



Palliative 101 and Health Care Consent: Advance Care Planning for the South Asian Population

Facilitators' Guide



This guide was compiled by
Central West Palliative Care Network
Punjabi Community Health Services
Heart House Hospice

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Important Phone Numbers

Heart House Hospice	905-712-8119
Bethell Hospice	905-838-3534
Central West LHIN Home and Community Care.....	905-796-0040
William Osler Health System: Etobicoke General Hospital	416-494-2120
William Osler Health System: Brampton Civic Hospital	905-494-2120
Headwaters Health Care Centre	519-941-2410

Introduction

The Central West Local Health Integration Network (LHIN) is home to a richly diverse population, including a large South Asian community. Within this South Asian community is a wide variety of cultures, each with its own attitudes, religious practices, languages, traditions, and end-of-life rituals.

Many members of the South Asian communities are not aware of the terms palliative care and/or advance care planning. In fact, some communities consider these topics to be taboo. In addition, language can be a barrier. There are many languages spoken within the Central West LHIN, and some of these languages may not have words for topics like palliative care or advance care planning. As a result, health care professionals must approach conversations about these topics carefully.

It is important that all community members, regardless of their cultural background, have knowledge of health care consent, advance care planning and palliative care so they – or their substitute decision maker(s) – can make informed decisions according to their wishes. To help with these conversations, the Central West Palliative Care Network (PCN) is conducting palliative care and advance care planning sessions for health care professionals and members of the public.

To support these sessions, the Central West PCN – in partnership with Punjabi Community Health Services and Heart Health Hospice – developed culturally sensitive slides in simple English that can be used with multiple groups, as well as a facilitator guide to accompany the slides.

It is recommend that facilitators conduct the session in one of the major languages (i.e. Urdu/Hindi/Punjabi) used by the group they are presenting to or the language requested by the group.

Group Guidelines

The facilitator should introduce the Group Guidelines prior to start the session.

Confidentiality

- ☀ Everything shared in the group is confidential and is not to leave the room. Trust is an important element of the session.

Responsibility

- ☀ All members share the responsibility to make the group work.

Acceptance

- ☀ The group accepts members just as they are, and avoids making judgments.

One Speaker at a Time

- ☀ Groups are most beneficial when all participants have the opportunity to share and discuss individual issues or concerns. Members must be mindful of limited time and give each person enough time to speak without interruptions.

Giving Attention

- ☀ Members will give supportive attention to the person who is speaking and avoid side conversations.

Avoid Interruptions

- ☀ If an interruption is necessary, return the conversation to the person who was speaking.

Sharing

- ☀ Sharing is encouraged, but not required.

Questions

- ☀ Group members have the right to ask questions and the right to refuse to answer.

Begin and End on Time

- ☀ Group will begin and end on time.

Tips for Facilitators

The facilitator will:

- ☀ Check the availability and functionality of the equipment in advance
- ☀ Discuss group guidelines with the group
- ☀ Remain non-judgmental and not stereotype
- ☀ Read the facilitator notes in the slide deck
- ☀ Maintain confidentiality
- ☀ Declare that any disclosure of abuse and/or harm must be reported
- ☀ Remain Punctual
- ☀ Remain professional by maintaining professional attire and communication
- ☀ Provide advance notice if unable to attend
- ☀ Order books from the Hospice Palliative Care Ontario website (www.speakupontario.ca)
- ☀ Start the session with the positive aspects of living and quality of life, rather than death
- ☀ Allow sufficient time for questions and answers
- ☀ Mention that participants can leave room anytime if they feel uncomfortable
- ☀ Connect or provide bereavement support as necessary

Session Outline

Ice Breaker (10 minutes)

Introduce yourself and group members. It's helpful to ask them about their stay in Canada to gauge the language competency.

Part 1: Palliative Care 101 (10 to 15 minutes)

The goal of this session is to help participants learn:

- ☀ Palliative care is an approach to care that starts from the diagnosis of any life-limiting illness
- ☀ Palliative care is all about quality of life and comfort
- ☀ The goal of palliative care is to provide care and comfort, and to treat and manage the symptoms rather than disease
- ☀ Palliative care supports living life to the fullest with the best and most achievable quality of life
- ☀ Palliative care is a right for all Canadians
- ☀ Good palliative care helps patients meet their care goals
- ☀ Good palliative care helps patient die in their preferred place
- ☀ Identifying patients with palliative care needs earlier in their disease trajectory helps them remain comfortable and prevent crises at the end of their lives
- ☀ Palliative care is a team approach, and patients and caregivers are part of the team

Part 2: Health Care Consent and Advance Care Planning (45 minutes)

Ask the group, what they know about advance care planning.

The goal of this session is to help participants learn:

- ☀ Advance care planning is about making ones values, wishes and beliefs known
- ☀ Advance care planning should be done by everyone and can be done at any age
- ☀ Advance care planning doesn't need to be in writing
- ☀ Patients have right to change their mind
- ☀ Patients have right to consent to treatment
- ☀ Patients need to know the elements of consent
- ☀ Patients need to be part of their care goal discussions
- ☀ Health care providers should always take consent prior to the treatment

The session will be conducted using the story of a fictitious family's journey with health care. The story is originally developed by Villy Simonetta (RN, Acclaim health). Please read the notes with the slide to highlight the important points regarding Advance Care Planning. The videos included in the slides can be skipped if time is limited however facilitator is encouraged to share the message in the video.