The Grey Method: Ethics and Palliative Care

May 22, 2026

Winifred Badaiki, MD MHE

Clinical and Organizational Ethicist, Hamilton Health Sciences

We are privileged to provide care on lands that Indigenous peoples have called home for thousands of years.

Webinar Housekeeping

- Everyone will be muted except the host, moderator and panelists
- Ask questions through the Teams chat box
- All webinars will be recorded and posted on the internal PEaCE Hub page and on the Regional Ethics Network Website
- Please take a moment to scan the QR code to complete the evaluation
- Next month’s speaker

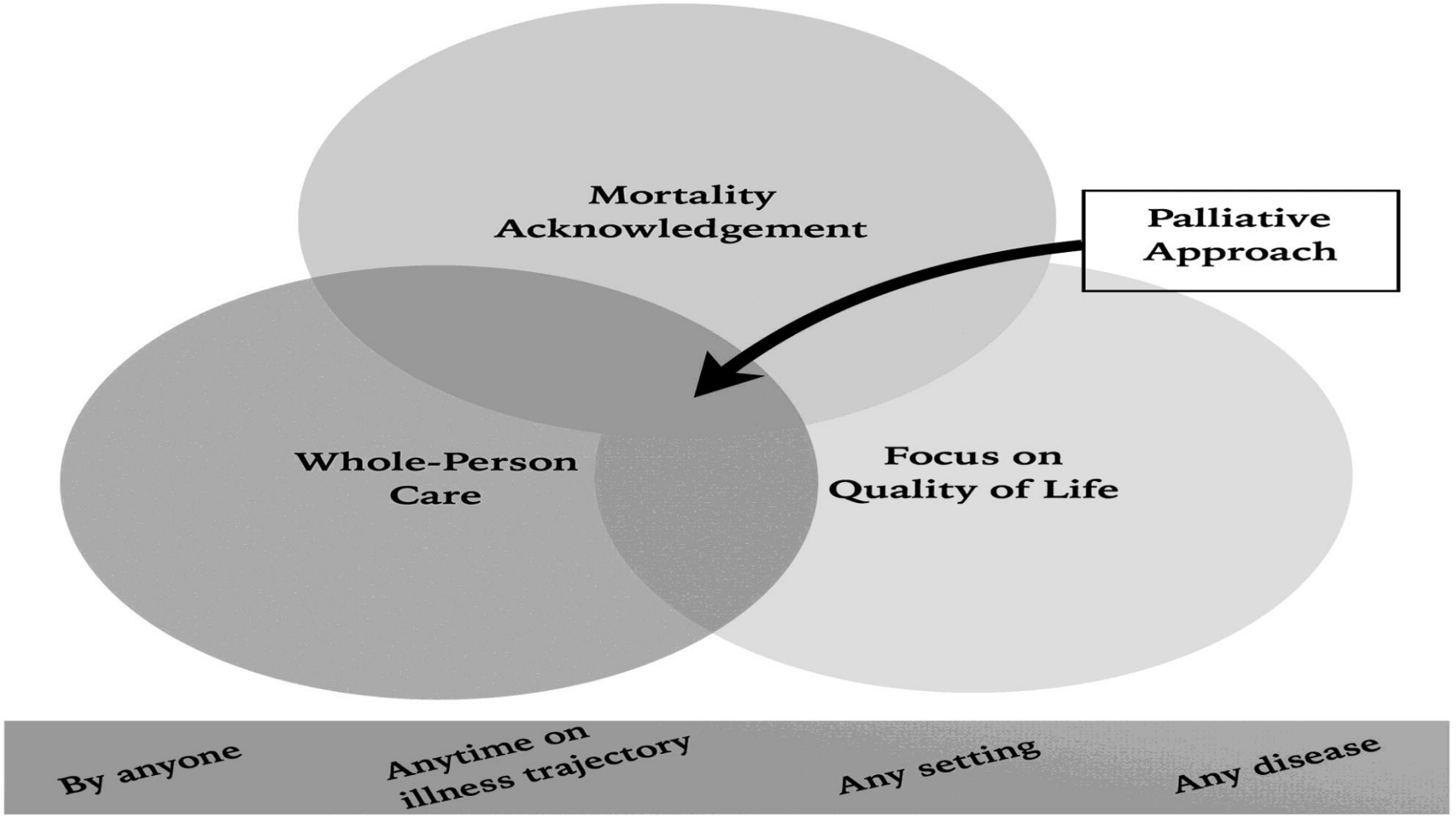
Objectives

- Explore what is the role of ethics in palliative care
- Recognize salient ethical issues surrounding palliative care and how clinicians can address them
- Explore how to approach situations where there is significant ethical uncertainty

Ethical principles related to Palliative care

- Autonomy
- Beneficence and Non-maleficence
- Proportionality
- Equity
- Trust
- Dignity
- Collaboration
- Respect
- Justice and Fairness
- Therapeutic relationship
- Communication

Conceptual Model of Palliative Approach



Touzel M and Shadd J. 2018. Content Validity of a Conceptual Model of a Palliative Approach. Journal of Palliative Medicine. 21(11)
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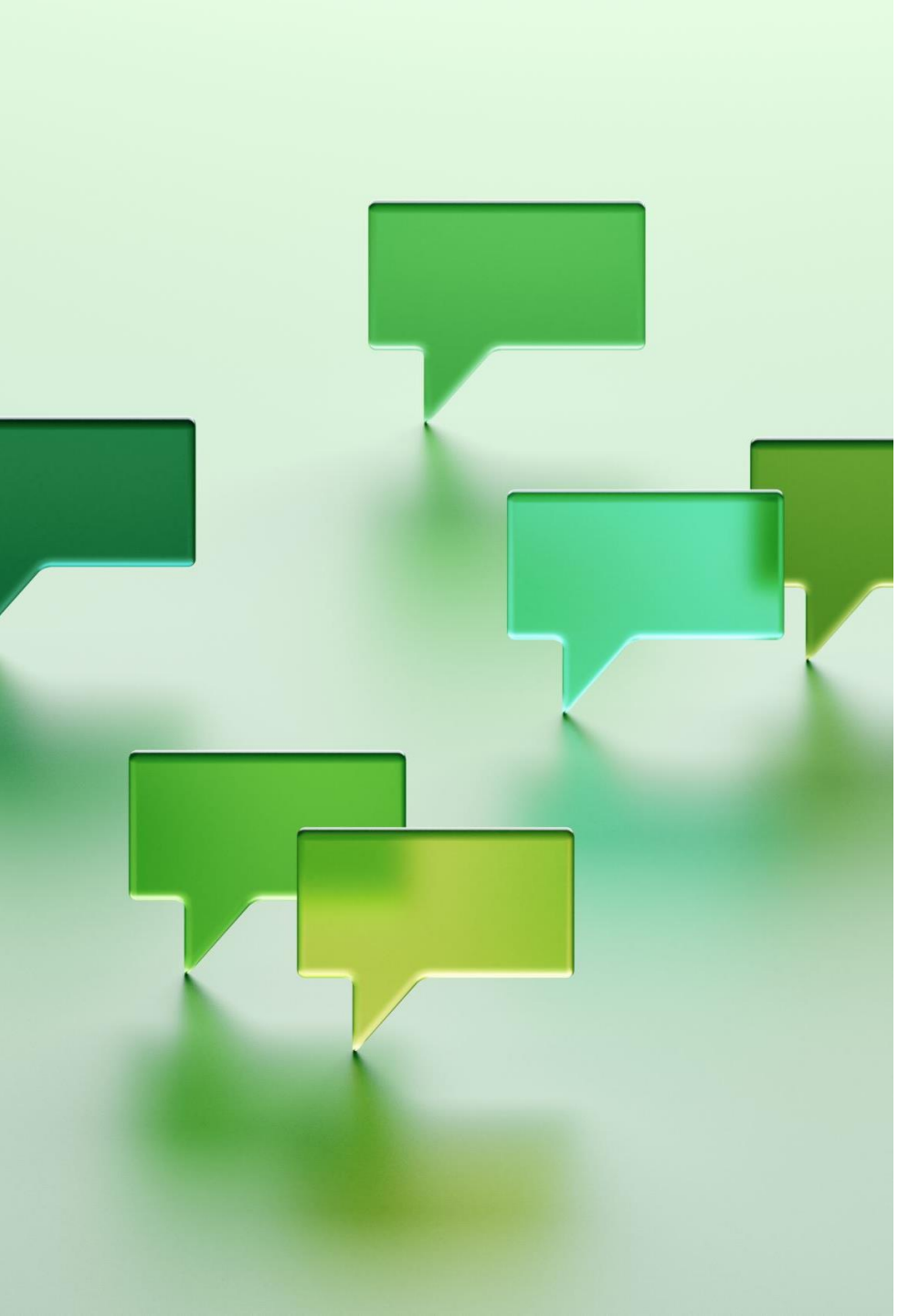


1 minute:

What ethical issues do you currently experience in delivering palliative care?

(Place answer in chat box)

ETHICAL ISSUES IN PALLIATIVE CARE

- Uncertainty around when to initiate procedures such as Voluntary Stopping of Eating and Drinking (VSED), Voluntary Stopping of Personal Care (VSPeC), Palliative Sedation, Palliative Psychiatry, etc. that may result in relief of experienced suffering.

-Prioritizing patient's wishes when they are in conflict with the needs/safety of others

-MAiD as part of end-of-life care

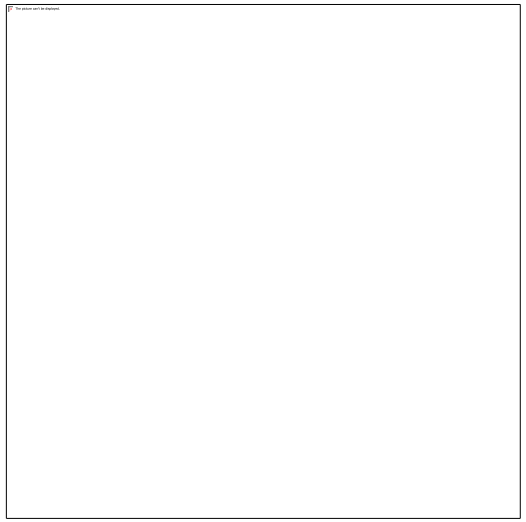
-Conflict in palliative care delivery

-Utilization of advanced care documents and Serious Illness conversations (SIC)

-Care for vulnerable patients and populations

-Late integration of palliative care

"**Suffering** is not a side issue; it is central to the **moral** life of medicine."- Atul Gawande (Author of Being mortal: Medicine and What Matters in the End)



PAUL'S JOURNEY

Meet Paul

- Paul is a 65-year-old man with chronic heart failure, and severe renal failure. He also has other comorbidities including diabetes and rheumatoid arthritis. Paul has been dealing with his conditions for years, including participating in a dialysis regimen.
- Paul is not actively dying but his illnesses has clearly taken their toll. He is also experiencing housing issues and is at risk of being unhoused.
- Paul was seen by a Palliative care clinician in the community who carried out a Serious Illness Conversation (SIC) and presented Paul with his care options.
- Paul made it clear that he is no longer interested in pursuing dialysis and further treatment and that he is no longer willing to suffer. According to him, he has lived a good life, continuing treatment will only prolong his suffering and dying process, and he is ready for “what’s coming for him”.
- He also told the clinician that he hopes to die someday at home.

Ethical process by the Palliative care clinician

Respect for Autonomy and Dignity

- Acknowledging and respecting and Paul's request and wishes

Benefit and Harms

- Consideration and exploration of Paul's physical or psychological sufferings

Informed Consent and Capacity

- Ensured that his decision is voluntary and not coerced
- Paul had been offered appropriate medical and social supports through his illness journey, and overall assistance in living
- Carried out a through assessment of Paul's rationale, reasons, determination, understanding and appreciation of his wishes and request
- Informed him of all possible consequences and outcomes related to his request to stop treatment

- The clinician had no concerns regarding Paul's request and wishes and found him to have clear understanding and capacity
- This information was documented in Paul's medical chart and a copy of the SIC was given to him

Paul's Journey

- Next time Paul was seen in the hospital (after his previous discharge), he has just been recently admitted to the hospital
- You (the clinician) learn that Paul has been underhoused for a while and fell through the cracks of the system; however, he had begun living with his daughter, Lindy in the past few weeks as he got worse.
- He now has end-stage renal disease, a very complicated medical profile, delirious, receiving full medical treatment including dialysis at the request of Lindy.

Paul's Journey

Paul's Sister- Jane

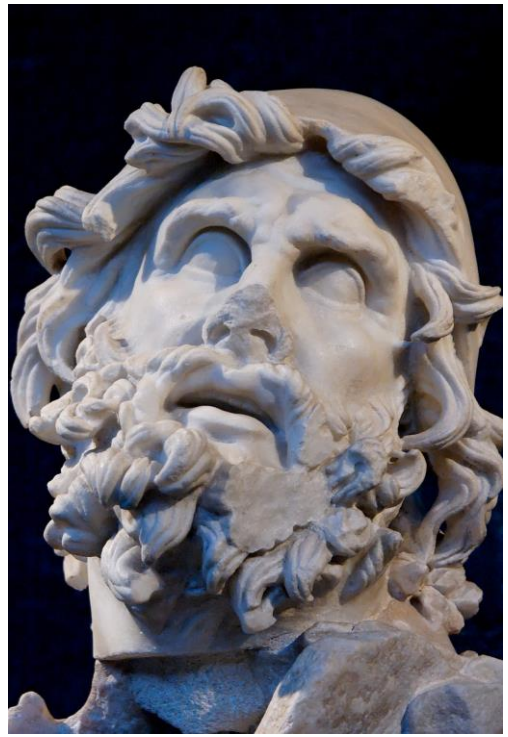
- On your visit to Paul's bedside, you meet Paul's sister, Jane and she reminds you about Paul's previous wishes.
- You are concerned as you realize that current care Paul is receiving may not be what he would want.
- Jane shows you an advanced directive where Paul documented his wishes around Voluntarily Stopping Eating and Drinking (VSED).
- According to her, Paul had informed her and others in the family that he has recently begun VSED and asked not be fed and hydrated even if he is requesting for food and water.
- She wonders if this can be considered a **Ulysses agreement** and if his daughter can be asked to not feed Paul.

Paul's daughter and Substitute Decision Maker (SDM)- Lindy

- You meet with his daughter, Lindy, who tells you that although she knows about his previous wish for no treatment, she believes that these wishes by Paul were made when he was not "of sound mind".
- Lindy shared that Paul asks to eat and that when Paul is presented with water or other beverages, he does not refuse them; thus, she continues to offer him water and food.
- Lindy wants him to live and wants everything to be done to achieve that goal.

Ulysses agreement

A Ulysses agreement, contract or pact is a voluntary commitment made by one in the present to restrict their future choices, ensuring that they don't deviate from their wish or goal, even when temptation strikes, or they feel differently.



What is the Ethical issue?

Ethical Dilemma:
Given that Paul does not have the capacity to make his care decisions currently, are his previously expressed wishes applicable and should they be respected, especially since he is requesting and accepting of water and other beverages?

Right to Self-determination (Autonomy) and Dignity

- Past self vs present self
- Persons with capacity can decide what they would want in specific circumstances, and this is recognized in the legislation (HCCA, 1996) however, previously expressed wishes must be **APPLICABLE** to the current circumstances

Beneficence and Non-maleficence

- Ensure that actions carried out are in the best interest of the incapable patient (HCCA, 1996)

The Grey: Ethical considerations of Ulysses contract before enactment

1. Does this involve a medical intervention (artificial nutrition, palliative sedation) or a basic human need (eating, drinking, grooming, personal care)?
2. Is the patient suffering exacerbated by the ongoing action that is contrary to the Ulysses contract?
3. Can the patient goals be met even by the ongoing action that is contrary to the Ulysses contract?
4. Is following the pact the only way to meet the patient goals?
5. Are the patient wishes applicable in this circumstance when they are requesting that the ongoing action that is contrary to the Ulysses contract continue?
6. Is the patient fully informed of the limitations of this contract?

Specific advice in the literature re VSED

Allatt and colleagues (2022)

"HCPs ensure that patients, whether or not they are capable, be provided food or fluid if they request it while undertaking VSED. As the dilemma of Ulysses contracts is raised, patients should be informed before VSED that if they request food or fluids, they will be provided"

Paul's Journey: Conflict

- Considering his poor prognosis, standard of care, medical evidence and his previously expressed wishes, the clinician propose a plan that includes withdrawal of dialysis and maximizes comfort interventions.
- However, his daughter, Lindy disagrees with this plan, and once more cites that she believes his previous wishes were made when he was not of "sound mind" and that based on him being a lifelong Christian, he would want to live by all means.

Contributors to conflict in delivering palliative care

- Miscommunication
- Misconceptions about palliative care
- Differences in the expectations of the involved parties
- Prognostic uncertainty
- Emotional, psychological and other factors such as grief, behavioural issues, clinician burnout, family dynamics, cultural differences
- Interprofessional disagreement
- System-level constraints

Options

Route 1:
Follow the directions of Paul's SDM (Lindy)

Route 2:
Follow Paul's previously expressed wishes

Route 3 (The Grey):
Pursue all conflict resolution pathway

Route 1: Follow the directions of Paul's SDM

Benefits

- Maintain therapeutic relationship with Lindy
- Reduced grief to Lindy by enabling her have more time to spend with Paul
- Possible for Paul to regain capacity and reinstate his wishes

Risk

- Paul continues to participate in treatment he has expressed that he does not want and is not in his best interests
- Paul continues to suffer with no clear pathway to resolution
- Reduction of trust in the health care system

Route 2: Follow Paul's previously expressed wishes

Benefits

- Paul wishes are prioritized
- Paul will not continue to suffer with no clear pathway to resolution

Risk

- Paul wishes were made months ago there is some uncertainty as to whether these wishes are his most current wishes

Route 3 (The Grey): Pursue conflict resolution

Benefits

- Clarification of intent, requests, processes, wishes and goals
- Even when it doesn't lead to desired result, conflict resolution process result in clearer options and action items

Risk

- Emotional strain
- Time and resource strain

Conflict resolution

- Communication about prognosis, recommendations, and best practices
- Explore with SDM their role and responsibilities
  - Follow previously expressed wishes of the patient if known
  - If unknown or not applicable to the circumstances, act in the patient's best interest
- Ethics mediation and involvement of other helpful and applicable services
- Consider an application to the Consent and Capacity Board regarding role of SDM

Paul's Journey

Paul's sister questioned why no clinician including the previous palliative care clinician raised the topic of MAiD given his suffering. She says "After all, palliative care is all about managing suffering".

You leave this conversation plagued with questions

Should palliative clinicians bring up MAiD as an option for patients when they have not raised the options themselves? And

Is this an ethical course of action?

Should palliative clinicians bring up MAiD as an option for their patients?

For
Clinicians are not prohibited from raising MAID in Canada
Not providing the information to a patient might • Undermine patient autonomy and informed consent • Cause inequity in access • Prolong suffering • Undermine transparency and trust

Against
Risk of undue influence and suggestion raising concerns about coercion, mistrust, and abandonment, and sending message of hopelessness and despair
Risk of undue bias to vulnerable patients
Consideration of Conscientious objectors
Against the philosophy of palliative care

The Grey approach

Follow a values-based, patient centred approach

Consider informed decision making

Provide more information or an adequate referral when MAiD inquiry is raised

If the clinician is unsure or uncomfortable with whether or not to raise MAiD as a care option, seek support and guidance from team and MAiD services within your organization

And one more thing ….

LET’S RETURN TO PAUL

Access and Equity: What are the ethical issues?

What we ought to do:

- Number 13 of *The Ontario Palliative Health Services Delivery Framework (***Model of Care: Adults Receiving Palliative Care in Community Settings)** recommends that
  - "Earlier identification of the patient who has palliative care needs and is also **homeless or vulnerably housed** will take into consideration the social and psychological challenges that the patient faces, recognizing that prognosis can be significantly shortened in this population."
  - "The palliative care needs of the patient who is homeless or vulnerably housed will be identified as early as possible, and care will be provided wherever the patient is."

- The third recommendation for the Adult Hospital Model of Care focuses on enhancing care coordination and communication within and across settings.

Access and Equity: What are the ethical issues?

Why we cannot do it:

Reduced access to palliative care for patients and populations stem from

- Structural and systemic limitations
- Socioeconomic and cultural barriers
- Resource allocation and funding limitations
- Patient factors
- Fragmented care coordination
- Geographic and demographic limitations

What happens when we cannot do what we ought to do:

Moral Distress which occurs from knowing what is the right thing to do but unable to do so

The Grey: Ethics in Inequity

- Patient and system advocacy
- Prioritization of the patient current needs
- Ensuring early and proactive access as much as possible
- Providing culturally safe and responsive care
- Community engagement and partnership
- Prioritizing transparency and accountability

All of the above ensures fidelity to the ethical principles of Beneficence, Autonomy, Dignity, and Justice

Values to facilitate ethical palliative care: Pearls from Paul's Journey

- **Autonomy:** Elicit what matters most to the patient; what are their goals; how do they define quality of life; what limits would they set on care; what suffering are they willing to experience.
- **Professional Duty:** Initiate GoC conversations and SIC. Make clear professional recommendations. Follow relevant and helpful policies.
- **Beneficence:** Remind SDM of legal roles. Consider the patient's best interests as defined in the HCCA.
- **Compassion**: Identify conflicts early as possible. Engaging in conflict resolution processes can be a form of compassion; engage supportive resources promptly such as Clinical Ethics services, community services, grief/spiritual supports.

Values to facilitate ethical palliative care: Pearls from Paul's Journey

- **Transparency:** Communicate effectively; communicate limits of care.
- **Justice:** Recognize power dynamics; consider literacy differences, cultural norms, social determinants of health and emotional vulnerability/needs.
- **Equity:** Ensure patient and family access to available resources; Continue advocacy for proper resource allocation.
- **Collaboration:** Ethics and palliative care working together can significantly help with uncertainty in clinical decision making.

How can an Ethics Consultation Service support “ethics in palliative care”?

- Immediate coaching for urgent issues
- Team support regarding strategies to address conflicts/ambiguities
- Team and family mediation/conflict resolution processes
- Thorough documentation of ethical issues and analysis
- Access to ethics resources such as an ethics framework, FAQ’s, tips, policies, literature
- Collaboration with services such as psychospiritual care or resilience integration, EFAP to support teams through morally distressing situations

More resources to support “ethics in palliative care”

- CPSO Decision-Making for End-of-Life Care policy
- Consent and Capacity Board
- Home and Community Care Services
- Canadian Medical Protective Association (CMPA)
- Palliative care delivery guidelines

References

1. Touzel M and Shadd J. 2018. Content Validity of a Conceptual Model of a Palliative Approach. Journal of Palliative Medicine. 21(11) https://doi.org/10.1089/jpm.2017.0658
2. Allatt, P., Kim, D. D., & Hébert, P. (2022). Voluntary stopping of eating and drinking in the age of medical assistance in dying: ethical considerations for physicians. *Palliative Care and Social Practice*, *16*, 26323524221112170.
3. *Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A*.

THANK YOU!