



# Battered hearts and broken dreams: thinking about medically assisted dying in children and youth

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# Goals

- Thinking about cases: human faces
- Current status: overview
- Overarching ethical context
- Bedside ethical considerations
- Organisational ethical and practical considerations in paediatrics
- Where do we go from here?

# Case 1

- T is a 17 y 4 m old oncology patient with non-Hodgkin lymphoma
- 3+ years Rx: surgery, chemo, post stem cell Tx
- GVHD (skin)
- Now a palliative care patient for considerable time but has also participated in several active clinical trials when feeling better
- Excellent student had been attending school but cannot now with significant pain and symptoms
- T has read a great deal about MAiD and asks why must wait until 18 for referral – she is ready now

# Current Overview: Federal

- June 17, 2016, Bill C-14 passes & outlines requirements patients must meet to be eligible to receive medical assistance in dying
- establishes safeguards that a doctor or nurse practitioner must follow to legally provide medical assistance in dying
- Under federal legislation, government is required to initiate independent reviews of issues relating to requests by mature minors, those with only mental health conditions, and advance requests for medical assistance in dying.
- December 2016, requested the Council of Canadian Academies (CCA) to undertake the independent reviews and table the resulting reports in Parliament by December 2018.



# Current Overview: Ontario

- May 10, 2017, Ontario's Medical Assistance in Dying Statute Amendment Act 2017 receives Royal Assent
  - addresses areas relevant to medical assistance in dying that fall under provincial jurisdiction
  - provides greater clarity and legal protection for health care providers and patients
  - establishes a new role for the coroner in overseeing medically assisted deaths
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# Overarching ethical context

- Informed Decision-making

  - Disclosure +/- and foreseeable consequences and same for alternatives

  - Understanding

  - Capacity

  - Voluntariness

  - Informed decision – may be revoked

- Capacity

  - point in time, particular

  - emerges over developmental continuum

  - historically case law reluctant to recognize in youth for 'life/limb' decisions



# Context: health care decisions

- Ontario allows capable young people to make medical decisions that will result in their death
  - capable patients may stop or discontinue life sustaining treatment that is currently under way
  - capable patients may refuse interventions even when those interventions are life sustaining
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# ethical context cont'd

- Recent evolution and elaboration of paediatric palliative care
- Population of those with life limiting conditions may die before attaining adulthood
- Earlier interventions ↑length and ↑qol (rather than at very eol)
- Increasingly 'foot in 2 camps' approach as patients wish
- Regional PPC services offered through RNH/CHEO



# and more ethical context

- Dominant issues in discourse (and debates) have centred around autonomy rights, equal opportunity, sanctity of life, parental/family authority
  - Reflect Western liberal bioethics discourse – U.S. principlism, legal traditions
  - ?relationships, diverse cultural values, indigenous populations, power, voice, inequities
  - What else do we need to think about?
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# Common Issues: Paeds Pall Care

- **Charlie Gard best interest** case in 2017 born with mitochondrial deletion syndrome(MDDS) causes progressive brain and muscle failure
- no treatment and usually causes death in infancy
- the medical team and parents disagreed about whether experimental treatment was in the best interests of the child
- A neurologist in New York, Michio Hirano agreed to proceed with an experimental treatment but after Charlie had seizures that caused brain damage, hospital believed that further treatment was futile and would prolong suffering - asked the High Court to override the parents' decision. In July, by consent, Charlie was transferred to a hospice, and he died the next day

# Case 1b

- T is a 17 y o oncology pt with GVHD post stem cell Tx who is now palliative
- She has exacerbations of GVHD difficult to manage and is increasingly frail and sometimes short of breath
- She continues to complete school work at home and has applied to several universities for media studies
- Her aspirations are (1) be accepted into a program (2) graduate from high school (3) attend at least one semester of university

# Ethics and some biology!

- Pre-frontal cortex (planning complex behaviours, expressing personality and controlling social behaviour) changes greatly during adolescence into mid 20's
- increase in connections and speed of neurons – a crucial component of mechanisms of complex behaviours and decision making
- adolescent brain has an overabundance of grey matter (building blocks of the brain) and undersupply of white matter (the connective wiring that helps information flow efficiently)

# more brain...

- teen brain is ~80% of the way to maturity
- Myelin (white matter) continues to be produced well past adolescence and even into a person's thirties
- a person's reasoning abilities are more or less fully developed by the age of fifteen.
- under stress, thinking becomes less flexible: in adolescence, the effects of stress may be long lasting and possibly irreversible

## Case 1c

- T is a 17 y o post stem cell transplant for non-Hodgkin lymphoma with GVHD
- significant burden of illness: disfigurement, pain, impaired mobility and is DNR
- She is a palliative care patient and both gives her family respite and gets respite with visits to RNH where she recently celebrated her birthday
- She is now fighting a major infection and begs staff not to let her die yet as she has so much still to do

# Practitioner issues concerning requests for MAiD by mature minors?

- practicing of MAiD within a framework of Child and Family-Centered Care, which locates the child at the centre of clinical concern and understands the family as central to the wellbeing of the child.
- How should MAiD be discussed with the patient? With parents, without parents, before a discussion with parents, after a discussion with parents?
- Does MAiD warrant any distinct approaches to protecting the patient's right to privacy and confidentiality?
- Should MAiD requests and administration be kept confidential from parents and other family members if the capable patient indicates they do not want family members involved?
- Would MAiD be provided without parental notification?



# Practitioner issues: drug protocols

- Are current drug protocols physiologically appropriate for young bodies?
  - Would alternative protocols need to be designed? If so, by whom?
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# Organizational Questions:

- How to practice MAiD within institutions actively working towards suicide prevention initiatives with young people
  - Should self-administration of MAiD become an option in paediatric institutions or is practitioner administration preferable in order to avoid being misinterpreted as contradicting anti-suicide initiatives?
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# Practicing MAiD in a multicultural setting

## Considerations:

- Respecting cultural diversity while ensuring the patient's physical and mental wellbeing.
  - What aspects of MAiD administration can be adjusted to accommodate the plurality of meaning systems, traditions, and rituals surrounding end of life, death and dying?
  - What aspects of MAiD administration must not be modified?
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# MAiD: social stigma & practitioner safety

## Considerations:

- Being secretive about MAiD (on an institutional and practitioner level) reproduces and may foster social stigma. Taking institutional and social response to treating HIV/AIDS as an example, would support being open about providing MAiD in order to normalize the procedure and reduce stigma?
- Could being open about providing MAiD (on an institutional and practitioner level) endanger MAiD providers. Taking institutional and social response to providing abortions as an example, should there be higher level of provider anonymity to protect MAiD providers?
- How should these competing concerns be balanced?

# Is MAiD a treatment option?

- Should MAiD conversations begin with patient request or with the duty of practitioners to inform patients (when medically appropriate) of all available treatment options?

## Considerations:

- Patients who are not already informed about the existence of MAiD will not be in a position to request it. This is most likely to be a problem for patients who are socially marginalized in other ways (linguistically, economically, etc).
- Care must be taken to ensure patients do not feel pressured to pursue MAiD by their clinicians
- Capable patients must be fully informed of all medically appropriate treatment options in order for them to make an autonomous decision about which course of action they wish to pursue



# Is term 'mature minor appropriate?

If MAiD access is extended to capable young people, the language used should be consistent with respect for persons in this category.

Considerations:

- The language of "Mature Minors" may be interpreted as demeaning/ dismissive to young people in this category. An alternative may be "capable patients" or "capable young people"
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# Issue of Practicing MAID consistent with distributive justice/ and resource allocation

Example:

- Should paediatric institutions admit patients solely for MAID when this is a procedure that can be safely and effectively carried out in community settings?
- Current Ontario data suggest most adult MAiD takes place in hospitals

# ?Justifications for restricting who is eligible for MAiD

- If MAiD remains inaccessible to capable young people who are under the age of 18, we need a rationale that is consistent with frameworks already in place for end of life decision making of young people.
- If steps are put in place to alleviate the suffering of adults *that cannot be addressed through palliative care*, we need to be clear about the ethical defensibility of denying access for potentially capable young people

# More policy considerations

- Is Organ donation medically viable following MAiD? Is it ethically appropriate to offer? Organ donation currently an option for patients and families when patient is already or expected soon to be (brain) dead
- currently offer organ donation as an option to patients who are over the age of 16
- age limit has been imposed based on the Trillium Gift of Life Network Act [Ontario] RSO 1990, Chapter H.20, Part 1, Sect. 3 (1) [Internet]. Toronto, ON: Government of Ontario; 1990.

# Where do we go from here?

- Is there an inevitability that MAiD will be made available to capable young persons?
- What more do we need to know?
- How will we decide whether evidence supports MAiD for youth?
- How will we continue to address (preserve and promote) eol needs for youth?
- Domains of practitioner and organizational concerns and overlap
- Who needs to be heard?
- Will we keep the human face central to inquiry?
- At present, many more questions than answers

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