




## Advance Care Planning in the Cardiac Program

2013



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### Learning Objectives

1. Briefly review the general concepts of Advance Care Planning (ACP). Understand core elements of ACP conversations and begin discussing interdisciplinary roles.
2. Briefly review consent hierarchy in BC.
3. Review regional ACP system processes.
4. Recognize patient and staff readiness for engaging in Advance Care Planning.
5. Discuss how to incorporate Advance Care Planning into your practice and how to support the sustainability in your program.



### Group Introductions

1. Introduce yourself, include your profession and work area.
2. Describe a learning goal for today's session



## Objective #1

Briefly review the general concepts of Advance Care Planning (ACP). Understand core elements of ACP conversations and begin discussing interdisciplinary roles.



## What is Advance Care Planning? What Advance Care Planning is NOT?

[View video clip Atul Gawande](#)



## 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



## What healthcare professionals should engage in ACP with clients?



## How are we communicating with these professionals within our program and outside of our program?



## Who should engage in ACP conversations?

EVERYONE – should recognize cues, assess for readiness and know who to refer to/connect with (outside of the program as well)

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



## 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).



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## Examples Questions for ACP Core Elements

1. S.P.E.A.K to adult
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?"



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## Examples Questions for 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 heart disease?"
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?



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## Objective #2

- Briefly review consent hierarchy in BC.



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## 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



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## 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.



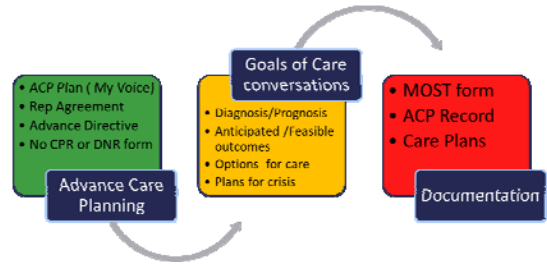
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### Objective #3

- Review ACP regional system processes.



### Advance Care Planning (ACP) cycle



### Let's start with the Greensleeve

#### Every chart should have a Greensleeve

- Kept at the very front of every chart
- If it's not there, put one in!
- Greensleeve for home use should be provided to all pts



### What goes in the chart Greensleeve & in what order?

- MOST**
  - Ensures quick and clear access when staff are responding to a code
- Provincial `No CPR` form**
- Advance Care Planning Record**
- Advance Care Plans.** This may include:
  - Advance Directive
  - Representation Agreement
  - List of TSDM
  - Written summary of values, beliefs and wishes (My Voice workbook)
- FHA Confirmation of Substitute Decision Maker form**



### What goes in the Greensleeve?

#### 1. MOST

(Medical Orders for Scope of Treatment)

FHA form. BCAS will honour.

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

The patient should keep the original

Kept on fridge in patient's home in a greensleeve



### What goes in the Greensleeve?

#### 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.

Original provided to the patient for their own records and to give to their other HCPs

Form titled "ADVANCE CARE PLANNING (ACP) RECORD". It includes a barcode, patient information fields (Name, Date of Birth, Page 1 of 1), and a table for recording conversations. The table has columns for "Date of Conversation", "Participants & Location", "Key indicators of conversations", and "Next Steps/Plan".

## Advance Care Planning Record

### Importance of charting conversations and previously expressed wishes!

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

**ALWAYS** chart Advance Care Planning conversations.



## What goes in the Greensleeve?

4. Advance Care Plans. This may include:
- Advance Directive
  - Representation Agreement
  - List of TSDM
  - Written summary of values, beliefs and wishes (My Voice workbook)

### 5. FHA Confirmation of Substitute Decision Maker form

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



## 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.



## Current Systems in Place: Transferring of Greensleeve Documents


- Encourage patients/SDM 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 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




## MOST and ACP Resources and Policy

- [http://fhpulse/clinical\\_programs/end\\_of\\_life/Pages/AdvanceCarePlanning.aspx](http://fhpulse/clinical_programs/end_of_life/Pages/AdvanceCarePlanning.aspx)






**Let's take a break**



**Objective #4**


Recognize patient and staff readiness for engaging in ACP



**Heart Failure Statistics**


- Improved prognosis due to many new advances in the past 20 years.
- In spite of this – still a 30-50% 5 year mortality.
- Life expectancy of patients admitted to hospital with heart failure is approx 2 years.
- The mortality rate of heart failure is higher than most cancers.
- Contrary to patients with cancers, HF patients at the end of life are less likely to access palliative resources, and more likely to access hospital care and CV procedures.
- CCS 2011 HF guidelines for Palliative care state that provision of palliative care needs should be integrated into the interdisciplinary care model for heart failure but we are still a ways away from that.

(Howlett J, 2011)

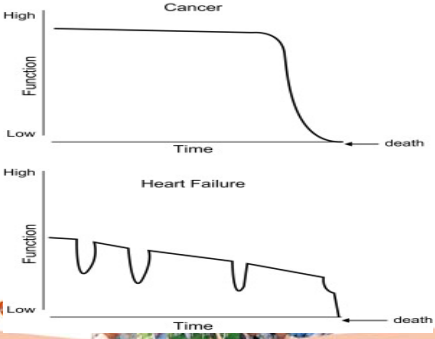


**Question**

Why the lack of Advance Care Planning & End of Life preparation in the Cardiac Population?



**Disease Trajectory – Cancer vs Heart Failure**



**Research on lived experiences – what do our HF patients say**

- Edinburgh Study- done to gain an understanding of the lived experience of HF patients and their care givers compared with lung cancer patients:
  - HF patients had less information about their disease and prognosis,
  - less involved in decision making,
  - progressive losses and social isolation,
  - stress of balancing and monitoring complex medication regimens dominated their lives.
  - HF patients received less health, social, and palliative care services and care was often poorly co-ordinated.
  - What impacted them the most was how the disease affected the wider aspects, ie how the disease impacted their daily and social lives, and had compromised their ability to maintain their sense of self.

(Johnson M and Lehman R, 2006)



## Research cont'd

- Current evidence shown in several studies tell us that patients (especially acutely ill or hospitalized patients) wish for end of life discussions to take place with their care providers.
- In one study 30% of patients wished for a discussion of treatment preferences for end of life care but were not given the opportunity by their care providers.
- Significant disparity between care provider and patient understanding of advanced care preferences has been shown.

(Howlett, J 2011)



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## Remember Communication is a Process, Not a Single Event

Johnson, M. & Lehman, R. (2006)



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## Barriers to Communication of End of Life discussions

- Patient
- Disease
- Professional
- System



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## Discussion Point with Group

- What are some of the barriers that you have faced in your practice?
  - With patients?
  - With families?
  - With your team?



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## Patient Barriers

- Lack of common language between patient and professional ie term "heart failure" and its connotation.
- Physical limitations affecting ability to engage in appointments or discussions:
  - Reduced exercise tolerance
  - Fatigue
  - Breathlessness
  - Other co-morbidities
  - Depression – leads to reduced compliance, inability to think clearly, logically
  - Social isolation



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## Disease Barriers

- Symptoms of cardiac insufficiency can affect patient's ability to communicate effectively with caregivers, professionals, family:
  - Confusion
  - Poor short term memory
  - Difficulty in retaining information



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## Professionals

- Hard to translate knowledge about a complex pathological condition into lay terms.
- Dr believe patients expect too much certainty especially with prognosis and being unable to provide this contributes to them avoiding communicating key information.
- Feelings of impotence ie not being able to foresee deteriorations in the illness trajectory due to the unpredictable nature of the disease.
- Doctors feelings of incompetence, embarrassment, feeling powerless and failing the patient, awkward in showing own emotions.



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## System

- Poorly coordinated care, especially between primary care and specialty care/providers, and during transition from hospital discharge to community, home.
- Lack of planning and continuity of care
- Time constraints – busy doctors, patients ideas, concerns and expectations cannot be fully explored, patients reluctant to bother their doctors.



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## 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."



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## 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."



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## How can we overcome these barriers?



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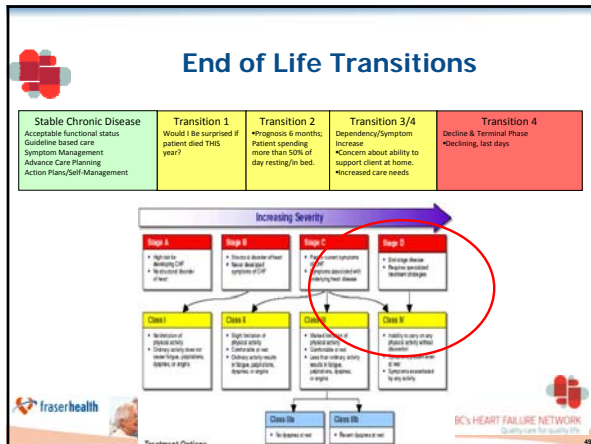
## Transition Triggers

How to know when to initiate or revisit end of life discussions.



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- ## Transitions – Trigger Questions
- (Gold Standards Framework)
- **Surprise Question** (In the next 6 months, would you be surprised to hear this individual had died?)
  - **Choice/Need** – Pt with advanced disease makes choice for comfort measures or is in special need of supportive palliative care (e.g. non a transplant candidate, VAD at end of life)
  - **Clinical indicators** (at least 2 of):
    - 1) NYHA III or IV;
    - 2) In last year of life;
    - 3) Recurrent CHF hospitalizations;
    - 4) Difficult physical or psychological symptoms despite optimal therapy.
  - **Difficult physical or psychological symptoms** despite optimal therapy.

- ## When should conversations occur?
- Potential transition points for discussion
- Within all 3 stages of Heart Failure Progression**
- At initial diagnosis,
  - New intercurrent illness,
  - Progression of disease – periodic review of goals during periods of significant clinical change especially hospitalization or development of a new clinical condition.
  - Change in family or life setting or other significant life events.
  - As the disease progresses increasing emphasis on symptom control is present.
  - **Readdress goals** as the patient nears end of life – balancing quantity and quality of life with a shift to quality.
  - Palliative care consultations should be considered at this time
- 2011 CCS guidelines for heart failure and palliative care

- ## Reaching the terminal phase, How do we know?
- **Difficult to determine for all professionals.** Several clues are the following:
    - Refractory NYHA Class 3b or 4 symptoms: inability to render euvolemic without concomitant symptomatic hypotension or increasing renal insufficiency (GFR<20),
    - need for inotropic support to maintain clinical stability,
    - continued need for hospitalization for HF>30 days,
    - need for progressive reduction of ACE inhibitor or beta blocker therapy due to patient intolerance.

- ## Use of Life Saving Devices (ie ICD's)
- ICD's used in heart failure in the attempt to prevent premature death due to arrhythmia.
  - May also prolong the dying process due to inappropriate firing, can increase distress.
  - Implications of both inserting and deactivating the device should be discussed prior to it's insertion, together with consideration of advantages and disadvantages.
- (Johnson M and Lehman R, 2006)

- ## Practice Conversations
- See handouts for examples ie Supplemental tables.
- Assessing Readiness for end of life discussions.
- Framework for discussing end of life discussions.
- Tools for estimating prognosis of patients.

## Recognizing Cues

Seeing signs of patient readiness by recognizing verbal and physical cues



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## Recognizing Verbal 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?



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## 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"



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## Recognizing Physical Cues

- Making or breaking eye contact
- Being physically relaxed versus fidgeting
- Maintaining topic of conversation versus suddenly changing it
- Others?



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## 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



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## Case Study – Mr. Smith, 83 years young

Dx and history documented in Meditech in Nov. 2012:

- 1. End stage congestive heart failure from nonischemic cardiomyopathy with severe LV dysfunction with an ejection fraction of 20 to 25 %)
- 2. ICD in place
- 3. Chronic lymphocytic leukemia
- 4. COPD
- 5. Type 2 diabetes
- 6. Atrial fibrillation



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## History of SMH admissions and coming to HFC at JPOCSC

- Hospital visits last few years (May 2009 and Feb. 2010 and Nov. 2012).
- Attended HFC at JPOCSC in March 2010. Last time he visited HFC at JP was in Nov. 2012, but few days later his condition got worse and was later admitted to SMH.
- In total, he visited HFC regularly for about 2.5 years (approx. once every 3 months) and his condition had been stable until the last visit.



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## Home Situation

- He rented a room in a condo and lived with a female friend Lynn who owned the condo.
- Lynn came to the HFC with him regularly and she appeared to be supportive and was also considered by the team as his caregiver.
- Mr. Smith was able to understand all the information and make his own medical decisions the whole time when he attended HFC.



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## Group Discussion

1. When and who should start to talk about ACP to Mr. Smith?
2. How much do we as a HFC team need to know about the role of Ms. Lynn? Is she his TSDM? Does Mr. Smith need a RA? Who is Mr. Smith's family?



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## Objective #5

- Discuss how to incorporate Advance Care Planning into your practice and how to support the sustainability in your program.



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## 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?!



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## 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



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## 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?



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## What next?

Based on what you have learned about ACP today, identify one thing that you will do differently in your practice tomorrow?



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## Action Planning for HFC Clinic Standardization



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## 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



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## 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)
- IntraNet [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)



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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



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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](mailto: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

# 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



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