We are in agreement with sharing the following Advance Care Planning materials. We assume no person or organization shall claim copyright over modified versions. We assume individual authors and organizations will be acknowledged as the author of the source publication.
Learning Objectives

1. Review the general concepts of Advance Care Planning (ACP).
2. Understand basic ACP concepts within a renal setting.
3. Recognize patient and staff readiness for engaging in ACP.
4. Reflect on your own values.
5. Discuss the importance of incorporating ACP into your practice.
What is Advance Care Planning:
Health Care Provider Perspectives

View video clip on introducing ACP from:

**Starting the Conversation:** Working
Advance Care Planning into Everyday
Health Care
What is Advance Care Planning?

- A process of shared decision making and planning for a time when you cannot make your own medical decisions

- An ongoing process of reflection and communication

- A process that involves discussions with Healthcare Professionals (HCP) and substitute decision makers (SDM)

- A process that may result in a written plan (Wishes/beliefs, Representation Agreement or Advance Directive)

- It is for capable adults for themselves
ACP is *not* meant to be:

- A task
- A code status (MOST) conversation
- One conversation about treatment options
- A document or form without conversations with SDM or HCP
- Strictly a refusal of medical treatment
- Power of Attorney (in BC for legal and finances only)
- Only for individuals who are palliative or elderly
Does ACP engagement take away hope?

- When ACP engagement is timely and appropriate it can "positively enhance rather than diminish patients’ hope."

Davison & Simpson, 2006
Why is ACP needed?

- Provides opportunities to prepare for living well and dying well
- Some adults are very clear about a treatment they want or do not want
- 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.
- Individuals wishes are honoured and have fewer life-sustaining procedures and lower rates of intensive care unit admissions
When do we engage in ACP

Initiating *Routine* discussions

- Introducing ACP prior to starting dialysis then revisiting at regular intervals
- Provide basic information first, then add more discussion over time
- Incorporate as a component of good patient care i.e. “we are trying to begin these talks with all of our patients”
Why is ACP particularly important with renal patients?

- Approximately 15-29% of deaths amongst dialysis patients occur after a decision to discontinue dialysis.

“Comprehensive care of ESRD patients, requires expertise not only in the medical and technical aspects of dialysis but also in palliative care, including advance care planning.”

Davison, Holley, & Seymour, 2010
In 2012 Jan.-Sept. (over a 9 month period)

A total of 303 ESRD patients died

- Chronic Kidney Disease (CKD) = 157
  - CKD patient mortality rate = 6.4% (157/2446 patients)

- Total Dialysis = 149
  - HD Patient (in-ctr & CDU) mortality rate = 17.5% (124/707)
    - Home HD = 0
    - Community HD = 4
    - In-centre HD = 120
  - PD = 25, a mortality rate of 9% (25/267)

FH Renal Program, Key Indicator Quarterly Reports 2012
When do we engage in ACP?
Patient Identification...Age

Increase risk of mortality with increased age at start of dialysis

Incident FH HD Starts January 1-December 31, 2010

Total incident patients: 268
- **106 patients were ≥75 yrs old** (40%) 

Of those that were ≥ 75 yrs,
- **32%** died within the time frame of Jan. 1/10-June 15/11 (18 months)

**Summary:** You have a 32% chance of dying within the first year after dialysis initiation if you are ≥ 75 yrs,

**Research:** Observational study that followed the rates of dialysis initiation and survival b/w 1996-2003 in the US. Median survival after dialysis initiation:
- 15.6 months for patients 80-84 years
- 11.6 months for 85-89
- 8.4 months if ≥90

When do we engage in ACP?

Patient Identification...Sentinel Events

1. MI and AKA (above knee amputation)
   - Have very high post-event mortality in ESRD patients on dialysis. Survival at 1 year less than 50%

2. Acute Malignancy

3. Serum Albumin
   - The lower the serum albumin level, the higher the risk of death
   - Alb of less than 35 g/L is associated with 1 year mortality of approx. 50%

4. Surprise Question
   - Would you be surprised if this patient were to die in the next 6-12 months?”
   - A strong predictor of mortality

5. Frequent Hospitalizations

6. Declining Functional Status
1. Thinking about the patients in your renal setting, how might you prioritize those in need of ACP?

2. What factors are contributing to your decision?
Successful conversations should include:

1. Capable adult who is **ready to talk**

2. Healthcare Professional prepared to:
   - Initiate conversations and follow up
   - Explore and clarify statements
   - Elicit beliefs, values, goals and quality of life
   - Assess understanding of medical condition
   - Understand cultural considerations
Who can do ACP?

EVERYONE – should recognize cues, assess for readiness and know who to refer to

With some basic ACP education, you can begin to engage patients and/or their SDM in a basic conversation

Each discipline has a role to play in the process
- Who are your Key Clinicians in your unit?
- When would it be appropriate to refer to a key clinician?
What does ACP include?
Core Elements of ACP

1. S.P.E.A.K to adult about Advance Care Planning
2. Learn about & understand the adult & what is important to them. Involve substitute decision makers.
3. Clarify understanding & provide medical information about disease progression, prognosis, & treatment options.
4. Ensure interdisciplinary involvement and utilize available resources/options for care
5. Define goals of care, document and create plan (including potential complications).
Examples of Approaches to ACP
Core Elements

1. S.P.E.A.K to adult about ACP

2. Learn about & understand the adult & what is important to them. Involve substitute decision makers.

- Clarify statements: “What do you mean when you say…” or “tell me more about that…”
- “What does it mean to live well? What gives your life meaning?”
- “How has your changing health status impacted you and your family?”
- “Have you had any experiences making health care decisions for a loved one, perhaps even end-of-life decisions?”
- “What did you learn through those experiences that might help you make your own decisions or help those you love make them for you?”
Examples of Approaches to ACP

Core Elements

3. Clarify understanding & provide medical information about disease progression, prognosis, & treatment options.
   - “Have you ever written down any of your thoughts about future medical care?”
   - “The last time you were hospitalized what was it like for you? Did it change any of your goals or values for the way you are living your life?”
   - “tell me what your understanding is of living with dialysis?”

4. Ensure interdisciplinary involvement and utilize available resources/ options for care
   - If treatment not available in current location, does the adult wish to be transferred from their current location? Options may include: acute care, hospice residences, residential care, and home.

5. Define goals of care, document and create plan (including potential complications).
   - Discuss specifics of plan to ensure understanding of possible complications and how to manage them.
   - If goal may not be attainable, what are the alternatives?
Recognizing Cues

Seeing signs of patient readiness by recognizing verbal and physical cues
1. What cues have you heard from patients?
2. How did you respond?
3. What cues have you heard that indicate a patient is not ready?
4. How would you respond to these comments?
5. What would you document on the ACP Record?
Recognizing Verbal Cues

• “I don’t want to be a burden”
• “I’ve had enough”
• “what happens if you stop dialysis”
• “I was thinking of writing a will”
• “Pt X was a good friend, I don’t want to die like that”
• “I’ve lived a good life”
• “I don’t want to be hooked up to a bunch of machines”
• “Is stopping dialysis committing suicide”
Recognizing Physical Cues

• Making or breaking eye contact
• Being physically relaxed versus fidgeting
• Maintaining topic of conversation versus suddenly changing it
• Others?
Fred is a new hemodialysis patient. He has received several weeks of hemodialysis.

- While hooking him up on dialysis he has expressed to you “I’m not sure how much longer I can do this dialysis thing”
- You look at his greensleeve and discover no information at all.

What are your next steps?
What might you say to him?
What would you document on ACPR?
1. What do you see as your professional role in ACP? Your colleagues role?

2. What barriers are hindering ACP in becoming a common part of routine care within your unit/program area?
Hmmmm….what are we supposed to be doing?

- Are we making it part of daily routine practice?
- What are the current systems in place?
- Who’s job is it anyway?
- How can we do this when we are already so busy doing the work we do?
- Do we believe it is essential, valuable and important work to engage in?
- Who really, really, really needs ACP?!
Understanding your own readiness

- Balance between personal readiness and professional responsibility
- Impact of burnout on ability to engage in ACP
- Do we have the option to “check out”?
- Acknowledging and recognizing cultural diversity
• Health Care Providers can feel uncomfortable & overwhelmed providing holistic care to the very diverse population in the renal program

• “There has been curiously little attention given to cross-cultural considerations in ACP” Johnstone & Kanitsaki (2009)
Diversity has broad inclusion

- Ethnicity
- Age
- Race
- Spirituality
- Ability
- Experiential
- Socioeconomic status
- Geography
- Minority Group
- Gender
Approaches to ACP

- Direct approaches valuing personal autonomy are not always beneficial
- Values based discussions are more useful than treatment based discussions (Poppel, 2003)
- Avoid singular story application to individuals & groups of people
View an example of an ACP Conversation….Bob’s scenario.

1. What do you think the HCP did well?
2. What examples of open ended questions did you hear the HCP use?
3. What would you do differently?
Every unit will have a location to store their pt ACP related information.

- Check at nursing station
- In resource room
- In SW office

Consider initially providing patient with a brochure prior to providing the complete Ministry of Health *My Voice* Guide.
Every medical chart should have a Greensleeve

- Kept at the very front of every medical chart - acute and renal

- If it’s not there, put one in!
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**
1. **MOST**

*(Medical Orders for Scope of Treatment)*

A physician order specifying code status and medical treatment, valid across all sectors of FH (GP office, community clinics, acute care & Residential care).

In Renal, this form is completed by the Nephrologist.

A copy is **always** given to the Patient.

At minimum, it is reviewed annually.

If MOST completed outside of renal, confirm it also reflects pt current wishes in renal setting, i.e. during dialysis. Have Nephrologist write this confirmation in an order then place copy of MOST in renal chart GS.
2. Provincial No CPR Form

Provincial form owned by BC Ambulance, BCMA and MOH

Original goes to patient

Copy kept in Greensleeve

Kept on Fridge in patient’s home

Able to obtain free medical alert bracelet

MOST will be honoured by BC Ambulance but it does not replace this form

Might be completed in conjunction with a DNR designation on MOST form
What goes in the Greensleeve?

3. ACP Planning Record

Communication tool.

Central place where all Disciplines document conversations regarding ACP.

Copy provided to the patient for their own records and to give to their other HCPs.
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.
What goes in the Greensleeve?

Another tool for renal patient to express wishes about initiating dialysis or circumstances under which they would stop dialysis

Not a legal document but can be part of ACP workbook

Encourage pt give a copy to their SDM and send copy to Health Records for uploading into Meditech

Part 5

Specific to individuals with kidney disease, undergoing dialysis

Even though I am satisfied with the quality of my life on dialysis, I realize that it is important to think about circumstances that might make me want to stop dialysis treatments. At some point in a medical crisis, I might lose the ability to express my wishes to my family and my doctor.

Dialysis is a life-prolonging treatment, and is not a cure. Please implement this treatment until such time as:

(Initial the box or boxes you want. Draw a line through anything you don’t want)

☐ I can no longer recognize my family and friends, and I cannot meaningfully communicate,
☐ I become permanently unresponsive or fall into a coma from which I won’t awake,
☐ When I have just had enough. In my own words, this is what I mean by “had enough”:

Understanding that if dialysis treatments are stopped I may live for only a few days or up to several weeks, depending on my health and my remaining kidney function. I expect my health care providers to provide appropriate comfort measures during this period.

Specific to individuals with kidney disease, not yet undergoing dialysis

Please do not start dialysis if:

☐ I can no longer recognize my family and friends and I cannot meaningfully communicate.
☐ Dialysis would cause more suffering for me than benefit.

Signature: ___________________________ Date: ___________________________
Greensleeve Considerations

It’s good practice to routinely look over any documentation in the Greensleeve to familiarize yourself with that patient’s current wishes, or instructions.

You don’t have to “double” chart. You can make reference in multidisciplinary notes such as “see note on ACP Record with date”.

If there are no entries do not assume the patient does not have ACP already completed. Ask them, look in Meditech or in the case of residential care, request the unit clerk to contact facility obtaining faxed copies.
My Voice Guide

A MOH booklet that explains ACP and contains an Advance Care Plan for patients to complete. It includes legal forms for Representation Agreements and Advance Directive.

Representation Agreement

A document in which a capable adult names their representative to make health care and other decisions on his/her behalf when incapable. There are two types:

1. Section 7 Standard Rep Agreement
2. Section 9 Enhanced Rep Agreement

For more information about Representation Agreements ask, your site Social Worker.

Staff must ask for a copy of the Advance Care Planning documents, understand them, Photocopy, and place it in the Greensleeve. Adult keeps the originals.
Healthcare Consent Hierarchy BC

1. Capable Adult (19 yrs)
2. Committee of Person (*Patient’s Property Act*)
3. Representative (*Representation Agreement Act*)
4. Advance Directive *NEW*
5. *Temporary Substitute Decision Maker (*Health Care Consent* and *Care Facility (Admission) Act*)
   1. Spouse (common law, same gender)
   2. adult children (equally ranked)
   3. Parent (equally ranked)
   4. brother or sister (equally ranked)
   5. Grandparent (equally ranked) *NEW*
   6. Grandchild (equally ranked) *NEW*
   7. Anyone else related by birth or adoption
   8. Close friend *NEW*
   9. A Person immediately related by marriage *NEW*
   10. another person appointed by PGT

*No conflict and contact within 12 months*
Role of the Substitute Decision Maker(s)

1. Consult with the adult to the greatest extent possible

2. Comply with any instructions or wishes, values, beliefs the adult expressed while capable

3. If no instructions or wishes, then decisions are based on best interests

4. Not make decisions based on SDM’s personal values, beliefs or wishes.
Advance Directive
is a capable adult’s written instructions that speak directly to their health care provider about the health care treatment the adult consents to, or refuses. It is effective when the capable adult becomes incapable and only applies to health care conditions and treatments noted in the advance directive.

NOTE: Enduring Power of Attorney or Power of Attorney
A document in which a capable adult authorizes another person (called their attorney) to make decisions in relation to the adult’s financial or legal affairs, business and property. The attorney does not make health care treatment decisions.

Staff must ask for a copy of the Advance Care Planning documents, understand them, Photocopy, and place it in the Greensleeve. Adult keeps the originals.
BC Ministry of Health No CPR Form: No

FH DNR: No
Current Systems in Place: Transferring of Greensleeve Documents

- Encourage patients/SMD to bring their ACP documents with them to the hospital, physician and other clinic visits.

- If you are aware a pt is in acute care, transferred to another dialysis unit/program or residential care, provide copies to the unit if the pt has not done so.

- Because faxes often get lost or missed, alert the PCC or SW at the receiving site of these forms, if patient has identified an SDM and that a fax is on its way.
Role Play...in pairs

HCP prompts pt for their SDM and pt has a complex reply

- What steps are taken by HCP?
- What is documented and where?
- What is the planned f/u?
Case Scenario

- Peggy is a 68 year old parachute new start hemodialysis patient. She has had 3 dialysis runs. She has a new diagnosis of multiple myeloma, is receiving chemotherapy and radiation and is being followed by the Cancer Agency.

- We do not have any documented ACP.

- Peggy was approached by a HCP who provided her with a *My Voice* workbook, an ACP brochure and an explanation regarding ACP that included an overview of the need for this information as “routine”. Peggy became angry and refused to discuss any issues related to ACP.
Activity

1. What was happening in this scenario?

2. What could we do differently?

3. Even if the patient is not ready, what can the team do in the meantime?
Mary has been a patient in the renal program for many years. You receive a call from her distraught family member stating she has had a stroke and is in emergency. The family member is concerned that there will be conflict over what to do next and this patient’s sons have a history of disagreement on their mother’s “best care”.

- You go to her medical chart and look in the Greensleeve discovering a lot of information, including a completed wishes/beliefs page and a Representation Agreement indicating her son Henry is her SDM.

- What are your next steps?
Case Study - Joe

Joe is a resident of Bevan Lodge. He is also a renal patient.
You happen to glance at his chart and discover a Greensleeve with no information at all.
You ask him if he has an advance care plan or MOST. He responds “I remember being asked about whether I wanted my heart restarted.”

What steps do you take?
Considerations prior to broaching ACP Topic

• Do your homework by checking Greensleeve for previous ACP documentation and documents prior before speaking with patient

• Reconsider approach and timing if patient struggling with a sentinel event

• Seek first to understand, letting patient tell their story

• Offer frequent opportunities over time

• Encourage patient to reflect

• Listen, explore and listen more
Based on what you have learned about ACP today, identify one thing that you will do differently in your practice tomorrow?
Homework

1. Clinical application:
   During your workday, listen for patient cues and respond to them. Document what you heard/observed and how you responded. Bring scenario and charting to next session.

2. Structural Process:
   Select several charts, review for Greensleeve completeness and correct organization.

3. Engagement:
   Complete your own advance care plan, identify your SDM and initiate a conversation about your wishes.
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
• **IntrAnet**
  http://fhpulse/clinical_programs/end_of_life/Pages/AdvanceCarePlanning.aspx
• **IntErnet**  http://www.fraserhealth.ca/your_care/advance-care-planning/
• 1-877-TALK-034 (1-877-825-5034)
• advancecareplanning@fraserhealth.ca
• Cari Borenko Hoffmann 604 587 4408
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
• 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 for these materials
Fraser Health Advance Care Planning Education

• On-line modules

• Education sessions

*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

- BCMA

- Healthlink BC
  - www.healthlinkbc.ca
• Dr Doris Barwich “Health care consent laws have changed – what you need to know”
http://www.youtube.com/watch?v=a-HFLkJ5I RK

• Fraser Health Advance Care Planning
http://www.youtube.com/watch?v=-M31-NiH3yU

• Speak Up! Advance Care Planning
http://www.youtube.com/watch?v=2aOX9abj hio

• Atul Gawande How to Talk EOL with a Dying Pt
http://www.youtube.com/watch?v=45b2QZxDd_o& NR=1
www.advancecareplanning.ca

Speak Up

Start the conversation about end-of-life care


4. Fraser Health Authority MOST ACP Policy


Special thanks to those who contributed

• Victoria Lakusta Lamberton, Renal ACP Lead
• Alex Kruthaup-Harper, Renal EOL Coordinator
• Nguyen Nguyen, CNE ACP
• Cari Borenko Hoffmann, Coordinator ACP
• Grace Steyn, Renal Social Worker
• Dawn Dompierre, VIHA Renal EOL Coordinator