Care**, section 2 – **Six Nations Shared Care Outreach Team**.

1. **Example SNGRT Shared Care Outreach Team Care Pathway**
2. **Example SNGRT Shared Care Outreach Team Description of Workplan**

Traditional Grief and Bereavement Program

This program was developed for family members of clients who received end-of-life care through the Six Nations of the Grand River Territory Palliative Care Program. The families were to have been on their grief journey for close to a year, and they were to be assisted in their grief with traditional practices. Family members attended ten weekly sessions that were facilitated by the Psychosocial/Spiritual/Bereavement Counsellor and a Traditional Knowledge Carrier. Five intended outcomes were sought and included: reawakening the spirit, holistic balance, teachings of self-care, and softening the grief and healing the heart to carry on.

The families were assisted to understand bereavement and the grief journey. They were offered traditional teachings with ceremonies, and taught self-care. They were assisted with listening, witnessing, companioning, and were supported and nurtured within a healing sharing circle. They were assisted to realize that we cannot change the past but learn to live in the future. The families were helped in healing their hurt with sharing of realistic expectations for grief and mourning, and by encouraging hope and giving honour and respect.

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

Four Strings Ceremony

Six Nations of the Grand River Territory experienced a high number of deaths in the community at the time that they were developing their Leadership Team. Health care providers were feeling a significant burden of grief and wondered how they would help heal the community when they needed to heal themselves.

The Leadership Team worked together with a Traditional Knowledge Carrier from the community, who lead the team through the "Four Strings Healing ceremony."

This ceremony is made up of major elements that include:

- A presentation of the traditional teachings surrounding this ceremony (these traditional teachings will not be described to maintain the sacredness of the teaching);

- Support of staff members to acknowledge their grief, process it, and let go of it;

- Regaining balance through cleansing; and

- Gaining coping skills and suggestions on how team members can lower their stress levels.

"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 [services in First Nations] especially 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, Peguis First Nation

This ceremony is useful for those coping with grief and loss issues and people who are interested in cultural based healing.

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.

5. Advocating for individuals and families

Advocating for individuals and families requires taking action to improve access to quality palliative care for those who need it. This can include managing challenges, getting additional resources, and developing new policies that are needed to sustain the palliative care program for clients in the First Nations community.

There were a number of strategies that the First Nations communities involved in the EOLFN project used to advocate for individual and families. Members of the Leadership Team and Chief and Council met with local, provincial and federal politicians, First Nations program funders, and provincial health care organizations/providers. They advocated for better service provision for their community members and more funding to meet the needs of their population. In addition, the EOLFN research team, which consisted of representatives from the four partnering First Nations communities, developed two policy documents which were shared nationally.

Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities document outlines an integrated approach to addressing the gaps in palliative care services in First Nations communities. It is based on the findings of the EOLFN research, and articulates a 10 point policy framework for palliative care in First Nations communities. Implementation of this framework would require collaboration and partnership between federal, provincial, and First Nations health services.

The document ***Recommendations to Improve Quality and Access to End-of-Life Care in First Nations Communities*** proposes recommendations to advance the Pan-Canadian Strategy for Palliative Care in a way that would adequately and equitably meet the need of First Nations people. This document was prepared at the request of federal MP Charlie Angus' office and focuses on the federal role and responsibility in providing health services to First Nations people.

"Cancer and addiction seems to be a big problem in our community and as a result we see a lot of chronic illnesses. Certainly that is increasing and I can see it as becoming more an epidemic problem down the road ... so definitely there's a need down the road for more palliative supports and community care."

Community Member, Fort William First Nation

The diagram **Palliative Care Programs for First Nations Communities: Integrating Two Systems** was created for health care decision makers and policy makers to guide their development of palliative care programs in First Nations communities (see page 73). It is based on the findings of the EOLFN project and, in particular, our learnings about the partnerships and collaborations that are essential within and across jurisdictions for successful capacity development.

The strengths and capacities that exist within First Nations communities and within regional health care systems across Canada are highlighted in relation to developing palliative care programs for First Nations communities. In the centre of the diagram, in the shaded area of overlap between the two systems, our capacity development strategies are listed. This space is a shared space, where First Nations communities and provincial and territorial representatives of Canada's health care system can bring their respective capacities together.

The capacity development strategies are building partnerships and relationships, as well as knowledge exchange and knowledge translation. Capacity development also requires an ethical space where equity, social justice, and humanistic care will be achieved through implementing both creative cross jurisdictional funding arrangement and Jordan's Principle (see https://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879) for people

"As we have had experience with the model, the tree model, that's been useful. We look at the community needs, we put in new partnering, and we also look at what the gaps in service. In the end it could be funding based, it could be distance to the next hospice or palliative care facility, and even the services such as the physicians the doctors, and local CCAC services that are available to the community. So the model definitely comes into play when you are looking at the program."

Community Lead, Six Nations of the Grand River Territory

of all ages who require palliative care and wish to die at home in a First Nations community.

We offer these documents to stimulate discussion and as resources to anyone who would find them useful. PDF versions of these documents can be found in **Phase 5 – Growing the Palliative Care Program** in the sub-folder **Advocating for Individuals and Families**.

1. **Framework to Guide Policy and Program Development**
2. **Recommendations to Improve Quality and Access to End-of-Life Care**
3. **Palliative Care Programs for First Nations Communities: Integrating Two Systems**
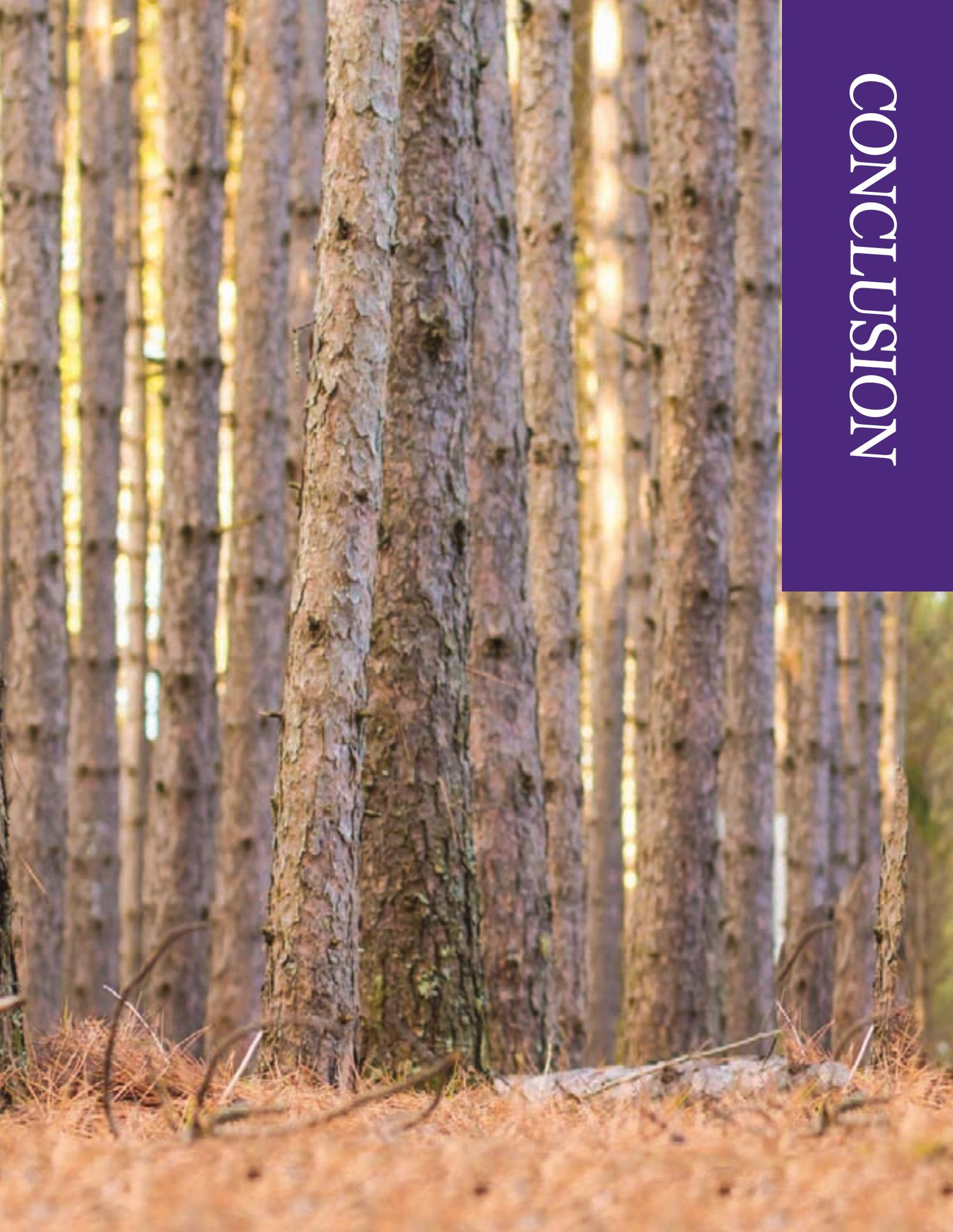
Conclusion

Based on the research conducted by the *Improving End of Life Care in First Nations Communities* team, this workbook offers an approach for creating local palliative care programs in First Nations communities. It provides a process for community development and change, practical guides, ideas, and lessons learned. It is intended primarily for use by First Nations communities; however, the research team hopes it is also useful for health care decision makers, policy makers, health care providers, and organizations.

All of the instructions provided are intended as guidelines, not requirements. We understand that our capacity development model and approach needs to be adapted to individual community culture and practices. We consider the workbook to be a living document; communities are encouraged to make adaptations as they use the contents. We respect the importance of empowering each community to develop their palliative care program in a way that best meets their needs and fits within their unique culture and context.

Our research findings indicated that developing palliative care programs in First Nations communities can be done using a process of community capacity development. Capacity development requires local communities to do the work described in this workbook. However, there is no doubt that new policy, more resources and better collaboration between the federal and provincial health care systems are needed to complement the local capacity development work. To promote national awareness of policy issues, the research team created a national stakeholder alliance of over 100 individuals and organizations. The research team also developed documents to address the policy issues and used them to create national awareness.

The first policy document, *Recommendations to Improve Quality and Access to Palliative Care in First Nations Communities*, is targeted at the federal government who has the mandate for Aboriginal health. This document provides four recommendations that are within federal jurisdiction; they can be implemented now through political will. The second document, *A Framework to Guide Policy and Program Development for Palliative Care in First Nations Communities,* targets health care decision makers at the First Nation, provincial and federal levels. Implementing these guidelines requires

Palliative Care Programs for First Nations Communities: Integrating Two Systems

Canada's Health Care Systems' Capacities

Health care services/organizations

Specialized palliative home care teams/programs

Skilled palliative care providers

Pain & symptom management experts

Specialized medication & equipment

Palliative care training & education

CAPACITY DEVELOPMENT STRATEGIES

Create partnerships & relationships between two systems

Engage in knowledge translation & exchange

Implement creative cross jurisdictional funding arrangements

Implement Jordan's Principle

OUTCOME

Customized palliative care programs that build on local assets & strengths in First Nations communities

First Nations Communities' Capacities

Leadership & vision for change

Local health care workers & services

Elders & Knowledge Carriers

Indigenous understandings of death/dying

Traditional caregiving practices

Natural helping networks

Advocacy

collaboration and overcoming jurisdictional confusion and barriers. Both policy documents are referred to in Phase 5 of the Workbook, in the section *Advocating for individuals and families* and are included with the resources.

How can Canada implement a new policy approach to support local capacity development and create customized palliative care programs for First Nations communities? The guiding principle of Two-Eyed Seeing from Mi'kmaw Elder, Albert Marshall, of Eskisoni First Nation in Nova Scotia, provides a vision. The EOLFN diagram, *Palliative Care Programs for First Nations Communities: Integrating Two Systems,* calls on health care decision makers to see with two eyes. One eye focuses on the strengths and capacities that exist in a First Nation community and the other eye focuses on the health care system as delivered by the provinces and territories. This approach offers the opportunity to engage in a shared capacity development process that incorporates the strengths and capacities of both. The EOLFN capacity development approach (the tree model) provides practical guidance for building partnerships, relationships, sharing knowledge, and skills and creating strategies together to overcome barriers in resources and policy.

We offer final words to inspire you from members of the Leadership Team, Naotkamegwanning First Nation:

"Now that we're doing this program, it's like a guideline of how things should be done and we're more knowledgeable now in that area that nobody wanted to touch on…"

"I don't know how many times I went to the hospital and seen elders scared in there, lonesome, and just being uncomfortable in that place."

"But I think, through this [palliative care] program, they'll feel more secure being at home knowing we did all that work for them. It will be more relaxing for them. They'll be around their family; they'll have a care plan in place. If that's their wish then they can be at home."

The research team wishes you well in your efforts.

Supplementary Resources

for developing palliative care programs in first Nations communities

National Resources

Organization	Description
Assembly of First Nations (AFN) http://www.afn.ca/en	AFN is a national advocacy organization representing the First Nations people of Canada. The AFN has passed a resolution to advocate for an increase in funding for Palliative Care in First Nations communities.
Canadian Hospice Palliative Care Association (CHPCA) http://www.chpca.net/	The CHPCA is the national voice for Hospice Palliative Care in Canada. Advancing and advocating for quality end-of-life/hospice palliative care. CHPCA has developed palliative care resources for Indigenous people; including: Training Manual for First Nations Home Support Workers and Knowledge Translation for Indigenous Communities - Policy Making Toolkit
Canadian Virtual Hospice www.virtualhospice.ca/	Canadian Virtual Hospice provides electronic information and support on palliative and end-of-life care, loss and grief. They have many relevant videos and other resources about providing palliative care for Indigenous people and to promote culturally safe care in the health care system.
First Nations and Inuit Health Branch (FNIHB) http://www.hc-sc.gc.ca/fniah-spnia/index-eng.php	FNIHB is the part of Health Canada that focuses on First Nations and Inuit health by providing support to community health promotion, home and community care, and the Non-insured health benefits program. They fund the Home and Community Care program that is the key local resource for caring for people with advanced chronic and terminal disease in First Nations communities.
First Nations Information Governance Centre http://fnigc.ca/	The First Nations Information Governance Centre is a dedicated Centre that will serve as the permanent home of the First Nations Regional Longitudinal Health Survey (RHS) and build upon that successful process to provide an abundance of information, research, training, data collection, analysis and dissemination services to First Nations at the community, regional and national levels. They collect data that is potentially relevant to document the need for palliative care in First Nations communities.
Institute of Aboriginal Peoples Health (IAPH). Canadian Institute of Health Research http://www.cihr-irsc.gc.ca/e/8668.html	IAPH fosters the advancement of a national health research agenda to improve and promote the health of First Nations, Inuit, and Métis peoples in Canada through research, knowledge translation and, capacity building. The Institute's pursuit of research excellence is enhanced by respect for community research priorities and Indigenous knowledge, values and cultures. This is a potential source of funding for research related to palliative care in First Nations communities.

Non-Insured Health Benefits (NIHB) http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestation/index-eng.php	Health Canada provides eligible First Nations and Inuit peoples with a specified range of medically necessary health-related goods and services when they are not covered through private insurance plans or provincial/territorial health and social programs. First Nations people who need access to medications and equipment for palliative home care access this from NIHB.
Pallium Canada http://pallium.ca/	Pallium Canada provides culturally appropriate inter-professional education in palliative and end-of-life care for health care providers, including for health care providers who work in First Nations communities or provide care to Indigenous people in hospitals or long term care homes.
Parliament of Canada http://www.parl.gc.ca/	The Parliament of Canada website has been included as a search tool that can be utilized to search for a Member of Parliament for advocacy. Indigenous Health issues are under federal jurisdiction under the Constitution of Canada. Contact your federal member of parliament to discuss the need for palliative care in your First Nations community.
Parliamentary Committee on Palliative and Compassionate Care (PCPCC) https://www.mcgill.ca/palliativecare/files/palliativecare/parliamentary_report_eng_dec_2011.pdf	The PCPCC was an ad-hoc all party group of MPs, dedicated to improving care for elderly, dying and vulnerable Canadians. Their report "Not to be Forgotten: Care of Vulnerable Canadians" was published in 2010 and includes recommendations for improving access and quality of palliative care delivery in First Nations communities.
The Way Forward http://www.hpcintegration.ca/	The Way Forward – a roadmap for an integrated palliative approach to care – seeks to achieve hospice palliative care that is available to Canadians when and where they need it. This includes providing palliative care for First Nations people. Their reports also address the need for culturally appropriate palliative care for First Nations people throughout the health care system.

Manitoba Provincial Resources

Organization	Description
Cancer Care Manitoba www.cancercare.mb.ca http://www.cancercare.mb.ca/home/patients_and_family/patient_and_family_support_services/aboriginal_services/	Resources for patients and families, prevention and screening information, statistics, community cancer programs, volunteers and research information. They provide Indigenous Services in conjunction with the Winnipeg Regional Health Authority.
Hospice & Palliative Care Manitoba www.palliativemanitoba.ca	Hospice & Palliative Care Manitoba is focused on helping individuals live as fully as possible until the end of life. They hold an annual conference each year that often includes presentations and workshops specific to palliative care in First Nations Communities.

Manitoba Regional Health Authorities http://www.gov.mb.ca/health/rha/	Each Regional Health Authority's Palliative Care Program provides services for people who have been diagnosed with a life-limiting illness. Click on the link provided to find the Regional Health Authority in your area. Health Authorities are important partners for First Nations communities to engage for providing palliative care.
Winnipeg Regional Health Authority http://www.wrha.mb.ca/aboriginalhealth/index.php	All services of the Winnipeg Regional Health Authority (WRHA) Aboriginal Health Services program are available for people who need palliative care. WHRA services include: Patient advocacy/support; Language interpretation and translation, Spiritual and cultural care; Community liaison, Discharge planning Dr. Mike Harlos, Director of Adult and Pediatric Palliative Care for the Winnipeg Regional Health Authority, has provided strong leadership for improving palliative care for First Nations people (see Palliative Info below).
Assembly of Manitoba Chiefs http://www.manitobachiefs.com/	The Assembly of Manitoba Chiefs (AMC) was formed in 1988 to act as an advocate on issues that commonly affected all of the First Nations of Manitoba. They have an important role to play in advocating for better access to palliative care in First Nations communities.
Palliative Info http://www.palliative.info/	This website was developed and is maintained by Dr. Mike Harlos who received the CHPCA Award of Excellence in 2006. The website includes many links and resources, including a section specific to First Nations/Aboriginal/Indigenous resources.

Ontario Provincial Resources

Organization	Description
Association of Ontario Health Centres - Aboriginal Health Access Centres (AHAC) http://www.aohc.org/aboriginal-health-access-centres	AHACs are Aboriginal community-led, primary health care organizations. They provide a combination of traditional healing, primary care, cultural programs, health promotion programs, community development initiatives, and social support services to First Nations, Métis and Inuit communities. Some staff of AHAC is engaged in providing palliative care services and they can be important members of local palliative care programs in First Nations communities.
Cancer Care Ontario https://www.cancercare.on.ca/	Cancer Care Ontario's primary focus is on cancer prevention, care, treatment, wait times, education, care, and research and resource information. They have an Aboriginal Cancer Strategy and one of their strategic priorities is to address the palliative and end-of-life care needs of Aboriginal people with cancer. They provide Aboriginal Patient Navigators in all Ontario Cancer Centres and have created a palliative care toolkit for families and communities involved in palliative and supportive care ("Tools for the Journey") that is available on their website

Centre for Education and Research on Aging & Health (CERAH) Indigenous Peoples Health and Aging Division https://cerah.lakeheadu.ca/indigenous-peoples-health--aging/	CERAH's Indigenous Peoples' Health and Aging Division seek to promote culturally relevant research, education and health care services for Indigenous people in Canada, especially in Northwestern Ontario. CERAH has a 2day First Nations based Palliative Care curriculum, 'Palliative Care for Front Line Workers in First Nations Communities'. This education can be accessed by contacting (807)766-7271
Chiefs of Ontario http://www.chiefs-of-ontario.org/	The Chiefs of Ontario is a political forum and secretariat for collective decision-making, action, and advocacy for the 133 First Nations communities located in Ontario. They have supported initiatives to improve access to quality palliative care for their members.
Caring for the Terminally Ill: Honouring the Choices of the People http://eolfn.lakeheadu.ca/wp-content/uploads/2013/01/Honouring-the-Choices.pdf	This is a resource book designed to support Indigenous people and their caregivers in rural and remote communities living with life-limiting illness. It was developed in Northwestern Ontario by 4 women who identified the need for a culturally appropriate palliative care resource.
Hospice Palliative Care Ontario http://www.hpco.ca/	HPCO envisions a future where every person and family in the province of Ontario can quickly and easily access the finest standard of hospice palliative care when required. This includes people living in First Nations communities. They organize an annual conference that includes presentations and workshops specific to palliative care in First Nations communities.
Ontario Telemedicine Network (OTN) http://otn.ca/en/programs/aboriginal-health-access-centres	OTN is working with Aboriginal Health Access Centres to integrate telemedicine in First Nations communities in Canada. OTN is a valuable resource for accessing specialist palliative care consultations for people living in First Nations communities. OTN can now be done using a tablet which is both inexpensive to purchase and portable to take to meetings and to clients' homes. It is a valuable resource to connect internal and external health care providers for care conferences.
Ontario Community Care Access Centres (CCAC) www.http://healthcareathome.ca	CCAC provides: support to patients transitioning from hospital to home; support to patients moving into long term care; help for patients to stay at home as long as possible; support to connect people with primary care providers and care for palliative care patients. Services include care coordination, nursing, personal support, and therapies in the home. In the Ontario First Nations communities in the EOLFN research, a Memorandum of Understanding was negotiated with the community's regional CCAC to describe what CCAC services could be accessed by clients needing palliative home care.

Palliative Pain and Symptom Management Consultants http://www.acclaimhealth.ca/wp-content/uploads/2013/10/Palliative-Care-Consultation-Network-Members-PublicApril-28-2015.pdf	Palliative Pain and Symptom Management Consultants are funded by the Ontario Ministry of Health and Long Term Care. They provide support to service providers in home care and other settings by offering: consultation, education, mentorship and linkages to palliative care resources. In the EOLFN project, the PPSM consultants were excellent resources and assisted the health care providers in the Ontario First Nations communities developing their programs.

Note: The EOLFN research team worked in Ontario and Manitoba, so provincial resources are limited to these provinces. This list is by no means exhaustive and we encourage you to look for similar programs in your home province, region, and community.