Sit Down, *Lean In*

The Importance Of Connection In Exploring Suffering

Community Cancer Care 2016 Educational Conference
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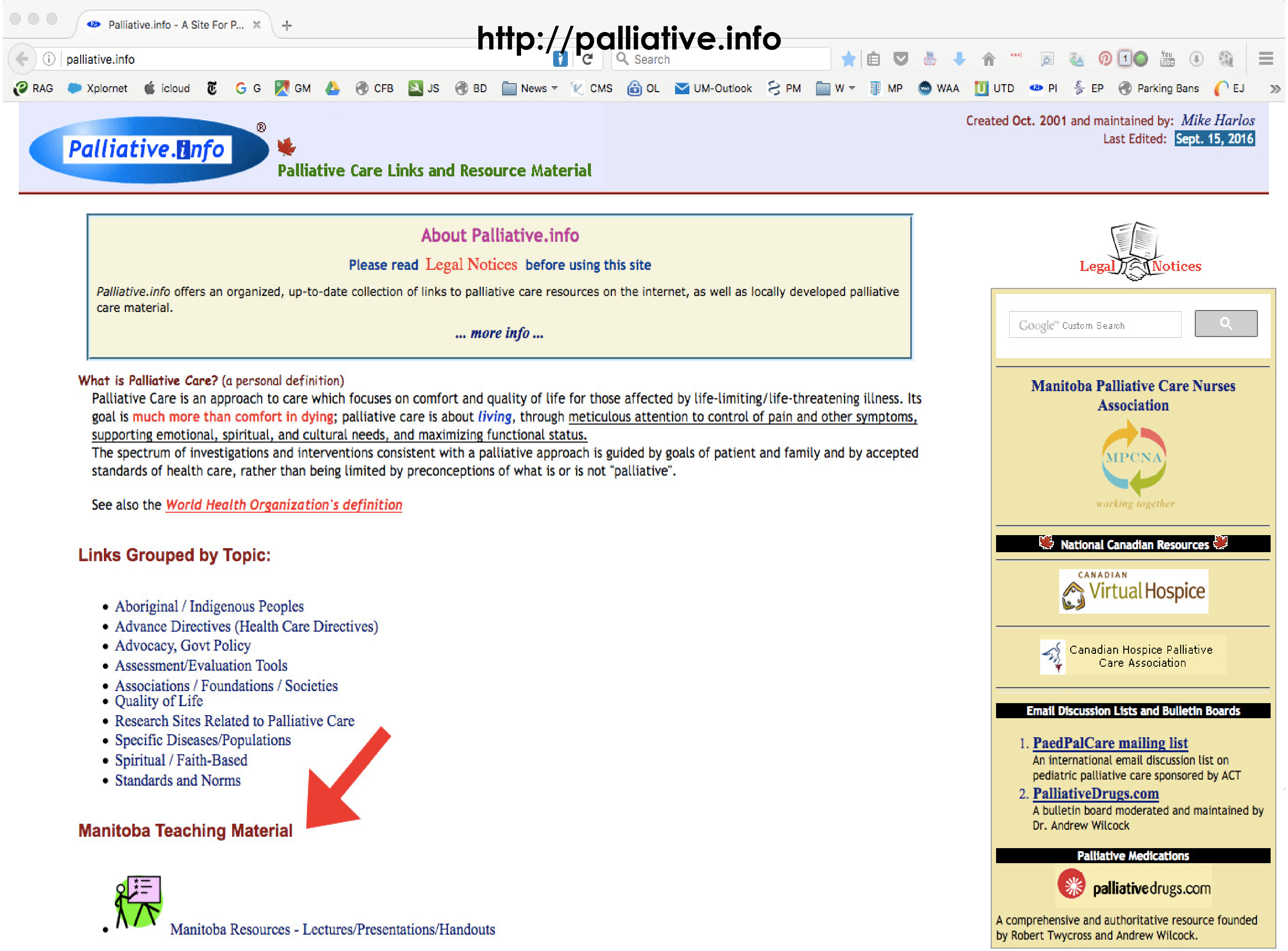
http://palliative.info



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Palliative Care Links and Resource Material

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About Palliative.info

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Palliative.info offers an organized, up-to-date collection of links to palliative care resources on the internet, as well as locally developed palliative care material.

... more info ...

What is Palliative Care? (a personal definition)

Palliative Care is an approach to care which focuses on comfort and quality of life for those affected by life-limiting/life-threatening illness. Its goal is much more than comfort in dying; palliative care is about *living*, through meticulous attention to control of pain and other symptoms, supporting emotional, spiritual, and cultural needs, and maximizing functional status.

The spectrum of investigations and interventions consistent with a palliative approach is guided by goals of patient and family and by accepted standards of health care, rather than being limited by preconceptions of what is or is not "palliative".

See also the *World Health Organization's definition*

Links Grouped by Topic:

- Aboriginal / Indigenous Peoples
- Advance Directives (Health Care Directives)
- Advocacy, Govt Policy
- Assessment/Evaluation Tools
- Associations / Foundations / Societies
- Quality of Life
- Research Sites Related to Palliative Care
- Specific Diseases/Populations
- Spiritual / Faith-Based
- Standards and Norms

Manitoba Teaching Material

- Manitoba Resources - Lectures/Presentations/Handouts

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Manitoba Palliative Care Nurses Association

MPCNA
working together

National Canadian Resources

CANADIAN Virtual Hospice

Canadian Hospice Palliative Care Association

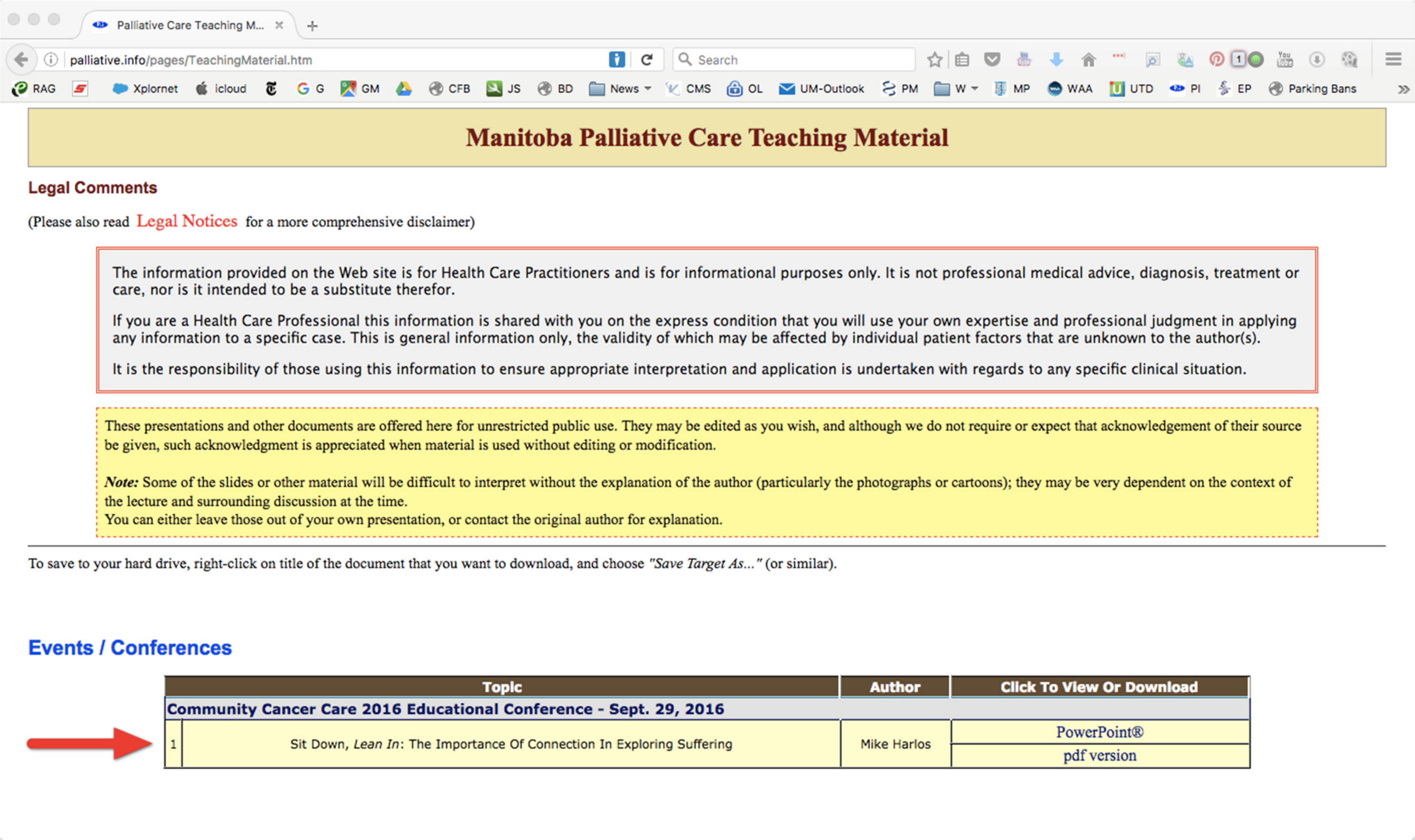
Email Discussion Lists and Bulletin Boards

1. **PaedPalCare mailing list**
   An international email discussion list on pediatric palliative care sponsored by ACT
2. **PalliativeDrugs.com**
   A bulletin board moderated and maintained by Dr. Andrew Wilcock

Palliative Medications

palliativedrugs.com

A comprehensive and authoritative resource founded by Robert Twycross and Andrew Wilcock.



Manitoba Palliative Care Teaching Material

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Events / Conferences

	Topic	Author	Click To View Or Download
Community Cancer Care 2016 Educational Conference - Sept. 29, 2016			
1	Sit Down, *Lean In*: The Importance Of Connection In Exploring Suffering	Mike Harlos	PowerPoint® pdf version

Presenter Disclosure

- **Faculty:** Michael Harlos
- **Relationships with commercial interests: None**

Mitigating Potential Bias

Not Applicable

Objectives

By the end this presentation, participants will:

- Realize that all health care providers have an obligation to explore the suffering that underlies a desire for MAID, regardless of their personal view on the issue
- Understand that the skills involved in exploring suffering can be taught and should be modeled in day-to-day clinical practice
- Appreciate the imperative to advocate for improved resources to address suffering related to serious illness.

Elements of Palliative Care

- attention to comfort and quality of life
- care is grounded in the "personhood" of the patient
  - who they are (or perhaps who they wish they had been, or who they hope to be)
  - their values, priorities, goals
- consideration of the impact of the illness on family, friends, community
- supporting involved health care providers with the emotional, ethical, and technical complexities of care

Arguably, these should be core elements of *all* health care

Palliative care includes the added context of a life-limiting illness

Difficult Conversations

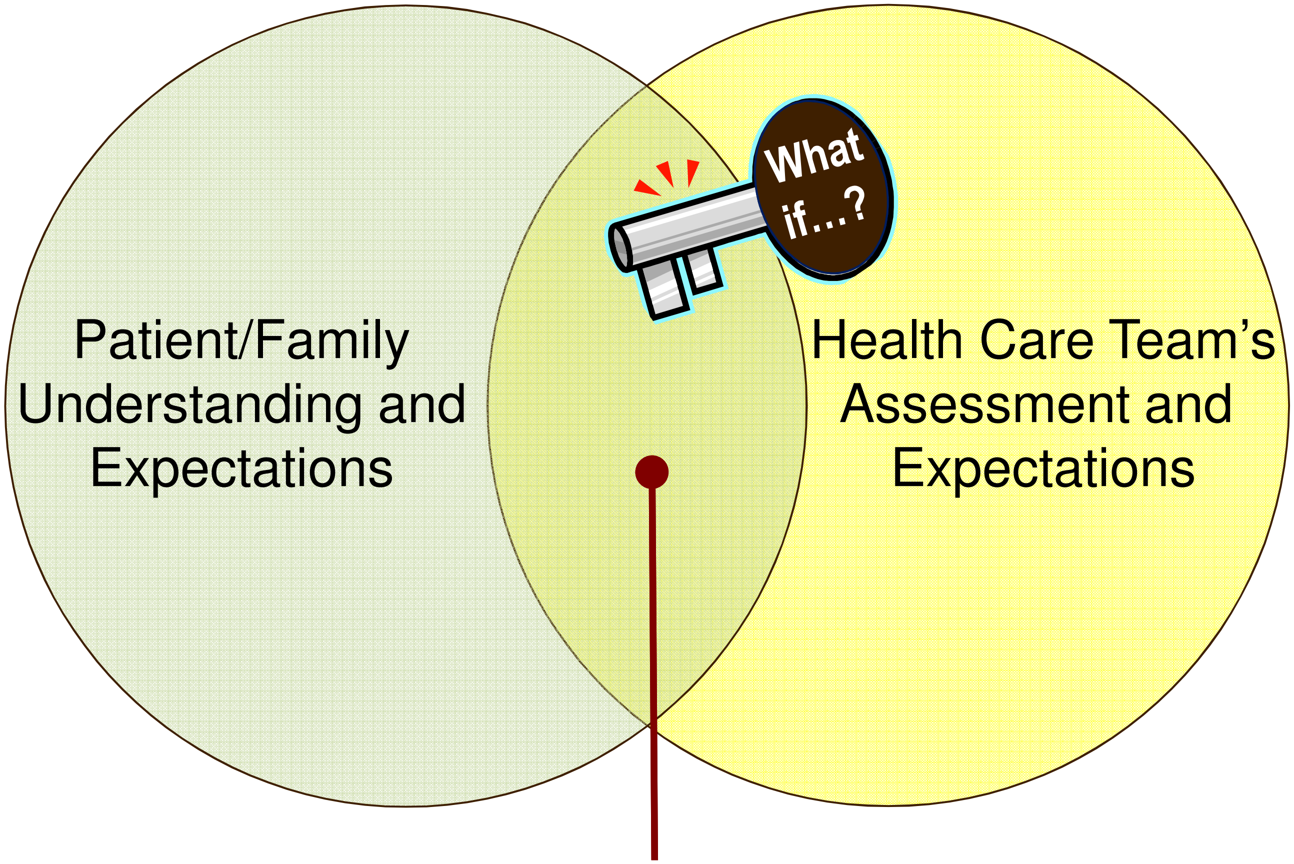
With difficult conversations, the hardest part is starting them; once they get going they tend to take their own direction.

Starting Conversations

Anticipate Concerns – Acknowledge, Normalize, Validate

- Seek permission – not everyone in the room may be ready for frank discussion of death and dying
- *“You might be wondering why your Mom is (more sleepy; weaker; not eating/drinking) – we’ve noticed that too, and thought it would be good to talk about these changes…”*
- *“Many families in such situations wonder about…*
- *“Sometimes when things start to change, families have concerns about…”*

Sometimes it seems that the health care team and patients/families are in two separate rooms – the patient/family in the “don’t get it” or “won’t accept it” room and the health care team in the “we know what’s coming” room



Patient/Family Understanding and Expectations

Health Care Team’s Assessment and Expectations

Common ground– the scary “what-if?...” territory

"I know it's been a difficult time recently, with a lot happening. I realize you're hoping that what's being done will turn this around, and things will start to improve… we're hoping for the same thing, and doing everything we can to make that happen.

Many people in such situations find that although they are hoping for a good outcome, at times their mind wanders to some scary 'what-if' thoughts, such as what if the treatments don't have the effect that we hoped?

Is this something you've experienced? Can we talk about that now?"

Displacing the Decision Burden

“If he could come to the bedside as healthy as he was a month ago, and look at the situation for himself now, what would he tell us to do?”

Or

“If you had in your pocket a note from him telling you that to do under these circumstances, what would it say?”

Life and Death Decisions?

- Families may feel as though they are being asked to decide *whether* their loved one lives or dies – i.e. to *choose* life/death
- It may help to remind them that the underlying illness itself is not survivable – *<u>no decision they make can change that</u>*

"I know that you're being asked to make some very difficult choices about care, and it must feel that you're having to make life-and-death decisions. You must remember that this is not a survivable condition, and none of the choices that you make can change that outcome.

We know that his life is on a path towards dying… we are asking for guidance to help us choose the smoothest path, and one that reflects an approach consistent with what he would tell us to do."

Sit Down, *Lean In*

1. Connect, acknowledge, validate – the expression of suffering and despair should be a show-stopper – “Sit down”
2. What is happening in this person’s life that leads them to feel they would rather not be alive? – Explore, *“Lean In”*

Connecting – “Sitting Down”

- We all have the skills, and the obligation, and the time, to connect – to metaphorically “sit down”

- the pause may be brief, the connection may be momentary yet meaningful and impactful if it is sincere
  - may be as simple as acknowledging the difficult situation and committing to help with it

- E.g.
  - physician in a busy clinic
  - patient transport staff
  - housekeeping staff

Connecting

- You're a person, your patient is a person
    - you almost certainly have thoughts/worries/fears about death and dying, as do they
    - you almost certainly have experienced loss, as they now are
- This is your foundational qualification – your "admission ticket" to the conversation; your credentials for having a role
- Your profession provides an added layer of technical information and skill to help explore suffering, but without connecting *as a person* you cannot effectively provide support

Exploring – *"Leaning In"*

- impacted by skill sets, scope of practice, time constraints, environment
- may need expertise of psychosocial and/or specialists spiritual care
- exploring doesn't mean "fixing the problem" or "talking out of MAID"

Responding To Difficult Questions

1. **Acknowledge/Validate and Normalize**

"That's a very good question, and one that we should talk about. Many people in these circumstances wonder about that…"

Responding To Difficult Questions

1. **Acknowledge/Validate and Normalize**

2. **Is there a reason this has come up?**

   "I'm wondering if something has come up that prompted this?"

Responding To Difficult Questions

1. **Acknowledge/Validate and Normalize**

2. **Is there a reason this has come up?**

3. **Gently explore their thoughts/understanding**
   - *“What is your understanding about what is happening with your illness and treatments, and what might be expected?”*
   - *“Sometimes people already have thoughts about what an answer might be. Is that the case for you?”*

Responding To Difficult Questions

1. **Acknowledge/Validate and Normalize**

2. **Is there a reason this has come up?**

3. **Gently explore their thoughts/understanding**

4. **Respond, if possible and appropriate**
   - If you feel unable to provide a satisfactory reply, then be honest about that and indicate how you will help them explore that

Functional fluency in the language of suffering should be a core competency of all health care providers, and be taught at all levels of training and practice, and modeled in day-to-day care.

Functional does not mean you’re an expert, but at minimum reflects a capacity to connect with (acknowledge, validate) rather than ignore the suffering person.

Take Home Points

1. **Effective health care – in fact, any effective interpersonal interaction with aspirations beyond superficial – requires connection at a level that acknowledges unique personhood**
2. **The imperative to recognize and address suffering has always existed in health care; the existence of MAID does not change that**
3. **We all have the capacity to acknowledge and connect with suffering ("Sit Down"), and the time to do so**
4. **Our ability to explore and address suffering ("*Lean In*") will depend on factors such as our skill set, scope of practice, time constraints, and the setting**