Family Practice Oncology Network
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Advance Care Planning:
Improving Person-Centred Care

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Who I am

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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

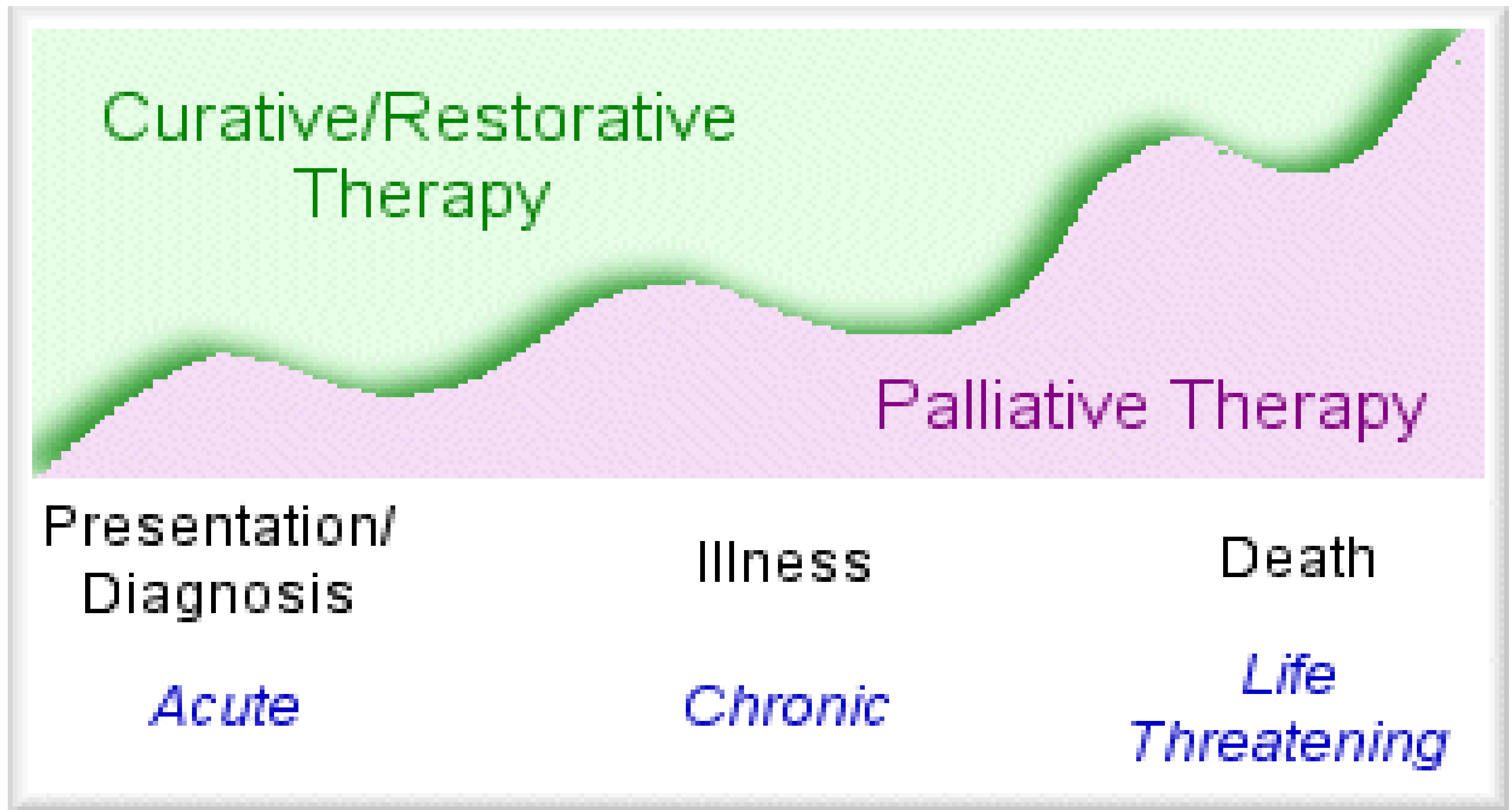
MOST form

- 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



Potential Triggers for End-of-Life Communication by Disease

Cancer[81]

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

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Potential Triggers for End-of-Life Communication by Disease

Chronic Obstructive Pulmonary Disease[6]

Lack of further treatment options

Functional decline

Symptom exacerbation

Ongoing oxygen requirement

Hospitalizations

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Potential Triggers for End-of-Life Communication by Disease

Congestive Heart Failure[82]

Increased symptoms

Reduced function

Hospitalization

Progressive increase in diuretic need

Hypotension

Azotemia

Initiation of inotrope therapy

First or recurrent shock

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Potential Triggers for End-of-Life Communication by Disease

End-Stage Renal Disease[83,84]

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

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

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]

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Alignment with new SPICT tool

Supportive and Palliative Care Indicators Tool (SPICT™)

Cancer

- Functional ability deteriorating due to progressive metastatic cancer.
- Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

- Unable to dress, walk or eat without help.
- Eating and drinking less; swallowing difficulties.
- Urinary and faecal incontinence.
- No longer able to communicate using verbal language; little social interaction.
- Fractured femur; multiple falls.
- Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

ate and coordinate the care plan.

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.

S**P**EAK: Preferences

- How do you like to receive medical information?
- How do you like to make medical decisions? Who helps you with these decisions?

SP**E**AK: 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.

SPE**A**K: Advance directive

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

SPEA**K**: 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*

  or

- 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

- JAMA Intern Med. 2014 Dec;174(12):1994-2003. doi: 10.1001/jamainternmed.2014.5271.

- 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

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Serious Illness Conversation Guide

CLINICIAN STEPS

- ☐ **Set up**
  - Thinking in advance
  - Is this okay?
  - Combined approach
  - Benefit for patient/family
  - No decisions today
- ☐ **Guide** (right column)
- ☐ **Summarize and confirm**
- ☐ **Act**
  - Affirm commitment
  - Make recommendations to patient
  - Document conversation
  - Provide patient with Family Communication Guide

Draft R4.2 12/10/13

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CONVERSATION GUIDE

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

Serious illness conversation guide

gaining more time?

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Serious illness conversation guide

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

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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.

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Serious illness conversation guide

Understanding	What is your understanding now of where you are with your illness?

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

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?

Serious illness conversation guide

Conversation Guide

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Table. Communication Tips

Do	Don't
Give a direct, honest prognosis[99,101]	Avoid responding to a patient request for information about prognosis[102]
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]	Provide vague, eg, "incurable" or overly specific information, eg, "you have 6 months"
Allow silence[104]	Talk more than half the time[104]
Acknowledge and explore emotions[105]	Provide factual information in response to strong emotions
Focus on the patient's quality of life, goals, fears, and concerns[33]	Focus on medical procedures[106]

Bernacki & Block. JAMA Intern Med. 2014 Dec;174(12):1994-2003.

Core Elements of ACP

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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

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5. **Define goals of care and create plan (include potential complications & location of care)**

Various Goals of Treatment

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

*from&EPEC&(Educa/ on&for&Physicians&on&End&of&Life&Care)&Module&7

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

fraserhealth

ADVANCE CARE PLANNING RECORD

* ADDI 101231C*

ADD101231C REV/Aug/[illegible] Page 1 of 1

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. 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).

Previous Advance Care Planning Documentation	Reviewed, copy in Greensleeve
Advance Care Plan (wishes)	
Advance Directive (instructions)	
Representation Agreement	
Provincial No CPR	
ACP Record	
DNR	
Degree of Intervention	

Date dd/m/year Participants & Location Name /Signature & Discipline of recorder	Key outcomes of conversations: (include which core element(s) discussed and completion of any forms). Document details in the adult's health record.	Next Steps/Plan

ORIGINAL 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

ADDI105016A [illegible] [illegible]

[illegible]

SECTION 1: CODE STATUS: [illegible]	
☐ [illegible]	
☐ [illegible]	
SECTION 2: MOST DESIGNATION [illegible]	
Medical treatments excluding Critical Care interventions & Resuscitation	
______ M1	Supportive care, symptom management & comfort measures. [illegible] [illegible]
______ M2	Medical treatments available within location of care. Current Location: ______________ [illegible]
______ M3	Full Medical treatments excluding critical care
Critical Care Interventions requested. [illegible]	
______ C1	Critical Care interventions excluding intubation.
______ C2	Critical Care interventions including intubation.

SECTION 3: SPECIFIC INTERVENTIONS [illegible]

[illegible] ☐ YES ☐ NO [illegible] ☐ YES ☐ NO [illegible] ☐ YES ☐ NO
[illegible] ☐ YES ☐ NO
[illegible]

SURGICAL RESUSCITATION ORDER
☐ [illegible]
☐ [illegible]

SECTION 4: MOST ORDER ENTERED AS A RESULT OF [illegible]

☐ CONVERSATIONS/CONSENSUS ☐ [illegible]	[illegible]	[illegible]
☐ [illegible]	[illegible]	[illegible]
☐ [illegible]	[illegible]	[illegible]

☐ PHYSICIAN ASSESSMENT and ☐ [illegible] ☐ [illegible]

☐ SUPPORTING DOCUMENTATION [illegible]

☐ [illegible] ☐ [illegible]	☐ [illegible] ☐ [illegible]	[illegible] ☐ [illegible] ☐ [illegible]	☐ [illegible]

Date [illegible]		Print Name		Physician Signature:
MSP #		Contact #		

[illegible]

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:
  - http://www.health.gov.bc.ca/hcc/advance-care-planning.html

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CO U B

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
- Doctors of BC (BCMA)
  - https://www.bcma.org/news/advance-directives
- Healthlink BC
  - www.healthlinkbc.ca
- Seniors BC website link:
  - http://www.seniorsbc.ca/legal/healthdecisions/

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

www.advancecareplanning.ca

Speak Up

Additional Resources

- Educating Future Physicians in Palliative Care and End-of-Life Care. 2007. *Facilitating Advance Care Planning: An Interprofessional Educational Program – Curriculum Materials* and *Teacher's Guide*. http://www.afmc.ca/efppec/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf
- Cross-cultural considerations in promoting advance care planning in Canada. Andrea Con for Health Canada. 2007. http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf
- The Glossary Report. Janet Dunbrack for Health Canada. 2006. www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index_e.html

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

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
- Gold Standards Framework Advance Care Planning (UK): www.goldstandardsframework.nhs.uk/advanced_care.php
- BC Framework for EOL Care http://www.health.gov.bc.ca/library/publications/year/2006/framework.pdf

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://articles.latimes.com/2009/jul/26/opinion/oe-welsh26
- http://theconversationproject.org/
- http://www.oprah.com/relationships/How-to-Talk-About-Dying-Ellen-Goodman-The-Conversation-Project

Discussion

Smooth sailing

Thank you!