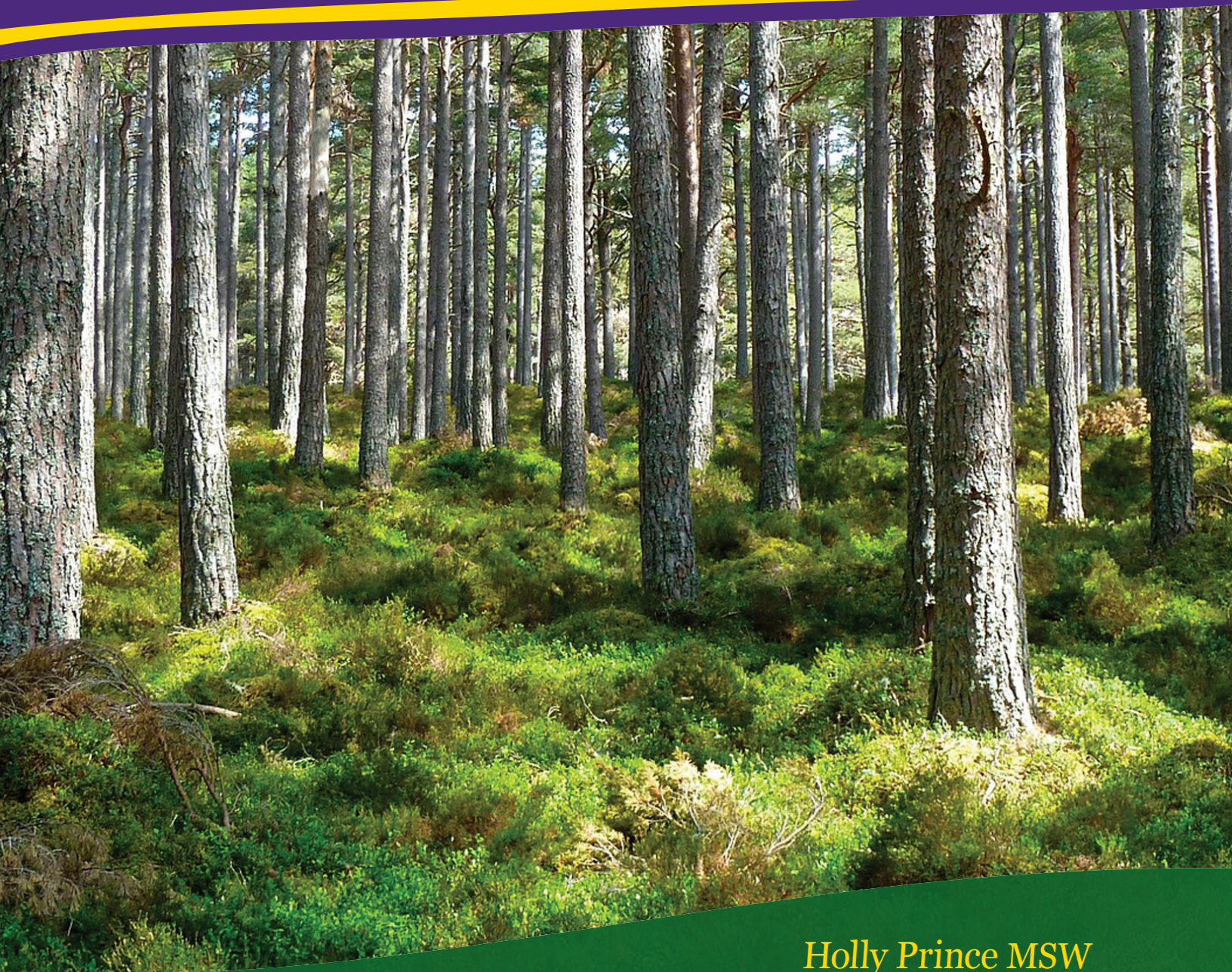
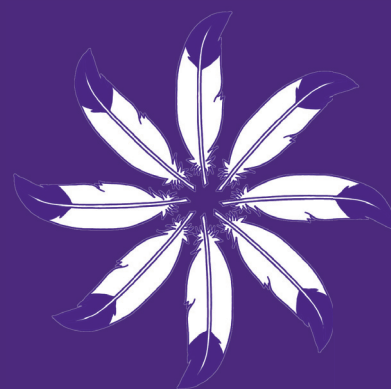
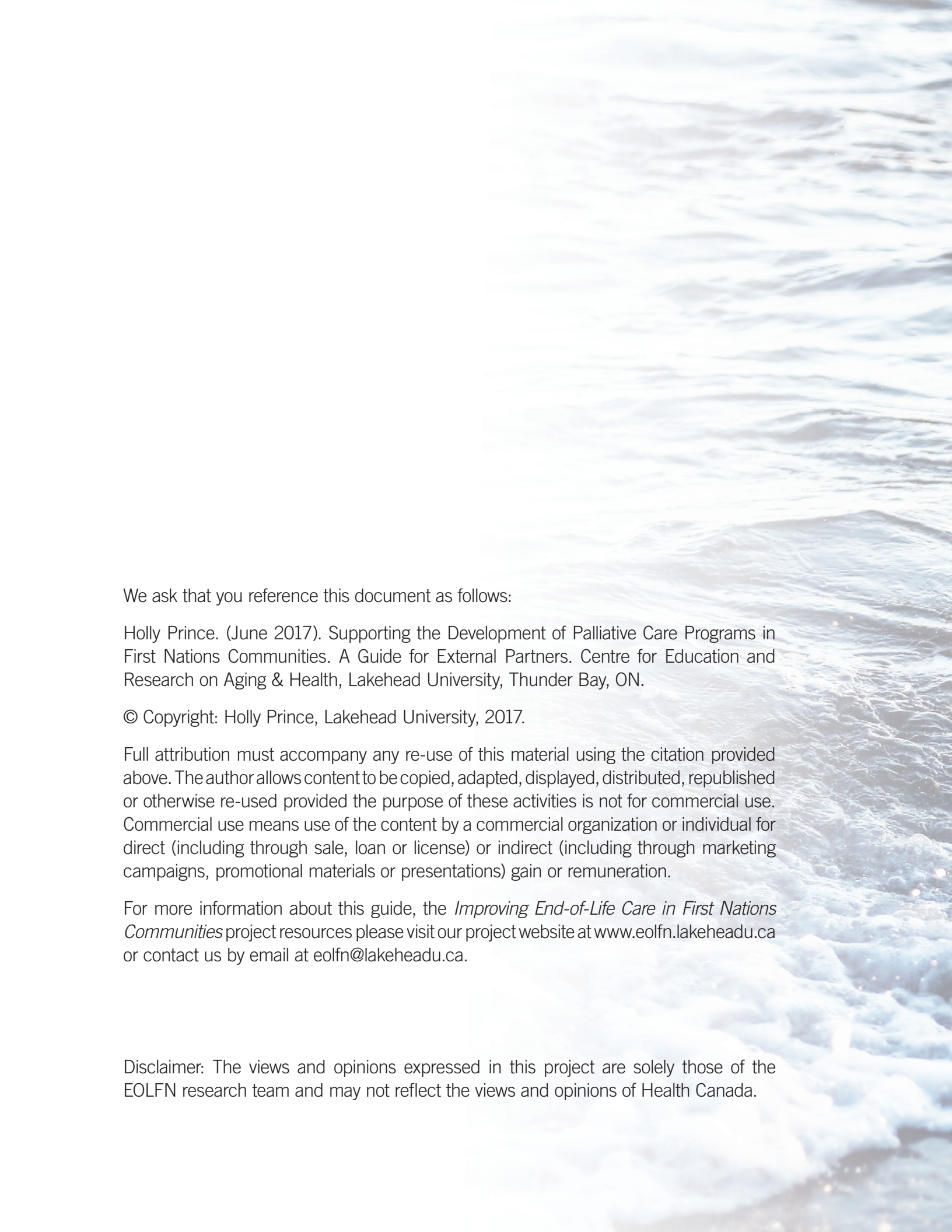


Supporting the Development of Palliative Care Programs in First Nations Communities

A Guide for External Partners



Holly Prince MSW

The background of the page is a photograph of ocean waves. The water is a light blue-grey color, and the waves are white with foam, breaking from the right side of the frame towards the left. The lighting is soft, creating a gentle, textured appearance on the water's surface.

We ask that you reference this document as follows:

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

Disclaimer: The views and opinions expressed in this project are solely those of the EOLFN research team and may not reflect the views and opinions of Health Canada.

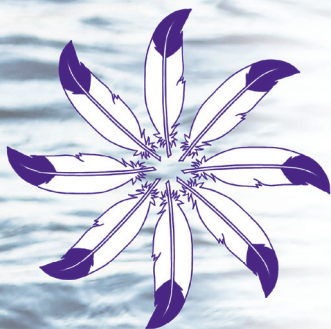


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We would like to thank the 24 First Nations communities in Ontario who participated in this Health Canada mentorship project. Their valuable insights and sharing their communities' experiences, strengths and challenges, has contributed greatly to the development of this guide. We would like to acknowledge the time and commitment of Vanessa Follon along with the staff at the First Nations and Inuit Home and Community Care, Ontario Regional Office who contributed to the success of this project. Finally, we would like to thank Health Canada for their financial contribution and support of the project.

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GLOSSARY






Glossary

Catalyst: In this guide, a catalyst refers to someone or something that stimulates and mobilizes change within the First Nations 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.

Community Capacity: In this guide, 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 guide, capacity development is the process of growth and change that occurs inside the First Nations 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 five 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. It does take a number of years to develop a sustainable palliative care program.

End-of-Life Care: In this guide, 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.

Life-Limiting Illness: In this guide, 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.

Palliative Care: In this guide, 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.

Two-Eyed Seeing: Mi'kmaw Elder Albert Marshall suggests a two-eyed seeing approach that incorporates Indigenous and Western ways of knowing and marrying the strengths from each

by using from both eyes (Bartlett, Marshall, & Marshall, 2012). First Nations communities may have different understandings of health, illness, wellness, care at the end of life, grief and loss as compared to accepted views of western medicine and formalized palliative care programs. Since palliative care is grounded in the social, psychological, and spiritual needs of the dying person, appropriately meeting and addressing the person's needs for pain and symptom management is critical.

Cultural Humility: Offering health care in a way that respects First Nations people as the decision-maker in their own care requires cultural humility. Cultural humility is a process of self-reflection to understand personal and systemic conditioned biases, and to develop and maintain respectful processes and relationships based on mutual trust (First Nations Health Authority, 2017). It recognizes the power/privilege imbalance that exists between clients and health care providers. The goal is the process, not the end product (Yancu and Farmer, 2017).



A vibrant photograph of a forest scene. In the foreground, a lush green grassy field is visible, with some fallen leaves scattered on the ground. The middle ground is filled with a dense canopy of trees, their leaves in various shades of green, some showing early autumn colors. Several tree trunks are visible, including a prominent one on the left covered in ivy. The background is a soft-focus view of more trees and foliage, creating a sense of depth. The overall lighting is bright and natural, suggesting a sunny day.

BACKGROUND



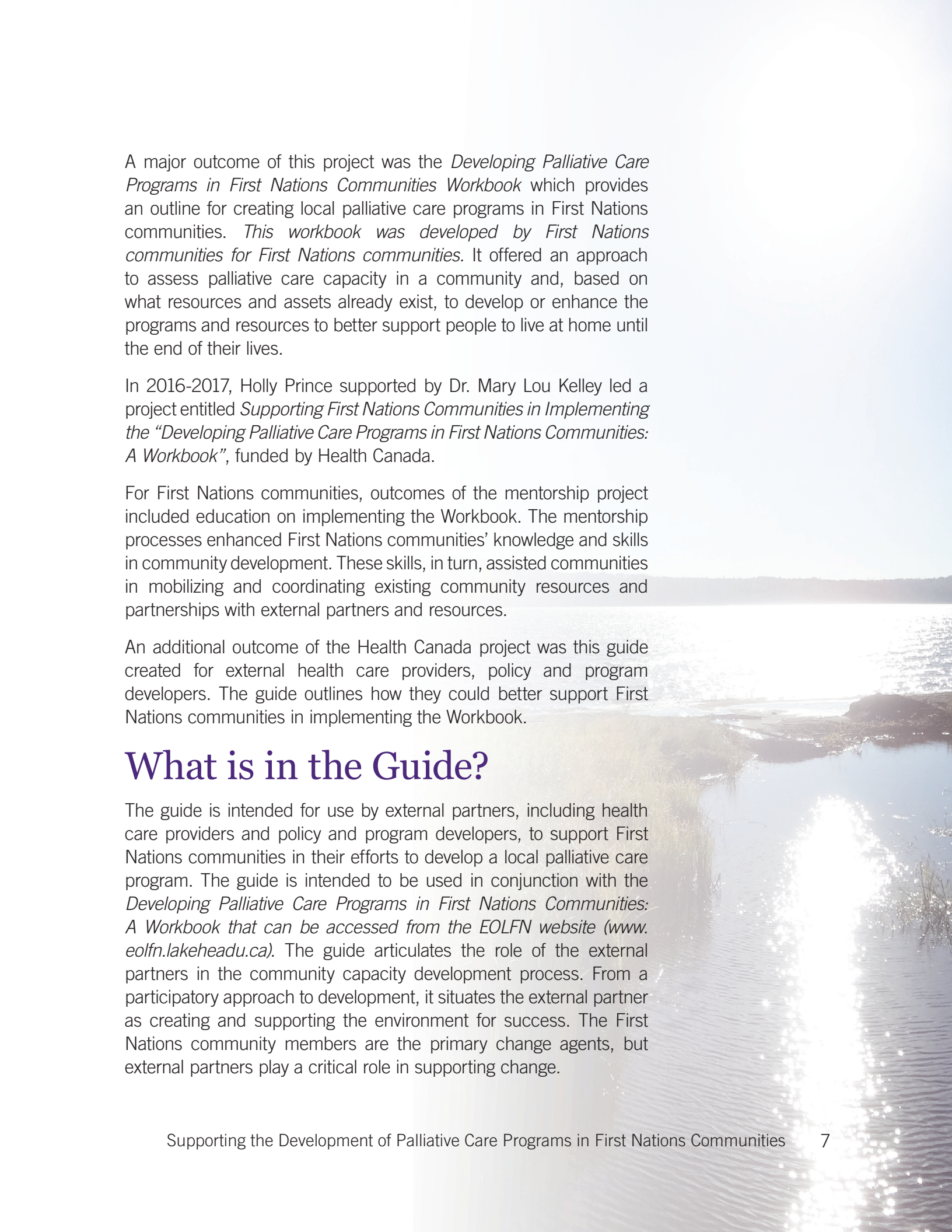
Background to the Guide

First Nations communities hold an enormous amount of traditional and community-based knowledge and expertise in negotiating the personal, familial, and community experiences of caring for community members who are very sick. However, through colonization, health systems have been imposed on First Nations people and western health systems typically do not support Indigenous approaches to care. In addition, the home and community care needs of seriously ill people living in First Nations communities have significantly increased in the last ten years due to an aging population and an increase in chronic and terminal illnesses.

Currently, First Nations communities lack the health services and other supportive community infrastructure to meet the growing demand for home care services for people with complex and high intensity care needs, in particular the very elderly, frail, and people at the end-of-life. There are few choices for people at end-of-life and local, formalized, culturally relevant palliative care programs in First Nations communities are rare. There was also little research evidence to guide First Nations communities in addressing the unmet need for palliative care services.

A research project entitled *Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Policy and Program Development (EOLFN)* developed a community-focused approach to addressing these gaps at the local level. This project was based at the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University, Thunder Bay, Ontario and funded by the Canadian Institutes of Health Research (2010-2015). The research was conducted in partnership with four First Nations communities in Ontario and Manitoba.

The goal of the EOLFN research was to improve the end-of-life care in the four First Nations communities by developing community-based palliative care programs and teams. This research 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.



A major outcome of this project was the *Developing Palliative Care Programs in First Nations Communities Workbook* which provides an outline for creating local palliative care programs in First Nations communities. *This workbook was developed by First Nations communities for First Nations communities.* It offered an approach to assess palliative care capacity in a community and, based on what resources and assets already exist, to develop or enhance the programs and resources to better support people to live at home until the end of their lives.

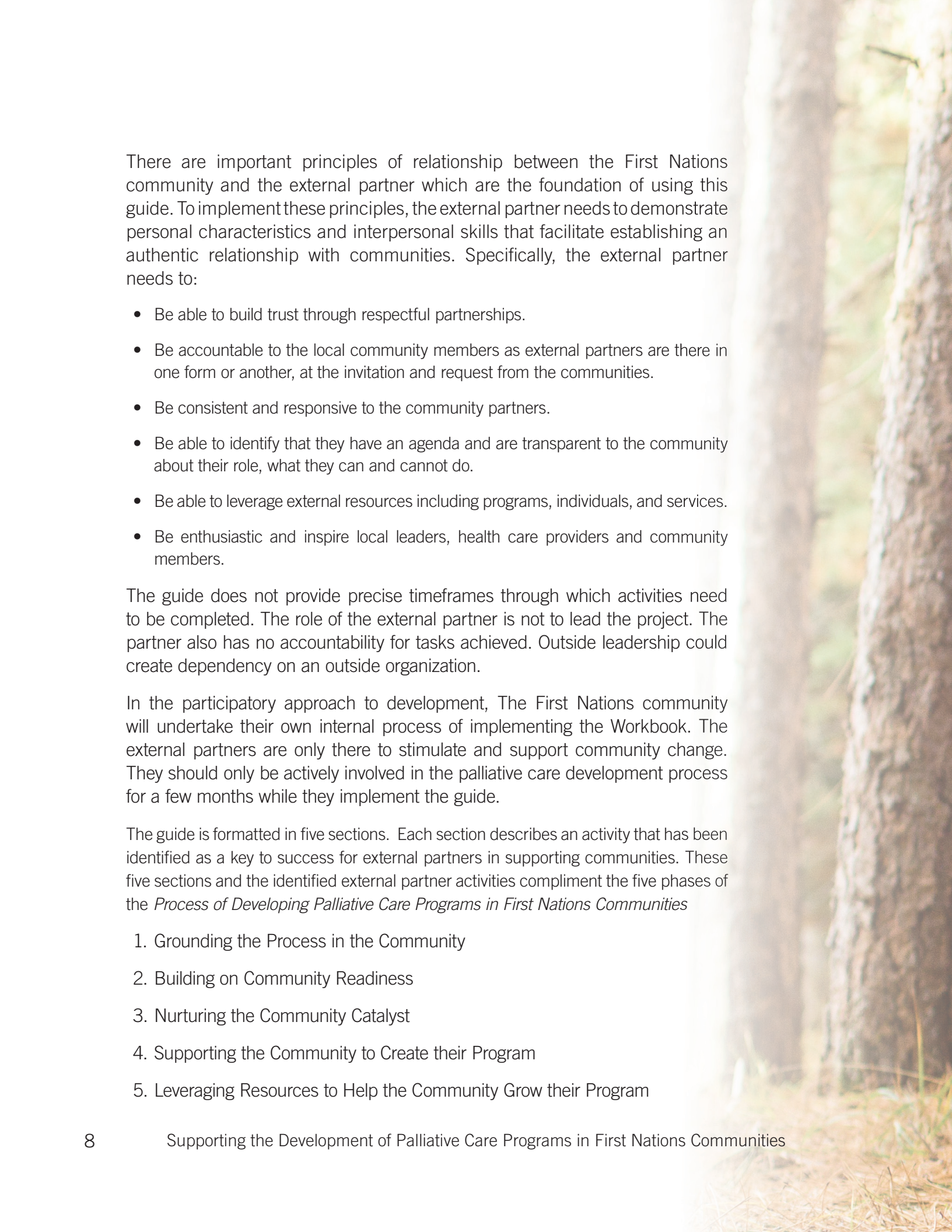
In 2016-2017, Holly Prince supported by Dr. Mary Lou Kelley led a project entitled *Supporting First Nations Communities in Implementing the “Developing Palliative Care Programs in First Nations Communities: A Workbook”*, funded by Health Canada.

For First Nations communities, outcomes of the mentorship project included education on implementing the Workbook. The mentorship processes enhanced First Nations communities’ knowledge and skills in community development. These skills, in turn, assisted communities in mobilizing and coordinating existing community resources and partnerships with external partners and resources.

An additional outcome of the Health Canada project was this guide created for external health care providers, policy and program developers. The guide outlines how they could better support First Nations communities in implementing the Workbook.

What is in the Guide?

The guide is intended for use by external partners, including health care providers and policy and program developers, to support First Nations communities in their efforts to develop a local palliative care program. The guide is intended to be used in conjunction with the *Developing Palliative Care Programs in First Nations Communities: A Workbook that can be accessed from the EOLFN website (www.eolfn.lakeheadu.ca)*. The guide articulates the role of the external partners in the community capacity development process. From a participatory approach to development, it situates the external partner as creating and supporting the environment for success. The First Nations community members are the primary change agents, but external partners play a critical role in supporting change.



There are important principles of relationship between the First Nations community and the external partner which are the foundation of using this guide. To implement these principles, the external partner needs to demonstrate personal characteristics and interpersonal skills that facilitate establishing an authentic relationship with communities. Specifically, the external partner needs to:

- Be able to build trust through respectful partnerships.
- Be accountable to the local community members as external partners are there in one form or another, at the invitation and request from the communities.
- Be consistent and responsive to the community partners.
- Be able to identify that they have an agenda and are transparent to the community about their role, what they can and cannot do.
- Be able to leverage external resources including programs, individuals, and services.
- Be enthusiastic and inspire local leaders, health care providers and community members.

The guide does not provide precise timeframes through which activities need to be completed. The role of the external partner is not to lead the project. The partner also has no accountability for tasks achieved. Outside leadership could create dependency on an outside organization.

In the participatory approach to development, The First Nations community will undertake their own internal process of implementing the Workbook. The external partners are only there to stimulate and support community change. They should only be actively involved in the palliative care development process for a few months while they implement the guide.

The guide is formatted in five sections. Each section describes an activity that has been identified as a key to success for external partners in supporting communities. These five sections and the identified external partner activities compliment the five phases of the *Process of Developing Palliative Care Programs in First Nations Communities*

1. Grounding the Process in the Community
2. Building on Community Readiness
3. Nurturing the Community Catalyst
4. Supporting the Community to Create their Program
5. Leveraging Resources to Help the Community Grow their Program



Grounding the Process in the Community

PHASE 1

Grounding the Process in the Community

Phase 1 of the Workbook “*Grounding the Program in Community Values and Principles*” acknowledges and respects that the local palliative care program needs to grow out of the roots of individual, family, community and culture.

The work done in this section focuses on the preparation and planning that the external partner needs to do to be prepared to work through the guide. This foundation of grounding the development process in the community acknowledges that community empowerment and mobilization are the keys to success in achieving sustainable change.

The external partner’s role in Phase 1 is to:

- Focus on the skills required to be an effective support
- Be willing to accept their role as an “outsider” who cannot control process or outcomes
- Be willing to adopt a stance of cultural humility and two-eyed seeing
- Develop a thorough knowledge of the Workbook
- Embrace the principles and approach of community capacity building and participatory approaches to development.
- Develop an understanding of the palliative approach to care and how it can be integrated into existing programs in First Nations communities.
- Develop an understanding of First Nations health and social care programs, accountability and funding frameworks.

1. Process of Developing Palliative Care Programs in First Nations Communities

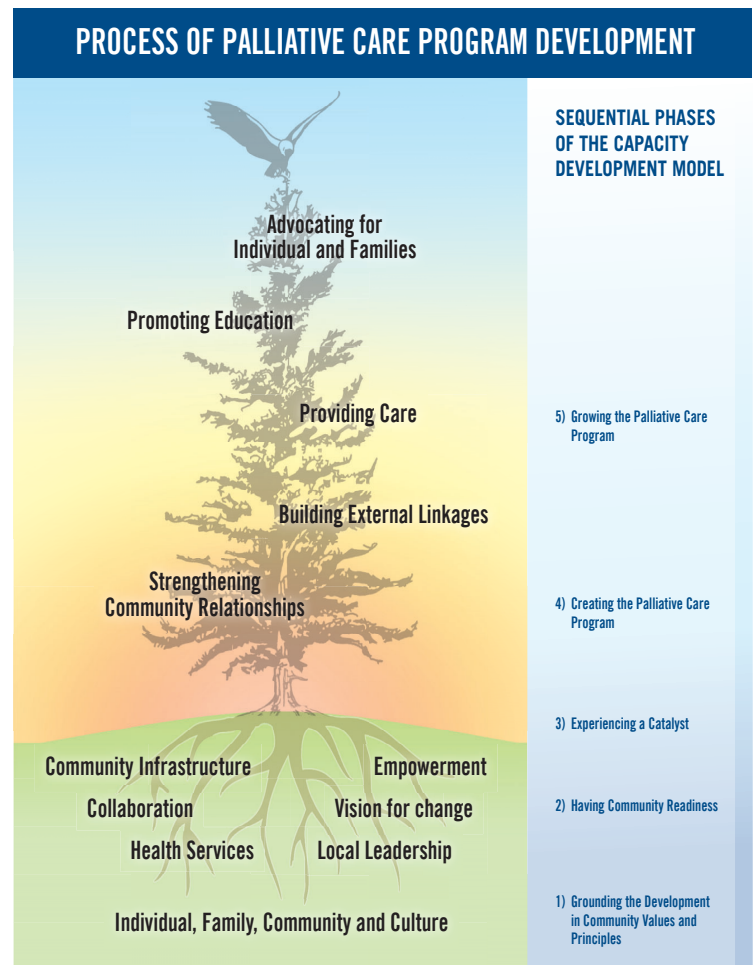
External partners must develop a thorough understanding of the Workbook to be successful in implementing this guide. Partners need to have in depth knowledge of the five phases that make up the *Process of Developing Palliative Care Programs in First Nations Communities*. There are also tools and resources developed for each phase that the external partners need to be familiar with in order to be effective in supporting First Nations communities.

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

The tree diagram outlines **five phases** of developing a palliative care program in a First Nations community. Beginning at the bottom, each phase needs to build on and evolve from the phase below; however, work in each phase is continuous and ongoing. The rate of progress in each phase and each community 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 may be affected.

The palliative care program ultimately becomes integrated into existing programs, such as Home and Community Care or Long Term Care, and is not a separate, specialty program. In the palliative approach to care, palliative care is understood to be an added layer of support that enhances services, but does not replace existing programs.

While palliative care program development may be led by the First Nations health care providers, it needs to involve the whole community such as Elders, families, and volunteers to be accepted and sustainable.



A PowerPoint Presentation which outlines all the five phases of the Workbook is included as a resource to accompany this guide. This presentation can be adapted by the external partner in their work with the First Nations community and used as an educational tool in outlining the process. The Workbook and all accompanying tools and resources can be found on the EOLFN website at www.eolfn.lakeheadu.ca.

2. Community Capacity Development

Community capacity refers to all 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 local palliative care program. The existing community capacity influences its readiness to move ahead with creating the palliative care program. Where significant gaps in community capacity exist, communities may need to address these gaps prior to beginning to create their local palliative care program. For example, if team work amongst community health and social care staff is limited, then efforts to engage others in providing palliative care and working together are important prior to proceeding further with a palliative care program.

Community capacity development is the process of growth and change that occurs inside the First Nations community as members work together towards their goal of creating the local palliative care program. Development follows the *Process of Palliative Care Program Development* 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. Barriers must be overcome along the way and communities may find themselves moving forward and backward in their capacity development journey.

Community capacity development is discussed throughout the Workbook and is the main concept represented in the tree model that

is used in every phase. Since development of the program builds on the existing community capacity, events and people outside of the community are not responsible for the direct creation, implementation, or evaluation of the First Nations palliative care program. The capacity development process acknowledges that events internal and external to the community can facilitate or become barriers to progress.

There is a role for external health and social care providers, policy and program developers in the community capacity development process. This role focuses on being a stimulus for community mobilization, supporting the work of the person who is the internal community catalyst, and creating a supportive external environment to promote and sustain the change. The external partner is there to support the establishment of local palliative care programs using existing resources with the goal of engaging with community members who are committed to working together.

In capacity development, outsiders can HELP CHANGE HAPPEN, but they cannot and should not try to MAKE CHANGE HAPPEN. Only people inside the community can make change happen. Change will evolve at the pace and direction that meets the overall needs of the community. Outsiders need to LET CHANGE HAPPEN in the unique way that meets community need. Outcomes will not be a standardized “one size fits all” palliative care program. Predetermined and standardized outcomes should not be expected or required.

3. Participatory Approaches to Development

A participatory approach to program development allows First Nations communities and their partners to create new knowledge through social innovation. Social innovation develops creative solutions to problems or issues that are more effective, because solutions are based on the experiences of individuals, communities, and organizations.

Like community capacity development, social innovation is a bottom up process. It is dynamic and non-linear. While it cannot be controlled, it benefits by external stimulus, incentives and

support. This suggests that a person or organization outside of the community (the partner) could create an environment to foster and support the catalyst. The catalyst, who is a person inside the community, takes the community vision and moves it from being an idea to becoming a concrete plan of action and a commitment to change.

Within a participatory approach to development, the key elements focus on collaboration, education, and action, which can guide not only those internal people leading the development of the program, but also provide a strong foundation of where to situate the external partner in the process of community capacity development.



A close-up photograph of a pine branch. The branch is covered in dense, vibrant green needles. A small, orange-brown cone bud is visible in the center of the branch. The background is a soft-focus view of other pine branches and a clear blue sky.

Building on Community Readiness

PHASE 2



Building on Community Readiness

Phase 2 of the Workbook *“Having Community Readiness”*, highlights the importance of building upon six characteristics that influence community readiness to develop a local palliative care program. These characteristics include sufficient community infrastructure, health services, collaboration, empowerment, vision for change and local leadership.

The external partner’s role in Phase 2 is to:

- Develop a collaborative, respectful partnership by building on the community’s readiness
- Engage with the community, focusing on their strengths and assets
- Mobilize existing resources
- Create linkages amongst First Nations communities, leaders and health care providers
- Identify individual roles, responsibilities and expectations in the change process
- Develop a trusting and respectful relationship with the community Lead

1. Invitation from the First Nations Community

The external partner would become involved with the First Nations community in implementing the Workbook only at the invitation and request from the communities. The request for external partner involvement may be initiated by either the partner or community as described below:

1. The external partner may have an organizational mandate to work with First Nations communities, providing services, and/or education. The external partner thus wishes to promote or provide education on the Workbook to First Nations communities with the goal of stimulating change. Through initial discussions between the First Nations community and external partner, the community

identifies that developing local palliative care is a priority in their community and they would like partner support in implementing the Workbook

2. The First Nations community has expressed an interest and vision to want to implement the Workbook in the community. Therefore, the community has reached out to external partners for help and support in doing so.


The external partner can become involved in the First Nations communities' process during any stage of their palliative care program development. However, it is ideal if the partner is involved from the beginning. This guide describes the role of the partner in the program development process from the very beginning of the community development and assumes the partner would be invited to assist when a local Community Lead is identified.

There is no timeframe on how long engaging with the community will take. It is a process that cannot be rushed and takes a great deal of time and effort to develop a trusting relationship. External partners need to acknowledge that their roles and the organizations that they come from places them in a position of power and that this has an impact on the development of genuine collaborative partnerships.

2. Developing a Trusting and Respectful Rapport with the Community Lead

The external partner would first engage with a local Community Lead who has been identified by the First Nations community. The Community Lead would be the person who will take the lead in creating, growing and promoting the palliative care program. The formal job title of the Community Lead is less important than the qualities and skills of that person. The Community Lead will inspire and help organize other health care workers and community members to achieve their goals.

If a Community Lead has not yet been identified by the community, the external partner could reach out to existing known contacts to discuss who might be appropriate and available for the role. The external partner can also provide the community with the description of Community Lead role which can be found in the **Phase 3 – Experiencing a Catalyst** section of the Workbook.



During this initial engagement, it is important to discuss the responsibilities and expectations of the external partner, identify cultural protocols and appropriate language to be used throughout the process, and to stimulate ideas of how to get more community members involved in the process.

The external partner's role is to encourage community mobilization, support the internal community catalyst, and create a supportive external environment to promote and sustain the change. They are not responsible for the development, implementation, or evaluation of the local palliative care program.

The Community Lead can help the external partner to identify language that would be culturally appropriate to use in describing the palliative care development work. Although the Workbook identifies creating a local *palliative care program* as the desired outcome, the process of developing capacity to provide care to the seriously ill is really the most important outcome.

Some communities may not want to use the term "program" because a *program* may seem too formal. For the external partner, the important thing to stress is that the desired outcome is formalizing and enhancing what the community already does to provide care for those who are very sick and/or at end-of-life. The capacity development is to enhance services and supports for people and their families so that people can die at home with good pain and symptom management, if that is their choice.

In addition to the above, the external partner may discover language about health and illness that is not culturally appropriate to use when working with First Nations communities, and the external partner needs to be aware of this. For example, providing care at home until the time of passing may be more acceptable as language than using the term palliative care. In some communities, explicitly talking about death or dying (anticipating death) may not be acceptable. Each community's situation will be unique and cultural humility will prevent inappropriate use of language.

Involving the whole community in capacity development is accomplished through creating an Advisory committee. This is a very important step as the work needs to be community driven

and not only the responsibility or vision of a single person. The external partner can help keep the focus of the work on the whole community and affirm that active participation in the community is needed.

The partner's discussion with the Community Lead would focus on stimulating ideas about how to get more people engaged in order to create an Advisory Committee. The Advisory Committee would include the Community Lead, along with other interested community members, including formal health care providers, members of leadership and spiritual or cultural leaders in the community. At this stage in the program development, it is highly recommended that the Advisory Committee remain small in number, for example 5-10 people. A small group is easier to organize and work with to create manageable plans.

The external partner could use this discussion as an opportunity to help the Community Lead to think outside the box and encourage them to work with people that they may not normally identify as care providers. Examples of community members who could participate in the Advisory Committee are volunteers, Elders workers, medical van drivers, or possibly the administrative person who is responsible for organizing travel arrangements. The external partner could prompt this discussion with:

“When someone is sick in your community and either wants to stay in the community to receive their care, or is wanting to come back to the community from the hospital, who are all the people that would help make this happen?”

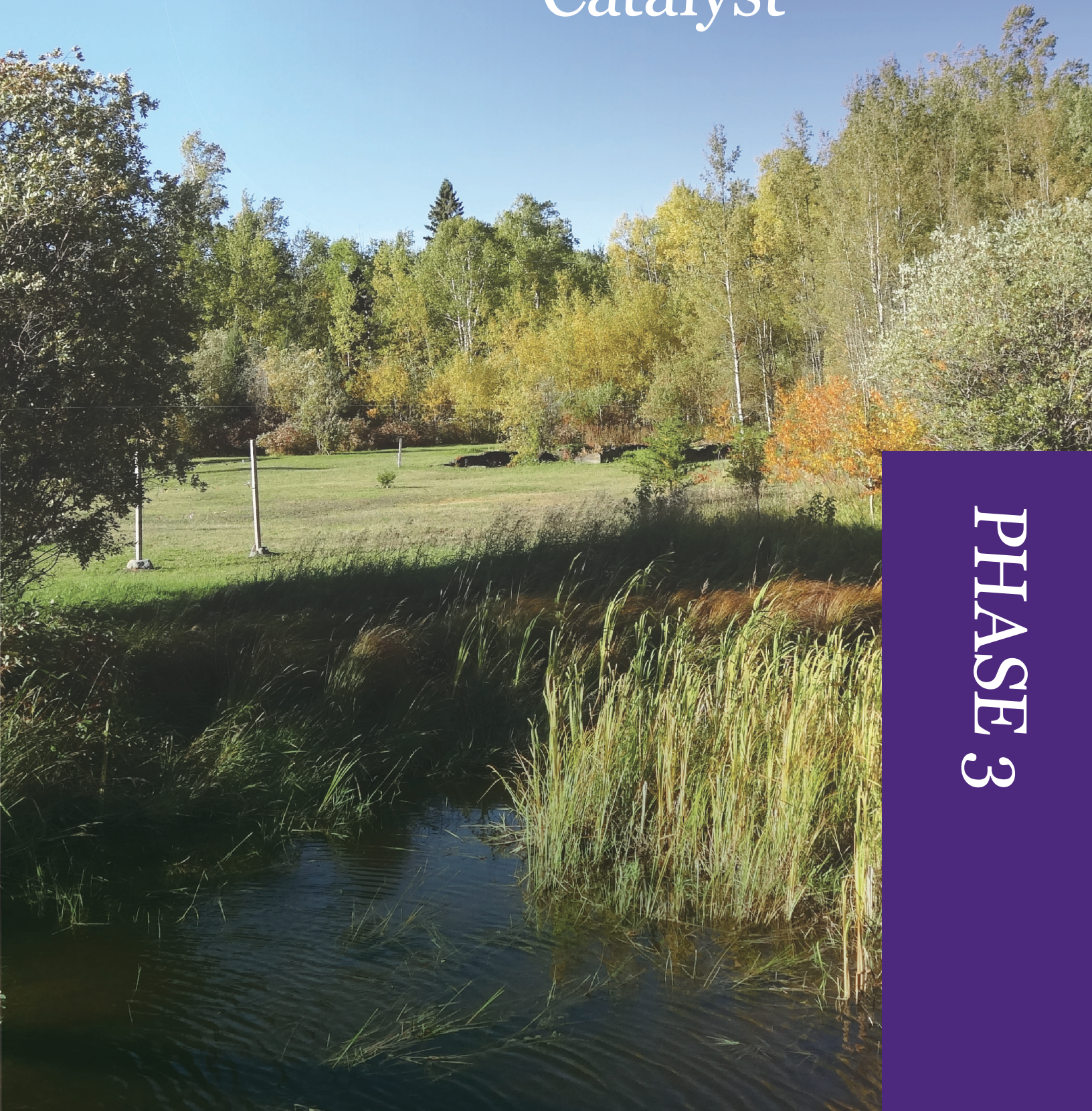
“Who are all the people that are involved in this process?”

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



Nurturing the Community Catalyst

PHASE 3





Nurturing the Community Catalyst

Phase 3 of the Workbook, *“Experiencing a Catalyst”* describes launching the process of community change that will create the palliative care program. Change is initiated in the community by 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 strengthens the community vision and moves it from being an idea or wish, to being a commitment to action that will create and formalize the new program. In the EOLFN research project, the catalyst was a local health care provider who was passionate about improving palliative care. She became the Community Lead who engaged other community members to form an Advisory Committee to guide the remainder of the community development process.

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 external partner’s role in Phase 3 is to:

- Mentor and support the Community Lead
- Provide education on the palliative approach to care
- Create opportunities to help the development of a palliative care program

The Community Lead would begin by organizing a meeting and inviting all of the identified people to attend. This event is described in the Workbook. This meeting could be formal or informal depending on the community’s needs. The intent of this meeting is to focus on community strengths, to build confidence and a sense of empowerment amongst community members, ensure local collaboration and educate care providers and community members.

The external partner may be present at this meeting and could provide support to the Community Lead along with providing education to the group about the palliative approach to care. The external partner may also help the Lead by co-facilitating a discussion to get the conversation started. Lastly, they could help facilitate the community in developing practical plans of action that start to address objectives and goals.

The following are some tools to help facilitate this meeting:

1. Education on the Palliative Approach to Care PowerPoint Presentation

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 did not have access to this care, especially those living in First Nations communities.

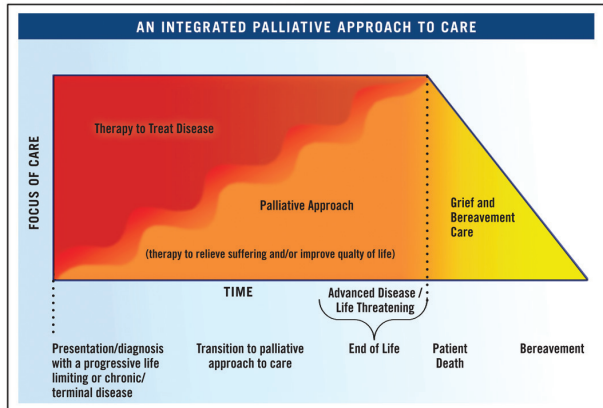
Today, national groups such as the Canadian Hospice Palliative Care Association and the Canadian Medical Association think of palliative care more as a philosophy and an approach to care. It can benefit people with any progressive and life limiting illness, not only cancer. Experts now think the palliative 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 as these 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.

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 the workbook.

Palliative Approach to Care

- In the past, palliative care used to be viewed as a specialty team or program that occurred in a hospital or hospice
- Only offered in the last few days or weeks of life, and usually only to cancer patients
- Now we think of it as a philosophy or approach to care
- Can benefit people with any progressive and life limiting illness, not only cancer
- Should be integrated into all settings of care
- Offered by all health care providers who provide primary care (doctors, nurses, PSW, social workers, etc.)

Integrated Palliative Approach to Care



This 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.

Begins at diagnosis with a progressive life limiting or chronic/terminal disease

- Care focuses on treating the disease
- Majority of care provided by primary health care providers in the community

The palliative approach focuses on:

- Open and sensitive communication about the prognosis and illness trajectory
- Advance care planning if culturally appropriate
- Psychosocial and spiritual support
- Pain and symptom management

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. Initially, there is a greater focus on therapies to modify the disease.

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.

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.

Over time, there is a gradual transition to end-of-life

- Disease is advanced and life threatening (last weeks/ days of life)
- Care focuses on relieving suffering and improving quality of life
- May require more consultation and support from PC experts
- Continues on to grief and bereavement care for family and friends after the person has died

A palliative approach focuses on:

- Reviewing goals of care
- Ongoing psychosocial and spiritual support
- Ongoing pain and symptom management
- Discussions of it and when to engage specialized palliative care providers

Benefits to introducing the palliative approach to care earlier:

- People may live longer
- Have better quality of life
- Health care providers, patients and families are better prepared and supported

2. Discussion Points on Strengths and Experiences in Providing Care

This exercise could be facilitated as a large group discussion. The intention is to get people to start talking about the strengths and assets in their community, to focus on what they do well, and to begin to develop confidence in taking on this new project. The following could be some questions to get the conversation started:

- What are the strengths of our community? What resources (knowledge, skills, organizations) do we have to build upon?
- What do you value or respect the most about our community?
- What makes our community unique and strong?
- Can you describe a time when you felt our community came together to support someone who was sick?

3. Assessing Community Readiness PowerPoint Presentation

This slide could be projected and/or handed out to participants. It is a tool that the group can use to assess where they are as a community in relation to developing a palliative care program. It also stimulates discussion of where the community would like to be and gets them to start thinking about what their vision is.

Assessing Community Readiness				
HAVING COMMUNITY READINESS	Just Started	On the Road	Nearly There	We're There
Do we have enough community infrastructure (e.g. housing, clean water, transportation, etc.) to support the development of a local PC program?				
Do we have enough local health services & health care providers to support the development of a local PC program?				
Are our health care providers committed to & able to work well together to meet new and important community needs?				
Do we have vision on how to provide better home care for people so that they can receive care in the community to the end of their lives?				
Do we feel empowered to be able to take action and responsibility to solve local problems?				
Do we have strong local leadership to initiate and guide this process?				

- Where are we as a community in having readiness to create our own local program?
- What are some things we as a community can do to move things from “just getting started” towards “we’re there?”
- What is our vision for how we want to care for our community members?



Supporting the Community to Create their Program

PHASE 4



Supporting the Community to Create their Program

Phase 4 of the Workbook “*Creating the Palliative Care Program*” is when community members begin to formalize the process of creating a palliative care program. This phase pulls together all of the preparatory work the community has done to get organized and get community members on board with the goal.

The external partner’s role in Phase 4 is to:

- Provide education on the Workbook to the members of the Advisory Committee
- Work with the community to facilitate the process, emphasizing tools and resources that could help the community to identify their capacities
- Assist the community with conducting the needs assessment and summarizing data
- Help the community document the process
- Help facilitate the community in developing practical plans of action that start to address objectives and goals
- Organize teleconferences to ensure ongoing support

In this phase of the Workbook, the community has already identified a Community Lead and developed an Advisory Committee who are responsible for the development, implementation, and evaluation of the palliative care program. They have identified their community vision, are meeting regularly, and are now looking at ways to formalize the process.

There is a lot of activity in this phase of the process as there are seven suggested steps to follow including hiring a Community Facilitator, creating a timeline, understanding community needs and perspectives, developing a work plan, forming a leadership team, creating program guidelines, and addressing outcomes. Within this phase there are many activities, tools, and resources in the Workbook that the community can adapt and use. Since this section of the Workbook provides a lot of guidance and direction, the external

partner can take less of an active role in the community, while continuing to mentor the Community Lead through the process.

One of the key activities in this phase is for the community to conduct a needs assessment. The needs assessment explores community member's understandings of end-of-life care, their perceptions and experience in providing palliative care, perceived barriers and supports in the community, current palliative care practices and policies, the educational needs of formal and informal community caregivers, and available resources inside and outside the community. The Workbook includes resources that can be used to gather this information in the form of surveys, focus groups, and interviews. The external partner could assist with the assessment by clarifying questions or content within the tools, providing mentorship and training on how to do an interview and could also help summarize the information into a community report.

Within this phase, the external partner may also be asked to become a member of the newly formed Leadership Team. The involvement of the partner depends on their role in the community and how actively their organization can support involvement in the community. As a member of the Leadership Team, the external partner may be asked to assist with the development and review of clinical documents and consent forms, guidelines, protocols, and care pathways.

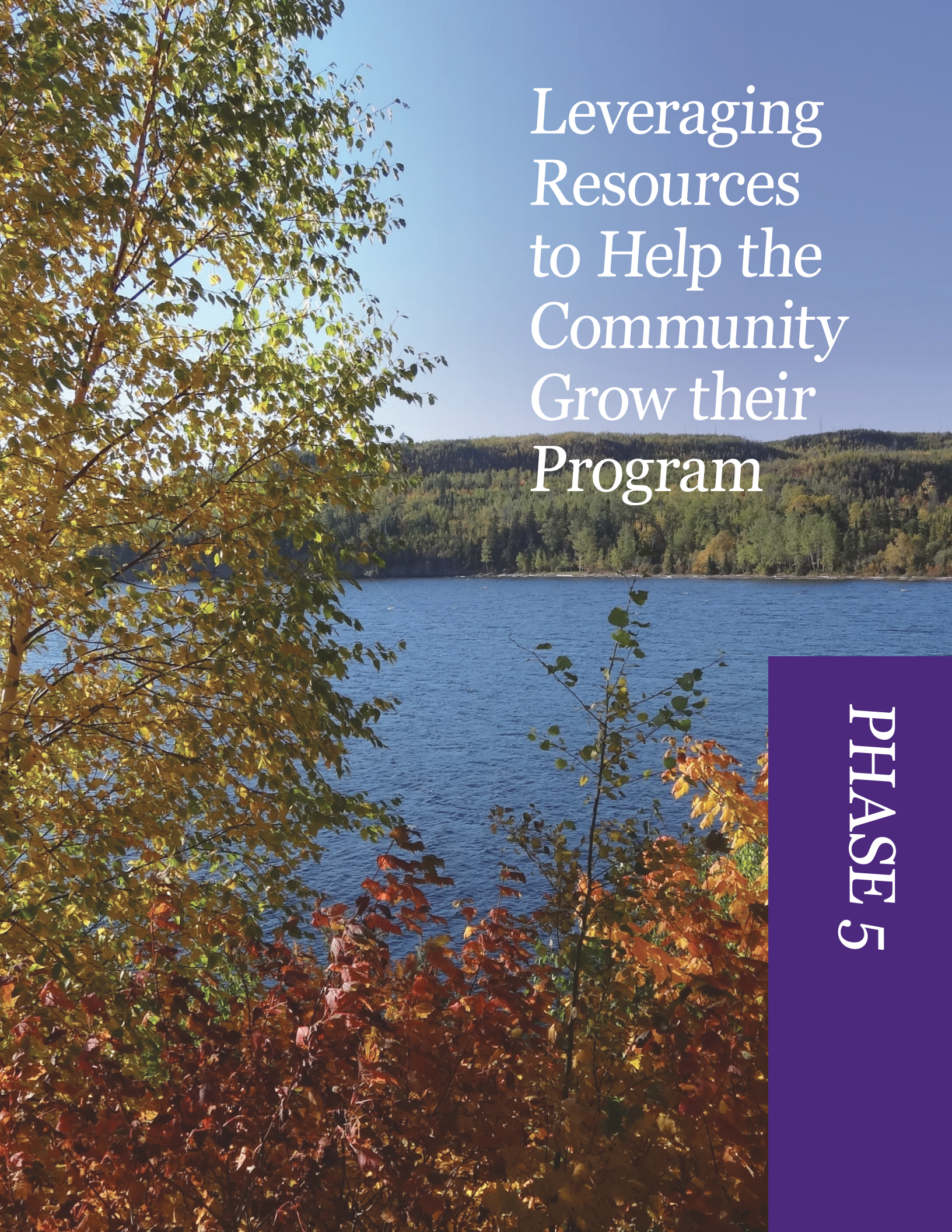
The external partner can facilitate some education sessions on the Workbook for the newly expanding Leadership Team. The education on the Workbook can occur over a series of meetings, once a month. They can be done in person or via teleconferencing. The time between the meetings gives the community the opportunity to mobilize their strengths and capacities and to do the work that is needed at each phase. *It is important to ensure that all members of the Advisory Committee and Leadership Team have a copy of the Workbook prior to the education.*

These sessions would go through each of the five phases of the Workbook, highlighting tools and resources, and offering suggestions on how they could be adapted to meet the needs of the community. The sessions are recommended to be delivered

in the order presented in the Workbook. Each step builds sequentially on the work completed in the previous one. It is very important that the First Nations community guides and controls all aspects of the process.

The external partner could then mentor the members through the community development process by facilitating bi-weekly teleconference calls with all members to provide updates, troubleshoot, and connect them to palliative care resources.



A scenic view of a lake with autumn foliage in the foreground and a forested shoreline in the background. The text is overlaid on the upper right portion of the image.

Leveraging Resources to Help the Community Grow their Program

PHASE 5

Leveraging Resources to Help the Community Grow their Program

Phase 5 of the Workbook *“Growing the Palliative Care Program”* describes how the Leadership Team can extend into the community and being to grow the program. The five strategies of this phase include strengthening community relationships, building external linkages, promoting education, providing care, and advocating for individuals and families.

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.

The external partner’s role in Phase 5 is to:

- Assist the community members with mobilizing and coordinating existing community resources
- Connect them with external partners and resources
- Work with the community to facilitate the process, emphasizing tools and resources that could help the community to identify their capacities
- Help the community document their process
- Connect people with existing resources that may not be familiar or known to the communities
- Help facilitate the community in developing practical plans of action that start to address objectives and goals
- Play an indirective and less active role in identifying strategies to meet community’s needs

In this phase of the Workbook, the community has already created their palliative care program and are now looking for opportunities to extend palliative care out into the community and put the program into practice. In each of the five strategies, there are many activities, tools, and resources in the Workbook

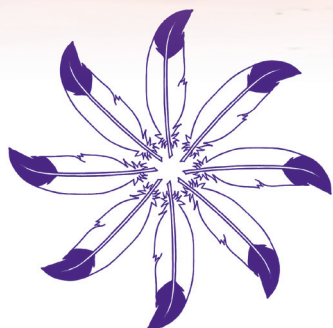
that the community can adapt and use. Since this section of the Workbook provides a lot of guidance and direction, the external partner can now take a less active role in mentoring the community through the process.

At the request of the community, the external partner may be involved in:

- Strengthening community relationships by participating in a community launch of the program or other community events
- Building external linkages by helping to establish linkages with regional care providers, organizations, providing feedback in the development of hospital discharge planning protocols or participating in journey mapping sessions
- Promoting education by facilitating palliative care education, advance care planning or grief and bereavement workshops to the community or care providers
- Providing care by helping the community to develop program guidelines and protocols, sharing resources and templates, connecting them with regional palliative care experts and providers
- Advocating for individuals and families by working with the community to advocate for resources and services, helping to develop funding applications, providing opportunities to disseminate information

Following the education and the direct support in implementing the Workbook, quarterly community-wide meetings could be set up where updates are given on community progress, and everyone at the meeting is engaged in reflections about lessons learned; this is followed by preparation of action plans for the next quarter.

At least one region-wide meeting during the year can be organized for representatives of communities and external partners. This meeting allows people to gather and celebrate local accomplishments, share ideas about accelerating the process, and draw together lessons learned about bottom-up development.



Conclusion

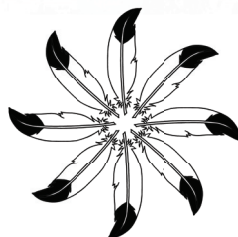
This guide is intended to be used in conjunction with the *Developing Palliative Care in First Nations: A Workbook*. The Workbook is for First Nations communities and guides communities through a five phase community capacity development process. The goal is providing effective and culturally appropriate home care services that will assist individuals to remain home in the community to receive end of life care if that is their wish.

This guide articulates the role of the external partners in the capacity development process. The guide highlights the role that external partners can play when First Nations communities want to develop a local palliative care program. It situates the external partner as stimulating community mobilization, supporting the internal community catalyst, and creating a supportive external environment to promote and sustain the change. The guide celebrates and reinforces First Nations communities' traditional and community-based knowledge and expertise in providing care for their community members.



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