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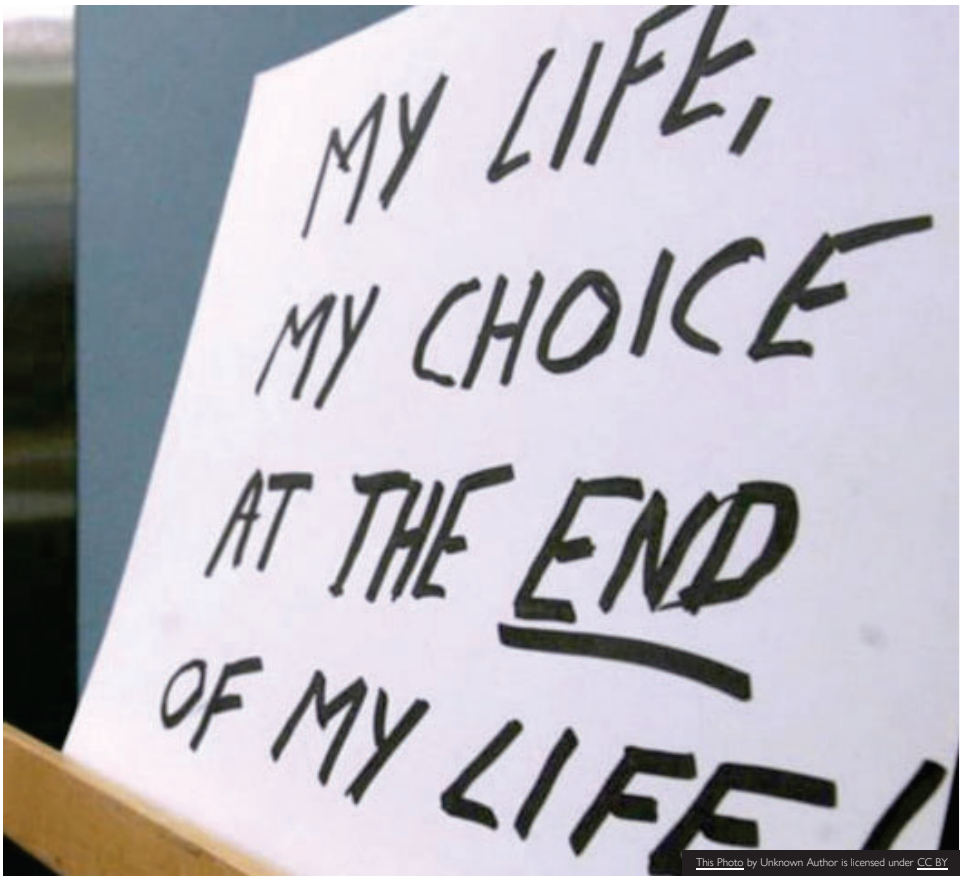
Joy, bureaucracy, burnout

Rural & Remote 2019 Halifax

Ashley White MD CCFP MPH



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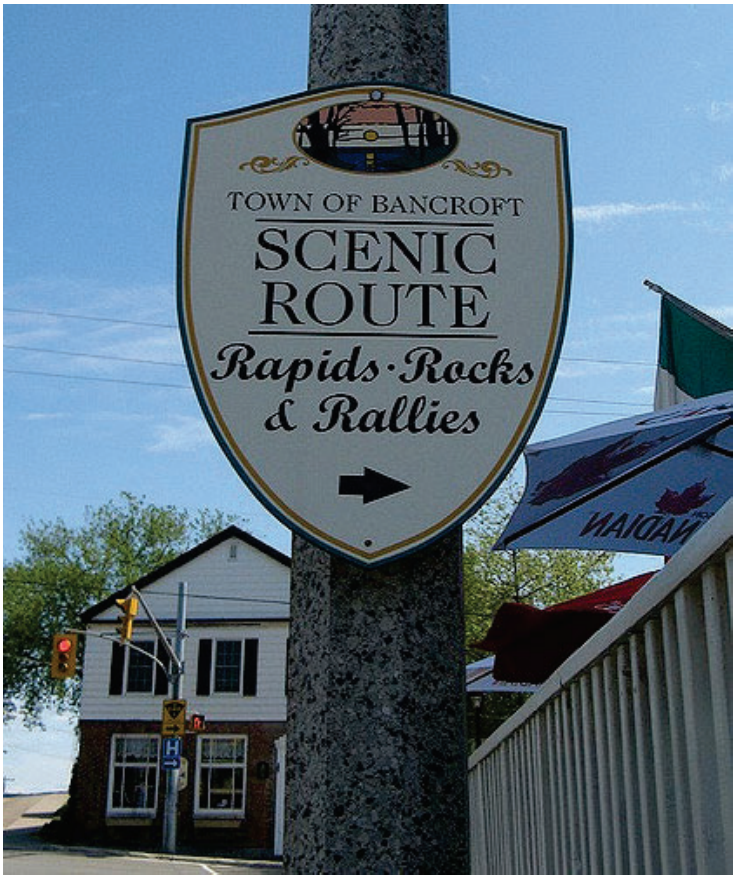
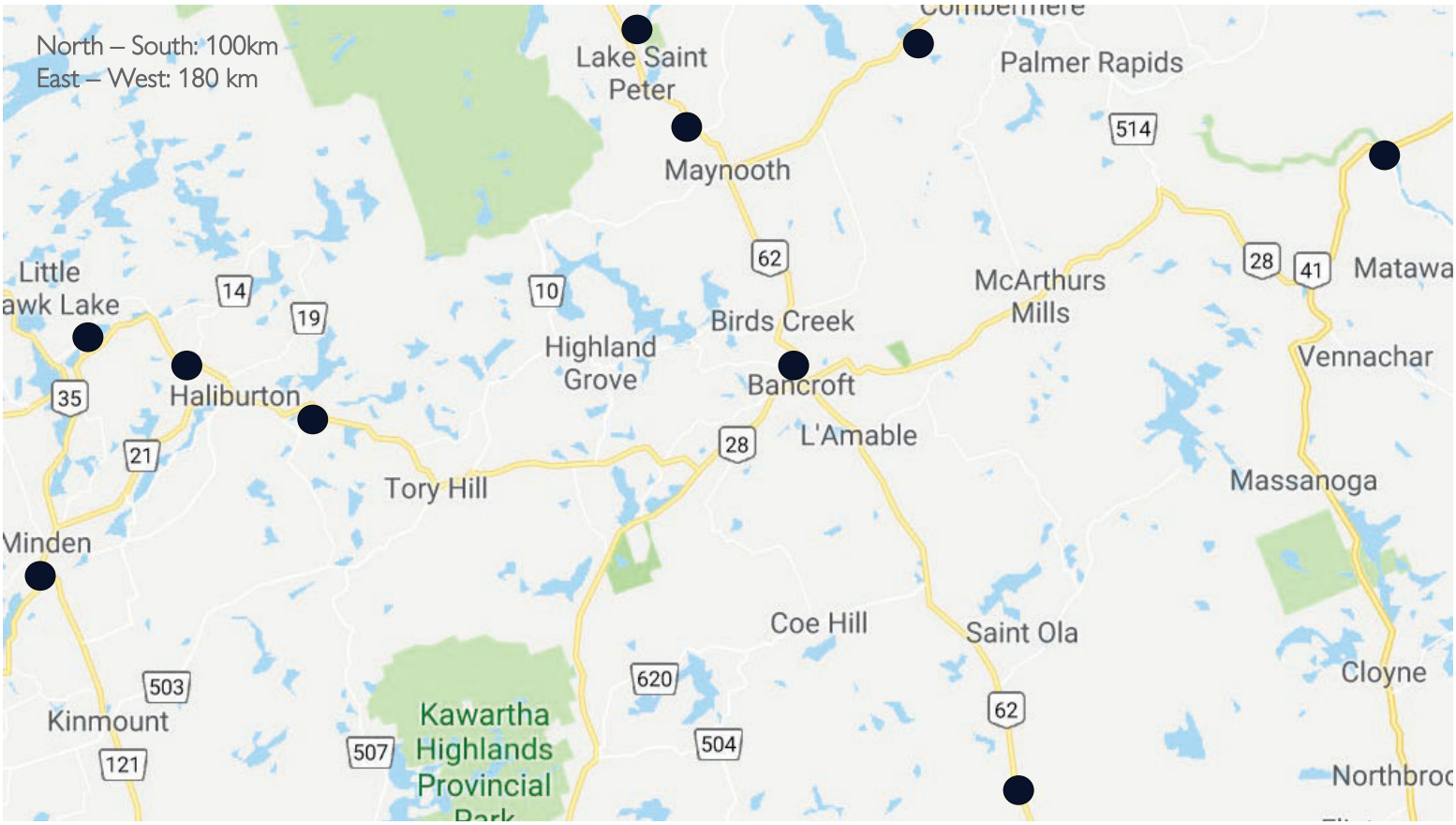
I have no conflicts to declare.

I am speaking for myself, and myself only.

Who am I?

1. Finished residency in 2017 in family medicine.
2. Practice in family medicine, ER, hospitalist and medical aesthetics in rural Ontario.
3. I run our area's MAiD practice off the corner of my desk, approximately two cases a month.
4. I am from this town. I am related to a lot of people.





Who are you?

1. MAiD Providers?
2. MAiD Assessors?
3. MAiD Allied?
4. MAiD Curious?
5. Other?

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What do you want to learn today?

- We will adapt to this as we go.
- Write your anonymous questions down and we will spend the last 15 minutes answering them.

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Context Matters:

Urban MAiD (Mostly in Hospital)

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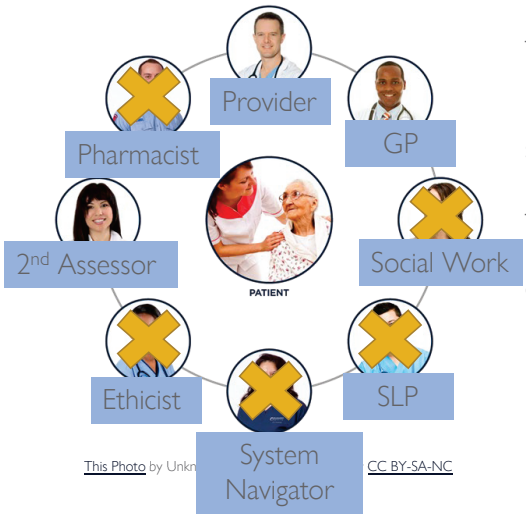
Rural MAiD (Mostly at Home)



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You home care team may have these people but they will not likely be skilled in MAiD enough to take the lead on many crucial issues.

Until you build it.

Objectives

1. Encourage you to share in this wonderful work.
2. Share 3 rural MAiD cases.
3. Share some of the personal benefits and costs of providing medical assistance in dying.
4. Provide some useful advice to rural providers interested in incorporating MAiD into their practice.
5. New:
6. New:

Joan

My first case.

77

Wife and step-mother. Gardener. Retired. Snow bird.

Carcinomatosis with unknown primary. PPS 30.

I was the MRP. She asked for MAiD. I told her I would figure it out. I had never been involved in a case before.

I read our hospital policy, the CEP tool, I spoke with the CMPA. I didn't take the course.

I kept asking her if she was ready, kept triple and quadruple checking myself. She was amused by this.

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Joan

My first case.

What I learned:

1. **Patients Know:** Patients have symptom improvement and an unearthly calm when they know there is a date. It is immensely reassuring to all involved.
2. **Know Their Story:** Knowing her life course, about her childhood, her work story, her relationship allowed me confidence in her capacity, and in my own theory of her case.
3. **This is within our scope.**

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Joan

My first case.

Issues:

1. **Ontario Quirk:** Patients must be informed of their eligibility (that they have a grievous and irremediable medical condition fulfilling 4 criteria) prior to signing their written request for MAiD. Timelimes are everything.
2. **Check your Witnesses:** Witnesses were not independent.
3. **Result**: Her Reflection Period had to restart three times before her final date was confirmed. This has major emotional consequences for family, in particular.

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Hans

Ultimately, ineligible.

89

Neuropharmacologist. Still publishing manuscripts.

Father to a physician. Husband to a clinical researcher.

Idiopathic Parkinson's Disease.

Major point of suffering: Abdominal pain. Not motor or cognitive symptoms, which were mild.

Followed by neurology and GI. Appropriately worked up.

Hans

Ultimately, ineligible.

A **grievous and irremediable** medical condition is defined as:

- having a serious and incurable illness, disease or disability; and,
- being in an advanced state of irreversible decline in capability; and,
- experiencing enduring physical or psychological suffering, due to the illness, disease, disability or state of decline, that is intolerable to the person and cannot be relieved in a manner that they consider acceptable; and, DUE TO THE ILLNESS
- where the person's natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without requiring a specific prognosis as to the length of time the person has left to live.

Eligibility hinged on: Was the abdominal pain due to GI dysmotility secondary to Parkinsonism?

Yes: Eligible
No: Ineligible

Hans

Ultimately, ineligible.

This question was posed to his neurologist and his gastroenterologist.

Neither gave me clear responses.

I spoke at length to the CMPA counsel. Many times.

I declared him ineligible. He was heart broken. I said I would return in a few months. I assessed again. Still ineligible. I encouraged him to reach out for second assessments and opinions.

Hans

Ultimately, ineligible.

While away doing extra training, I received an email stating that he was going to end his life by drowning himself in the lake. His wife was not there.

I called 911. His wife and son were grateful. He was furious.

I reassessed him a third time. Still ineligible. Asked for opinions again from neurology and GI. "Maybe".

Hans went on a hunger strike and died a few weeks later.

Medical Assistance in Dying

Hans

Ultimately, ineligible.

What I learned:

1. **Eligibility has nuance:** Suffering must be attributed to the disease.
2. **Patients don't always appreciate the stakes you face:** Making a decision about eligibility must be taken very seriously.
3. **Ineligibility is always harder than eligibility:** Patients know when they're ready to go.

Would/Should I keep doing this work?

Then I got my next referral.

Darlene & Todd

Ontario's first couple.

86 + 87

Parents to five. Grandparents to many.

Entrepreneurs.

Renal Cell Carcinoma + CHF with Class 4 symptoms.

They wanted to die together at home.

Darlene & Todd

Ontario's first couple.

Issues:

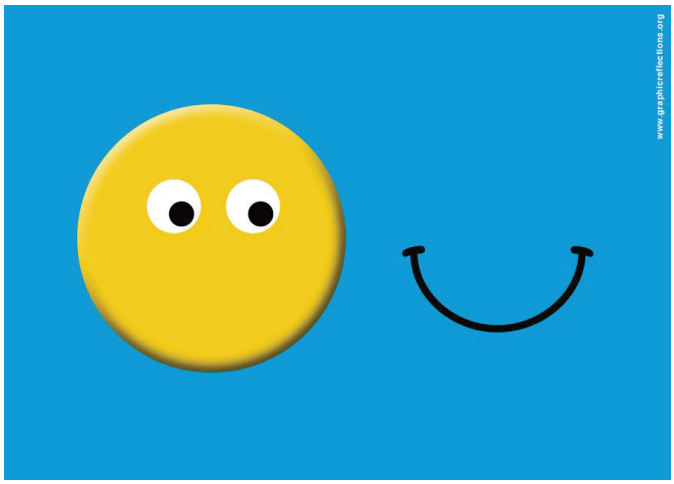
1. Can requests for simultaneous MAiD ever be considered truly voluntary?
2. How do I provide to two people at once when there isn't another provider in the area?

Darlene & Todd

Ontario's first couple.

What I learned:

1. **Ask the Lawyers:** The CMPA will not tell you what to do. They will discuss precedent and the law. You have to make the decision.
2. **Assess them as separately as possible:** I was able to talk through their own individual decision making. If not together, they would go alone.
3. **Meet them. Again. Then Again:** In cases where I am not sure, I make many trips. I will become sure soon enough.
4. **Explore your Team:** Todd's GP eventually decided to provide alongside me. He hasn't been involved in subsequent cases.
5. **Living funerals are the best:** The family had a huge party the night before. The children and the patients were so content and prepared. They had a beautiful goodbye.



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I should keep doing this work.

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Then I called the Coroner….

And she said "Oh no!"

"We've never had this before!"

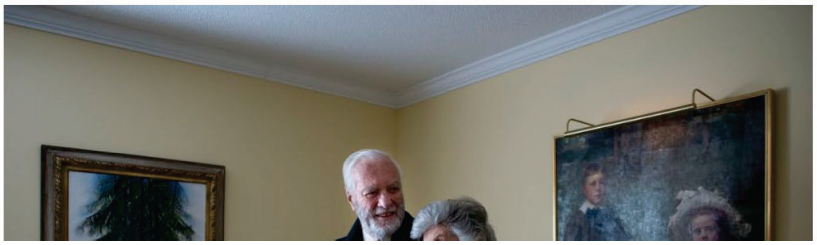
"Are you sure you did it right?"

ASSISTED DYING

Medically assisted death allows couple married almost 73 years to die together

The Brickendens are one of the few couples in Canada to receive a doctor-assisted death together, and the first to speak about it publicly

KELLY GRANT > HEALTH REPORTER
PUBLISHED APRIL 1, 2018
COMMENTS



Organized systems help you get from Referral to Provision. It gets easier every single time.

Personal Benefits and Costs

Costs

- Shuffling schedules to accommodate urgent provisions. Costs to my family practice patients.
- Opportunity cost ($) because MAiD does not pay. Especially when I travel distances.
- The cost of the dissonance inside created when you provide death. Usually, this dissonance is small.
- Lack of formalized debriefing (except in hospital, where we always debrief).
- The pain of ineligibility.
- Solo. Only one of my FHT colleagues will provide a second assessment.
- "Dr. Death" + Contradictions of my Work
- Exposure to ? Protest.

Benefits

- The joy of a good death.
- Allowing patients their dignity.
- Giving patients certainty.
- Becoming intimate with a patient's real life story, not just their HPI.
- Watching the weight lift from caregivers' shoulders.
- The challenge of thoughtful, pensive, nearly legal, work.
- Improved relationships with hospice.
- Precedent setting for tiny hospitals in our hospital corporation.
- Providing my colleagues & their patients this legally enshrined right/resource.

Burnout Antidote.

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WHAT WOULD YOU LIKE TO KNOW?

THANK YOU

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