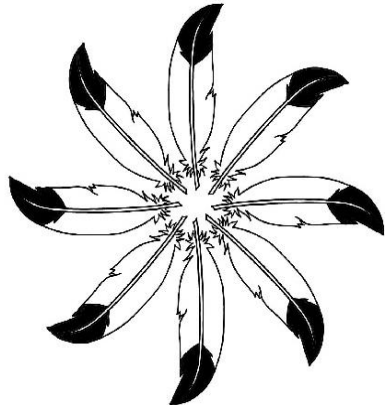


Improving End-of-Life Care in First Nations Communities:



Culturally Appropriate Advanced Care Planning
Resources for First Nation Community Members:
Resources and Strategies

"Culturally Appropriate Advanced Care
Planning Resources for
First Nation Community Members:
Resources and strategies"

Canadian Hospice Palliative Care
Association Conference

October 29th-November 1st, 2015

Overview of Research Project

- Project is funded for 5 years (2010-2015) by CIHR
- CERAH, Lakehead University is host organization
- 4 First Nations communities are partners in this project:
 - Fort William First Nation
 - Naotkamegwanning First Nation
 - Peguis First Nation
 - Six Nations of the Grand River Territory

Goals of the Project

- The overall goal of this project is to ***improve end-of-life care*** in four First Nations communities by developing local palliative care programs and teams, and
- Create a ***workbook for developing palliative care*** programs in First Nations communities that can be shared nationally

PC Program Development

- Developed a local palliative care program using a process of community capacity development.
- Based on local needs assessments and priorities.
- Identified need for education of local health care providers and community members in palliative care and advanced care planning.

Education is Needed:

“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 you know, 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”.

Nautkamegwanning First Nation Health Care Provider

Talking About Death and Dying:

“Our Elders before us, grandmothers, and older relatives, it wasn’t talked about with them. So it’s changing, changing our ways, changing our thinking and, and planning and preparing and knowing all that is entailed.”

Fort William Community Member

Importance of Advance Care Planning:

- ACP is a key process for supporting First Nations people to die at home or to receive culturally appropriate care in a hospital or long term care home.
- Everyone involved in the circle of care needs to know the **wishes** of the dying person.
- Tools and resources are required to empower First Nations people to make choices about their end of life care.

Partnerships:

- EOLFN, CHPCA/the Way Forward, Quality End-of-life Coalition of Canada and Health Canada
- Create and evaluate a culturally appropriate suite of ACP tools and educational resources
 - understandability, cultural acceptability and usability by First Nations' community members, their families, and local health care providers.

Resource Development:

- 1) culturally appropriate pamphlets and posters
- 2) guidelines for a community ACP workshop including presentation and facilitators guide
- 3) a culturally appropriate video to create awareness on ACP

Base Point:

Canadian Hospice Palliative Care Association
“Speak Up” resources, SNGRT resources,
EOLFN resources:

- How understandable is the information?
- Are there terms or words that are not easy to understand, or confusing?
- Was it culturally appropriate? If not please explain why?
- What can be added to make this resource culturally appropriate for your community?

Methodology:

- ACP resource poll assessing need of community members
- First and second focus group to evaluate CHPCA resources
- First draft of resources developed
- Elders focus group held in SNGRT to evaluate developed resources
- Second and third revisions by EOLFN team of resources
- Final feedback session on developed resources with FWFN
- Final revisions made to improved resources
- Developed print resources evaluated at Canadian Home Care Summit in Banff
- Developed video resource evaluated for national applicability by 44 FN's participants at the Assembly of First Nations Mental Wellness Policy Forum, completed August 2015.

Evaluation:

Recommendations for resource development:

- Language needs to be clear and concise
- Using less aggressive words
- Highlight the benefits
- Recognize that every community will have different views
- Basic information to catch attention
- Storytelling while presenting
- Pictures of FN people in developed resources
- Do not use medical jargon

Evaluation cont...

A focus group with 32 HCC program staff at the Canadian Home Care Summit in Banff.

- Positive feedback on developed resources
- Translation to aid with language barriers
- Majority of participants stated they would use the developed resources to promote advance care planning in their community

Evaluation cont...

Forty-four FN's participants at the Assembly of First Nations Mental Wellness Policy Forum evaluated the resources for national applicability:

- Too long
- Too wordy
- Add drumming music throughout
- Stronger Elder representation

Culturally Appropriate Promotion of Advance Care Planning:



Photographs



Pamphlet 1:



WHAT IS ADVANCE CARE PLANNING?

Entering the health care system, for example, going into the Hospital, can be overwhelming and stressful. Advance Care Planning encourages you to talk about what is important to you before you get seriously ill.

It is a process of thinking about and talking with your close family and friends. You share your values and beliefs involving healthcare treatments that you want and don't want.

THE BENEFITS OF ADVANCE CARE PLANNING:

- Provides peace of mind for you and those who may be making decisions for you.
- You are reassured that your wishes are known.
- Your wishes help your family and those making decisions know what to do and helps to avoid conflict and stress.
- You have a say in who provides care to you and who doesn't provide care to you.

WHAT DO I NEED TO KNOW?



In the event you are not capable to make decisions for yourself, a person called a Substitute Decision Maker (SDM), will be asked to give consent for healthcare treatments.

It is especially important to know who your SDM is. You can decide who your SDM will be. It is important to talk to him or her.

You need to follow the law that is applicable to the province or territory in which you live when you choose someone to be your Substitute Decision Maker.

I WANT TO TALK ABOUT MY WISHES... NOW WHAT?

Ask someone you trust who is willing and able to be your SDM.

Discuss your care wishes with your SDM and the important people in your life so that everyone is aware and supports your choices.

Maintain contact with your SDM.

Continue to talk about your health care wishes with your SDM and with other necessary people such as health care providers. Your values and beliefs may change over time; talk about what matters to you.

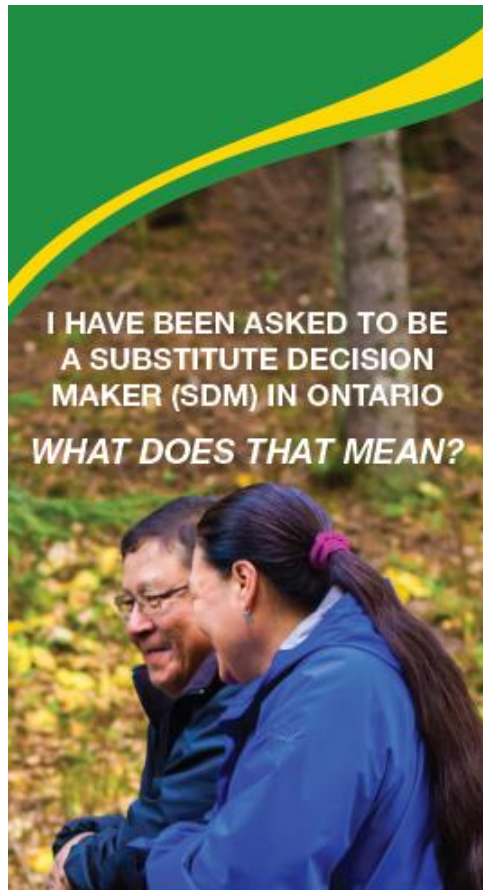
Understand that health conditions are complex and it is not possible to discuss or anticipate every situation. Continued conversations with your SDM while you are **capable** will guide your SDM to make the best decision

Your **health care wishes** includes treatment options as well as your physical, emotional, social and spiritual needs.

You and your loved ones have the right to make an informed decision for your health care.

Talking about your values and beliefs day-to-day can guide others about your wishes.

Pamphlet 2:



www.eolfn.lakeheadu.ca



WHAT IS A SUBSTITUTE DECISION MAKER (SDM)?

Someone who makes health care decisions for another person in the event the person is **not mentally capable** of making a health care decision.

There are **certain requirements** that must be met under the Health Care Consent Act for you to be considered not mentally capable.

A Substitute Decision Maker is willing and available, and listed on the Ontario SDM ranking.

Someone who is at least 16 years of age. More than one person can share the responsibility of SDM.

You can choose someone (or more than one person) to be your Substitute Decision Maker by preparing a Power of Attorney for Personal Care.

WHO CANNOT BE A SDM?

Someone who is paid to provide health care, residential, social, training or support services (such as your doctor, landlord or social worker).

Someone who is mentally incapable.

I HAVE AGREED TO BE A SUBSTITUTE DECISION MAKER ... WHAT NOW?



Be available when needed to make decisions.

Maintain contact with the person who has named you their substitute decision maker.

Continue to have conversations with the person as their values and beliefs may change over time.

Reflect on the values, beliefs and wishes of the person.

Be mindful and aware of your own beliefs and values and how these may impact your decisions.

Be aware of where any important documents are stored.

Know that a SDM has no authority to make financial decisions.

Understand that health conditions are complex and it is not possible to discuss or anticipate every situation. Continued conversations with the individual while they are **capable**, will guide you to making the best decision.

If there is more than one substitute decision maker, **promote conversations** to lessen or ease conflict and stress when decisions are being made.

WHAT ARE MY RIGHTS AS SUBSTITUTE DECISION MAKER?

You should **only** be asked to give consent for a treatment when the person is **mentally incapable**.

You have the right to say no or withdraw from being someone's substitute decision maker.

You have the right to know the benefits, risks and alternatives of any course of treatment.

You have the right to refuse treatments being suggested.

WHY ADVANCE CAREPLAN?



It reduces unwanted health treatments, care or healings.

If you are not able to make decisions for yourself, Advance Care Planning helps guide your decision maker

It can lessen your loved ones and your community's stress, anxiety and guilt.

It can help your community respect your wishes.

It can lessen conflict or arguments.

It provides you the opportunity to choose your substitute decision maker.

It can aid in navigating western medicine.

Entering the health care system, for example going into the Hospital, can be overwhelming and stressful. Advance Care Planning encourages you to talk about what is important to you before you get seriously ill.



Poster:

- Reflects the benefits
- Use of less aggressive words
- Pictures of First Nations people
- Use of consistent language



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Publication of this brochure was made possible through a grant from the Canadian Institutes of Health Research (CIHR) and Government of Canada. The views expressed herein do not necessarily represent the views of the CIHR or Government of Canada.

Presentation

- The environment is crucial to participation
- Use of storytelling while presenting
- Use of language
- Create tool that can be translated
- Have options of presenting for facilitators
- Walking someone through the process
- Speak about the benefits of advance care planning
- Use of consistent language

Sample Slide of Presentation:

Benefits of ACP

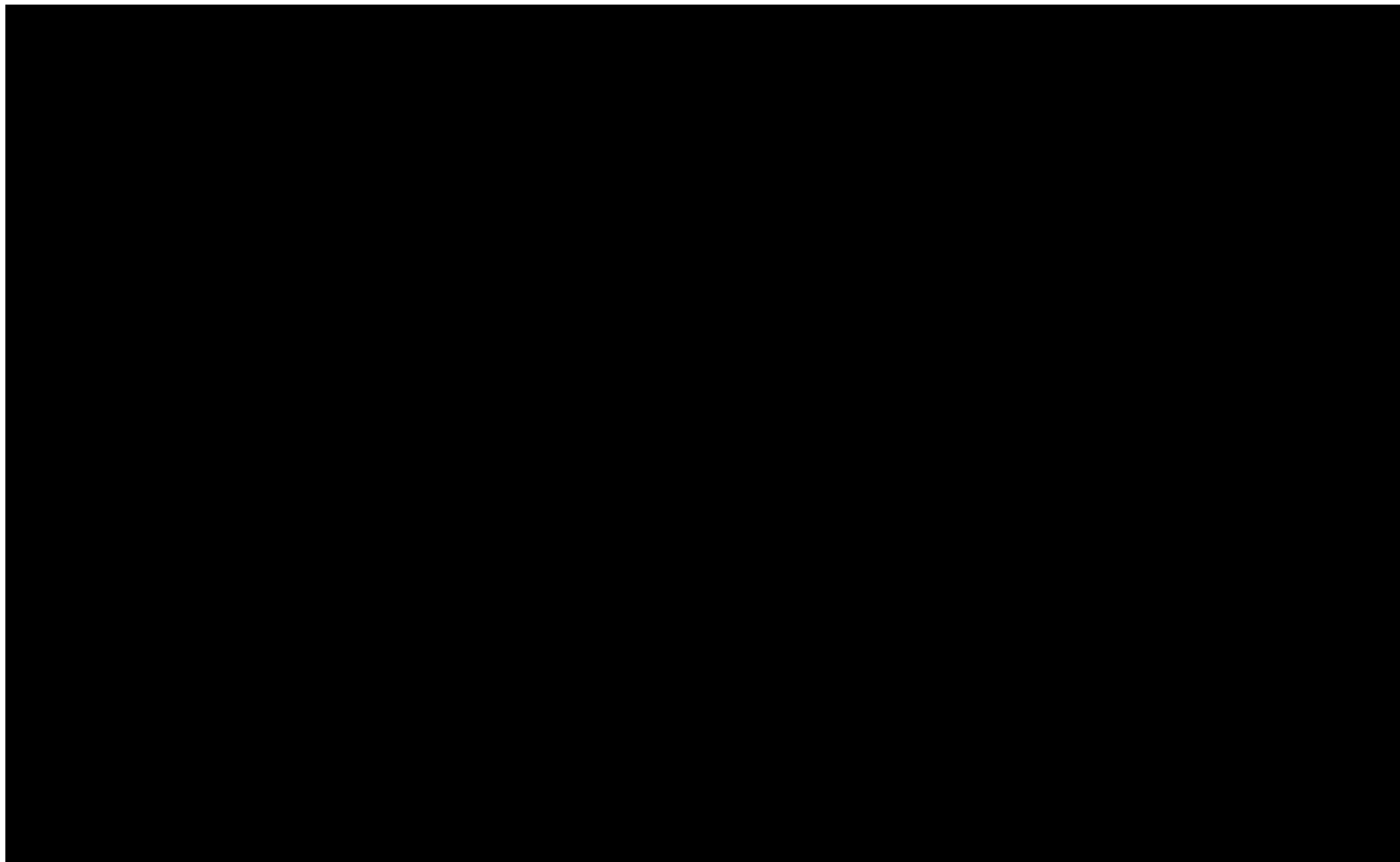
- **Peace of Mind**
- **Honours Your Wishes**
- **Helps Avoid Conflict**



Video:

Recommendations:

- Storytelling is the best way to communicate
- Having First Nation people speaking about the benefits of ACP
- Cover the basics –who, what, where, when and why
- Use of consistent language
- Should be translated into other languages



Dissemination:

- National Home Care Summit, November 2014
- Assembly of First Nations Mental Wellness Conference, March 2015
- Saskatchewan End-of-Life Conference, March 2015
- HPCO, April 2015
- Manitoba Palliative Care Conference, Sept 2015
- CHPCA, October 2015
- www.eolfn.lakeheadu.ca
- Four communities
- Local health care services

Conclusions:

- The content, format and education methods used to promote ACP in existing Canadian resources are not culturally appropriate for many First Nations people.
- Strategies such as the use of storytelling are important in First Nations communities and need to be utilized.

- Talking about death and dying may not be culturally appropriate in many First Nations communities, therefore ACP needs to promote engaging in discussions regarding healthcare treatments wanted or not wanted if an individual becomes unable to speak for themselves and not on end-of-life care discussions.
- Five new culturally appropriate print and video resources will now offer First Nations communities flexible options to promote advance care planning.

Questions:



Acknowledgements:



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