Caring for our patients:

How to respond to a question regarding medical aid in dying?

Wendy Johnston
Eric Wasylenko
Branko Braam
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Thank you
With respect to medical aid in dying:
1. Understand background, world experience and current regulations in AB
2. Explore a few ethical and moral considerations
3. Develop a personal and professional response to request to discuss medical aid in dying.
General introduction
Barbara Ballermann

Approaching the question from 3 perspectives:

What can we learn from other countries that have legalized and regulated physician-assisted death?
Wendy Johnston

Alberta’s preparedness response, and some remaining challenging issues.
Eric Wasylenko

How can we respond to a question regarding physician-assisted dying?
Branko Braam
What can we learn from other countries that have legalized and regulated physician-assisted death?

Wendy Johnston

Disclosures / Conflicts of interest:

None.
What can we learn from other countries - **Wendy Johnston**

50 years of Parallel Social/Medical Movements 1960s to the present day:

<table>
<thead>
<tr>
<th>I</th>
<th>II</th>
<th>III</th>
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<tbody>
<tr>
<td>• Advances in life sustaining treatment</td>
<td>• Resurgence of right-to-die societies</td>
<td>• Emergence of modern hospice movement</td>
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<tr>
<td>• Development of intensive care units</td>
<td>• Right to refuse life-sustaining treatment</td>
<td>• Palliative care a medical specialty</td>
</tr>
<tr>
<td>• Respiratory support, enteral feeding</td>
<td>• Legalization of assisted death</td>
<td>• Comfortable death as a medical goal</td>
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Physician Assisted Death: Countries with laws permitting

- United States
  - Oregon
    - (1994 - implemented 1997)
  - Washington (2008)
  - Vermont (2014)
  - California (2015)
  - [Montana (2009)]
  - [New Mexico (2015)]
- Columbia (1997 – 2015 law)
- Canada (2016)
  - Quebec (2015)

- The Netherlands (2002)
- Belgium (2002)
- Luxembourg (2009)
- Switzerland (1940)
  - illegal if undertaken for selfish reasons, may be prosecuted
  - only country allowing “tourists”
  - mainly provided by “Dignitas” and “Exit”
- Canada (2016)
  - Quebec (2015)
Oregon data (1998 to 2015)

- Eligibility based on terminal disease, not suffering
- Law explicit and standard of practice clear, no formal training
- Complaints reviewed but not each death

**Public Health Reports:**
- Low but persistent use
- Small number of prescribing physicians (106/15,250)
  - Physicians tend not to be present at time of death (+/-10%)
  - # prescriptions per doctor 1-27
- Low (but real) failure rate

What can we learn from other countries - Wendy Johnston
Research studies:

1. Patient characteristics correlate with requests not diagnosis, socioeconomic status, insurance, symptom burden, hospice care
2. Quality of death comparable or better in PAD (caregiver report)
3. Doctor-patient relationship of shorter duration in PAD deaths
4. Medically assisted personal choice
Netherlands (pre-legalization to 2015)

- Formal training and review process
- Eligibility: based on suffering, terminal disease not required

**Statistical reporting**

- Low utilization of PAD vs. euthanasia
  - correspondingly high presence of physicians at time of death
- Gradual rise in granted requests, though low overall
- Expanding eligibility to dementia and mental health patients
- Low (but real) incidence of unrequested euthanasia
• **Research**

  • Requests/completion correlated with personal characteristics, not disease, socioeconomic status, utilization of palliative care
  • Increased use of palliative sedation after legalization
  • PAS favored for existential and euthanasia for physical suffering
  • PAD as part of medical care, embedded in long standing physician patient relationships

What can we learn from other countries - Wendy Johnston
Ever had the question for PAD for the future
Ever had a specific request
Request in the last year for PAD in the foreseeable future
Performed PAD in the last calendar year

<table>
<thead>
<tr>
<th></th>
<th>2011 % (95% BI)</th>
<th>2005</th>
<th>2001</th>
<th>1995</th>
<th>1990</th>
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</thead>
<tbody>
<tr>
<td>Ever had the question for PAD for the future</td>
<td>82 (79-84)</td>
<td>84</td>
<td>90</td>
<td>88</td>
<td>84</td>
</tr>
<tr>
<td>Ever had a specific request</td>
<td>77 (75-80)</td>
<td>67</td>
<td>77</td>
<td>77</td>
<td>76</td>
</tr>
<tr>
<td>Request in the last year for PAD in the foreseeable future</td>
<td>51 (48-53)</td>
<td>41</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Performed PAD in the last calendar year</td>
<td>60 (58-63)</td>
<td>51</td>
<td>57</td>
<td>53</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>28 (26-31)</td>
<td>19</td>
<td>21</td>
<td>22</td>
<td>-</td>
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</table>
What can we learn from other countries - Wendy Johnston

Euthanasia and Assisted Suicide evolution in countries that have legalized these practices  Gamondi et al Lancet, 2014,

Index evolution calculated for incidence per 1,000 deaths in each country
What can we learn from other countries - Wendy Johnston

Common themes in Oregon and the Netherlands (and others)

• Legalization associated with improved access to palliative care, more open discussion about end of life, increase in use of alternate end of life practices (e.g. palliative sedation, withdrawing or forgoing medical interventions or hydration/nutrition)

• PAD favoured by better educated, older (majority >65 y.o.) and white males

• Those opting for PAD do not differ in their access to or use of palliative services

• Low prevalence of depression and religious practices in those completing PAD

• Concerns centre on quality of life, loss of autonomy, loss of participation in meaningful activities, desire for a good death including place and timing of death
Summary of lessons from other countries where PAD is legal:

- Main models of PAD differ
  - Europe, Quebec: in the spectrum of medical care
  - Oregon and other US: social contract, medically provided
  - Eligibility differs (wrt terminal disease, suffering)
- Evidence and reporting differ
- Societal and medical cultures role in interest and delivery of PAD
- Evidence suggests that PAS differs from euthanasia, even where both are offered (NL)
- PAD use remains low (4% of all deaths in NL in 2005, 0.4% OR) but rising in all reporting jurisdictions
- Implementation in NL, OR and Quebec more measured and cultural shifts less profound than we are experiencing in Alberta
Alberta’s preparedness response, and some remaining challenging issues.

Eric Wasylenko MD CCFP MHSc (Bioethics)

Disclosures / Conflicts of interest:

Contractor to AHS, Health Quality Council of Alberta
Appointments at U of C, U of A
No conflicts of Interest to report
3 things the ruling in Carter asked to be in place

1. Access to assisted death for eligible Canadians
2. Harmonization of clinicians’ conscience rights and right of eligible Canadians to access
3. Robust system of safeguards for vulnerable persons
Basics of eligibility criteria

• Competent adult with a grievous and irremediable medical condition who is suffering intolerably and where death is reasonably foreseeable

• Must voluntarily request and provide consent, with 10 clear days between formal request and provision (interval can be shortened)

• Eligible for funded health services delivered by a Canadian jurisdiction
Alberta’s preparedness response, remaining challenges  

Eric Wasylenko

Alberta’s response

• **Process** – Secretariat, Expert panels, patient voices, coordinated response between agencies

• **Content** – clinical Directive, policy waiting for legislation, legal protection for providers

• **Care Coordination Service** – universal pharmacy protocol

• **Federal Legislation** – now in place as of June 17, 2016. Provincial Regulation and AHS Policy are in compliance.
Key motivations of the Federal legislation

- Focus on accommodation of divergent views
- Strong language about protection of vulnerable persons
- Assisted death is not to be a default mechanism to deal with suffering
- Dignity and autonomy respected
- Inherent value of all persons
- Further study on contentious issues
Alberta’s response

• Allows reasonable access and makes consistent the means to explore and receive assisted death, allows non-participation or participation without sanction

• Focuses on the response to requests for information about, and potential access to, assisted death

• 5 phases, including care during the deliberative process

• Adherence to moral commitments honored
Alberta’s response

- Education, training and development of tools to assist clinicians in their roles
- Assure awareness of and access to palliative care, psychiatric care, disease-specific resources
- Monitoring body
Focus on clinical care and safeguards

- Attendance with patient
- Chain of custody of drugs
- Same processes inside and outside of AHS
- Consent and conversion of route, right to withdraw consent
- Reporting and review mechanisms

only ME can sign the Death Certificate
Alberta’s preparedness response, remaining challenges  Eric Wasylenko

Oregon


Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2015

*As of January 27, 2016
Many challenging issues remain (1)

- ‘Reasonable foreseeability of death’ provision
- Transfers and continuity of care/relationships
- Instrumentalization of physicians/NPs
- Debriefing and supportive conversations
- Potential for internal team friction
Many challenging issues remain (2)

- Treating underlying conditions and effect on irremediability
- Suicidality
- What is vulnerability, how do we assess for it
- Confidentiality and bereavement
Areas requiring continued attention

- Rogue practice
- What is not on the table but will be studied further
  - non-adults
  - advance directives
  - mental illness as primary condition motivating the request
How can we respond to a question regarding physician-assisted dying?

Branko Braam

Disclosures / Conflicts of interest:

Trained / practised in The Netherlands.
Currently training for ‘Support and Consultation for Euthanasia in the Netherlands’ (SCEN) physician, Royal Dutch Medical Association.
How can we respond to a question regarding physician-assisted dying? Branko Braam

- How to recognize that a patient is in need to communicate about death?
- How to get the suffering more clear?
  - Suffering is more than symptoms and diagnoses
- What if you are not comfortable with the discussion?
- Is the patient competent, awake and aware?
- Communicate with your peers, with the team, with family
- Consult an independent second physician.
- Palliative sedation, PAD ... or to whither by not eating or drinking?
- That difficult day and time...
How can we respond to a question regarding physician-assisted dying? Branko Braam

‘I do not want this anymore! Can you help?’

‘You have to help me, I need physician assisted death.’

‘This, this is something she never would have wanted to happen to her.’

‘The things that are going to come, I lose my dignity, I do not want to lose it.’

‘I am just done, there is nothing for me to live for anymore, and there is really no future for me.’

‘All this pain, you give me meds, it does not help and I get more and more drowsy, please help me.’

‘I miss her, I miss my life, I can only lay here, people have to help me and I dirt myself every few hours, no more please…’

‘All suffering is existential suffering’ (prof den hartogh, med ethicist)
How can we respond to a question regarding physician-assisted dying?

Branko Braam
Try to get the suffering as clear as possible:

1. Suffering in time
   • Current suffering
     • in the ‘here and now’ (synchronous complaints)
     • in time (diachronous issues)
   • Future suffering
     • what suffering? timeline? treatable condition? acceptable to the patient?

2. Suffering and personality
   • How does the patient experience the situation? What are the worst issues? What is the patient’s fear?

3. Suffering and personality developing over lifetime (biography)
   • (Previous) profession? Religion? Disease experiences?

4. Environment
   • At home? Support?
How can we respond to a question regarding physician-assisted dying? **Branko Braam**

**What if you are not comfortable with the discussion?**

*As a physician: ‘conflict of duties’*

- Providing (curative or palliative) treatment to a disease
- Providing care if untreatable disease leads to unbearable suffering

*As a person: Your own morals and beliefs*

**What to do if the patient brings up questions around the end of life, and your personal morals/beliefs lead to the situation that you can not help your patient?**

- The Royal Dutch Medical Association advises physicians who can not help patients with such a request to let the patient know at a relatively early stage of the disease where they stand.
- Which other physicians are involved in the treatment that know the patient (relatively) well?
- Can you discuss with your immediate colleagues a) the care question of the patient, b) whether somebody would be willing to take over care?
- There will be End-of-Life consultants with specific training to assist.
How can we respond to a question regarding physician-assisted dying? Branko Braam

<table>
<thead>
<tr>
<th>Competence: Competence:</th>
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<tbody>
<tr>
<td>Given the nature of the care request in case of MedAssistD, a formal consult from psychiatry seems advisable in all cases.</td>
</tr>
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<table>
<thead>
<tr>
<th>Awake/aware: Awake/aware:</th>
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<tbody>
<tr>
<td>• GCS 3-6:  Coma Not awake, not aware</td>
</tr>
<tr>
<td>=&gt; no suffering</td>
</tr>
<tr>
<td>• GCS 7-12: Decreased LOC Not awake but (sometimes) partially aware</td>
</tr>
<tr>
<td>=&gt; suffering can not be excluded</td>
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<table>
<thead>
<tr>
<th>Of note: Of note:</th>
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<tbody>
<tr>
<td>- Vegetative state: Awake but not aware</td>
</tr>
<tr>
<td>- Minimally conscious state: Somewhat awake, somewhat aware</td>
</tr>
<tr>
<td>- Locked in syndrome Aware, awake</td>
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Excluded from guidelines about MedAssistD in NL...

Derived from Royal Dutch Medical Association
How can we respond to a question regarding physician-assisted dying? Branko Braam

Communicate with your peers, with the team, with family

Peers

Disease related aspects:
- symptom burden
- prognosis
- similar cases
- alternatives to approach the suffering of the patient

Family

Person-related aspects:
- How has the patient talked about death with the family.
- How does the question relate to the person’s context?

Team

Care related aspects:
- Nurses
- Social work
- PT/OT
- Pharmacist
- Spiritual worker

Patient’s care question

Environment:
- How much social/mental support has the patient?

Healthcare organization

Law/guidelines:
- Guidelines
- Legal
- Ethical
Other End-of-life trajectories

1. The patient may **die without interventions**
2. The patient can **refuse a lifesaving treatment**
3. The treatment team can **stop a treatment** if the treatment is considered futile.
4. **Palliative sedation** could be part of a palliation trajectory.
5. The patient can **decide to stop eating and drinking**.
### How can we respond to a question regarding physician-assisted dying?

Branko Braam

<table>
<thead>
<tr>
<th></th>
<th>Palliative Sedation</th>
<th>MedAssistD</th>
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<tbody>
<tr>
<td><strong>Goal</strong></td>
<td>Diminish suffering</td>
<td>End suffering</td>
</tr>
<tr>
<td><strong>How</strong></td>
<td>Decrease LOC</td>
<td>End life</td>
</tr>
<tr>
<td><strong>Medical treatment</strong></td>
<td>Within normal medical care</td>
<td>Outside of regular medical care</td>
</tr>
<tr>
<td><strong>Indication</strong></td>
<td>Symptom burden that can not be relieved with any alternatives</td>
<td>Unbearable suffering</td>
</tr>
<tr>
<td><strong>Phase of disease</strong></td>
<td>Last phase of life</td>
<td>Not necessarily last phase of life</td>
</tr>
<tr>
<td><strong>Patient consent</strong></td>
<td>If possible</td>
<td>Obligatory</td>
</tr>
<tr>
<td><strong>Consultation necessary</strong></td>
<td>Only if insufficient expertise</td>
<td>Obligatory</td>
</tr>
<tr>
<td><strong>Medication</strong></td>
<td>Sedatives</td>
<td>Hypnotics and muscle relaxants</td>
</tr>
<tr>
<td><strong>Dosage</strong></td>
<td>Titrate to mitigate complaints</td>
<td>Overdose</td>
</tr>
<tr>
<td><strong>Reversible</strong></td>
<td>Yes (up to a certain point)</td>
<td>No</td>
</tr>
<tr>
<td><strong>Shortens life</strong></td>
<td>Not necessarily</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Natural death</strong></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Legal</strong></td>
<td>Like regular medical treatment</td>
<td>Separate law</td>
</tr>
<tr>
<td><strong>Reporting / evaluation</strong></td>
<td>No</td>
<td>Obligatory</td>
</tr>
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Source: Royal Dutch Medical Association, Guideline Palliative Sedation
That difficult time and day

The night before ‘the day’ I could not get to sleep, my mind went back and forth between all the words and feelings I had exchanged with my patient, his deep wish, my profession, my role as a helper, my role as a ‘savior’, the oath. For all those years that night has stayed with as much of the day to follow, it was a night of reconciliation, for myself, for my patient. It felt so right, but also so difficult.

That morning, all went smooth, it was surrealistic: my patient thanked me, the nurses and my staff for all the support, said bye to his wife and children, we all hugged. The infusion was started, my dear patient smiled, fell asleep and stopped breathing shortly after. It was sad yet beautiful: we had not been able to cure him, we had been able to assist him in his wish.
How can we respond to a question regarding physician-assisted dying? Branko Braam

That difficult time and day

Aftercare...

- The patient’s family.
- Your team
- Yourself
Key resources - national

• Federal government’s backgrounders describing the reasonings behind components of their legislation:

http://www.justice.gc.ca/eng/rp-pr/other-autre/ad-am/ad-am.pdf

• Vulnerable Persons Standard

www.vps-npv.ca/

• Bill C14

Key resources - provincial

• AHS:  [www.ahs.ca/MAID](http://www.ahs.ca/MAID)
  - For Public: “How Do I Access”; Public FAQ
  - For Physicians/other providers: Process Map; Physician FAQ;
  - Links to other Resources including Palliative Care, Clinical Ethics and links to government and Regulatory College sites

• Email Active
  - [PAD.secretariat@ahs.ca; MAID.secretariat@ahs.ca](mailto:PAD.secretariat@ahs.ca; MAID.secretariat@ahs.ca)
  - Also connects you to Care Coordination Service
  - Alberta HealthLink (811) will also connect providers and patients to the Care Coordination Service
Key resources - provincial

- CPSA:
  

- AMA:
  
  https://www.albertadoctors.org/leaders-partners/leaders/rf/maid-2016