

# Provincial Stroke Rounds

## Advance Care Planning in Stroke

Kelvin Ng Kuan Huei MD  
Associate Professor, McMaster  
University

Gillian Maguire RN (EC)  
Stroke Program Nurse  
Practitioner

Leigh Barr MSc.  
SLP Integrated Stroke Program  
Adjunct Assistant Professor,  
McMaster University

# Mitigating Potential Bias (Provincial Stroke Rounds Committee)

The Provincial Stroke Rounds Committee mitigated bias by ensuring there was no Industry involvement in planning or education content.



# Disclosure of Affiliations, Financial Support, & Mitigating Bias

- Nothing to disclose



# Objectives

- Stroke as a Serious Illness
- Discuss stroke and critical treatment decisions
- Advance Care Planning in Stroke
- Describe special considerations for stroke patients and palliative care including Medical Assistance in Dying (MAiD)

# Stroke as a Serious Illness



# Stroke as a Serious Illness

- Stroke prevalence is on the rise
- Number one cause for disability in Canada
- 50% of stroke survivors are chronically disabled





# Stroke as a Serious Illness

- The unseen burden of stroke
- Persistent multidimensional impairment of health related quality of life <sup>1</sup>
- Dependent on wide spectrum of factors; modifiable and non-modifiable



1. Clarke P., Marshall V., Black S. E., Colantonio A. Well-being after stroke in Canadian seniors: Findings from the Canadian Study of Health and Aging. *Stroke*. 2002;33(4):1016–1021.

# Stroke as a Serious Illness

- Stroke has persistent impact on family and social circles
- Financial impact of stroke



1. Brocklehurst JC, Morris P, Andrews K. Social effects of stroke. *Soc Sci Med*. 1981;15:35–39.
2. The Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Can Med Assoc J*. 1994;150:899–913.





“She shouldn’t have to work at her age to keep the household going. It affects my self-esteem. I’m not ‘macho’ but it is very undermining.”

“Did they understand I had aphasia? No. They just seemed to think I was thick.”

“We have to try to manage on what we have; people do not understand that life is very hard and just getting harder.”

“We eat less; turn off the lights and heating more. Use less of everything.”

“I have to depend on close friends to care for me, whilst my carer has a part time job so we can pay the mortgage.”

# Talking about Stroke and Critical Treatment Decisions



# Talking about Stroke and Critical Treatment Decisions

- Cost-effective health care utilization
- Goal-concordant care; do not assume death is the worst outcome
- Improved satisfaction, patient expectations and health-related quality of life



# The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,<sup>1</sup> Andrew D Hancock, project officer,<sup>1</sup> Michael C Reade, physician,<sup>2</sup> William Silvester, intensive care physician and director<sup>1</sup>

## Abstract

BMJ 2010;340:

**Objective** To investigate the impact of advance care planning on end of life care in elderly patients.

**Design** Prospective randomised controlled trial.

**Setting** Single centre study in a university hospital in Melbourne, Australia.

**Participants** 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

**Interventions** Participants were randomised to receive usual care or usual care plus facilitated advance care planning. Advance care planning aimed to assist patients to reflect on their goals, values, and beliefs; to consider future medical treatment preferences; to appoint a surrogate; and to document their wishes.

**Main outcome measures** The primary outcome was whether a patient's end of life wishes were known and respected. Other outcomes included patient and family satisfaction with hospital stay and levels of stress, anxiety, and depression in relatives of patients who died.

**Results** 154 of the 309 patients were randomised to advance care planning, 125 (81%) received advance care planning, and 108 (84%) expressed wishes or appointed a surrogate, or both. Of the 56 patients who died by six months, end of life wishes were much more likely to be known and followed in the intervention group (25/29, 86%) compared with the control group (8/27, 30%;  $P<0.001$ ). In the intervention group, family members of patients who died had significantly less stress (intervention 5, control 15;  $P<0.001$ ), anxiety (intervention 0, control 3;  $P=0.02$ ), and depression (intervention 0, control 5;  $P=0.002$ ) than those of the control patients. Patient and family satisfaction was higher in the intervention group.

**Conclusions** Advance care planning improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.

**Trial registration** Australian New Zealand clinical trials registry ACTRN12608000539336.



# Talking about Stroke and Care Decisions

- Structured communication framework to support discussions in patients with serious illness
- Stroke care is littered with preference-sensitive medical decisions
- Elicit patient goals and priorities
- Describe treatment options and encourage shared decision making





# Advance Care Planning (ACP) in Stroke





HEART &  
STROKE  
FOUNDATION

CANADIAN  
**Stroke**  
**BEST PRACTICE**  
RECOMMENDATIONS

# Advance Care Planning following a Stroke

**10.0** Patients surviving a stroke, as well as their families and informal caregivers, should be approached by the stroke health care team to participate in advance care planning [Evidence Level C].

- i. The primary goal of advance care planning conversations is to prepare patients and substitute decision makers for providing consent in future situations (for example, in light of recent significant illness such as stroke) [Evidence Level B].
  - a. Advance care planning may include identifying a substitute decision-maker (proxy, agent or Power of Attorney), and discussion of the patient's personal values and wishes which they can apply in future if the need arises to make medical decisions or provide consent on behalf of the patient [Evidence Level B].
  - b. Advance care planning discussions should be documented and reassessed regularly with the active care team and substitute decision-maker [Evidence Level C].
- ii. The advance care planning conversation should be revisited periodically, such as when there is a change in the patient's health status [Evidence Level B].
- iii. The interdisciplinary team should have the appropriate communication skills and knowledge to address the physical, spiritual, cultural, psychological, ethical, and social needs of stroke patients, their families, and informal caregivers [Evidence Level C].
  - a. Respectful discussion of patient's values and wishes should be balanced with information regarding medically appropriate treatment related to ongoing stroke management and future medical care [Evidence Level C].
- iv. Capacity related provincial legislation should be reviewed and appropriate substitute decision makers should be identified if a survivor is deemed incapable of making specific decisions re: their personal health care and/or discharge related finances [Evidence Level C].

# Advance Care Planning (ACP) in Stroke

- All stroke survivors should have a discussion to participate in ACP
- Proxy and directive ACP
- Prepare patients and substitute-decision makers for future situations



# The Serious Illness Conversation Guide (SICG) Benefits Patients and Families

- Enhanced goal-concordant care
- Improve quality of life
- Higher patient satisfaction
- Better patient and family coping
- Eased burden of decision-making from families
- More and earlier hospice care
- Fewer hospitalizations
- Improved bereavement outcomes





# Serious Illness Conversation Guide

## CONVERSATION FLOW

## PATIENT-TESTED LANGUAGE

### 1. Set up the conversation

- Introduce purpose
- Prepare for future decisions
- Ask permission

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"

### 2. Assess understanding and preferences

"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?"

### 3. Share prognosis

- Share prognosis
- Frame as a "wish...worry", "hope...worry" statement
- Allow silence, explore emotion

"I want to share with you **my understanding** of where things are with your illness..."

*Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."

OR

*Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as \_\_\_\_ (*express as a range, e.g. days to weeks, weeks to months, months to a year*)."

OR

*Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."

### 4. Explore key topics

- Goals
- Fears and worries
- Sources of strength
- Critical abilities
- Tradeoffs
- Family

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **abilities** are so critical to your life that you can't imagine living without them?"

"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"

"How much does your **family** know about your priorities and wishes?"

### 5. Close the conversation

- Summarize
- Make a recommendation
- Check in with patient
- Affirm commitment

"I've heard you say that \_\_\_\_ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we \_\_\_\_\_. This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

### 6. Document your conversation

### 7. Communicate with key clinicians





# Palliative Care and Stroke



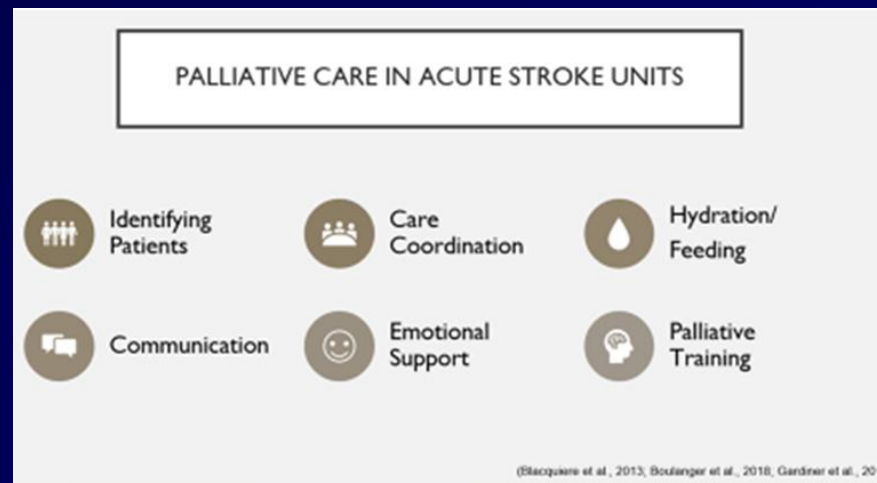


HEART &  
STROKE  
FOUNDATION

CANADIAN  
**Stroke**  
**BEST PRACTICE**  
RECOMMENDATIONS

# Palliative Care

- **Focuses on comfort and quality of life** for those affected by life-limiting illness, such as large hemispheric strokes, and severe hemorrhagic stroke
- **Aims to prevent and relieve** physical, social, psychological, or spiritual suffering of stroke patients, their families and informal caregivers
- Can complement life-prolonging or disease-modifying therapies and **need not be reserved for those whose death is imminent**





HEART &  
STROKE  
FOUNDATION

CANADIAN  
**Stroke**  
**BEST PRACTICE**  
RECOMMENDATIONS

# Goals of Palliative Care

- Objective of establishing **consensus on a direction** which incorporates previously **stated wishes/advanced** care planning in addition to current status and needs
- Intent is to then have a **written communication for the healthcare** team to assist in the individualized palliative plan
- Status can **change over time**, written plan should be **reviewed q shift**
- Goals of care can be amended/revised at any time

“an approach that focuses on comfort and quality of life for those affected by life-limiting illness, such as large hemispheric strokes, and severe hemorrhagic stroke”

PALLIATIVE  
CARE



HEART &  
STROKE  
FOUNDATION

CANADIAN  
**Stroke**  
**BEST PRACTICE**  
RECOMMENDATIONS

## RATIONALE

### Canadian Best Practice Recommendations:

- A palliative care approach should be applied when there has been a catastrophic stroke or a stroke in the setting of significant pre-existing comorbidity, to optimize care for these patients, their families, and informal caregivers.

### Currently at HHS:

- No clearly defined palliative care pathway



**Canadian Stroke  
Best Practices**

(Boulanger, 2018)

<p><b>1 PROBLEM STATEMENT</b></p> <p>Current state on 7 South/Acute Stroke, the team does not have a palliative care pathway which is clearly delineated. The use of a palliative care pathway is a suggested guideline from the Canadian Stroke Strategy. It is noted, however that despite this the stroke team, consisting of MDs, nurses and allied health professionals do good work with communicating and planning, when a patient is declared palliative.</p> <p><b>Background</b></p> <ul style="list-style-type: none"> <li>➢ # of stroke patient's who become palliative at HHS/Acute stroke? (May consider including this number?)</li> <li>➢ What is the estimated # of stroke patient's who do not survive the hyper-acute or acute phase? (May consider including this number from the database?)</li> <li>➢ If a patient arrives to the ward/7 South, outcome measures are captured by the Allied Health team. This tool is called the AFIM. An AFIM score of 20, implies that the patient's current state is one of total dependency. On 7 South a patient who has an AFIM &gt; 20 is not considered for entry to stroke rehabilitation. The term Band 5 (P/H) officially subordinates is</li> </ul>	<p><b>3 Target State</b></p> <ol style="list-style-type: none"> <li>What are we trying to accomplish?             <ul style="list-style-type: none"> <li>➢ Best Practice Guidelines for palliative care pathway</li> <li>➢ Better understand the pt's values and wishes</li> </ul> </li> <li>What would process look like without problem?             <ul style="list-style-type: none"> <li>➢ Remain the status quo</li> </ul> </li> <li>What change can we make that will result in improvement?             <ul style="list-style-type: none"> <li>➢ Consider what a palliative care pathway for stroke pt's would look like?</li> </ul> </li> <li>If we make a change, what will it impact?             <ul style="list-style-type: none"> <li>➢ Anticipate that this will impact patients, families and medical team on 7 south</li> </ul> </li> </ol> <p><b>Hypothesis Statement (if, then)</b></p>
---	--

## Problem statement:

-acute stroke unit does not have a palliative care pathway which is clearly delineated

<p><b>2 What is your work?</b></p> <ul style="list-style-type: none"> <li>➢ Once a patient is declared to be on the Palliative route the Palliative care team are consulted, and the MDs, and nurses, SW, RD, SLP, OT and PT provide care</li> </ul> <p><b>4 What could we do to better?</b></p> <ul style="list-style-type: none"> <li>➢ In cases where outcomes suggest a devastating outcome for future independence (Describe based on the literature what this suggests)</li> </ul> <p><b>7. Is current process efficient? Is it documented?</b></p> <ul style="list-style-type: none"> <li>➢ Need to better explore</li> </ul> <p><b>8. Are we doing things the right way?</b></p> <ul style="list-style-type: none"> <li>➢ This will be better understood upon a review of the suggested guidelines, in comparison with current practice</li> </ul> <p><b>9. Describe process: how it works?</b></p> <ul style="list-style-type: none"> <li>➢ This will be better understood upon a review of the suggested guidelines, in comparison with current practice</li> </ul> <p><b>10. What have you observed?</b></p> <ul style="list-style-type: none"> <li>➢ At times it is a very clear process while at other times outcomes and clinical picture suggest a poor outcome, and based upon family communication that their loved ones would not want to live like this and at other times family not fully being informed on the gravity of the current situation, they will decide to feed their beloved person or so wish and request IV hydration. Over the next week, do not begin to wake and now the situation is one of optimism for the family, however the outcomes have not changed in the predictive information...</li> </ul>	<p>(Joiner), CNS (Robson), Palliative care team Create a draft algorithm to review with stakeholders</p> <p><b>Follow Up Plan</b></p> <ol style="list-style-type: none"> <li>Review proposal with manager Krista Trow on Monday, May 1, 2017. (completed)</li> <li>Make changes to draft document (completed),</li> <li>Share with manager of 7 South/Laura Sheehan, and co-manager of B2 North/Krista Trow as she has offered to sponsor the project (thank you). Want to ensure with Laura that this project does not overlap with the ALC project</li> <li>Plan to speak with Krista again before communicating with potential stakeholders.</li> </ol>
---	--

**5 Why's: CAUSE ANALYSIS** (Ask 'WHY' 5 times to arrive at the root of the problem)

Why	Activity, Connection, Pathway
1	Activity, Connection, Pathway
2	Activity, Connection, Pathway
3	Activity, Connection, Pathway
4	Activity, Connection, Pathway
5	Activity, Connection, Pathway



# Partnership between HHS and McMaster SLP program



Maddy Brûlé



Dorit Greenspan



Harunya Satgunarajah



Lindsey Trotter

FRAMEWORK



(The ADAPTE Collaboration, 2009)

1

Locate existing  
stroke guidelines

2

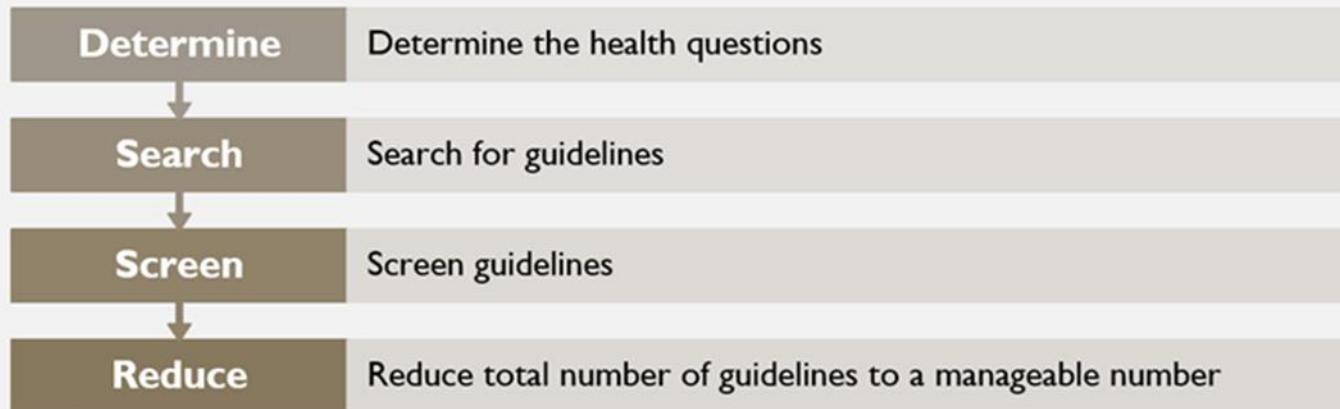
Adapt palliative care  
recommendations

3

Propose to the HHS  
acute stroke unit

PROJECT AIM

## ADAPTATION PHASE: DATA COLLECTION



(The ADAPTE Collaboration, 2009)

## GUIDELINES

- Canadian Stroke Best Practice Guidelines - **Canada** (Boulanger et al., 2018)
- Palliative and End-of-Life Care in Stroke Guidelines - **America** (Holloway et al., 2014)
- National Clinical Guideline for Stroke - **Britain** (Bowen, James, & Young, 2016)
- Australia Clinical Guidelines for Stroke Management - **Australia** (The Stroke Foundation, 2017)
- Best Practice Statement for End of Life Care Following Acute Stroke - **Scotland** (Healthcare Improvement Scotland, 2010)



The top 3 guidelines presented for us to select were:







HEART &  
STROKE  
FOUNDATION

CANADIAN  
**Stroke**  
**BEST PRACTICE**  
RECOMMENDATIONS

Content to be discussed  
with patients, families  
and informal caregivers  
in a palliative care  
discussion

- a. the appropriateness of life-sustaining measures including mechanical ventilation, enteral/intravenous feeding, and intravenous fluids [Evidence Level B];
- b. reassessment of all medications, and recommendations for cessation of medications no longer necessary when the goals of care shift to comfort measures only (e.g., antiplatelets, anticoagulants, statins, hypoglycemics) [Evidence Level C];
- c. cessation of routine vital sign checks, bloodwork and diagnostic tests [Evidence Level C];
- d. oral care [Evidence Level C];
- e. assessment and management of pain [Evidence Level B];
- f. assessment and management of delirium [Evidence Level C];
- g. assessment and management of respiratory distress and secretions [Evidence Level B];
- h. assessment and management of incontinence, nausea, vomiting, constipation, and skin and wound care [Evidence Level C].
- i. assessment and management of seizures [Evidence Level C];
- j. assessment and management of anxiety and depression [Evidence Level C]. **Refer to Canadian Stroke Best Practice Recommendations Mood, Cognition and Fatigue Module section 1 for additional information** [Evidence Level C];
- k. Preferred location of palliative care (e.g. Home, Hospice another supportive living environment) [Evidence Level C];
- l. Preferred person to be notified upon time of death [Evidence Level C].

# Medical Assistance in Dying (MAiD) And Stroke



# Medical Assistance in Dying (MAiD) in Canada

## *Carter v. Canada*

**Feb 2015:** Section 14 and paragraph 241(b) of the *Criminal Code* deemed unconstitutional because they prohibit physicians from assisting in the consensual death of another person.

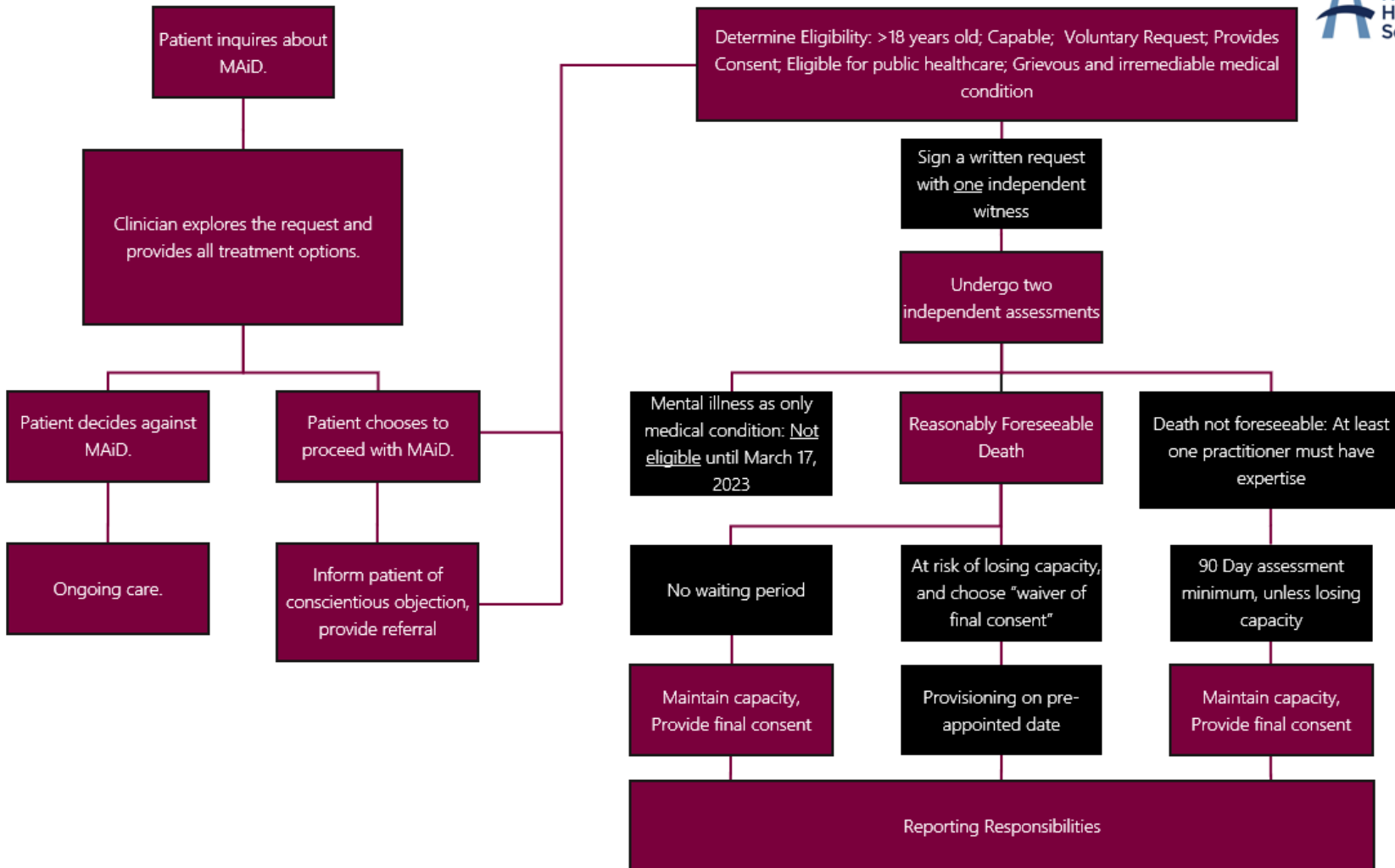
## Bill C-14

**June 2016:** Parliament passes Bill C-14, legalizing medically assisted death.

## Bill C-7

**March 2021:** Parliament passes Bill C-7, adjusting legalities on medically assisted death.

# Summary of MAiD Process



# Conscientious Objection

- Practitioners have a legal right to conscientiously object to MAiD.
- Practitioners have a legal duty to continue caring for the patient for all other health related reasons aside from MAiD.
- Practitioners have a legal duty to refer patients to access MAiD.
  - ADRAS team



# Medical Assistance in Dying (MAiD)

## Bill C7:

- New population: persons without a reasonably foreseeable natural death
- Allows for final consent to be waived in persons with a reasonably foreseeable natural death who may lose capacity

## At HHS:

- Referral to the ADRAS team

## Considerations:

- Can't be requested by a substitute decision maker
- Right to not participate directly, must make an effective referral upon request from patient

## Resources:

- MAiD on HHS intranet
- Archived interprofessional practice rounds

# Death not foreseeable: Safeguards

- A practitioner with *expertise* in the medical condition causing suffering must be consulted.
  - Informed of all available means to relieve suffering.
  - Offered all relevant consults and contacts.
  - **All** agree that the patient has seriously considered all relief measures.
- Minimum 90 day assessment period.
  - \*Unless at risk of losing capacity in that timeframe.
- Give express consent immediately prior to provisioning.

# Waiver of Final Consent

- Conditions:
  - Must have a reasonably foreseeable death.
  - A practitioner has informed them they are at risk of losing capacity.
- Form a written arrangement with the practitioner to receive MAiD on or before a specified day.
- Consent is withdrawn if the patient demonstrates refusal or resistance to the administration of MAiD by words, sounds or gestures.

# Objectives

- Stroke as a Serious Illness
- Discuss stroke and critical treatment decisions
- Advance Care Planning in Stroke
- Describe special considerations for stroke patients and palliative care including Medical Assistance in Dying (MAiD)

Questions?





# Evaluation

For the **Provincial Stroke Rounds Planning Committee**:

- To plan future programs
- For quality assurance and improvement

For **You**: Reflecting on what you've learned and how you plan to apply it can help you enact change as you return to your professional duties

For **Speakers**: The responses help understand participant learning needs, teaching outcomes and opportunities for improvement.

<https://www.surveymonkey.com/r/G52SRK2>



Please take 2 minutes to fill out the evaluation form,  
either online or in the room.

Thank you!

Thank you for having us present.



Please contact us if you have questions:

Dr. Kelvin Ng - [kelvin.ng@phri.ca](mailto:kelvin.ng@phri.ca)

Leigh Barr - [barrl@hhsc.ca](mailto:barrl@hhsc.ca)

Gillian Maguire - [maguiregi@hhsc.ca](mailto:maguiregi@hhsc.ca)