Joint Centre for Bioethics
UNIVERSITY OF TORONTO

Ontario Shores
Centre for Mental Health Sciences

Medical Assistance in Dying: the Mental Health Context

CFMHN Conference Workshop
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Kelly Delaney
Rosanna Macri
Kevin Reel

Disclosure statement

- None to report.

Mark & Graeme Quotes

‘There is no situation in which depression – or any mental health problem – needs to be terminal, irremediable, or even nearly as disabling as it can be...There is no evidence that any mental health problem is irremediable in the same way as some physical ailments’ (Henick 2016)

‘It’s 2016, and in Canada, the suicidally depressed still don’t have the right to die. They still don’t have the right to end their suffering with dignity; they still don’t have the right to spare the people they love the shock of losing them, of knowing that they died alone in terrible pain’ (Bayliss 2016)

Workshop Plan

- Introductions
- Some initial thoughts
- Legal review and update
- Key arguments
- MAiD stats and clients
- Clients perspectives to ponder
- Some thinking about what's next and how

Workshop Learning Objectives:

- Participants will review the evolving legal, ethical and moral context of assisted dying as it relates to mental health.
- Participants will have an opportunity to hear and discuss a range of perspectives on the topic of assisted dying, including:
  - faith-based perspectives
  - service user/consumer/survivor voices, and
  - colleagues currently involved in responding to requests for MAiD

Introductions & Initial Thoughts

- Who are we all?
- Any initials thoughts on the subject?
- What has been your experience with MAiD?
- What were you hoping to discuss/explore?

We ‘see’ things differently

That infamous dress that was white and gold or black and blue….depending on what your eye saw.

Our “hardwiring” may be at play…

More to the point…

- We can be inclined to see complex issues in very personal ways
  - Think about meat versus vegetarian diets
    - Draw the line at veal, or not?
  - Do you choose free run or free range eggs…or is there no problem with battery farmed caged hen's eggs in your mind?

And on a societal level…

We must reconcile

- **differing personal moral views**

with a

- **societal legal/ethical framework**
  - **Think about ongoing differences of opinion on matters like same sex marriage, marijuana use and abortion.**
  - **We've arrived at (or will soon) legal frameworks that include these things, despite difference of opinion**

MAiD – A strange change

- For some, this change in the law is long overdue
- For others, it is a first terrible step toward more terrible things
  - How do we navigate the many feelings about this?
  - How do we support clients who ponder these options?
  - How do we preserve relationships if we have very different opinions?

CNA Code of Ethics & National Nursing Framework on MAiD

The 7 primary values are:

1. Provide safe, compassionate, competent and ethical care
2. Promote health and well-being
3. Promote and respect informed decision-making
4. Honour dignity
5. Maintain privacy and confidentiality
6. Promote justice
7. Be accountable

Do we know why we feel the way we do?

	Primary Value Theme	Values Statements
1.	**Respect for Limits of Human Authority**	A human being does not have the authority to take another human being's life, no matter what the circumstances.
2.	**Respect for the Divine**	The decision to end life sits with a higher being/power (God, Allah, the Creator, etc.) and so humans should not interfere with this greater plan.
3.	**Sanctity of Life**	Life is sacred; therefore, we should never actively end another
4.	**Minimizing Suffering**	
5.	**Respecting Patient Wishe (Autonomy)**	
6.	**Promoting Fairness/Justice**	supportive relationships can currently seek medical assistance in dying internationally, whereas those without these resources cannot.
7.	**Preserving Dignity**	People who are suffering from incurable or terminal conditions may wish to avoid living in states that they perceive to lack dignity or want to be remembered in particular ways (e.g. independent, vibrant) and so should have control over the timing of their death.
8.	**Prolonging Life**	Without access to medical assistance in dying, patients who have degenerative conditions may act to end their lives sooner than they might otherwise choose while they still have the physical capacity to do so.

	Primary Value Theme	Values Statements
9.	**Care over the entire span of life, including death**	Medical professionals are obliged to develop skills and deliver care over the complete span of life, including death. The care, attention, and energy that so often goes in to prolonging life should be matched by efforts toward ensuring that patients receive expert and compassionate care at the end of their lives
10.	**Commitment to Life-Saving Approaches**	The availability of medical assistance in dying could lead to a devaluing of life within medicine which could result in a more cavalier attitude among physicians about hastening death, putting others at risk.
11.	**Protection of the Vulnerable**	The availability of medical assistance in dying could lead to greater pressure on vulnerable others (sick, elderly, disabled) to
	Being	assisted death.
15.	**Accountability and Organizational Support**	It is important for me that I understand the process. I need to know more about how MAID will be provided, and specifically what my role would be and how I would be supported by the organization in discharging this role before I get more involved.
16 a.	**Preserving Harmonious Relationships**	It is important for me to retain a positive image and have harmony with others. I do not want to be stigmatized or challenged by colleagues or friends/family/neighbours/members of my faith community, which may occur if I become involved in medical assistance in dying.
16 b.	**Preserving Harmonious Relationships**	It is important for me to retain a positive image and have harmony with others. I do not want to be stigmatized or challenged by colleagues or friends/family/neighbours/members of my faith community, which may occur if I do not become involved in medical assistance in dying.

- **Choose the top 3 values that resonate with you personally.**
- **Share those with your group and explore where you have the most overlap**
- **If comfortable, in an open and non-judgmental manner discuss the values that are different**

Corresponding Perspectives: The Shades of Grey

- **Perspective 1:** Ethically object to MAiD in principle (i.e. due to principled concerns)
- **Perspective 2:** Ethically object to MAiD on conditional grounds (i.e. concerns about consequences)
- **Perspective 3:** Not assisting with MAiD based on inadequate information, practical or personal concerns
- **Perspective 4:** Not ethically in support of the procedure, but able to assist with MAiD in a limited fashion
- **Perspective 5:** Ethically in support of the procedure, but only able to assist with MAiD in a limited fashion
- **Perspective 6:** Ethically accepting of MAiD and willing to be involved as much as is needed

MAiD: the Legal Controversy

- For some, this change in the law is long overdue
- For others, it is a first terrible step toward more terrible things
  - How do we navigate the many feelings about this?
  - How do we support clients who ponder these options?
  - How do we preserve relationships if we have very different opinions?

Where are we at in Canada?

Suicide was decriminalized long ago

- it's not a crime to end your own life, or to try

Assisting someone to end their life has been only partially decriminalized

- this is what we now call medical assistance in dying or MAiD

MAiD *in Canada* is:

a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or

b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.

‘Carter carve out’ of Criminal Code

- ‘Counselling or aiding suicide’ ***remains*** a criminal offence…and for good reasons
- The MAiD provisions create a lawful assisted dying option that is exempt from any wrongdoing
- Must meet all criteria and follow all safeguards

MAiD Eligibility Criteria

A person may receive medical assistance in dying only if they meet all of the following criteria:

a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;

b) they are at least **18 years of age** and **capable** of making decisions with respect to their health;

c) they have a **grievous and irremediable medical condition**;

d) they have made a **voluntary request** for medical assistance in dying that, in particular, was not made as a result of external pressure; and

e) they give **informed consent** to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

Grievous & Irremediable

A person has a *grievous and irremediable medical condition* only if they meet all of the following criteria:

a) they have a **serious and incurable illness, disease or disability**;

b) they are in an **advanced state of irreversible decline in capability**;

c) that illness, disease or disability or that state of decline causes them **enduring physical or psychological suffering** that is **intolerable** to them and that **cannot be relieved** under conditions that **they consider acceptable**; and

d) their **natural death has become reasonably foreseeable**, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

‘Carter carve out’ of Criminal Code

Current review of the law will look at:

- Under 18 – mature minors
- Advance requests – anticipating incapacity
- Mental health – sole underlying medical condition
  - *But other non-terminal illnesses are not being reviewed for eligibility*

Current Possibilities

- Clients with mental health conditions can be eligible for MAiD where other physical conditions mean they meet the eligibility criteria
- Such clients need not be terminally ill, but their overall health may mean their 'natural death has become reasonably foreseeable'
- The mental health related suffering may be the trigger for the request, even though another condition confers eligibility

Safeguards

- Written, signed* and witnessed (x2) formal request
  - Standard forms available, but not mandatory
- Two independent assessments of eligibility
- 10 days ‘reflection’ between request and provision of MAiD
  - Can be shortened in certain circumstances
- Capable and consenting up until the moment of administration of the medications
- Change of mind always possible

* Proxy signer where necessary

Other Expectations, Exemptions and Clarifications

- Reasonable knowledge, care and skill
- Informing pharmacist (others, too, one would expect)
- Clarifications
  - No individual compelled to provide
  - No offence if providing information to a person on the lawful provision of medical assistance in dying
  - No offence in providing MAiD or aiding the provision of MAiD including assisting with self-administration
    - even where “reasonable belief” is mistaken

Key Arguments/Assumptions

1) People living with mental illness do not have the capacity to consent to MAiD
2) People with mental illness are vulnerable and in need of protection
3) All physicians, particularly psychiatrists, have an ethical obligation to “do no harm” and to prevent suicide at all cost, and are not socialized to the act of intentionally hastening death
4) There are no mental illnesses that can be determined to be irremediable
5) The recovery philosophy of care in mental health is not compatible with the provision of MAiD services.

Can capacity be assessed?

- The CPA acknowledged there are no specific guidelines for the assessment of capacity in the context of assisted dying
  - Are they needed?
- The CPA asked for a year to work on them
  - Does this seem reasonable?
- Is this also part of countering stigma associated with mental health?

It is possible... for an individual to be deeply depressed...and also capable of making treatment decisions.

That an individual suffers from a mental illness does not automatically mean he or she cannot "clearly consent to the termination of life", as required in the Carter *decision.*

Walker-Renshaw & Finley 2015

“Vulnerable Persons Standard”

Canadians living with severe disabilities, mental illness and dementia, as well as seniors living in long term care may be more vulnerable to stigma, abuse, coercion, isolation and depression.

Consequently, they may be more inclined to suicidal ideation, intent and behaviour.

The psycho-social needs of vulnerable Canadians can be met by providing appropriate care and support, significantly reducing mental anguish as well as a person’s motivation to request physician-assisted death

Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups

Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D Onwuteaka-Philipsen

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See end of article for authors' affiliations

Correspondence to: Margaret P Battin, Department of Philosophy, 260 South Central Campus Drive, Rm 341, University of Utah, Salt Lake City, UT 84112, USA; battin@utah.edu

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Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a "slippery slope", predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period.

Methods: The data from Oregon (where PAS, now called death under the Oregon Death with Dignity Act, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought.

Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

Who is Vulnerable to Whom?

To be a competent decision-maker one does not have to dispel all doubts or be free of external influences.

Such a condition is likely unattainable...

(T)he current debate over assisted dying blurs two very different ways that people can be vulnerable.

In one case, they are vulnerable to an untimely death brought on by an unsound decision.

Here protection is appropriate.

In the other, they are vulnerable to a life of irremediable suffering.

Having the choice to escape from it can be enormously liberating, not only for those who choose this path, but also for those who don't.

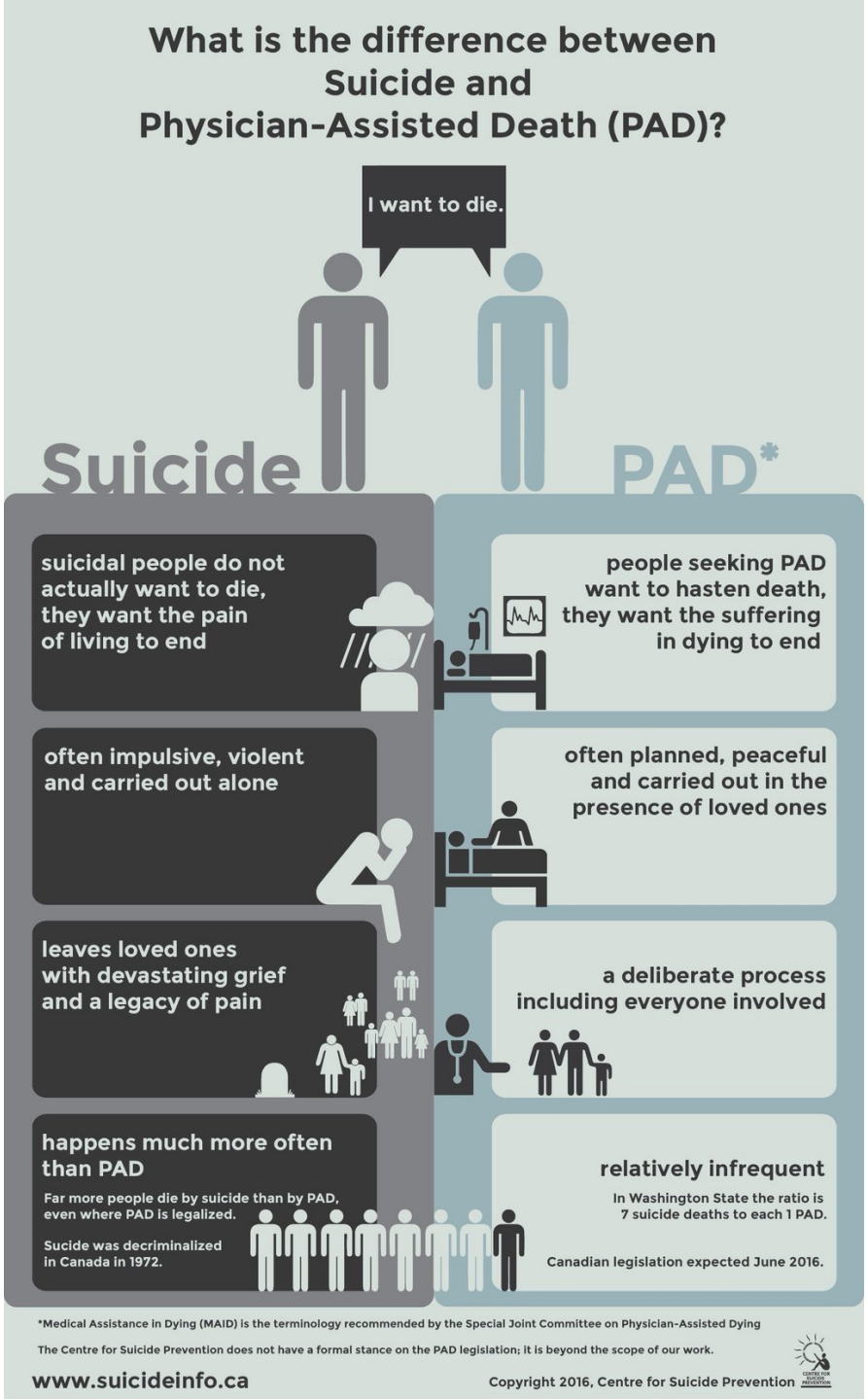
Don Lenihan, National Newswatch, May 9 2016

Conflicting Duties?

If physician-assisted death becomes an accepted practice in mental health care, how will that be reconciled with the well-established impetus in mental health care to prevent suicide?

Under Ontario's Mental Health Act, a physician performing a psychiatric assessment "shall admit" the person to a psychiatric facility on an involuntary basis if the person meets certain criteria, including risk of serious bodily harm to the person, often demonstrated by suicidal ideation or intent.

Walker-Renshaw & Finley 2015


What is the difference between Suicide and Physician-Assisted Death (PAD)?
I want to die.
Suicide
PAD*
suicidal people do not actually want to die, they want the pain of living to end
people seeking PAD want to hasten death, they want the suffering in dying to end
often impulsive, violent and carried out alone
often planned, peaceful and carried out in the presence of loved ones
leaves loved ones with devastating grief and a legacy of pain
a deliberate process including everyone involved
happens much more often than PAD
Far more people die by suicide than by PAD, even where PAD is legalized.
Sucide was decriminalized in Canada in 1972.
relatively infrequent
In Washington State the ratio is 7 suicide deaths to each 1 PAD.
Canadian legislation expected June 2016.
*Medical Assistance in Dying (MAID) is the terminology recommended by the Special Joint Committee on Physician-Assisted Dying
The Centre for Suicide Prevention does not have a formal stance on the PAD legislation; it is beyond the scope of our work.
www.suicideinfo.ca
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“Suicide”?

In the mental health care context, will health care providers need to rise to the challenge of distinguishing between suicidal ideation and intent that is ***a symptom of pathology****, of a treatable mental illness, on the one hand and suicidal ideation and intent that is, perhaps,* ***a capable and thoughtful response*** *to a “grievous and irremediable” condition, on the other?*

Walker-Renshaw & Finley 2015

And t**he language of assisted dying**

- Suicide
  - "conventional" vs. "rational"

- Euthanasia
- "Medical Assistance in Dying"

'Irremediable' in the Mental Health Context

- The Canadian Psychiatric Association, 2015
  - If "irremediable" is considered to mean incurable, this could apply to many psychiatric diagnoses. In the context of mental illness, this definition should not be used as this would set the threshold for identifying a condition as irremediable too low
  - If "irremediable" is considered untreatable, then very few situations in psychiatry would apply
- CMHA National, 2017
  - "serious and incurable illness", excludes most mental illnesses based on the availability of treatment and recovery-based philosophies

'Irremediable' Continued

- the term “grievous and irremediable medical condition” is not defined, and if given a dictionary definition, it could include conditions that are not life-threatening or terminal; and the declaration is framed largely in terms of subjective criteria (i.e., suffering that is intolerable to that person)
- there is no established standard of care that sets a threshold for when a mental illness should be considered irremediable (Gaind, 2016)

= unclear definition of irremediable

Principles: Recovery vs. MAiD

- Recovery is a central principle in much mental health service provision
- Recovery may seem at odds with MAiD
- The principles underpinning recovery may also be relevant when seeking MAiD – some or all

Definition of Recovery?

- Recovery is a varying concept
  - In turn referred to as model, paradigm, movement, orientation, approach, process, tools and outcomes among others

From *Out of the Shadows at Last*

*"Recovery is not the same thing as being cured. For **many** individuals,* it is a way of living a satisfying, hopeful, and productive life even with limitations caused by the illness; for **others**, recovery means the reduction or complete remission of symptoms related to mental illness."

From *Out of the Shadows at Last*

"The Committee is aware that **not everyone** living with a mental illness will be able to recover, but...it believes recovery to be the **primary** goal around which the mental health delivery system should be organized."

MAiD Principles

Principle	Associated Goal
Accountability	Implement PAD in a manner that clearly identifies lines of authority, an oversight mechanism and associated responsibilities for all relevant stakeholders, including boards of directors, patients, their families, HCPs, professional colleges and associations, and policy makers such that pubic trust in the process is preserved and enhanced.
Collaboration	-Build, preserve and strengthen inter-professional, inter-institutional, ***inter-sectoral,*** and where appropriate, inter-provincial/territorial collaborations and partnerships to facilitate consistent implementation of PAD. -Partner to collectively establish evidence-based best practices.
Dignity	Recognize and preserve the inherent worth of each person and their individual experience of pain and suffering and associated decisions across the life continuum.
Equity	-Promote fair and just access to PAD for all eligible individuals irrespective of healthcare setting or geographic area. -Support procedural fairness such that like PAD cases are treated in a similar manner and dissimilar PAD cases are treated in a manner that takes into account the differences.
Respect	Demonstrate the highest regard for persons, organizations and their associated beliefs and values related to PAD and the myriad of concepts, issues and practices associated with it.
Transparency	Foster and maintain public, patient, and healthcare provider trust and confidence in health system

There's more to recovery-oriented care than 'hope'

1. Promoting Citizenship
2. Organizational Commitment
3. Working Relationship
4. Personally Defined Recovery
   A) connectedness
   B) hope and optimism about the future
   C) identity
   D) meaning in life
   E) empowerment

Who is obtaining an assisted death?

- **2149*** across Canada (as at June 30th)
- Almost exclusively administered by a Nurse Practitioner or Physician.
  - Self-administration almost unknown.
- Roughly 50/50 split by women/men
- An increasing majority occurred *outside* hospitals
- Large urban centres > rural settings
- Mainly cancer related, also neurodegenerative, cardio-respiratory and 'other'

Office of the Ontario Chief Coroner: Present Day Stats (As of Aug 31/17)

Total number of cases completed in Ontario: 781

Type:

Clinician-administered:	780
Patient-administered:	1 *

Who is opting for an assisted death?

- Gender:
  - Female: 390
  - Male: 391

- Age:
  - Average Age: 73
  - Range: 22-101

Who is opting for an assisted death?

Cancer-Related:	516	*66%*
Neurodegenerative:	106	*14%*
CV/Resp:	97	*12%*
Other:	62	*8%*

Who is providing assisted death?

- <u>Number of Unique MAiD Providers:</u>
  - Clinicians: 221
    - Physicians: 213
    - Nurse Practitioners: 8*
  - Hospitals: 79

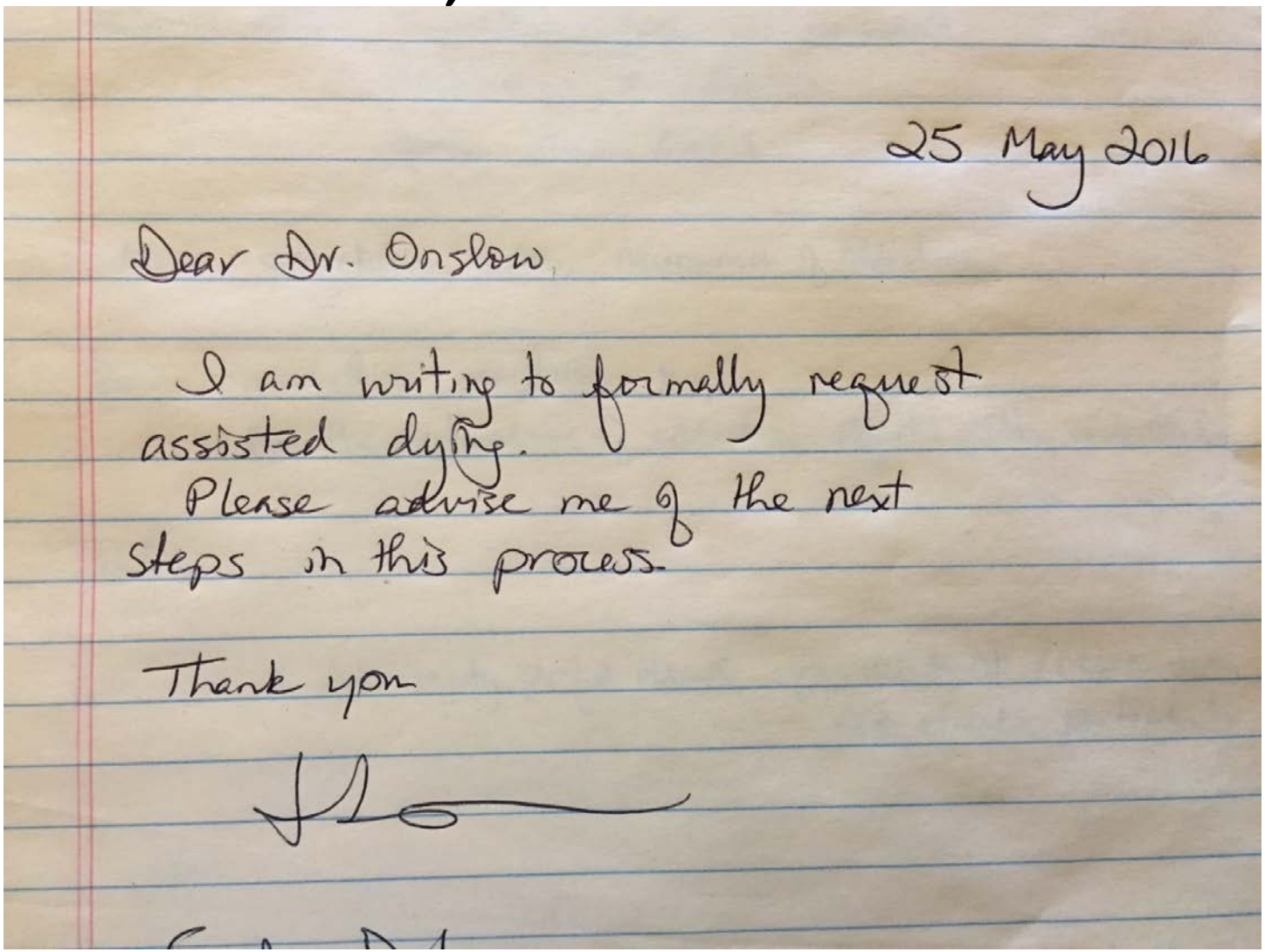
Where is assisted death happening?

Hospital:	411	*53%*
Private Residence:	304	*39%*
LTCH/Nursing Home:	41	*5%*
Senior Res/RH:	25	*3%*

Some other likely client stories

- Client refusing chemo for a cancer diagnosis
- Huntington's patient with a history of depression.
- Client refusing dialysis.
- Client has struggled with addiction for decades. Many repeated admissions to multiple treatment programs. Asks for assisted dying rather than continue on this ‘see saw’.

Meanwhile, back at the office...



Thinking about what next and how

What do you need to be able to help prepare within your role, your organization?

- Policies & processes
- Information – staff, clinicians, clients, families
- Tools – decision making supports, assessment & documentation guidelines
- Educational approaches, reflective exercises
- Support/consultation approaches amongst peers

Service user/consumer/survivor views

The Empowerment Council (a consumer/survivor/service user advocacy group based at the Centre for Addiction and Mental Health) held an event earlier this year to begin hearing the voices of those who live with mental illness.

You can check out the Empowerment Council event through the recording available here:

- https://www.youtube.com/watch?v=rsNQomwa8WE

More Questions...

- What did you think of the assertion that *'there is no situation where depression needs to be as disabling as it is*'?
- What do you feel about the claim that '*the suicidally depressed still don't have the right to die*'?
- If it is acknowledged that some individuals might be experiencing intolerable suffering because of a grievous and irremediable mental illness or substance use, then what reasonable safeguards must be in place to ensure an assisted death would be the 'last, best judgement' by all involved in decision making?
- Do we need guidelines for capacity assessment for MAiD?

Questions, Comments, Concerns

There is no escape. Moral risk cannot, at times, be avoided. All we can ask for is that none of the relevant factors be ignored.

Isaiah Berlin

The true enemy of man is generalization.

Czesław Miłosz

delaneyk@ontarioshores.ca
macrir@ontarioshores.ca
kevin.reel@utoronto.ca

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