

# ADVANCED PLANNING FOR MEDICAL CARE AND CAPACITY ISSUES

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# Learning Objectives

At the end of this presentation, audience members will be able to:

1. State prevalence for ACP for Canadians
2. Discuss MD supports for EoL Planning and roadblocks
3. Differentiate AD for EoL from AR for MAID

I have no conflicts

but

Member of AR Expert Panel for the Council of  
Canadian Academies

# Legal Tools



## Legal Tools in B.C.

Note: legal advice recommended but not required.

1. Representation Agreements  
(7 or 9) 2001
2. Advance Directives 2011

# Legal Tools - continued



## Rep 7

- Cannot refuse treatment that would preserve life

## Rep 9

- Can consent to or refuse treatment that would preserve life

## Advanced Directives

- Signed and 2 witnesses (1 if lawyer or notary)

# Reference

## Facilitating Effective End of Life Communication - Helping People Decide

Dr. Chris Frank and Dr. John Puxty

CGS Journal, Volume 6, 2016

# Advanced Care Planning



Is a process of reflection and communication in which a capable person makes and expresses their wishes with regard to future health and/or personal care preferences and identifies people entrusted to ensure those wishes are followed should they become incapable of giving consent.

This process should involve conversations with the patient and the primary health care professional and family members, where possible.

Advanced Care Planning really involves setting goals of care

All of this involves communication by the patient about their values now and what they perceive them to be in the future in terms of expressing their wishes.

# Prevalence

- 95% of Canadians feel EOL communication is important
- 30% have had discussions about medical preferences in case of serious illnesses
- 15% have recorded an ACP/directive
- 9% have had EOL discussions with the physician

*Reference:*

*CMA End of Life: A National Dialogue 2016*

- Older Patient Engagement in ACP in Canadian Primary Care Practices

Howard et al. CFP Journal, May 2018



- 20 FPs from 3 sites (AB BC ON)
- 810 patients over 50

# Study - continued

1. 66% had thought about kinds of medical care they would want, or not want
2. 52.8% had talked to someone about what they would want
3. 32% had written down their wishes
4. 50.4% had named an SDM

23% had engaged in all 4 activities

# Study Continued

- Of those who had talked to someone, 15.5% had talked to FPs
- Conclusion:
  - FPs should initiate discussion of values and communication about medical disorders and wishes for treatment

# Roadblocks

- Physicians
  - Discomfort with discussing the topic
  - Time
  - Passing on information (move to facility)
  - Family involvement?
- Patient
  - Uncomfortable discussing EoL
  - Procrastination
  - Lack of knowledge about ADs

# Roadblocks - continued

- Family
  - Conflicts
  - Emotional turmoil
  - Unwillingness to act at time according to patient wishes
- Miscellaneous
  - Where is AD kept?
  - Communication to other HCPs and ERs.

# When should this discussion happen?

- A change in health care status
- Recent hospitalization
- Decline in function
- Decline in cognition
- Changes in social situation
- Transitions in care
- Frailty (Clinical Frailty Scale Rockwood)

# Clinical Frailty Scale (by Rockwood)

## Clinical Frailty Scale\*



**1 Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.



**2 Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.



**3 Managing Well** – People whose **medical problems are well controlled**, but are **not regularly active** beyond routine walking.



**4 Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being “slowed up”, and/or being tired during the day.



**5 Mildly Frail** – These people often have **more evident slowing**, and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.



**6 Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.



**7 Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).



**8 Very Severely Frail** – **Completely dependent**, approaching the end of life. Typically, they could not recover even from a minor illness.



**9. Terminally Ill** - Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise evidently frail**.

### Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

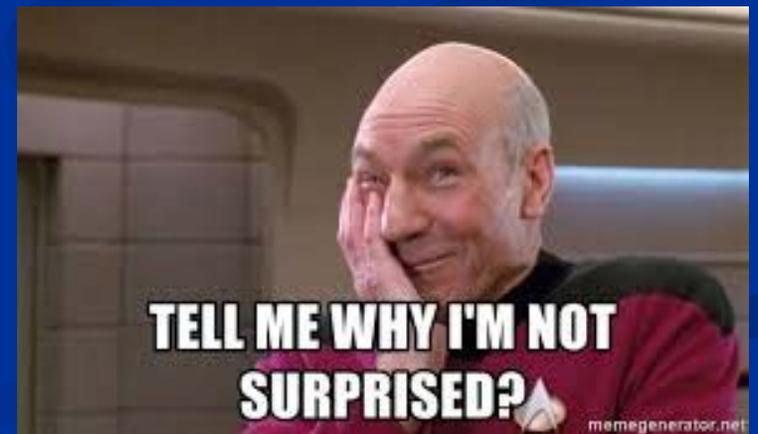
In **severe dementia**, they cannot do personal care without help.

\* 1. Canadian Study on Health & Aging, Revised 2008.

2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005; 173:489-495.

# The *surprise* question:

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



# Being Mortal by Atul Gawande

## ■ Directions for physicians:

1. Does the patient know their prognosis?
2. What further goals do they have?
  - What would they like to achieve with the time left?
3. What is their biggest fear for what lies ahead?
4. What are they willing to suffer or sacrifice for a longer prognosis?

# Patient-tested Language: [www.ariadnelabs.org](http://www.ariadnelabs.org)

## Setup

- I'm hoping we can talk about where things are with your illness and where they might be going. Is this ok?

## Assess

- What is your understanding now of where you are with your illness?
- How much information about what is likely to be ahead with your illness would you like from me?

## Share (Prognosis)

- What are your most important goals if your health worsens?
- What are your biggest fears and worries about the future with your health?

# Patient-tested Language (continued)

## Explore

- What gives you strength?
- What abilities are so critical to your life that you cannot imagine living without them?
- How much does your family know about your priorities and wishes?

## Close

- Given your goals and priorities and what we know about your illness at this stage, I recommend ...

**WE'RE IN THIS TOGETHER!**



# Communication Skills Used

- Ask permission
- Ask, tell, ask
- Deal with emotions
- Discuss patient goals of care
- Address potential problems,  
and
- **Discuss next steps**

# Reviews

- At transitions of care
- Q X time periods proportional to frailty
- Involve family for both Rep Agreements and Advanced Directives as long as the patient agrees

# Advanced Directives for Dementia: Meeting a Unique Challenge

Gaster *et al.* JAMA, Dec 2017



- Need brief, accessible form but detailed enough to:
  1. Address changes in cognition with progression
  2. Changes in goals patients would want along continuum of disease

# Resources

- My voice (BC Fraser Health Document)
- PATH - Palliative and Treatment Harmonization
- [eprognosis.ucsf.edu](http://eprognosis.ucsf.edu)
- [Healthlinkbc.ca/health-topics](http://Healthlinkbc.ca/health-topics)

# How to do Advance Care Planning in your office (or in the nursing home)



- Slowly, over time, as part of holistic care
- Always review Goals of Care episodically with patients (and families as is appropriate)
- Following Choosing Wisely Canada Directions, don't delay Advance Care Planning conversations and don't delay Palliative Care for a patient.

# How to do Advance Care Planning in your office (or in the nursing home)

cont'd

- Lack of, or delayed, end of life discussions can lead to reduced quality of life, greater anxiety, family distress, caregiver burden and burnout  
and
- conversely, proactive End of Life conversations can contribute to improved clinical outcomes, better quality of life, improved mood, longer survival and reduced costs.

*Reference: Zhang et al, Health Care Costs in the Last Week of Life, Associations with EOL Conversations, Archives of Internal Medicine 2009*

# My Ideas on ARs

Slides on ARs are my ideas,  
and are not from the Council  
of Canadian Academies' report

# Differences between ARs and ADs

For MAID, consent is mandatory now, no SDM allowed

- MAID is accomplished by an overt act which causes death – an *active* process.
- ADs involve SDMs and are not overt causes of death, rather they withdraw or withhold life-sustaining treatments – a *passive* process.

## Differences - continued

- ARs - for MAID - are not currently legal.
- Will ARs require intolerable suffering?
- ARs will require consent at the time they are created –  
but
- What about when they are put into effect?

# Similarities between ARs and ADs

1. Withdrawing or withholding life-sustaining treatment causes death
2. Continuous palliative sedation may lead to death
  - 48 hours
  - 14 days less clear
3. Voluntary refusal to eat and drink may lead to death

# Similarities - continued

- In both ADs and ARs values and goals must be defined
- There may be a long time between writing them and enacting them

# International Experience with ARs

- Belgium
  - Valid for 5 years
  - Only for unconscious persons
- Luxembourg
  - Mimics Belgian rules, thus valid for 5 years
  - Only for unconscious persons
- Colombia (2015)
  - No restrictions on consciousness
  - No data
- Netherlands
  - Must have some level of consciousness
  - Doctors now conflicted re ARs for moderate-to-severe dementias

# Summary

- Only 25-30% of Canadians have discussed ADs with someone
  - Only 8-9% with FPs
- There is clear evidence that ADs
  - improve EOL clinical outcomes, including Q of L and Mood, and
  - they reduce costs

## Summary - continued

- I suggest FPs take an even more active role in initiating discussions, encouraging dialogue with patients and follow-through to have patients write legal documents
- ARs have some similarities to ADs but are more complex

**Stay Tuned!**





Thanks!

Questions?

Extra slides follow



[www.trustee.bc.ca](http://www.trustee.bc.ca)

**Under Personal Planning  
Tools see**

**‘Consent to Health Care’**

# The Test of Capacity

**A patient is presumed capable unless it is demonstrated that he/she is not able to:**

- **Understand the information given by the health care provider**
- **Understand that the information applies to the patient's situation**

# Ranking of Substitutes

1. **Committee or guardian of person**
2. **Representative under Representation Agreement Act**
3. **Temporary substitute decision maker under Health Care Consent Act**

# Temporary Substitute Decision Makers

- **Spouse (includes common-law or same sex partner)**
- **Adult's child (if  $\geq 19$ )**
- **Parent**
- **Sibling**
- **Grandparent**
- **Grandchild**
- **Anyone else related to the adult by birth or adoption**
- **A close friend**
- **A person immediately related to the adult by marriage**
- **Public Trustee as last resort**

# **Advance Directives in BC**

## **Legal as of September 1, 2011**



# Why make an advance directive?

- You do not have anyone you want to name as a rep
- You may have strong feelings about certain medical treatments
- You have a rep, but you do not want that person to make certain decisions

Who can make it?

**An adult (over 19) who is  
capable of understanding  
the nature and  
consequences of the  
document**

# How is an advance directive made?

- It must be **signed** and **witnessed**
- Two witnesses are required, except if one is a lawyer or notary in BC
- Some people may not be witnesses (less than 19 or paid for personal services)



# Representation Agreements

## Representation Agreement Act

- This is an agreement where you ask someone to be your Representative. This person is to follow your directions with respect to decision making. It can be for finances, health care or personal care.
- There are two “types,” section “7s” and section “9s” (enhanced)

# Who can make an RA?

Any adult (over 19) unless incapable



# How is an RA made?

- In writing, properly signed and witnessed
- Legal advice from a lawyer or notary is recommended, but not required
- The Ministry of Attorney General has published forms for making RAs

# RA Rules

- **You must sign in front of witnesses**
- **If you can not sign you may instruct someone to sign on your behalf**
- **Two witnesses are required unless the witness is a lawyer or a notary**
- **Your Rep can not be a witness or the Rep's spouse, child or parent**
- **Your Rep must sign the agreement before it can be used**