

# Advance Care Planning in Primary Care: Lessons Learned

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## Background

“Advance care planning (ACP) is a process of reflection and communication, a time for you to reflect on your values and wishes, and to let others know your future health and personal care preferences in the event that you become incapable of consenting to or refusing treatment or other care. It means having discussions with family and friends, especially your Substitute Decision Maker (SDM) – the person who will speak for you when you cannot.”<sup>1</sup>

Research shows that ACP improves quality of life and quality of end-of-life care; reduces stress and anxiety for patients, families and caregivers; improves communication between patients, families and the healthcare team and reduces strain on the health care system.<sup>2</sup>

Primary care providers (PCPs) are in an ideal position to discuss ACP with their patients. These discussions can be incorporated into routine care during initial and follow-up visits, and allow for enhanced awareness and normalization of the planning process.<sup>3</sup>

In 2013, the Jane Finch Family Health Team (JFFHT) implemented an ACP program with patients to introduce them to the concept of ACP and discuss with them the importance of a SDM and the benefits of discussing their healthcare wishes with their SDM and family. It was believed that information provided by the team’s social worker in the individual sessions would increase the patients’ understanding of basic ACP concepts and their satisfaction with the sessions. While there was anecdotal evidence that these sessions were beneficial, pre- and post-session surveys were administered to collect quantifiable data.

## ACP Quality Improvement Plan (QIP) Toolkit

Cancer Care Ontario has published an ACP QIP Toolkit for primary care multi-disciplinary teams (i.e. Family Health Teams, Aboriginal Health Access Centres, Community Health Centres, Community Care Access Centres, Nurse Practitioner Led Clinics) that are looking to initiate a quality improvement initiative focused increasing the number of ACP discussions with patients. The toolkit can be found at <https://www.cancercare.on.ca/pcs/primcare/qitoolkit/>

Below is a sample planning tool intended to support the development of a practice’s ACP QIP:

AIM	QUALITY DIMENSION	Patient-centred care
	OBJECTIVES	All patients over 50 years old have an ACP or it is documented that they did not wish to have an ACP.
MEASURE	MEASURE / INDICATOR	% of patients within target population who have participated in an ACP education session or consultation, or documentation that they did not wish to participate
	UNIT / POPULATION	Target population identified by the care practice (i.e. all patients over 50 years old)
	SOURCE / PERIOD	Patient list generated from existing data set over duration of project (i.e. billing data/ EMR)
	CURRENT OR BASELINE PERFORMANCE	If documented and data obtainable, identify how many patients have been offered an ACP discussion or consultation and how many have participated.
CHANGE	TARGET PERFORMANCE	If current state is known (documented and data available) calculate the % of the target population that has been offered an ACP discussion or consultation and how many have participated. Set a target for improvement.
	TARGET JUSTIFICATION	Based on how many people are in the target group and the capacity of staff to provide the consultation
	PLANNED IMPROVEMENT INITIATIVES	1. Staff will receive opportunities to learn about ACP and health care consent. 2. ACP will be introduced to all people within the target population or those identified through the surprise question.
CHANGE	METHODS	Provide staff with materials and access to educational resources Introduce ACP to patients within the target group when they are in the practice for an appointment Plan and deliver group education sessions about ACP
	PROCESS MEASURES	Number of eligible staff who have learned about ACP Number of ACP consultations offered. Documentation of patient response in patient record (EMR) (refused, not sure, consultation booked)
	GOAL FOR CHANGE IDEAS	All eligible staff learn about ACP
		All eligible patients in target population are identified. Targets for offering ACP discussions or consultations and documenting response are met.

## Methodology

**ACP Info Sheet**  
Talk to Your Health Care Provider

**ADVANCE CARE PLANNING**

**THINK**  
about what’s right for you  
What’s most important to you about your end-of-life care?

**LEARN**  
about the different medical procedures that can be offered at the end of life. Some may improve your quality of life, others may only prolong life.

**CHOOSE**  
your Substitute Decision Maker. Choose a loved one who is willing and able to speak for you if you can’t speak for yourself.

**TALK**  
about your wishes with your Substitute Decision Maker, loved ones and health care provider.

**RECORD**  
Your end-of-life wishes – write them down, record them or make a video.

Speak Up  
www.advancecareplanning.ca

Source: Speak Up Canada Website

**ACP Work Sheet**  
Thinking about my wishes for future health care

This document is meant to help you think about your values and to express your wishes for future health care. It is not intended to be a document that tells your doctors what to do in the future. It is meant to help prepare you for talking to your doctors about the kinds of medical treatments you do or do not want if you develop a serious illness. Also, it can help your substitute decision maker make decisions if the time arises when you are unable to make decisions for yourself. There is also a space where you can record who your substitute decision maker is. Remember that you can change your mind at any time – just be sure that you talk to your substitute decision maker(s) about any changes.

You can find more information in Speak Up: Advance Care Planning Workbook – Ontario Edition found at [www.advancecareplanning.ca](http://www.advancecareplanning.ca).

1. These first questions are intended to help you think about the use of life-sustaining medical treatments as a part of your care. Please see the Word List if you are not sure what some of these terms mean.

Please circle one number for each question where 1 means that this is not at all important and 10 means that it is very important.

How important is it that I be comfortable and suffer as little as possible?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is it that I have more time with my family?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is it that I live as long as possible?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is it that I avoid being attached to machines and tubes?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is it that my death is not prolonged?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is a belief that nature should be allowed to take its course?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is the belief that life should be preserved?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure
How important is it that I respect the wishes of other family members regarding my care?	Not at all important	1	2	3	4	5	6	7	8	9	10	Very important	Not sure

Speak Up  
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Source: Speak Up Canada Website

The importance of ACP was first broached with the patient by the PCP and, if agreeable, the patient would be given a handout about ACP and then booked for a 45 minute session with the social worker to discuss this information further (e.g. definition of SDM and power of attorney [POA], healthcare decisions, wishes and values)

Starting in January 2015, patients were surveyed immediately prior to, and then again after the ACP session to assess the impact of this session on their understanding of basic concepts of ACP. To date, the JFFHT has conducted over 300 sessions with patients and members of the Jane Finch Community to introduce them to the benefits of ACP.

The following statements were presented to patients both prior to and after the ACP intervention:

### SURVEY STATEMENTS

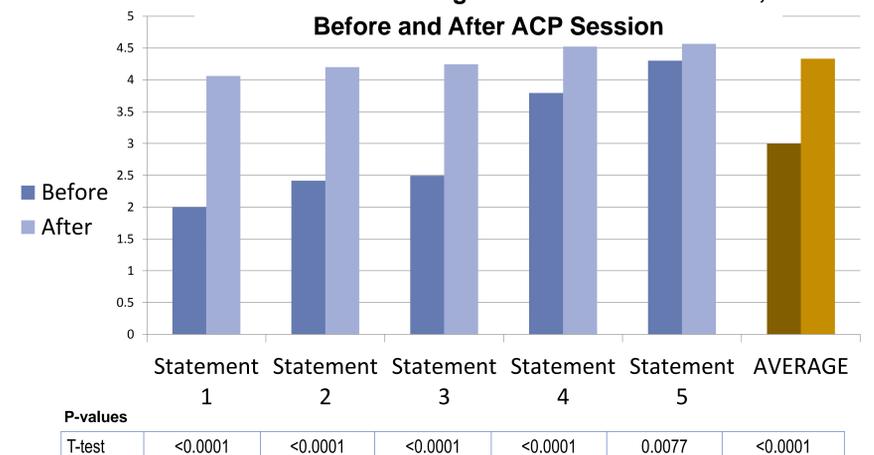
1. I understand the concept of ACP
2. I understand the importance of a SDM
3. In the event that I am not able to make decisions on my own regarding my healthcare, I have/will discuss my wishes with my SDM and my family
4. I am satisfied this will be/has been a useful discussion about ACP
5. I would recommend this information session to my family and friends

The patients ranked each statement from 1-5 ranging from “very little knowledge or agreement with each question” (1) to “very good knowledge or agreement” (5) with respect to each question.

## Results

65 pre- and post-session surveys were collected and analyzed. Data shows an increase of the weighted average in the statements from the pre-survey to the post-survey indicating a clear benefit resulting from the ACP intervention. Results were statistically significant according to a paired t-test and a Wilcoxon signed-rank test.

**TABLE 1: Patients’ Agreement with Statements, Before and After ACP Session**



## Conclusions

The results indicate that this session was valuable for increasing patients’ understanding of basic ACP concepts and their satisfaction with the sessions. These findings may be useful for other multi-disciplinary teams that are considering including ACP discussion with their patients at the primary care level.

## References

1. Speak Up. (2015). About Advance Care Planning. Retrieved from <http://www.advancecareplanning.ca/about-advance-care-planning.aspx>
2. Wright, A. A., et al. (2008). Associations between end-of-life discussion, health care expenditures, JAMA, 300(14) 1665-1673.
3. Canadian Hospice Palliative Care Association. (2012). Advance Care Planning in Canada: National Framework. Retrieved from <http://www.advancecareplanning.ca/media/40158/acp%20framework%202012%20eng.pdf>