



# Engaging in Advance Care Planning

Part 2: Building a Sustainable  
Future in the Renal Setting

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Best in health care.

# Disclaimer



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# Group Introductions



1. Introduce yourself, include your profession and work area.
2. Describe a learning goal for today's session.
3. Do you have any lingering questions or reflections since attending the Part 1 session?

# Learning Objectives



1. Explore ways of incorporating Advance Care Planning conversations into everyday clinical practice and normalize ACP conversations.
2. Explore ways to overcome common barriers to initiating ACP conversations.
3. Identify and articulate the benefits of having “values” focused versus treatment based conversations with family and health care providers.
4. Practice scenarios for increasing comfort and practicing wording and responses during ACP conversations.
5. Identify when and to whom to make referrals for ACP support and further facilitation.
6. Engage in building team capacity and identifying approaches for sustainability.

# Sharing of Personal ACP Experience



1. What was it like for you to complete your own Advance Care Plan?
2. Did you involve anyone? Did their response(s) surprise you?

# Identifying a Substitute Decision Maker (SDM)



1. Did you choose a SDM?
2. Why did you choose this person?
3. How did you ask them and did they accept this role?
4. Did you engage in an ACP conversation?
5. What types of questions did they ask?

# Group Discussion



Reflecting on your own ACP and SDM experience and/or in listening to your colleagues' stories, what did you learn that you will incorporate into your professional practice?

# Learning Objective #1



Explore ways of incorporating and normalizing Advance Care Planning conversations into everyday clinical practice.



# With whom should we be initiating ACP conversations?



Since attending the Part 1 session, has your perspective on who you would engage in ACP with changed?

Ideally, I would start with....

More imperative, I would start with...

Absolutely, I would start with...

# With whom should we be initiating ACP conversations?



## **Ideally with:**

- Healthy capable adults, to create awareness, normalize ACP and being with culture change

## **More imperative with:**

- Capable adults with chronic disease before they become ill with complications

i.e. CKD, new starts once 'settled' on modality, patients with known family conflict, patients with known cognitive decline (i.e. early dementia/Alzheimer's diagnosis)

# With whom should we be initiating ACP conversations?



## **Absolutely with:**

- Capable adults with life expectancy of less than 6 to 12 months\*

i.e. Age of +75yrs, experienced a sentinel event, frequent hospitalizations, decline in physical/cognitive functional status, additional disease diagnosis,

### ***\*Surprise Question:***

*As the HCP, would you be surprised if this patient died in the next 6 to 12 months?*

# Video Clip



*Learning From Experienced ACP  
Facilitators* from the DVD titled:  
*Starting the Conversation, working ACP  
into Everyday Health Care*

# Sharing of the Cues you recognized in Practice



Since attending the Part 1 session:

1. What cues did you pick up on from your patients?
2. How did you respond?
3. What did you document?
4. How did you follow up?

# Recognizing Verbal Cues



- "What am I doing all of this for?"
- "I'm so tired of all this fuss!"
- "I'm afraid that I'm becoming a burden to my family"
- "This is not living. This isn't quality of life."
- "I don't want to seem like I am giving up."
- "How come they can't do more for me? I want to keep fighting."

# Why is ACP needed?



- Provides opportunities to prepare for living well and dying well
- Decreases not knowing what decision to make in a crisis
- Promotes patient/family-centered care
- Decreases moral distress for families and HCP
- Can provide a peaceful end of life experience for the patient, family, and staff.

# What is ACP?

## The Core Elements



1. Learning & understanding the adult & what is important to them. *Involve substitute decision makers.*
2. Clarifying with the adult their understanding of disease progression, prognosis and treatment options then providing medical information enabling them to make informed decisions.
3. Ensuring interdisciplinary involvement and utilizing available resources/options for care
4. Defining goals of care, documenting and creating a plan (including potential complications).



- Visual Representation of ACP Overview
- See separate attachment

# Learning Objective #2



Explore ways to overcome common barriers to initiating ACP conversations.

# Types of Barriers



- Patient
- Family
- HCP
- Clinic Environment
- System/program

# Group Discussion

## Barriers to ACP



What are some examples of patient or family “barriers” (i.e. statements/comments) that you have encountered when speaking with them about Advance Care Planning?

# Examples of patient & family ACP Barriers



1. *"I don't know how to talk to my family about this."*
2. *"I have tried talking to my family but they don't want to listen/talk about it."*
3. *"I am not sure if my family member could be my spokesperson (SDM)"*
4. *"My family will know what to do."*

# *Examples of patient & family ACP Barriers*



5. *"I don't want to talk about ACP."*
6. *"I have a Will and/or Power of Attorney."*
7. *"My doctor will know what to do."*
8. *"My friend had an ACP and when she got really sick, no one followed it."*

# Overcoming Barriers to ACP



In Part 1, participants identified the following barriers:

- Language
- Lack of time/too busy
- Workload/short staffing
- Trust/relationship not yet established with patient
- Unit/clinic Culture
- Differing staff beliefs
- Lack of privacy

In pairs select 2 barriers and propose a strategy for each to overcome them

# Where to start?

## S.P.E.A.K to adult



- Chosen a **S**ubstitute Decision Maker
- Thought about **P**references for treatment options
- Any previously **E**xpressed wishes
- Written an **A**dvance Directive or appointed a Representative
- Level of **K**nowledge regarding diagnosis, treatment options risks and benefits



# What could you say to introduce ACP?



1. *"We would like to talk to you about how we can best care for you as your illness progresses."*
2. *"Tell me about what represents good quality of life for you?"*
3. *"Tell me about your past experiences with illness. What about serious illness or death of anyone close to you?"*
4. *"What do you hope for your future?"*
5. *"In times of stress and difficulty, who or what provides you with support?"*
6. *"If you were to ever become unable to direct your own medical care, tell us, who would you want to help us make medical decisions for you?"*

# Learning Objective #3



Identify and articulate the benefits of having “values” focused rather than treatment based conversations with family and health care providers.

# Values Question Treatment Question



Values question	Possible responses?
<p>Some people say they want medical treatments as long as they can eat chocolate ice cream, watch football, dance, etc. What kinds of things come to mind?</p>	

# Values Question Treatment Question



Treatment question	Possible responses?
Do you want to be resuscitated if your heart stopped?	

# Learning Objective #4



Practice scenarios for increasing comfort and practicing wording and responses during ACP conversations.

# Video Clip...then in pairs discuss the following:



1. What worked in the ACP conversations?
2. What would you do or say differently?  
**Write down your actual words.**
3. Why might patients and/or family members not want to engage in ACP conversations?

# Role Play Scenarios



1. Role Play 2 Scenarios in 2s or 3s
  
2. Debrief Scenarios
  - How did it feel to be the patient?
  - What did you learn as the clinician?

# Considerations prior to broaching ACP Topic



## Discuss accomplishments/challenges:

- checking Greensleeve for previous ACP documentation and documents prior before speaking with patient
- Reconsidering approach and timing when patient has had a sentinel event
- Seeking first to understand, letting patient tell their story
- Offering frequent opportunities over time
- Encouraging patient to reflect
- Listening, exploring more intentionally



# Completeness of Greensleeve



After attending the Part 1 session, were you able to select a few charts and review the greensleeve for completeness?

1. What did you find?
2. What steps did you take?
3. Did you involve any colleagues?
4. How difficult or easy was this task?

# What goes in the Greensleeve & in what order?



1. **MOST**
  - Ensures quick and clear access when staff are responding to a code
2. **Provincial `No CPR` form**
3. **Advance Care Planning Record**
4. **Advance Care Plans. This may include:**
  - a. Advance Directive
  - b. Representation Agreement
  - c. List of TSDM
  - d. Written summary of values, beliefs and wishes (My Voice workbook)
  - e. Dialysis wishes document (previously known as part 5)
5. **FHA Confirmation of Substitute Decision Maker form**

## Importance of charting conversations and previously expressed wishes!

Many patients may not have other Advance Care planning documents (My Voice, Rep Agreement, Advance Directive etc.) mentioned in the Greensleeve, but they may have had a conversation with you about their wishes.

**ALWAYS** chart Advance Care Planning conversations.

# Learning Objective #5



Identify when and to whom to make referrals for ACP support and follow up.

Core element #1 SPEAK – screen;

Core element #4: Ensure interprofessional involvement

- ACP Roles and Responsibilities visual representation....pending

# Learning Objective #6



Engage in building team capacity and identifying approaches for sustainability.

# Making ACP Sustainable



1. Senior and Clinical Leadership Engagement
2. Staff involvement and training to sustain process
3. Staff behaviour towards sustaining the process
4. Infrastructure for sustainability
5. Credibility of Evidence
6. Benefits beyond helping patients
7. Fit with the organization's strategic aims and culture
8. Adaptability of improved process
9. Effectiveness of the system to monitor progress

Source: NHS, Institute for Innovation and Improvement

# Group Activity



1. Partner up with colleagues within your site and/or broader clinical setting
2. Identify 5 strategies for making ACP sustainable in your area
3. Which 2 barriers previously identified commonly occur in your work setting and how might you and your colleagues address them?



# Suggestions for Sustainability within your clinical setting



## Developing a plan:

- to review all existing charts for completeness of ACP documents
- for how the team can maintain ACP annual reviews
- for sending all existing ACP documents to health Records for uploading into Meditech (beyond order entry of MOST and SDM by UC)
- Identifying team member roles in the assessment of patient ACP readiness with all new patients
- Identifying team member roles in the revisiting of ACP content annually and with patient's whose health is deteriorating
- Identifying a long term strategy for addressing both staff and patient's ACP educational needs

# We challenge & support you to...



- Engage in the Advance Care Planning process yourself
- Begin implementing Advance Care Planning into your daily practices with patients and families
- Set small achievable goals

# Presenters and Contributors



- Victoria Lakusta Lamberton, Renal ACP Lead
- Alex Kruthaup-Harper, Renal EOL Coordinator
- Nguyen Nguyen, CNE ACP
- Cari Borenko Hoffmann, Coordinator ACP
- Grace Steyn, HD SW

# FHA Resources



- **IntrAnet**  
[http://fhpulse/clinical\\_programs/end\\_of\\_life/Pages/AdvanceCarePlanning.aspx](http://fhpulse/clinical_programs/end_of_life/Pages/AdvanceCarePlanning.aspx)
- [http://fhpulse/initiatives/scope\\_of\\_treatment/Pages/Default.aspx](http://fhpulse/initiatives/scope_of_treatment/Pages/Default.aspx)
- **IntErnet** [http://www.fraserhealth.ca/your\\_care/advance-care-planning/](http://www.fraserhealth.ca/your_care/advance-care-planning/)
- 1-877-TALK-034 (1-877-825-5034)
- [advancecareplanning@fraserhealth.ca](mailto:advancecareplanning@fraserhealth.ca)
- Cari Borenko Hoffmann 604 587 4408  
[cari.hoffmann@fraserhealth.ca](mailto:cari.hoffmann@fraserhealth.ca)

# Available from: Central Stores and/or Forms Imprint



- Provincial My Voice Guide.....349976
- Provincial ACP brochure.....423969
- Provincial Aboriginal brochure.....424725

## Also in Forms Imprint "Alerts and Directives"

- Advance Care Planning Record.....341997
- MOST.....430438
- Provincial No CPR

# Available to Fraser Health cost centres from: Central Stores



- Medical Orders for Scope of Treatment (MOST) Brochure
  - *English*.....262736
  - *Punjabi*.....262739
  - *Hindi*.....262740
  - *Chinese Simplified*.....262741
  - *Chinese Traditional*.....262742
- MOST Poster.....257282
- MOST Wallet Card.....257291

# Available from: FH Advance Care Planning Program



- Green document holder for home use
- ACP Wallet Card
- ACP Referral Card
- ACP Posters in 7 languages
- ACP Educational DVDs in English, Punjabi & Chinese
- Contact [cari.hoffmann@fraserhealth.ca](mailto:cari.hoffmann@fraserhealth.ca) for these materials

# Fraser Health Advance Care Planning Education



- On-line modules

- <https://ccrs.vch.ca/Secure/StartOnlineCourse.aspx?cid=2222>
- <https://ccrs.vch.ca/Catalog.aspx?cid=3099>

- Education sessions

- <https://ccrs.vch.ca/Catalog.aspx?cid=2383>

\*MOST education for physicians:  
michelle.veer@fraserhealth.ca



# Provincial Resources



- Provincial My Voice Guide:  
Includes Advance Directive and Representation Agreement forms
- Provincial Introductory Brochure
- Provincial Aboriginal Brochure
- Provincial Informational Videos

<http://www.seniorsbc.ca/legal/healthdecisions/>

# Additional Provincial Resources



- Health Care Providers Guide to Consent
  - <http://www.health.gov.bc.ca/library/publications/year/2011/health-care-providers'-guide-to-consent-to-health-care.pdf>
- BCMA
  - <https://www.bcma.org/news/advance-directives>
- Healthlink BC
  - [www.healthlinkbc.ca](http://www.healthlinkbc.ca)

# Videos



- Dr Doris Barwich “Health care consent laws have changed – what you need to know”  
<http://www.youtube.com/watch?v=a-HFLkL5IRk>
- Fraser Health Advance Care Planning  
<http://www.youtube.com/watch?v=-M31-NiH3yU>
- Speak Up! Advance Care Planning  
<http://www.youtube.com/watch?v=2aOX9abJhio>
- Atul Gawande How to Talk EOL with a Dying Pt  
[http://www.youtube.com/watch?v=45b2QZxDd\\_o&NR=1](http://www.youtube.com/watch?v=45b2QZxDd_o&NR=1)

[www.advancecareplanning.ca](http://www.advancecareplanning.ca)



# Speak Up

Start the conversation  
about end-of-life care

# International Society of Advance Care Planning and End of Life Care



International Society of

**Advance Care Planning  
& End of Life Care**

[www.acpelsociety.com](http://www.acpelsociety.com)



# References



1. American Nephrology Nursing Association. (no date). *Module 1: Techniques to Facilitate Discussion for Advanced Care Planning (ACP)*. ANNA National Office, Pitman, NJ. [www.annanurse.org](http://www.annanurse.org)
2. Davison, S. N., Holley, J. L., & Seymour, J. (2010). Advance care planning in patients with end-stage renal disease. In E. J. Chambers, E. A. Brown, and M. J. Germain. *Supportive Care for the Renal Patient* (2<sup>nd</sup> ed.). Oxford University Press Inc. New York, USA.
3. Davison, S. N. & Simpson, C. (2006). *Hope and advance care planning in patients with end stage renal disease: qualitative interview study*. *BMJ*, 333:886-889. *BMJ* doi 10.1136/bmj.38965.626250.55
4. Fraser Health Authority MOST ACP Policy  
[http://fhpulse/clinical\\_resources/clinical\\_policy\\_office/Documents/MOST\\_ACP\\_Clinical\\_Policy/1.%20Medical%20Orders%20for%20Scope%20of%20Treatment%20\(MOST\)%20and%20Advance%20Care%20Planning%20\(ACP\)%20-%20Clinical%20Policy.pdf](http://fhpulse/clinical_resources/clinical_policy_office/Documents/MOST_ACP_Clinical_Policy/1.%20Medical%20Orders%20for%20Scope%20of%20Treatment%20(MOST)%20and%20Advance%20Care%20Planning%20(ACP)%20-%20Clinical%20Policy.pdf)

# References



5. Fraser Health Renal Program. (2012). *Key Indicator Quarterly Reports* (unpublished).
6. *Humane Medicine*, Hutchison (1988) Johnstone, M. J., & Kanitsaki, O. (2009). Ethics and advance care planning in culturally diverse society. *Journal of Transcultural Nursing*, 20(4): 405-416.
7. Kurella, M., Covinsky, K. E., Collins, A. J., & Chertow, G. M. (2007). Octogenarians and nonagenarians starting dialysis in the US *Ann Int Med*.146(3):177-83
8. Poppel, D.M., Cohen, L.M., & Germain, M. J. (2003). The renal palliative initiative. *Journal of Palliative Medicine*, 6(2): 321-326.

# References



9. Fraser Health Renal Program. ***Starting the Conversation: Working Advance Care Planning into Everyday Health Care (DVD). August 2008. Fraser Health Renal Program.***



# Special thanks to those who contributed



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