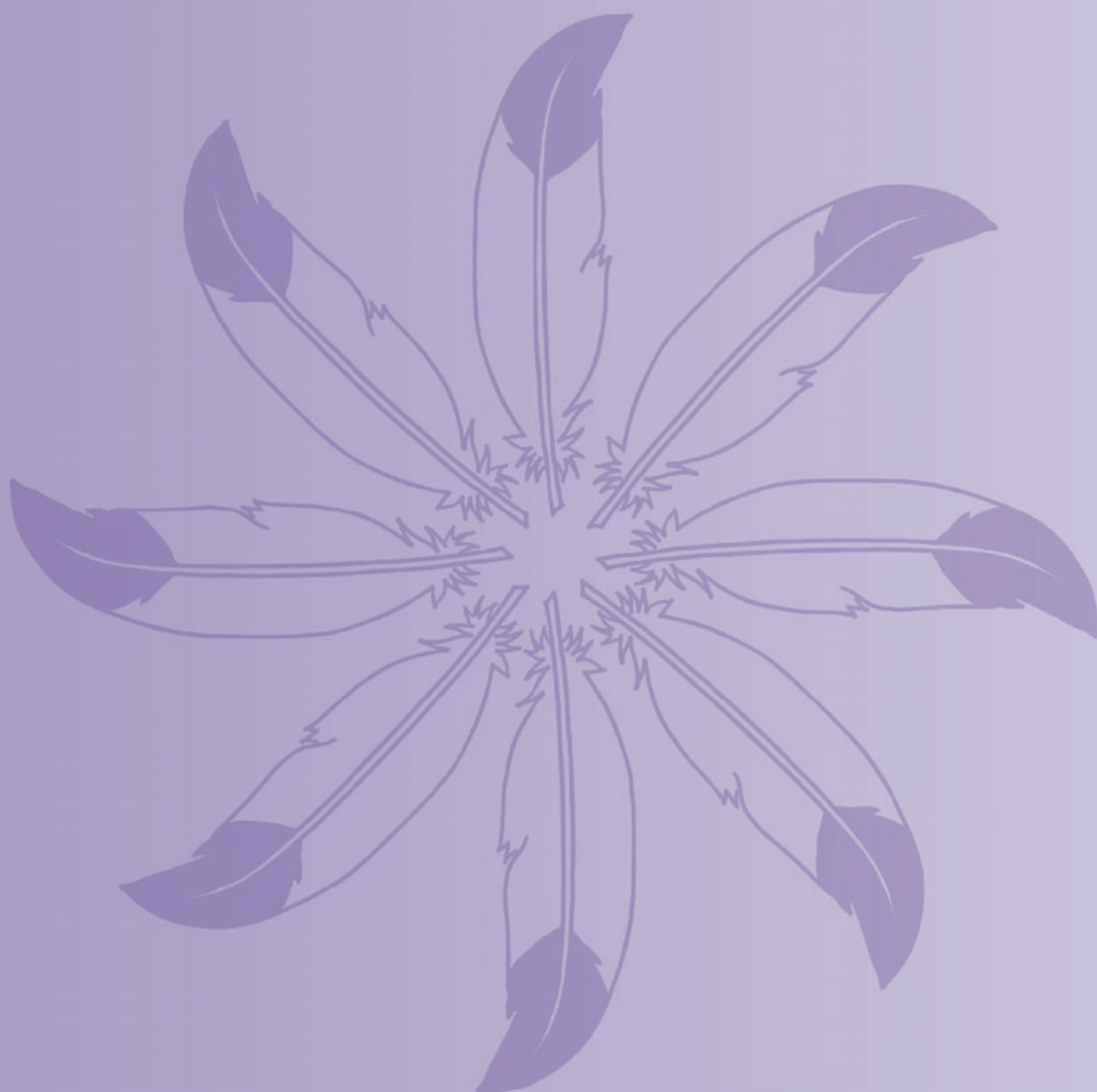


**Advance Care Planning Presentation for First Nation Communities**

# **Facilitators Guide**





# Advance Care Planning Presentation for First Nation Communities

## Facilitators Guide

### Introduction

The Improving End-of-Life Care in First Nations Communities research project (EOLFN) conducted a needs assessment in 4 First Nations (FN) communities (2010-11) that revealed 86% of community members who responded (N=183) would prefer to die at home if palliative care services were available in their community. Further, most respondents indicated that they have not had end-of-life discussions, however, they viewed having these conversations with their family and health care providers as important. Respondents also identified the need for culturally appropriate advance care planning (ACP) resources that could assist them with these important discussions.

The Canadian Hospice Palliative Care Association, The Way Forward and the EOLFN project have collaborated to create and evaluate culturally appropriate ACP resources for FN communities. The presentation was developed in collaboration with FN communities with a focus on cultural appropriateness in order to best guide FN peoples in ACP.

The results and recommendations from the collaboration is that the presentation needed to be visually stimulating with pictures of nature, the community and community members. Minimal writing or text may be preferred on the slides by community members. It was recommended that the facilitator use storytelling to associate the learnings, education and benefits of ACP to FN peoples.

5 New ACP resources have been created for use by FN Communities:

- 2 Pamphlets and a Poster
- An Instructional Video on the Process of Having ACP Conversations
- A Presentation and Facilitator's Guide

### The goals of the presentation are:

1. To educate community members on the benefits of ACP;
2. To guide community members on choosing a substitute decision maker (SDM);
3. To aid community members in navigating the western medical system.



## Determine the best way to facilitate for the community:

Establish the best way to present information in the community and provide any ceremonies or practices that are welcomed by the community. Offering a ceremony, for example a smudge or prayer, before the presentation starts may be appreciated by participants. Determine the best way to facilitate this presentation on ACP to the community.

The environment is a vital part of interaction and can facilitate or hinder participation. Placing chairs in circular shape is recommended. It was also suggested that the facilitator sit while presenting as sitting is a way of showing respect and humility.

Facilitators should share reflective success stories about why ACP is important and speak about how planning can lesson conflict in families. Facilitators should consider that the presentation be more interactive and less academic. A relaxed environment is crucial for presenting on an emotional topic.

## Adaptability:

The presentation/PowerPoint® was developed to be adaptable for individual FN communities. It is important to incorporate pictures, logos, language and legislation that are specific to your community. Be aware that legislation about ACP and SDM acts or laws are very specific to each province and territory of Canada and information for your own area may differ from that included in the presentation. It is important to familiarize yourself with your local/provincial legislation on ACP and substitute decision acts and adapt the presentation if needed. This will also prepare you for any questions that may arise during or after the presentation. There are several websites listed in the reference section that can assist a facilitator with any questions on ACP or on choosing a SDM.

The presenter should add speaker notes to aid them in providing all relevant information on ACP and SDM. Sharing personal or related health care experience stories can help people identify with the benefits of ACP.

## Guidelines for Facilitation:

1. If the presenter/facilitator is not from the community they should meet with an Elder or community members well in advance and discuss cultural teachings that might influence discussion of the subject matter in the presentation.
2. It is important to know if there are any important ceremonies or rituals to practice before or after the presentation for the community members.
3. It is recommended to place the chairs in a circle.
4. It is recommended that the facilitator sit while presenting.
5. Incorporate personal story telling into the presentation.
6. Incorporate pictures relevant to the community into the presentation.
7. Facilitators need to review local legislation to make sure that the language and laws regarding ACP and SDM are correct in their province or territory.

**Remember:** These guidelines are only recommendations and should be adapted to best fit the specific community where you are presenting.





# Advance Care Planning

## Beginning the Presentation

### What is ACP?

Entering the health care system, for example, going into the hospital, can be overwhelming and stressful for many people. ACP encourages a person to talk about what is important to them before they get seriously ill. It is a process of thinking about and talking about their wishes for care with their close family and friends. A person shares their values and beliefs involving health care treatments that they would want and would **NOT** want.

Often people misunderstand what ACP is and it can be confused with a living will. ACP is simply conversations that a person has with their SDM that guide health care decisions and only in the event that they are unable to make those decisions for themselves.

# Advance Care Planning Is Not:

- A Will
- About death



## Slide 2 - ACP is not:

ACP is not about a will or living will. ACP includes wishes that guide an SDM or chosen SDMs in the event an individual is **UNABLE** to speak for themselves. Rankings or hierarchy of legislated SDM will vary depending on province. ACP is about how a person wants to live their life, about controlling what care they receive and maintaining control of their body in the event they are unable to speak for themselves.

**Note** - Facilitators should share that ACP is about guiding their loved ones in making health care decisions for them, but **ONLY** in the event the individual is **UNABLE** to do so for themselves.



# What is advance care planning?



- Mapping out your wishes
- Choosing a spokesperson

## Slide 3 - What is ACP?

Facilitators should discuss with participants that having conversations about their values and beliefs can guide the care they would want or do not want. Explain that they do not have to take part in formal or structured conversations as it is the everyday conversations that reflect their values and beliefs that can aid their loved ones in making decisions.

ACP comes into effect when individuals are unable to speak for themselves. Explain what “mentally incapable” means (for example...not being able to understand the risk or benefits of a recommended health care treatment). Facilitators may need to look at territory/provincial legislation that explains what defines mentally incapable. It is also important that a facilitator is aware of the hierarchy/ranking of legislated SDM in their province/territory. Everyone has a SDM that is chosen by law. This ensures that health care providers have a person to make health care decisions in the event that they are unable to do so for themselves. However, everyone has the right to choose someone other than what the legislated hierarchy or ranking chooses for them. It is important for facilitators to discuss that if a person is not happy with the legislated SDM then the individual can **APPOINT** a SDM of their choice.

Discuss how ACP can ensure that people are fully informed about their illness and treatment options. ACP can assist people in clarifying their views regarding acceptable and unacceptable outcomes if their condition deteriorates.

# What is a Substitute Decision Maker?



- Spokesperson
- Hierarchy

## Slide 4 - What is a SDM?

**Recommendation:** a facilitator should familiarize themselves with provincial/territory legislation in relation to SDM.

A SDM is someone who will give consent or refuse consent for health care decisions if mentally incapable, at that time, to make health care decision for themselves.

A SDM:

- Must meet certain requirements
- Is someone who is willing and able to act on the wishes that you expressed while you were capable
- Should only be asked to give consent for healthcare decisions **ONLY** if you are mentally incapable of making the decision.
- Someone who can needs to be at least 16 years old and mentally capable
- An individual cannot be an substitute decision maker if they are not mentally capable or if they are someone who is paid by the individual (for example a health care provider, a landlord, or a social worker)

Discuss with participants that a person can choose more than one person to be their SDM. When choosing a SDM they need to understand what the law in their province/territory says about what they must do to appoint someone as their SDM.

Ask the participants to think carefully about who they think would understand, honour and follow their wishes. It is important that the person trusts the person that they choose as their SDM and that they have a good consistent relationship. As wishes and values may change, a person may change their mind about health care treatments they would want or **NOT** want. Discuss the importance of having consistent relationships and continued conversations with the person who is their substitute decision maker. These conversations will guide the SDM to make health care decisions based on best interests of the individual.



# Hierarchy

- 1) A court appointed SDM
- 2) Power of attorney for personal care
- 3) Someone appointed by the Consent and Capacity Board
- 4) Spouse or common law partner
- 5) Your children or your parents
- 6) Parent with right of access
- 7) Any other relative



## Slide 5 - Hierarchy

Discuss with the participants that whether they know it or not, everyone who is incapable of making personal health care decisions has a substitute decision maker. This would be an appropriate time to go through the hierarchy as shown on slide 5.

However, if there is no one to take the role of substitute decision maker then the office of the Public Guardian and Trustee will assume control.

**It is important to note that the hierarchy/ranking may differ depending on province/territory and it is necessary to familiarize yourself with legislation in your jurisdiction.**

Discuss the individual's rights to choose someone else or someone other than those listed in the hierarchy. This is achieved by using a document called a power of attorney for personal care. Explain that a lawyer is **NOT** needed to choose a SDM and that any individual can fill out a Power of Attorney for Personal Care to choose a SDM. They can download the document to name a chosen SDM and it is important to follow the legal requirements, as stated in the document, to do so. **Remind** participants that Power of Attorney for Personal Care (POAPC) documents will differ depending on province/territory.



# Why advance care plan?

- Respects your values and beliefs
- Guides loved ones
- Aids in navigating western medicine



## Slide 6 - Why ACP?

Discuss with participants how ACP can guide loved ones so that they can respect the individual's wishes and in decision making for treatments. The use of a personal experience or sharing an ACP success story would be beneficial here.

# Benefits of advance care planning



- Peace of Mind
- Honors your wishes
- Helps avoid conflict

## Slide 7 - The benefits of ACP.

Discuss with participants that one benefit of ACP is for a person to maintain a continued say in care and control of their body, even if they become too sick to speak for themselves (explain what it means to not be able to speak for yourself, for example coma or mentally incapable).

Discuss how ACP can give the individual peace of mind; knowing that they are more likely to receive the medical treatments they would want and not receive those they do **NOT** want.

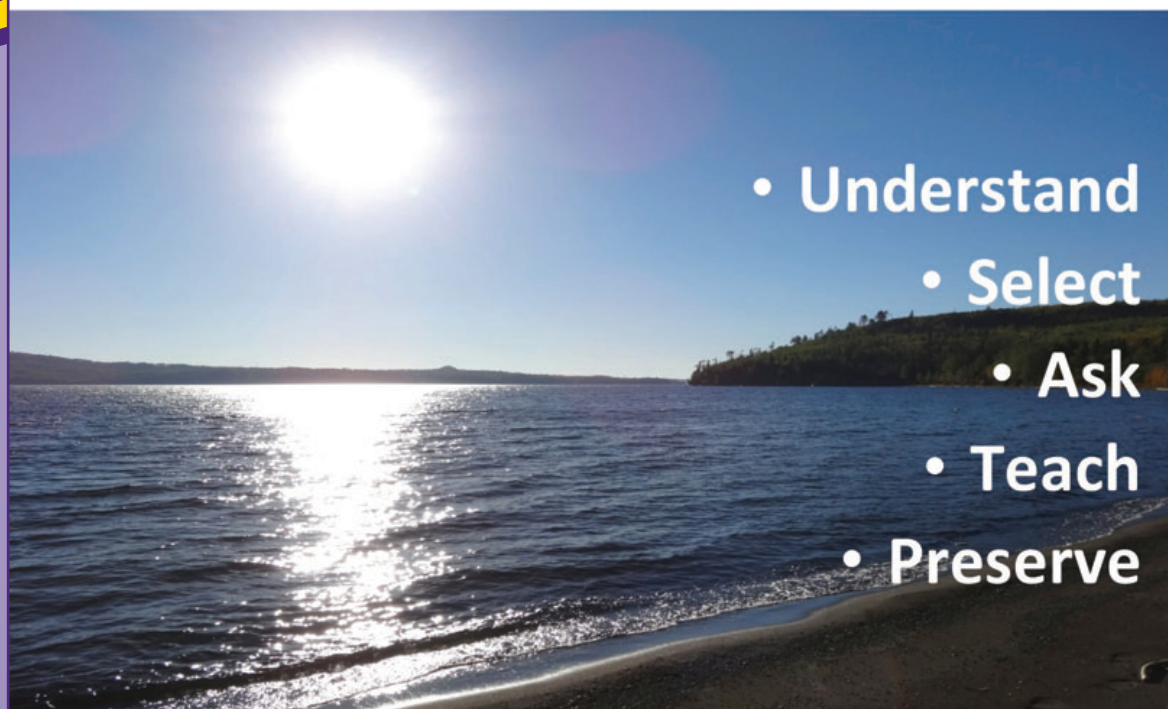
Discuss how family, friends, or SDM may be relieved of the burden of having to make difficult decisions in highly stressful situations when they do not know the individual's wishes.

Discuss that research evidence also show that if doctors inform people about possible future treatments and listen to their wishes, people are more likely to receive the end-of-life care they want.

Studies conducted in a range of health care settings suggest that ACP can improve individual and family satisfaction with care, reduce the number of unwanted transfers to hospitals; and reduces stress, anxiety, and depression in surviving relatives.



# Next Steps



- Understand
- Select
- Ask
- Teach
- Preserve

## Slide 8 - Next Steps

Discuss with participants that not every care wish can be discussed; further that health care wishes can be holistic- physical, emotional, spiritual, and social needs can be met with ACP. Discuss that it is important to select a SDM that is willing and able to act in their best interests. Best interests are stated in the Ontario Substitute Decision Maker Act as:

### Best interests

In deciding what the person's best interests are for the purpose of subsection (3), the guardian (SDM) shall take into consideration:

- (a) The values and beliefs that the SDM knows the person held when capable and believes the person would still act on if capable;
  - (b) The person's current wishes, if they can be ascertained; and
  - (c) The following factors:
    - 1. Whether the SDM decision is likely to:
      - i. Improve the quality of the person's life,
      - ii. Prevent the quality of the person's life from deteriorating, or
      - iii. Reduce the extent to which, or the rate at which, the quality of the person's life is likely to deteriorate.
    - 2. Whether the benefit the person is expected to obtain from the decision outweighs the risk of harm to the person from an alternative decision.
- 1996, c. 2, s. 43 (3).

**Remember:** This law may vary depending on provincial/territorial legislation.

Discuss with participants that when choosing a SDM they should pick someone they trust. Discuss the importance of teaching their SDM about their values and beliefs and that it is also important to preserve their relationship with their SDM. Discuss with the participants that as life changes so may their values and beliefs change. This is why it is important to have continued conversations that inform the chosen SDM.

# Rights



- To refuse treatments
- Educated choices
- Clarification

## Slide 9 - Rights

Discuss with the participants that the individual and the SDM have the right to refuse any treatment. Discuss how SDMs have the right to say no or to withdraw from being someone's SDM. Discuss with the participants that the individual and the SDM have the right to know the nature of the treatment, the expected benefits, risks, side effects, alternative course of treatment and the likely consequences of not having the treatment. Discuss with the participants that an individual and the SDM have the right to make informed decisions and should ask for clarification if needed from health care providers.





## Remember

- **Not every care wish can be discussed**
- **You have the right to ask questions**
- **Ask for the Aboriginal Patient Navigator**

### Slide 10 - Remember

Discuss with the participants to 'think and reflect' about what is important for the person's loved ones and SDM to know if the person is not able to make decisions for themselves.

Health care systems can be overwhelming and stressful. It can be helpful to share personal stories that can aid community member's while manoeuvring the western medical system.

Suggest to the participants that individuals should ask for an Aboriginal Patient Navigator or for someone else who can provide them with support or clarification if needed. The individual and the SDM have the right to ask questions and a right to make informed decisions.

Discuss the importance of having continued conversations about the individual's wishes. These conversations can include mapping out how they would like family and loved ones to celebrate their life.

**Note:** Facilitators should reference any service or agency that can aid or be beneficial to individuals in ACP in the region/province or territory.



This presentation and facilitator guide was prepared for use in Ontario. People living in other provinces and territories should consult the appropriate legislation. This presentation and facilitator guide can be adapted to your province or territory.

This material, was prepared by The Improving End-of-Life Care in First Nations Communities research project and is intended to provide general information. The content does not constitute legal advice or legal recommendations and should not be relied upon as such.

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