Advance Care Planning: What We Can Learn from Primary Care Providers in the East Toronto Health Link

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Session Objectives

- Understand the challenges of Advance Care Planning (ACP) as identified by primary care providers in the East Toronto Health Link
- Show how those challenges were used to inform the approach to Advance Care Planning at ETHeL
- Overview of the ACP facilitator model adapted at ETHeL
- Material produced by ETHeL to support patients and providers with ACP

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ETHeL ACP Process

Information gathering

- Needs assessment of primary care providers
- Patient engagement panel

Product Generation

- ETHeL workbook and pamphlets
- Conversation guides
- Provider education sessions

ACP conversations

- Ongoing support for providers facilitating ACP conversations

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Lesson #1: Lack of A common Language

Glossary of end of life planning terms:

Advance Care Planning: A process of discussion and reflection of an individual's wishes and preferences for future care. It will be based on current health conditions but refers to potential care needs in the future. Only a person with capacity to engage in ACP can do this, a Substitute Decision Maker (SDM) cannot.

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Lesson #1: Lack of A common Language

Glossary of end of life planning terms:

Goals of Care Discussions: Between a capable patient or their SDM and healthcare provider. These discussions attempt to align available treatments with a person's goals of care. They are discussions about current rather than future medical care.

Treatment Plan: These may arise out of a goals of care discussion. The health care provider proposing treatment must obtain consent from either a capable patient or SDM.

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Lesson #2: Primary Care Providers Need Educational Support For ACP

Facilitator Training

- Based on Respecting Choices® model developed by Gunderson Health System, and facilitator training from Fraser Health
- Recognizes that facilitating conversations that help individuals explore their values, perceptions of quality of life, personal trade-offs, benefit and burden tolerance are an advanced communication skill
- Basic ACP education for all healthcare providers

Educational Strategies for Interdisciplinary Health Care Providers

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Basic Education

- For all healthcare providers
- Objectives:
  - Working knowledge of ACP definitions, benefits
  - Help patients understand differences between SDM and POA
  - Advise patients on the desirable attributes of an SDM

Facilitator Training

- For interested providers who will become ACP facilitators
- Objectives:
  - Gain comfort and confidence with discussions that will help patients explore their values and perceptions of quality of life and benefit/burden trade-offs.
  - Be able to support individuals through the ACP process

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Lesson #3: Focus on Values and Essential Abilities Rather Than Treatments

Emphasis in facilitator training, public engagement sessions

- Inherent uncertainty in predicting future healthcare needs
- Rather than focusing on specific interventions that may or may not occur, focus on how that individual defines quality of life, what abilities are essential to their enjoyment of life
  - Being aware of one's environment
  - Able to communicate with family and friends
  - Ability to perform ADLs

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Lesson #3: Tailor ACP to Individual Patients

- **Stage of Health**
  - Healthy Adult
  - Adult with Chronic illness
  - Adult with less than 12 months prognosis
- **Cultural Humility**
- **Readiness to participate in ACP**

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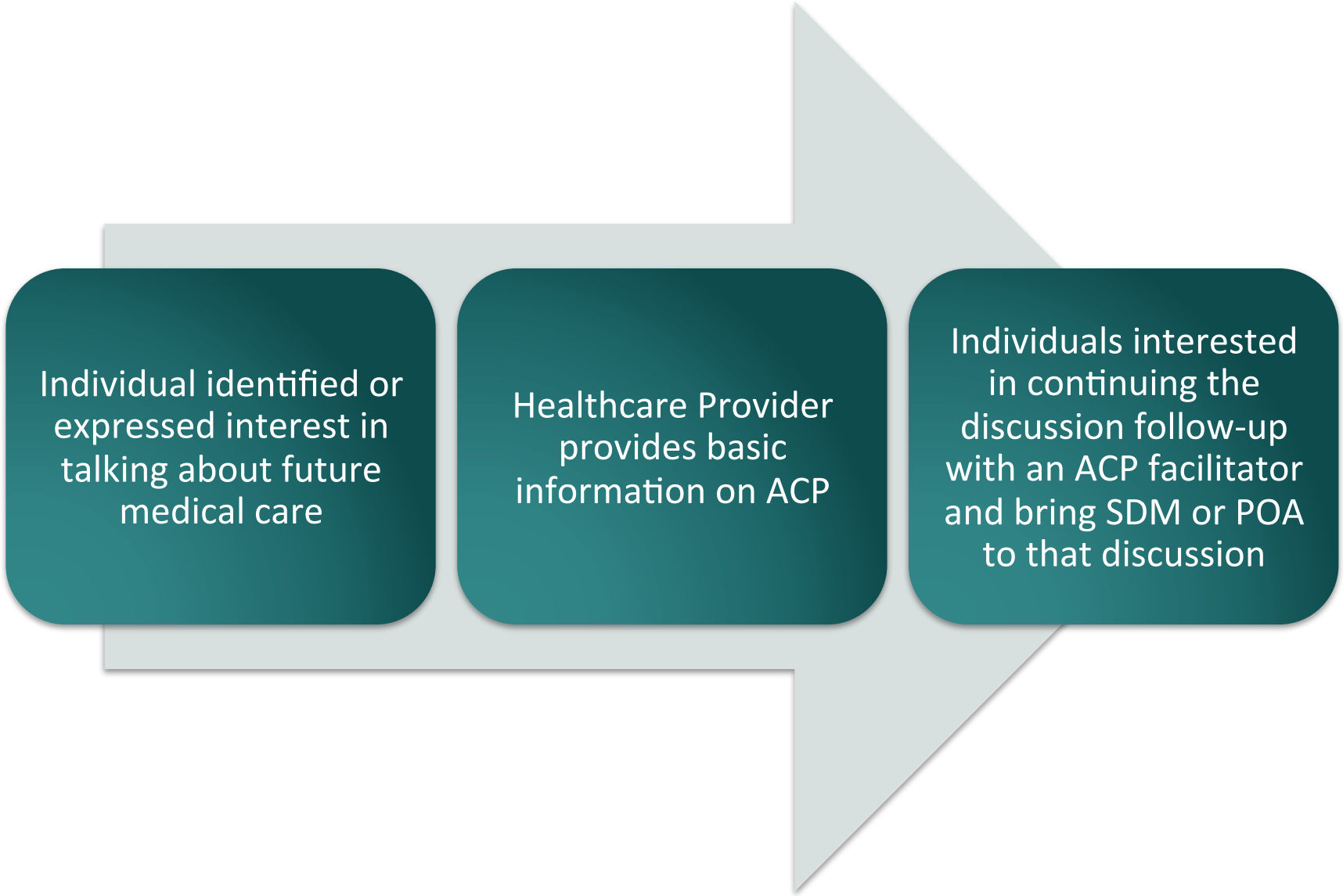
ACP Interdisciplinary Facilitator Model



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Benefits of a Facilitator Model for ACP

- Allows an opportunity for interested healthcare providers to develop an enhanced skill
- Well suited to interprofessional healthcare teams where professions other than MDs can lead the conversation.
- Addresses the barrier of "Not enough time" identified by primary care physicians by allowing others to take on the task

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ETHeL Resources to Support ACP

- Working Group comprised of members from partner organization and community representatives
- Reviewed existing ACP material from Speak Up, Canada, US and Australia
- Products reviewed by Patient Engagement Committee
- Language inclusive of chronic disease population

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ETHeL Resources to Support ACP

Pamphlet:

- **Intended use: to introduce ACP to clients/ patients**
- **Provides an overview of ACP**

Advance Care Planning
Information Guide

A gift for you and your family

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ETHeL Resources to Support ACP

Workbook:

- **For individuals to work through on their own**
- **For use once someone is open to thinking about and discussing ACP**
- **Helps individuals work through the ACP process with their chosen support network**

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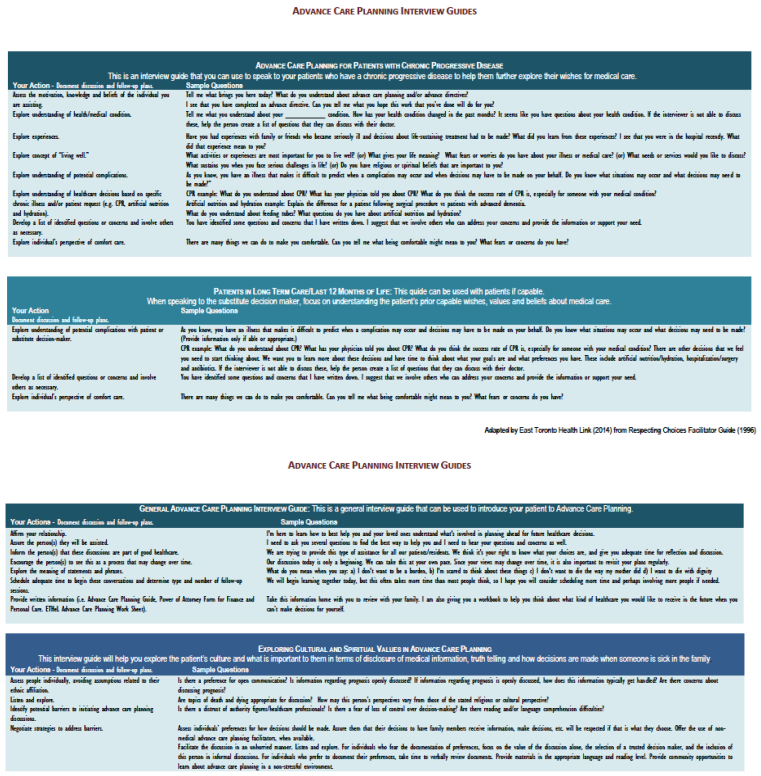
ETHeL Resources to Support ACP

Discussion Guides for Providers:

- Health Adult
- Adult with Chronic Disease
- Adult with less than 12 months prognosis
- Cultural Humility



Advance Care Planning Interview Guides

Advance Care Planning for Patients with Chronic Progressive Disease

This is an interview guide that you can use to speak to your patients who have a chronic progressive disease to help them further explore their wishes for medical care.

Your Action - Document discussion and follow-up plans.	Sample Questions
Assess the motivation, knowledge and beliefs of the individual you are assisting.	Tell me what brings you here today? What do you understand about advance care planning and/or advance directives? I see that you have completed an advance directive. Can you tell me what you hope this work that you've done will do for you?
Explore understanding of health/medical condition.	Tell me what you understand about your _____ condition. How has your health condition changed in the past months? It seems like you have questions about your health condition. If the interviewer is not able to discuss these, help the person create a list of questions that they can discuss with their doctor.
Explore experiences.	Have you had experiences with family or friends who became seriously ill and decisions about life-sustaining treatment had to be made? What did you learn from these experiences? I see that you were in the hospital recently. What did that experience mean to you?
Explore concept of "living well."	What activities or experiences are most important for you to live well? (or) What gives your life meaning? What fears or worries do you have about your illness or medical care? (or) What needs or services would you like to discuss?
Explore understanding of potential complications.	What matters you when you face serious challenges in life? (or) Do you have religious or spiritual beliefs that are important to you? As you know, you have an illness that makes it difficult to predict when a complication may occur and when decisions may have to be made on your behalf. Do you know what situations may occur and what decisions may need to be made?
Explore understanding of healthcare decisions based on specific chronic illness and/or patients request (e.g. CPR, artificial nutrition and hydration).	CPR example: What do you understand about CPR? What has your physician told you about CPR? What do you think the success rate of CPR is, especially for someone with your medical condition? Artificial nutrition and hydration example: Explain the difference for a patient following surgical procedure vs patients with advanced dementia. What do you understand about feeding tubes? What questions do you have about artificial nutrition and hydration?
Develop a list of identified questions or concerns and involve others as necessary.	You have identified some questions and concerns that I have written down. I suggest that we involve others who can address your concerns and provide the information or support your need.
Explore individual's perspective of comfort care.	There are many things we can do to make you comfortable. Can you tell me what being comfortable might mean to you? What fears or concerns do you have?

Patients in Long Term Care/Last 12 Months of Life: This guide can be used with patients if capable.

When speaking to the substitute decision maker, focus on understanding the patient's prior capable wishes, values and beliefs about medical care.

Your Action Document discussion and follow-up plans.	Sample Questions
Explore understanding of potential complications with patient or substitute decision-maker.	As you know, you have an illness that makes it difficult to predict when a complication may occur and decisions may have to be made on your behalf. Do you know what situations may occur and what decisions may need to be made? (Provide information only if able or appropriate.) CPR example: What do you understand about CPR? What has your physician told you about CPR? What do you think the success rate of CPR is, especially for someone with your medical condition? There are other decisions that we feel you need to start thinking about. We want you to learn more about these decisions and have time to think about what your goals are and what preferences you have. These include artificial nutrition/hydration, hospitalization/surgery and antibiotics. If the interviewer is not able to discuss these, help the person create a list of questions that they can discuss with their doctor.
Develop a list of identified questions or concerns and involve others as necessary.	You have identified some questions and concerns that I have written down. I suggest that we involve others who can address your concerns and provide the information or support your need.
Explore individual's perspective of comfort care.	There are many things we can do to make you comfortable. Can you tell me what being comfortable might mean to you? What fears or concerns do you have?

Adapted by East Toronto Health Link (2014) from Respecting Choices Facilitator Guide (1996)

Advance Care Planning Interview Guides

General Advance Care Planning Interview Guide: This is a general interview guide that can be used to introduce your patient to Advance Care Planning.

Your Actions - Document discussion and follow-up plans.	Sample Questions
Affirm your relationship.	I'm here to learn how to best help you and your loved ones understand what's involved in planning ahead for future healthcare decisions.
Assure the person(s) they will be assisted.	I need to ask you several questions to find the best way to help you and I need to hear your questions and concerns as well.
Inform the person(s) that these discussions are part of good healthcare.	We are trying to provide this type of assistance for all our patients/residents. We think it's your right to know what your choices are, and give you adequate time for reflection and discussion.
Encourage the person(s) to see this as a process that may change over time.	Our discussions today is only a beginning. We can take this at your own pace. Since your views may change over time, it is also important to revisit your plans regularly.
Explore the meaning of statements and phrases.	What do you mean when you say: a) I don't want to be a burden, b) I'm scared to think about these things c) I don't want to die the way my mother did d) I want to die with dignity
Schedule adequate time to begin these conversations and determine type and number of follow-up sessions.	We will begin learning together today, but this often takes more time than most people think, so I hope you will consider scheduling more time and perhaps involving more people if needed.
Provide written information (i.e. Advance Care Planning Guide, Power of Attorney Form for Finance and Personal Care, ETHeL Advance Care Planning Work Sheet).	Take this information home with you to review with your family. I am also giving you a workbook to help you think about what kind of healthcare you would like to receive in the future when you can't make decisions for yourself.

Exploring Cultural and Spiritual Values in Advance Care Planning

This interview guide will help you explore the patient's culture and what is important to them in terms of disclosure of medical information, truth telling and how decisions are made when someone is sick in the family

Your Actions - Document discussion and follow-up plans.	Sample Questions
Assess people individually, avoiding assumptions related to their ethnic affiliation.	Is there a preference for open communication? Is information regarding prognosis openly discussed? If information regarding prognosis is openly discussed, how does this information typically get handled? Are there concerns about discussing prognosis?
Listen and explore.	Are topics of death and dying appropriate for discussion? How may this person's perspectives vary from those of the stated religious or cultural perspective?
Identify potential barriers to initiating advance care planning discussions.	Is there a distrust of authority figures/healthcare professionals? Is there a fear of loss of control over decision-making? Are there reading and/or language comprehension difficulties?
Negotiate strategies to address barriers.	Assess individuals' preferences for how decisions should be made. Assure them that their decisions to have family members receive information, make decisions, etc. will be respected if that is what they choose. Offer the use of non-medical advance care planning facilitators, when available. Facilitate the discussion in an unhurried manner. Listen and explore. For individuals who fear the documentation of preferences, focus on the value of the discussion alone, the selection of a trusted decision maker, and the inclusion of this person in informal discussions. For individuals who prefer to document their preferences, take time to verbally review documents. Provide materials in the appropriate language and reading level. Provide community opportunities to learn about advance care planning in a non-stressful environment.

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- Adapted by East Toronto Health Link (2014) from Respecting Choices Facilitator Guide (1996), Gunderson Health System

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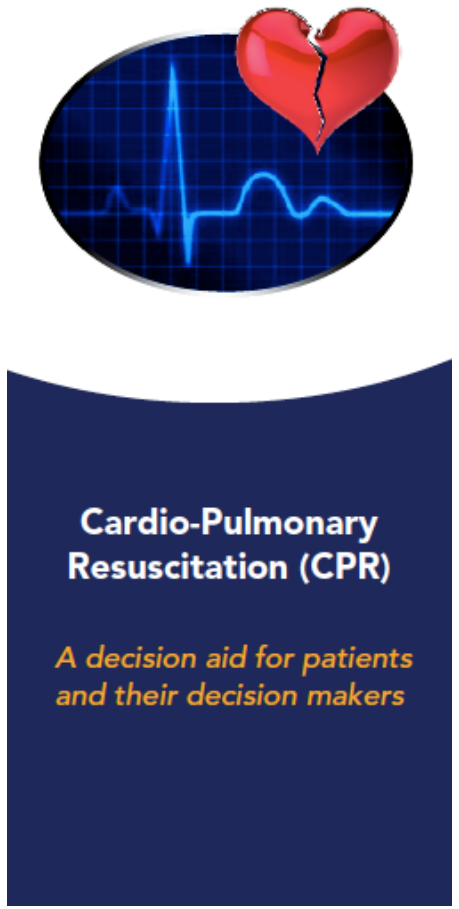
ETHeL Resources to Support ACP

CPR Discussion Aid:

- **Intended for patients**
- **Tool for providers to discuss benefits and burdens of resucitation**



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QUESTIONS? COMMENTS?

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THANK YOU