Who I am

- Palliative Care Consultant with FH
  - Royal Columbian Hospital and New Westminster
  - Physician Lead, Education
- Program Director, Pall Med Residency
  - UBC, Clinical Assistant Professor, Dept of Med
- Chair, ACP HCP Education Working Group
  - BC Centre of Palliative Care

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Disclosure

• Not aware of any actual or potential conflict of interest
• No industry sponsorship
Objectives

By the end of the presentation, the participant will be able to:

1. Identify patients deserving of ACP conversations
2. Initiate and follow-up ACP conversations with patients
3. Describe some BC consent legislation that pertains to ACP
Invitation is to consider and try something new
My Goals

Enable physicians to have

more conversations &

more effective conversations.
Ultimate Goal

To respect and honour patients’ wishes & deliver Patient-centred care
Engagement exercise

• You’ve been shipped-wrecked on an island.
• You receive a message in a bottle stating that at some time in the future, there may be a boat that comes by.
• You need to decide now if you want to get on it.
• You write yes or no on the note, place it back in the bottle, and send it back to sea.
What kind of island?
What kind of boat?
How safe is the boat-trip?
Where will boat take you?
Analogy to treatment binary question – ie, Do you want CPR?

- What kind of island?
- What kind of ship?
- How safe is the trip?
- Where is it going to take me?
- What are my current problems & prognoses?
- What kind of treatments are offered? Risks/benefits?
- How safe are these treatments?
- Are the treatments going to get me where I want to go?
Healthcare is not a Chinese menu

• Not a series of yes/no questions

• But if ACP is not about yes/no choices, then what is ACP?
Myth busting

Advance care planning 
is not about filling out forms.
And it is definitely not about filling out the MOST form.
MOST form

• The MOST form is a **physician order**
• It is not an Advance Directive
• It is not a form that patients complete themselves

• (to be continued)
What is Advance Care Planning?

- A process whereby a capable adult thinks and talks about their beliefs, values, fears, and wishes
- And about the health-care they wish to consent to or refuse
- Conversations with their health care providers and family, in advance of a situation when they are incapable of making health-care decisions.
- To inform current or future medical care.
Ambiguous dying

Curative/Restorative Therapy

Presentation/ Diagnosis
Acute
Chronic

Illness

Palliative Therapy

Death
Life Threatening
Potential Triggers for End-of-Life Communication by Disease

**Cancer**

Prognosis-related triggers

“Would you be surprised if this patient died in the next year?”

Disease-based/condition-based criteria

All patients with non-small cell lung cancer, pancreatic cancer, glioblastoma

Patients older than 70 years with acute myelogenous leukemia

Treatment-based identification

Third-line chemotherapy
Potential Triggers for End-of-Life Communication by Disease

**Chronic Obstructive Pulmonary Disease**
Lack of further treatment options
Functional decline
Symptom exacerbation
Ongoing oxygen requirement
Hospitalizations

Potential Triggers for End-of-Life Communication by Disease

**Congestive Heart Failure**

- Increased symptoms
- Reduced function
- Hospitalization
- Progressive increase in diuretic need
- Hypotension
- Azotemia
- Initiation of inotrope therapy
- First or recurrent shock

## End-Stage Renal Disease

Prognosis-related triggers

- “Would you be surprised if this patient died in the next year?”

- Albumin level less than 3.5 g/dL

- Age (as a continuous variable)

- Dementia

- Peripheral vascular disease
Potential Triggers for End-of-Life Communication by Disease

**General**

Older than 80 years and hospitalized\(^3\)

Prognosis-based criteria (http://www.eprognosis.org)\(^85\)

Alignment with new SPICT tool

<table>
<thead>
<tr>
<th>Supportive and Palliative Care Indicators Tool (SPICT™)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cancer</strong></td>
</tr>
<tr>
<td>Functional ability deteriorating due to progressive metastatic cancer.</td>
</tr>
<tr>
<td>Too frail for oncology treatment or treatment is for symptom control.</td>
</tr>
<tr>
<td><strong>Dementia/ frailty</strong></td>
</tr>
<tr>
<td>Unable to dress, walk or eat without help.</td>
</tr>
<tr>
<td>Eating and drinking less, swallowing difficulties.</td>
</tr>
<tr>
<td>Urinary and fecal incontinence.</td>
</tr>
<tr>
<td>No longer able to communicate using verbal language; little social interaction.</td>
</tr>
<tr>
<td>Fractured femur, multiple falls.</td>
</tr>
<tr>
<td>Recurrent febrile episodes or infections; aspiration pneumonia.</td>
</tr>
<tr>
<td><strong>Neurological disease</strong></td>
</tr>
<tr>
<td>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</td>
</tr>
<tr>
<td>Speech problems with increasing difficulty communicating and/or progressive swallowing difficulties.</td>
</tr>
<tr>
<td>Recurrent aspiration pneumonia; breathlessness or respiratory failure.</td>
</tr>
<tr>
<td>ate and coordinate the care plan.</td>
</tr>
</tbody>
</table>
Core Elements of ACP

1. SPEAK to the adult about ACP
2. Learn about and understand the adult (as well as family or substitute decision makers)
3. Clarify understanding and provide medical information regarding diagnosis, prognosis, and options of treatment
4. Ensure interdisciplinary involvement and utilize available resources/options
5. Define goals of care and create plan (include potential complications & location of care)
Core Elements of ACP

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

Substitute decision maker
such as a Representation Agreement
Preferences for information/decision
Expressed wishes
(advance care plan)
Advance Directive
Knowledge regarding diagnosis,
treatment options, risks & benefits
SPEAK: Substitute decision maker

If there came a time, due to illness or injury, when you could not clearly speak for yourself, who knows you the best – who do you trust – to be able to speak on your behalf to help us make medical decisions for you?

• Do you have a Representation Agreement?
• I would like to have a copy.
SPEAK: Preferences

• How do you like to receive medical information?
• How do you like to make medical decisions? Who helps you with these decisions?
SPEAK: Expressed wishes

• Are there any medical treatments that you know of, that you’ve already thought about, and that you would never want to have?
  – How did you come to these decisions?
• Have you written anything down in a plan?
• I would like to have a copy, and please update me whenever you make changes.
**SPEAK: Advance directive**

- Have you completed an advance directive?
- I would like to have a copy.
SPEAK: Knowledge

• What other medical information would you like to have in order to make further advance care plans?
Who makes medical decisions?

1. The capable adult 19 years or older
2. Committee of person (Patient's Property Act)
3. Representative (Representation Agreement Act)
4. Advance Directive
5. Temporary Substitute Decision Maker* (Health Care (Consent) and Care Facility (Admission) Act)
Formally Appointed Substitute Decision Makers (Long Term)

**Two types (listed in order of priority):**

1. Personal Guardian appointed by the court under *Patients Property Act* (also called Committee of the Person)

2. Representative named by capable adult - bound by Representation Agreement and *Representation Agreement Act*
Representation Agreement

• Two different types of Representation Agreements

• Agreement under Section 7 vs. agreement under Section 9
Representation Agreement

*Representation Agreement Act*

- **Section 7**
  - Standard Powers, no lawyer required; minor and major health care

- **Section 9**
  - Additional Powers, lawyer no longer required; minor and major health care and life support
Health Care Defined

• Major Health Care
  – major surgery, any treatment involving a general anesthetic, major diagnostic or investigative procedures, or any health care designated by regulation as major health care;

• Minor Health Care
  – routine tests to determine if health care is necessary, and routine dental treatment

References: FH Consent Policy
Health Care (Consent) and (Care Facility) Admission Act
Rep Agreement or Advance Directive

Must be signed by the adult when capable

• be witnessed by two witnesses*
• one witness who is a notary public or lawyer

*A witness cannot be a person who provides personal care, health care or financial services to the adult for compensation, nor the spouse, child, parent, employee or agent of such a person
Advance Directive

Must state that the adult knows that:

– a health care provider may not provide to the adult any health care for which the adult refuses consent in the advance directive; and

– a person may not be chosen to make decisions on behalf of the adult in respect of any health care for which the adult has given or refused consent in the advance directive
Temporary Substitute Decision Makers (Short Term)

The following may be a TSDM (in order):

– The adult’s spouse (married or cohabitating; same gender)
– The adult’s child (ranked equally)
– The adult’s parent (ranked equally)
– The adult’s brother or sister (ranked equally)
– The adult's grandparent – New (ranked equally)
– The adult's grandchild – New (ranked equally)
– Anyone else related by birth or adoption to the adult
– A close friend of the adult – New
– A person immediately related to the adult by marriage – New
– Public Guardian & Trustee will appoint or act as TSDM if no TSDM available, qualified or there is a dispute

*No conflict and contact within 12 months
Current and Long Standing Consent Rights

• Part 2. #4. Every adult who is capable of giving or refusing consent to health care has

a) the right to give consent or to refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death,…

b) the right to expect that a decision to give, refuse or revoke consent will be respected

Health Care (Consent) and Care Facility (Admission) Act [HCCCFA]
Roles & Responsibilities

• Part 2. #12.1

“A health care provider must not provide health care... if the health care provider has reasonable grounds to believe that the person, while capable...expressed an instruction or wish applicable to the circumstances to refuse consent to the health care.”

Health Care (Consent) and Care Facility (Admission) Act [HCCCFA]
Core Elements of ACP

1. **SPEAK** to the adult about ACP
2. **Clarify understanding and provide medical information regarding diagnosis, prognosis, and options of treatment**
Do we all have the same understanding of the medical landscape?
Core Elements of ACP

1. SPEAK to the adult about ACP
2. Clarify understanding and provide medical information regarding diagnosis, prognosis, and options of treatment
3. Learn about and understand the adult (as well as family or substitute decision makers)
Impact of communication about serious illness care preferences

- Improved clinical outcomes
- No increase in anxiety, depression, and loss of hope
- Reduction in surrogate distress
- Reduction in costs
Communication about serious illness care goals: a review and synthesis of best practices


• Rachelle E. Bernacki, MD, MS;
• Susan D. Block, MD;
• for the American College of Physicians High Value Care Task Force
Box 4. A Systematic Approach to Discussions of Serious Illness Care Goals

- Train clinicians
- Identify patients at risk
- “Trigger” conversations in the outpatient setting before a crisis
- Educate patients and families
- Use a checklist or conversation guide
- Improve communication of critical information in the EMR
- Measure and report performance

### CONVERSATION GUIDE

<table>
<thead>
<tr>
<th>Understanding</th>
<th>What is your understanding now of where you are with your illness?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information preferences</td>
<td>How much information about what is likely to be ahead with your illness would you like from me?</td>
</tr>
<tr>
<td><strong>FOR EXAMPLE</strong></td>
<td>Some patients like to know about time, others like to know what to expect, others like to know both.</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Share prognosis, tailored to information preferences</td>
</tr>
<tr>
<td>Goals</td>
<td>If your health situation worsens, what are your most important goals?</td>
</tr>
<tr>
<td>Fears / Worries</td>
<td>What are your biggest fears and worries about the future with your health?</td>
</tr>
<tr>
<td>Function</td>
<td>What abilities are so critical to your life that you can’t imagine living without them?</td>
</tr>
<tr>
<td>Trade-offs</td>
<td>If you become sicker, how much are you willing to go through for the possibility of gaining more time?</td>
</tr>
<tr>
<td>Family</td>
<td>How much does your family know about your priorities and wishes?</td>
</tr>
<tr>
<td></td>
<td>(Suggest bringing family and/or health care agent to next visit to discuss together)</td>
</tr>
</tbody>
</table>
Serious illness conversation guide

gaining more time?
Serious illness conversation guide

<table>
<thead>
<tr>
<th>Worry / Concern</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>what are your biggest fears and worries about the future with your health?</td>
<td></td>
</tr>
</tbody>
</table>

| Function | What abilities are so critical to your life that you can’t imagine living without them? |
Serious illness conversation guide

What are your biggest fears and worries about the future with your health?
Serious illness conversation guide

Some patients like to know about time, others like to know what to expect, others like to know both.

Share prognosis, tailored to information preferences.
Goals

• If your health were to deteriorate, what would be most important to you?
  – What do you think will happen?
  – What do you most want to accomplish?
  – What is most important in your life right now?
  – What represents quality of life for you?
  – What represents dignity for you?
Fears

• What medical treatments are you already aware of that you really don’t want to have to go through?
• What do you hope to avoid?
• What are you afraid will happen?
• What about your care causes you anxiety or concern?
• What physical condition would represent poor quality of life?
Serious illness conversation guide

For example:
Some patients like to know about time, others like to know what to expect, others like to know both.
Serious illness conversation guide

Understanding

What is your understanding now of where you are with your illness?
Trade-offs

- As we work together, there may be treatments that we could offer that may prolong your life, but have side-effects and/or less than ideal results.

- What would be your desired balance between added time versus comfort and functional ability?
## Table. Communication Tips

<table>
<thead>
<tr>
<th>Do</th>
<th>Don’t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Give a direct, honest prognosis⁹⁹,¹⁰¹</td>
<td>Avoid responding to a patient request for information about prognosis¹⁰²</td>
</tr>
<tr>
<td>Provide prognostic information as a range; acknowledge uncertainty, eg, “we think you have weeks to a small number of months, but it could be shorter or longer”¹⁰³</td>
<td>Provide vague, eg, “incurable” or overly specific information, eg, “you have 6 months”</td>
</tr>
<tr>
<td>Allow silence¹⁰⁴</td>
<td>Talk more than half the time¹⁰⁴</td>
</tr>
<tr>
<td>Acknowledge and explore emotions¹⁰⁵</td>
<td>Provide factual information in response to strong emotions</td>
</tr>
<tr>
<td>Focus on the patient’s quality of life, goals, fears, and concerns³³</td>
<td>Focus on medical procedures¹⁰⁶</td>
</tr>
</tbody>
</table>

Core Elements of ACP

1. SPEAK to the adult about ACP
2. Learn about and understand the adult (as well as family or substitute decision makers)
3. Clarify understanding and provide medical information regarding diagnosis, prognosis, and options of treatment
4. Ensure interdisciplinary involvement and utilize available resources/options
Teamwork

• Other team members
• What parts of the Serious Illness Conversation do you own?
• Which parts are best suited for fellow team members?
• Other resources?
Core Elements of ACP

1. SPEAK to the adult about ACP
2. Learn about and understand the adult (as well as family or substitute decision makers)
3. Clarify understanding and provide medical information regarding diagnosis, prognosis, and options of treatment
4. Ensure interdisciplinary involvement and utilize available resources/options
5. Define goals of care and create plan (include potential complications & location of care)
### Various Goals of Treatment

<table>
<thead>
<tr>
<th>Aspect of Care</th>
<th>Curative</th>
<th>Life-Prolonging, Palliative</th>
<th>Symptomatic Palliative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on disease</td>
<td>Eradicate</td>
<td>Arrest progression</td>
<td>Avoid complications</td>
</tr>
<tr>
<td>Acceptable adverse effects</td>
<td>Major</td>
<td>Major-moderate</td>
<td>Minor-none</td>
</tr>
<tr>
<td>Psychological attitude</td>
<td>“Win”</td>
<td>“Fight”</td>
<td>“Accept”</td>
</tr>
<tr>
<td>Preference for CPR</td>
<td>Yes</td>
<td>Probably</td>
<td>Probably not</td>
</tr>
<tr>
<td>Hospice candidate</td>
<td>No</td>
<td>No</td>
<td>Probably</td>
</tr>
<tr>
<td>Symptom prevention/relief</td>
<td>Secondary</td>
<td>Balanced</td>
<td>Primary</td>
</tr>
<tr>
<td>Support for family</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Advance care planning</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

*from [SPECOncEd/online/PhysiciansOnEndOfLifeCare/Module7](http://www.speccoedonline.com/PhysiciansOnEndOfLifeCare/Module7)*
3 W’s

- Wish
- Worry
- Wonder

For example, I also wish for the best possible results for you, but I worry that we may not be able to achieve everything you hope for; I wonder what your thoughts are in case things don’t go as well as planned.
Language to describe goals of care

• I want to give the best care possible.

• **We will concentrate on improving the quality of your life.**
  - We want to help you live meaningfully in the time that you have.
  - I’ll do everything I can to help you maintain your independence.
  - I want to ensure that your father receives the kind of treatment he wants.
  - I will focus my efforts on treating your symptoms.
  - Let’s discuss what we can do to fulfill your wish to stay at home.
  - Your mother’s comfort and dignity will be my top priority.
Documentation

• Patient
  – Informal
    • My Voice Workbook
    • Advance Care Plan
    • Living Will
  – Legal
    • Representation Agreement (If indicated; Section 7 or 9)
    • Advance Directive (if indicated)

• HPC team
  – Advance Care Planning Record form
  – Serious Illness Conversation documentation
  – Medical Orders for Scope of Treatment
  – Detailed Care Plans
ADVANCE CARE PLANNING RECORD

* ADDI 101231C *

**CORE ELEMENTS:**
1. S.P.E.A.K to adult about Advance Care Planning (see back).
2. Learn about & understand the adult & what is important to them.
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).

<table>
<thead>
<tr>
<th>Previous Advance Care Planning Documentation</th>
<th>Reviewed, copy in Greensleeve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Care Plan (wishes)</td>
<td></td>
</tr>
<tr>
<td>Advance Directive (instructions)</td>
<td></td>
</tr>
<tr>
<td>Representation Agreement</td>
<td></td>
</tr>
<tr>
<td>Provincial No. CPR</td>
<td></td>
</tr>
<tr>
<td>ACP Record</td>
<td></td>
</tr>
<tr>
<td>DNR</td>
<td></td>
</tr>
<tr>
<td>Degree of intervention</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date dd/mm/yy</th>
<th>Participants &amp; Location Name / Signature &amp; Discipline of recorder</th>
<th>Key outcomes of conversations; (include which core element(s) discussed and completion of any forms). Document details in the adult's health record</th>
<th>Next Steps/Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<tr>
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</tbody>
</table>

ORIGINALLY located in GREEN SLEEVE AND ACCOMPANIES PATIENT/CLIENT/ RESIDENT.
RETAIN A CHART COPY when person is TRANSFERRED/ DISCHARGED and FAX COPY to FAMILY PHYSICIAN.
MEDICAL ORDERS for SCOPE of TREATMENT (MOST)  
End of Life Care Program

* ADDI 105016A *

SECTION 1: CODE STATUS: (Mark one)
- [ ] Do Not Resuscitate [DNR]
- [ ] Medical Order Not Resuscitation [MNR]
- [ ] Resuscitation

SECTION 2: MOST DESIGNATION
Medical treatments excluding Critical Care interventions & Resuscitation

- [ ] M1 Supportive care, symptom management & comfort measures. [Instructions]

- [ ] M2 Medical treatments available within location of care. Current Location: [Instructions]

- [ ] M3 Full Medical treatments excluding critical care

Critical Care Interventions requested. [Instructions]

- [ ] C1 Critical Care interventions excluding intubation.

- [ ] C2 Critical Care interventions including intubation.

SECTION 3: SPECIFIC INTERVENTIONS
[Instructions]

SURGICAL RESUSCITATION ORDER
- [ ] CVA or Bradycardia

SECTION 4: MOST ORDER ENTERED AS A RESULT OF

[ ] CONVERSATIONS/CONSENSUS

[ ] CONVERSATIONS/CONSENSUS

[ ] PHYSICIAN ASSESSMENT

[ ] SUPPORTING DOCUMENTATION

Date entered: Print Name: Physician Signature:

MSP #: Contact #
Care planning

• What will the actions of the care team be should a particular complication arise?
• How will the patient be managed if the choice is not to transfer the patient to acute care?
• How will comfort be ensured?
Resources – Provincial My Voice

• My Voice Document now available

• BC Ministry of Health ACP webpage:
Additional Provincial Resources

• Health Care Providers Guide to Consent

• Doctors of BC (BCMA)

• Healthlink BC
  – [www.healthlinkbc.ca](http://www.healthlinkbc.ca)

• Seniors BC website link:
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
Additional Resources


Additional Resources

• Catholic Health Association of BC
  – http://www.chabc.bc.ca/

• Should I Receive CPR and Life Support
  – http://www.healthlinkbc.ca/kb/content/decisionpoint/tu2951.html

• The Conversation Project
  – http://theconversationproject.org/
Additional Resources

- Respecting Choices® – Gundersen Lutheran Medical Center: www.gundluth.org/eolprograms
- Australia: Respecting Patient Choices: www.respectingpatientchoices.org.au
- Calgary Health Region – Care at the End of Life Initiative- Advance Care Planning: http://www.albertahealthservices.ca/services.asp?pid=service&rid=1023351
Additional Resource Links

• Ian Anderson Program  
  http://www.cme.utoronto.ca/EndOfLife/default.htm
• The Pallium Project  
  www.pallium.ca
• CHPCA  
  http://www.chpca.net/
• Dalhousie University – The End of Life Project  
  http://as01.ucis.dal.ca/dhli/cmp_advdirectives/default.cfm
Additional Resources

• The New Yorker Aug 2, 2010
  “Letting Go: What should medicine do when it cannot save your life” Atul Gawande

• LA Times July 26, 2009 “100 things, leading to a single choice” By Dr. Martin Welsh

• http://theconversationproject.org/

• http://www.oprah.com/relationships/How-to-Talk-About-Dying-Ellen-Goodman-The-Conversation-Project
Discussion
Smooth sailing

Thank you!