Advance Care Planning: not just for Geriatrics

RAIsing Awareness, A Geriatric Refresher Day

March 4, 2015

St. Elias Centre 750 Ridgewood Avenue, Ottawa ON K1B 6N1

Disclosure

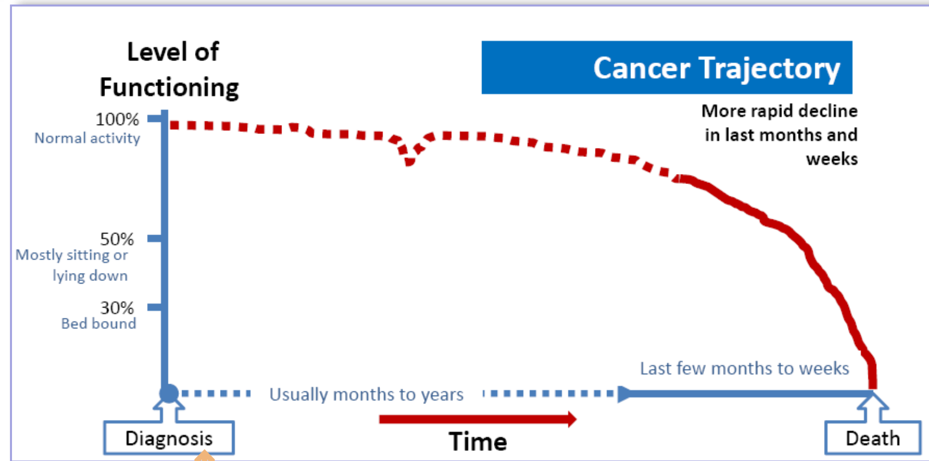
- No conflicts of interest
- No outside sources of funding

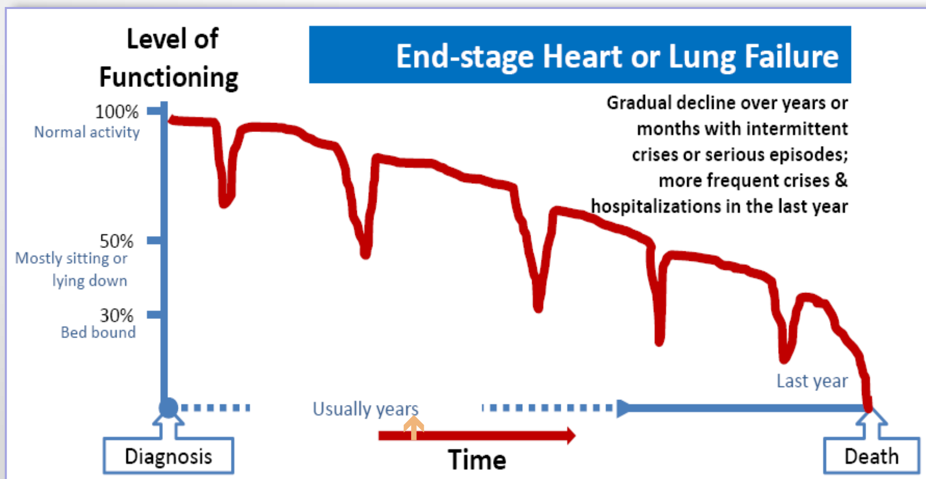
Objectives:

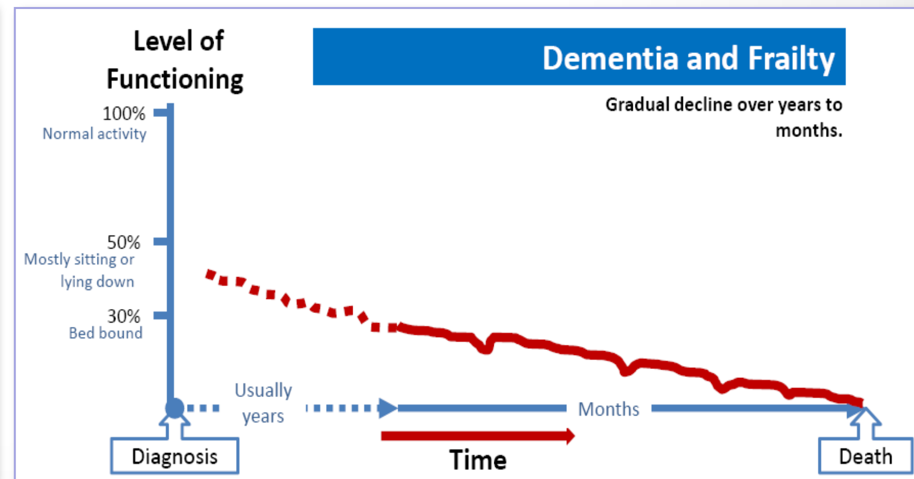
At the end of the session participants will:

- Be able to identify key elements of advanced care planning (ACP)
- Understand why Advance Care Planning is important for everyone (who makes their own care decisions)
- Be able to identify issues in Care Planning for those without capacity or at the "edges" of capacity.
- Understand the difference between Power of Attorney and Substitute Decision maker
- Have some strategies to help facilitate ACP discussions with patients and families (patients' and our own)

Only 10% die suddenly







Advance Care Planning: Definition

- **A *process*** of **reflection and communication** about values, beliefs, culture and goals of care etc…
- **A *process*** of ***planning*** *for a time when a person cannot make their own medical decisions*
- **A *process*** that involves **discussions** with healthcare professionals and significant others
- **A *process*** that **may** result in an advance directive

(Speakup , CHPCA)

Opportunities for ACP

- Henry and Maria bring their 4 month old daughter in for her well baby check
- Connor, just finished college, comes in for a physical for his new job
- Mary and Fred's daughter finishes university and moves back to Ottawa
- Jane and Mark have been dating for 3 years and are talking about getting married next year
- Helen is diagnosed with early dementia
- Stephen has metastatic non-small cell lung cancer

Why is ACP Important?

- For the patient
  - Fosters personal resolution, helps lessen anxiety
  - Ensures that wishes are known and will be followed
- For the patient's loved ones
  - Empowers the substitute decision-maker
  - Helps avoid disputes among family members
- For Health Care providers
  - Helps HCPs feel more comfortable that they are providing care in accordance with their patient's wishes

(CHPCA Speakup Website)

How are we doing? ACCEPT study

- September 2011- March 15, 2012
- 12 large hospitals in B.C., Alberta, Ontario, Quebec
- Patients with: Advanced pulmonary, cardiac, or liver disease or metastatic cancer
- Or 80 + and admitted w acute medical or surgical conditions
- Or Caregivers would not be surprised if died in 6 m.
- Approached 48-120 hrs after admission to allow for acute symptom control

D.Heyland et al JAMA INTERN MED 173(9) May 2013 pp. 778-787

ACCEPT Study:

- **Three-quarters** of patients had thought about life-sustaining treatments that they may or may not want; **85%** had talked to someone about this and **70%** had formally designated a substitute decision maker
- **30%** had talked about their wishes with their family doctor
- **55.3%** of patients had discussed them with at least 1 member of the hospital team during the admission

Daren K. Heyland, et al. ACCEPT (Advance Care Planning Evaluation in Elderly Patients) Study Team and the Canadian Researchers at the End of Life Network (CARENET).JAMA INTERN MED April 1, 2013

The "BUT":

- When admitted to hospital **only 25%** were asked whether they had had prior discussions about their wishes
- For **27.9% of patients** with a preference there was **no written order** in the record stating the goals of care.
- Agreement between expressed preferences and documented goals-of-care order was **30.2%**
- **28.1% of patients** (56 of 199) preferred comfort measures
  - Documented in **4.5%** (9 of 199) of stated goals

Who is a capable adult?

- Capacity depends on treatment
- Capacity depends on time
- "The issue … is not whether the person's actions or choices appear reasonable or will put them at increased risk, but whether the individual is able to **understand** critical information and **appreciate the reasonably foreseeable consequences** of his or her decisions or lack of them"

(Guidelines for Conducting Assessments of Capacity, 2005: I-2)

Basis for ACP:

A **capable adult** is able to:

- Refuse medical treatment
- Request that a treatment be withdrawn
- Choose a substitute decision maker:

  Power of Attorney for Personal Care

- Provide guidance for a time when they are not capable (if they are at least 16 years old)
  - A "prior expressed capable wish" which must be considered if the person is later incapable.

Health Care Consent Act Ontario

Why does it matter?

There is a hierarchy in Ontario isn't there?

Alice

- Alice is 66 years old
- She is divorced
- She has always been healthy and helps care for her elderly parents
- She lives in a two story house
- She has 4 children. Two sons live nearby. One daughter lives in Toronto, the other in Vancouver

Alice

- Alice is in a car accident
- She suffers a major head injury and c-spine fracture
- She is currently unconscious on a ventilator
- She has no Power of Attorney
- She has not talked about her healthcare wishes though her daughter thinks she once said she would not want to be "a vegetable"

The medical team needs consent for a care plan……

Hierarchy of SDMs

- Guardian of the person
- Attorney for personal care
- Representative appointed by the Board under section 33
- Spouse or partner.
- A child or parent. This paragraph does not include a parent who has only a right of access.
- A parent who has only a right of access.
- A brother or sister.
- Any other relative.

(Health Care Consent Act 1996, c. 2, Sched. A, s. 20 (1).

If there is disagreement

- If two or more persons who are equal in the hierarchy disagree about whether to give or refuse consent, and if their claims rank ahead of all others, **the Public Guardian and Trustee** shall make the decision in their stead.

Healthcare Consent Act, Ontario 1996, c. 2, Sched. A, s. 20 (6).

Carl

- Carl is an 86 year old married man who lives with his wife in a bungalow
- He had a heart attack 5 years ago
- He has well controlled hypertension and diet controlled diabetes.
- They have no children

Carl

- Carl is found outside by his neighbour
- He collapsed while shovelling snow
- The neighbour did CPR until paramedics arrived and he had a "successful" resuscitation but has not regained consciousness……
- Did I mention that his wife has moderate Alzheimer's dementia and he has been her primary caregiver?

OBLIGATIONS OF THE SUBSTITUTE DECISION MAKER

Pamela

- Catherine is 78 years old with mild dementia and COPD
- She gets pneumonia and becomes delirious. She is needing BiPaP.
- She has two sons. One lives with her and she has supported him for many years. The other lives nearby, visits rarely, is deeply in debt.
- The first son wants all medical interventions to prolong his mother's life . The other thinks she should have only "comfort" and wants the BiPaP stopped.

Paul

- Paul has mild cognitive impairment
- He has told his health care providers that he
  - Does not want CPR
  - Would never accept a feeding tube
  - If he is no longer able to recognize his family he would want no further life prolonging interventions but
- His wife reports that this does not matter because once she is the decision maker she will do everything possible to keep him alive

Decision making for incapable patients

- Must follow a prior capable wish that applies to current situation if it is possible. Ontario recognizes informal and oral advanced directives as well as written
- If there is no knowledge of wishes the substitute decision maker must act in

The Best interests of the patient

The Health Care Consent Act 1996

Best interests

- **As defined by**:
  - Values and beliefs held by patient
  - Current wishes if able to determine
  - Potential to improve quality of life
  - Prevent worsening quality of life
  - Benefits outweigh the risks of treatment/non-treatment

Consent and Capacity Board

FORM G:

Applying to Determine Whether or Not the Substitute Decision Maker has Complied with the Rules for Substitute Decision Making

Mary

- Mary is being admitted to Long term care.
- She has many medical problems and mild dementia
- The staff have been hearing about the importance of Advance Care Planning and wonder if they can still do this with Mary.

Can they????

Capacity to give instructions:

Instructions contained in a power of attorney for personal care with respect to a decision the attorney is authorized to make are valid if, **at the time the power of attorney was executed, the grantor had the capacity to make the decision.**

Substitute Decisions Act 1992, c. 30, s. 47 (4).

Capacity

A person is capable of giving a power of attorney for personal care if the person,

- has the ability to understand whether the proposed attorney has a genuine concern for the person's welfare; and
- appreciates that the person may need to have the proposed attorney make decisions for the person.

A power of attorney for personal care is valid if, at the time it was executed, the grantor was capable of giving it even if the grantor is incapable of personal care.

Substitute Decisions Act 1992, c. 30 s. 47 (1) (2)

Cash and Penny

- Cash is an 87 year old man who has been married to Penny for 65 years.
- The deed to the house and investments are in his name
- Penny has a small government pension
- Cash develops a brain tumour. He no longer seems to understand what is said to him and does not speak.
- His swallowing is intact
- His prognosis is several months

Ontario

Power of Attorney for Property

- Must be in writing with two witnesses (no lawyer required though banks strict about documents)

Role as a Health Care Provider

Encourage patients to:

- Think about the people who they trust to make personal care decisions, in accordance with his/her wishes (It may not be the most obvious person)
- Decide who the substitute decision-maker should be
- Appoint a substitute decision-maker
- Talk through potential disagreements

Role as a Health Care Provider

- Ensure we ASK
  - Is there an advance care plan?
    - Does it still reflect wishes?
  - Who is the substitute decision maker?
- Ensure we DOCUMENT
  - Advance care plan
  - Appropriate Substitute decision maker
  - Conversations we have about the patients wishes/goals/values (later expressions over-ride earlier)

How to Initiate the Conversation

- There is no one-size fits all formula
- Many people do not like to talk about illness, mental incapacity or death
- Patient should think about their
  - Values
  - Wishes
  - Resources
- Encourage your patients talk these things over with people who are close to them, who can provide guidance

Speakup , CHPCA

How to Initiate the Conversation

- Choose time and place, during a crisis or at the time of bad news likely not optimal
- "Do you have an advance directive?"
- If yes, the conversation can focus on:
    - What it says?
    - When it was made?
    - Does it need updating?
    - Does it name a substitute decision-maker?
    - Has the patient discussed its contents with loved ones?

Key Resources

- Speak Up Campaign: Canadian Hospice Palliative Care Association

http://www.advancecareplanning.ca/

- Health Care Consent Act

http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm

- Substitute Decisions Act

http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_92s30_e.htm

- Consent and Capacity Board

http://www.ccboard.on.ca/scripts/english/index.asp