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- We declare that we have no affiliation (financial or other)



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Health Sciences North
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Noojmowin Teg Health Centre

LEARNING OBJECTIVES

- Identify potential barriers to effective clinician-family communication
- Provide models of care to resolve conflicts or disagreements that might arise during discussions
- Demonstrate a person-centred approach to conversations with patients' families and friends

OVERVIEW

- Introductions
- ACP/SDM
- SPIKES Model
- Barriers
- Triggers
- Cases
- Resources
- Bibliography

A word cloud featuring various terms related to healthcare, caregiving, and patient experience. The words are arranged in a dense, overlapping cluster. The colors of the words include shades of blue, green, red, orange, and pink. The words are of varying sizes, with some being significantly larger than others. The terms include:

- BURNOUT
- SUPPORT
- RESPECT
- CAREGIVER
- HEALTH
- LOVE
- LOSS
- PANIC
- DEATH
- ACKWARD
- STRESS
- RELATIONSHIP
- LOVERS
- DREAMS
- CARE
- PATIENT
- FINANCIAL
- LANGUAGE
- TEAM
- ROLES
- DIGNITY
- CHALLENGING
- SPOUSE
- STRANGED
- SILENCE
- PARENTS
- CULTURE
- CHILDREN
- CONVERSATION
- SPIRITUALITY
- SDM
- PAIN

Advance Care Planning

- Ongoing and dynamic conversations
- Identifies a Substitute Decision Maker (SDM)
- ACP allows **capable** patients to reflect on and express:
 - Wishes, values and beliefs
 - What's important to them
 - What they value about life and their health

Substitute Decision Makers

Court Appointed Guardian

Attorney for Personal Care

Representative appointed by the
Consent and Capacity Board

Spouse or Partner

Parent or Child
(Children's Aid Society)

Parent with right of access

Brother or Sister

Any other Relative

Public Guardian and Trustee

LEGALLY
APPOINTED
SDMs

AUTOMATIC FAMILY
MEMBER SDMs

SDM of LAST RESORT



ACP Conversation Guide

1. What do you **understand** about your health or illness?
-What have you been told?
2. **Information** Sharing:
-What information is important for you to know?
3. What brings **quality** to your life? What do you value?
4. If critically ill or if EOL, what **worries& fears** come to mind?
5. What **trade offs** are you willing to make for the possibility of added time?
6. If you were near the end of your life, what would make this time **meaningful**?

ACP Conversation Template:

How to get started

- **Preparation - Yourself**

- Be ready to invite and listen - are you willing, ready to listen?
- Allow for **time**, feedback
- Support emotions
- If you are not sure, Seek Support from the Health Care Team

- **Preparation - Patient**

- Schedule a meeting with patient and encourage SDM to attend
- Permit patient time to prepare for the meeting

Resource

Advance Care Planning Conversation Guide: Clinician Primer

- <http://acpww.ca/wp-content/uploads/2016/01/ACP-Conversation-Guide-Clinician-Primer.pdf>
- © 2016 by Dr. Nadia Incardona and Dr. Jeff Myers. ACP Conversation Guide - Clinician Primer This work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/4.0/>

Spikes Model

Baile et al., 2000

TABLE 2

The SPIKES model (13, e4)

S	“Setting” the setting of the discussion	good preparation for the discussion in a suitable environment where there will be no disturbances
P	“Perception” the patient’s state of knowledge	What does the patient know about the disease?
I	“Invitation” the patient’s invitation to the physician to provide information	How much information would the patient like to receive? Can currently available information and findings be discussed in this setting?
K	“Knowledge” the imparting of knowledge	imparting new information to the patient (new diagnosis and prognosis, changes in the treatment plan) introducing bad news with a warning that bad news is to come
E	“Exploration of Emotions” perceiving and addressing the patient’s emotions and reacting with empathy	joint bearing of emotions; the physician’s task is not to talk the patient’s feelings away, but rather to show empathy and understanding. This factor determines how much information (perhaps only partial) can be imparted. Some patients can only accept the new facts if they are imparted in a multistep process (14).
S	“Strategy and Summary” summarizing and making plans for the future	summary of the discussion, looking ahead to coming treatment, setting the next appointment

Welsch K, Gottschling S.; (2021) "Wishes and needs at the end of life: communication strategies, counseling, and administrative aspects". *Dtsch Arztebl Int*; 118: 303–12.

Table 1. The Ask-Tell-Ask Strategy: Sample Phrases and Rationales

Strategy	Example phrase for AP	Rationale
Ask	"I am hearing that you have a lot of questions that seem to be about your prognosis. I am happy to answer your questions. What worries you the most?"	This is a patient-centered method that draws upon principles of negotiation. This question allows the AP to know what kind of prognostic information to disclose at this particular time.
Tell	The AP discloses the prognostic information that the patient wishes to know at this particular time.	Disclosure of specific prognostic information that the patient wishes to know, fosters trust and the therapeutic relationship
Ask	"Did my response help answer your question?"	This question helps to clarify the patient's understanding and need for information.

Note. AP = advanced practitioner. Information from Back & Arnold (2006) and Campbell et al. (2010).

Table 2. SPIKES Used in Conjunction With Ask-Tell-Ask

SPIKES step	Explanation	Corresponding ask-tell-ask step
Setup	Ensure that surroundings are conducive to a serious discussion of life-changing matters.	
Perception	Ask open-minded questions to ascertain how the patient perceives her medical situation.	Ask: Establish what patient knows
Invitation	Find out how much information the patient is comfortable receiving and discussing at this time.	
Knowledge	Disclose information to the patient and check for understanding repeatedly.	Tell: Deliver news
Empathy	Respond to the patient in a way that acknowledges her strong emotions and reassures her that these feelings are normal and expected.	
Summary and Strategy	Determine whether the patient is ready to discuss the next steps. When she is ready, check for understanding and questions and discuss treatment goals and strategies.	Ask: Check for understanding and query about concerns and fears

Note. Information from Baile et al. (2000).

Welsch K, Gottschling S.; (2021) "Wishes and needs at the end of life: communication strategies, counseling, and administrative aspects". *Dtsch Arztebl Int* ; 118: 303–12..

TABLE 3

Communication tips (from 3, 5, 7, 14, 15, e5–e7)

Setting	<ul style="list-style-type: none"> – discussion in person, – optimally with a physician whom the patient knows already – appropriate atmosphere without disturbances – enable the patient to have a trusted person present – hold such discussions in the morning if possible, and not right before the weekend, so that the patient can ask follow-up questions in the afternoon or the next day – if necessary, divide the information to be imparted into smaller portions and communicate these bit by bit
Attitude	<ul style="list-style-type: none"> – sincerity – empathy – esteem, non-judgmental respect – giving a feeling of trust and security – active listening – awareness of emotions and behaving in a supportive way by leaving room for the patient's fears and uncertainties – let the patient ask questions
Patient-centeredness	<ul style="list-style-type: none"> – see each patient (and relative) with their own personality and deal with them accordingly – respect the patient's current preferences
Clarity	<ul style="list-style-type: none"> – mention dying and death explicitly – empathically and appropriately to the situation; this increases patient satisfaction and lessens mental stress in the dying phase, both for patients and for their relatives – check continually that the imparted information has been understood and provide summaries – avoid medical terminology, or explain it if necessary
Maintain hope, offer help	<ul style="list-style-type: none"> – discuss multiple scenarios for the future (e.g., best, worst, and typical cases) – if a cure is no longer possible, offer help nonetheless (e.g., give hope for the best possible quality of life, minimal symptom burden, and so on)
Culture-sensitive communication	<ul style="list-style-type: none"> – take account of the patient's cultural and religious conceptions – make a connection with the corresponding local cultural and religious organizations for an exchange of ideas

Conversation Tips:

3 W's: Wish (or Hope), Worry, and Wonder

- “*I wish* that things were different.”
- “*I worry*, as a person with (health issue), you could get sick quickly.”
- “*I wonder* if there are things you can do to prepare.”

Wish, Worry and Wonder Framework

To start the conversation:

- For example: “I **wish** we weren’t in this situation but I **worry** what might happen if your health worsens and I **wonder** if we can talk about it?”
- “I wish” things were different
 - Allows for aligning with the patients hopes
- “I worry” things may worsen/get sick quickly
 - Allows for being truthful while sensitive
- “I wonder” what we can do to prepare...
 - Subtle way to a recommendation to talk.

Discussing End-of-Life

- When starting to decline, end of treatment, comfort measures, re-address ACP
- If you can **WAIT** for that conversation
 - **Appropriate timing**
- Review understanding of health situation
- Provide new medical information
- Introduce support to patient and to families to avoid distress
- Collaborate with patient to develop a treatment plan

Statements to avoid

- Are you palliative?
- Do you have a DNR form?
- Do you have your affairs in order?
- Have you thought of going to hospice instead of home?

Conversation tips:


- “Nothing more we can do”
 - **Instead: We will continue to keep you comfortable**
- “Give up” (fighting the disease)
 - **Instead: Promotion of good quality of life.**
- “Stop active treatment”
 - **Instead: Refocus your care, I’m still continuing to treat you but with a different goal**
- “DNR”
 - **Instead: Allow natural death (with symptom management)**

Summary: ACP

- ACP is an on-going conversation that allows capable patients to express their wishes, values and beliefs, what's important to them, and what they value about life and their health.

ADVANCE CARE PLANNING

Speak Up
Start the conversation
about end-of-life care



Advance Care Planning Workbook

It's about conversations.
It's about decisions.
It's how we care for each other.

www.advancecareplanning.ca

Speak Up is a Canadian Hospice Palliative Care Association / Société Canadienne d'Hospice Palliatif (SCHP) initiative. © 2014 SCHP. All rights reserved.

WHY ADVANCE CARE PLAN?



- It can help control your care needs.
- It reduces unwanted health treatments, such as life support.
- It can help you to make decisions for yourself. Advance Care Planning helps guide your decision making.
- It can ensure your loved ones and your community's wishes are fully understood.
- It can help your community understand your wishes.
- It can ensure you are in control.
- It provides you the opportunity to discuss your end-of-life decisions.
- It can help in managing health care costs.

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.

For more information contact www.advancecareplanning.ca



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BARRIERS

- No appropriate meeting location
- Fear of reactions of patient or SDM (avoidance)
- Lack of clarity in role of team members in meeting
- Misunderstanding of diagnosis
- Lack of training/confidence
- Time constraints/workload
- Language/Lack of Interpreter services

TRIGGERS

- Disease progression/recurrence
- Non-response of treatment
- Side effects
- Miscommunication
- Needing to review EOL wishes
- Caregiver/Family burnout and/or stress

TRIGGERS

- Lack of interest/apathy/withdrawal
- Discharge planning
- Lack of community services
- Family dynamics
- Expressed fears and worries
- Physical decline of patient
- Recurrent hospital admissions

CASE 1

- Case – Mr. H
- Late 50's still working, could be confrontational, thought he would get better if he tried hard
- Multimorbid – diabetes type 2, peripheral vascular disease with amputation, Congestive Heart Disease, Obesity
- ER visits, recurrent admissions, physically and functionally declining, interrupting his work life, becoming more irritable with family and workmates
- Wife fearful, caregiver burnout, voiced she is afraid she will find him dead in bed or in the driveway

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- Frustration/anger over loss of independence, more days missing work, requires more assistance with activities of daily living
- Feels badly about stressing his wife and family out
- Limited understanding of his disease... just keep going day by day and see how it goes
- Discussion/understanding of CPP disability pension – help with paperwork

- Series of conversations – multiple touch points in ER, hospital visits, connect to a Palliative Care physician who had office and home visits with wife and patient
- Supported palliative approach to care – support independence with increased services, support offered to caregiver, ie social worker, pastoral care, support groups, also offered support to adult children
- Support comfort, goal to limit ER/hospital visits, continued connection with palliative care physician and supports
- Discussion of legacy work...family wanted to work on this on their own
- Documentation in the EMR, palliative care binder/home care binder, SDM/POA, DNR
- Wife felt supported and had someone to share her concerns

CASE 2

- Young 23 old female student attending community college, living independently
- Diagnosed with mets Melanoma
- Parents lived out of town
- Mom moved in patient's apt during treatment. Patient received chemotherapy in her community.
- Mom became primary caregiver for patient
- Patient became less vocal during her treatments and appointments as Mom was present and actively participating during consultations with patient care.
- Patient gradually provided consent for HCP to call her mother to schedule appointments

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- RN requests patient be seen for psychosocial support.
- SW only had telephone consultations with patient as she was receiving treatment in her community
- Patient had no quite space or private space available as her mother was either in the same room or in the next room. SW was challenged in engaging patient in an assessment as patient not able to fully disclose her emotions or her concerns.
- Unwillingness from Mom and patient to engage in ACP conversations
- Unfortunately, patient was brought to ED as she was in +++ Pain and weak....ED Dr suggested patient be transferred to their Palliative Care Unit. Mother felt she had to quickly explain Palliative Care Unit and goals of care to her daughter...

CASE 3

- Mr. M
- 60 years old
- Severe lung disease COPD, on home oxygen, coronary heart disease, obesity, limited family support, lives by himself, history of anxiety and depression
- Has been admitted twice to ICU due to hypercapnic respiratory failure requiring intubation in the last year
- Has been referred to a lung specialist for transplant assessment
- Has quit smoking 5 months ago and has asked to see a dietician to lose weight for the possible pending transplant

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S	"Strategy and Summary" summarizing and making plans for the future

- Multiple discussions about his knowledge of his disease, what information does he want to know, how does he see his life going forward in the privacy of his home
- What is his understanding of the possible lung transplant... where would he be on the list... what does his family physician say...his specialists...
- Discussion of his wishes, POA, what other supports to have in the home.... does he want to be intubated again.... has he had this discussion with his POA
- Still in process of having these discussions with him...I have reached out to his physician to get his thoughts and what he has discussed with the client

CASE 4

- Mr. C
- Diagnosis of cancer 10 years ago after two years of mis diagnosis (this from the family)
- Has had chemo and radiation treatments 10 years ago
- In 2020 told his cancer is back and it has metastases and is offered palliative chemo
- He starts treatment...has to take a break due to side effects...started chemo again late 2020
- Told chemo not working and referred to palliative care physician
- Much discussion with family about palliative approach...second opinion from another oncologist...

S	“Setting” the setting of the discussion
P	“Perception” the patient’s state of knowledge
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- Client and wife agree to palliative approach...no more chemo as it is causing him a lot of health issues and stated he understands it is not helping or controlling the disease.
- Wants to be at home and die at home...DNR family preparing for his death... support given by home care staff and social work and palliative care physician
- -Wife called 911...has client taken to hospital as she feels he had an “episode”
- Arrives at hospital emergency... emergency physician has discussion with the wife. Understands client is a DNR and palliative approach...client admitted...client unresponsive. Wife told he is dying... three days later he is more alert...wife upset that he is not being “treated” ... demanding to see the palliative physician...
- Palliative physician comes to see client...agrees he is more alert but still dying...wife wants treatment.

- COVID protocols also affecting family to visit...this is frustrating to wife... wife very upset and angry...
- Client in hospital 4 days ...wife upset he is not being treated ... feels he is just being ignored... client not able to make decisions so his wife is making his decisions as she is POA/SDM
- Discussion with palliative physician again... agreed that the children can visit one at a time...
- Social worker visited family daily... discussing his diagnosis has not changed... he is still dying... any treatment will not change this...wife says she understands this... revisited our previous discussions...with client and what he wanted...comfort measures provided
- Wife wants to take him home after 4 days in hospital as she wants his children to be able to visit
- Client goes home and dies at home 3 days later...
- Wife angry feels her husband did not get the treatment he required...feels team dropped the ball
- Where do you go from here...

RESOURCES

ACP Clinician's Guide

<http://acpww.ca/wp-content/uploads/2016/01/ACP-Conversation-Guide-Clinician-Primer.pdf>

Canadian Virtual Hospice

<https://livingmyculture.ca/culture/>

Ministry of Attorney General

[Power of Attorney - Ministry of the Attorney General \(gov.on.ca\)](#)

Pallium Canada

www.pallium.ca

Speak-up Ontario

www.advancecareplanning.ca

- <https://livingmyculture.ca/culture/>

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QUESTIONS



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