

Permit me to introduce myself. My name is Donna Farmer. Below are some excerpts from my Resume. For those who require a summary of my Memoire you may consult the Conclusion found on page 37.

PRIVATE SENIOR HOMES

2011- 2016 COORDINATOR ACTIVITIES, SYMPHONY, West Island, Quebec
2009 -2012 DIRECTOR OF ACTIVITIES, MANOIR OUTREMONT, Outremont, Quebec.
2007- 2009 DIRECTOR OF ACTIVITIES, RÉSIDENCE LE MONACO, St-Laurent, Quebec

FULLTIME CAREGIVER

1993-2006 FULLTIME CAREGIVER, St-Laurent, Quebec

VOLUNTEER AND COMMUNITY GROUPS

2008- 2009 REGROUPEMENT PROVINCIAL COMITÉS USAGERS (RPCU), Montreal, Quebec.
2006- 2009 JEWISH GENERAL HOSPITAL, USERS COMMITTEE, Montreal, Quebec .
2002- 2009 RÉSEAU MONTRÉALAIS POUR LES AVC(RMAVC), Montreal, Quebec
 « Projet de développement d'un continuum de services pour les personnes victimes
 d'un accident vasculaire cérébral ou à risque de le devenir »
2002- 2005 AQPA
1998- 2010 RAANM, Montreal, Quebec
2005- 2010 ECCOM, Montreal, Quebec

PRESENTED BRIEFS RE:AUDIENCES PUBLIQUES, CONSULTATIONS

- General Consultation National Assembly of Quebec: 'Guaranteeing Access Meeting the challenges of equity, efficiency and quality', 06-06-06- 2006.
- Public Consultation on Seniors' Living Conditions: A Social Issue that is the responsibility of all Quebecers, (without brief –consultation populaire)02-10-07
- Regional consultation Agence de développement de réseaux locaux de services de santé et de services sociaux, 'Building Local and Social Services Networks in Montreal', 03-2004
- Regional consultation Agence de développement de réseaux locaux de services de santé et de services sociaux, 'Planification Stratégique 2003-06 La Santé en Action'. Forum régional de Montréal in lieu of public audience, 12-10-04.
- General Consultation National Assembly of Quebec : 'Bill 112, An Act to Combat Poverty and Social Exclusion', 17-10-02.
- Regional Consultation Régie Régionale de la Santé et des Services Sociaux de Montréal Centre, 'Financing and organization of Health and Social Services' 26-09-2000.

PUBLISHED ARTICLES

- 'A caregiver testimony' June 2007, Volume 13, Number 2, Vital Aging, Bulletin published by the Centre de Recherche et d'Expertise de Gériatrie Sociale of the CSSS Cavendish – Centre Affilié Universitaire
- 'The Effectiveness of Case Management: A client's point of View', May 2002, Volume 8, Number 2, Vital Aging, Bulletin published by the CLSC René Cassin/Institute of Social Gerontology of Quebec and the Foundation for Vital Aging.

➤ ‘Dangers of Being Aphasic and Being in the Hospital’ Winter, 2004, Volume 6, number 2, L’Abri, publication Officielle de l’Association Québécoise des Personnes Aphasiques.

➤ **PUBLIC SPEAKING ENGAGEMENTS**

➤ Presentation of National Film Board vignette of Les Chuchotements de l’Âme followed by panel discussion for FICCDAT The Festival of International Conferences on Caregiving, Disability, Aging and Technology, Toronto, June 16-19, 2007

➤ Presentation and témoignage of Les Chuchotements de l’Âme at CLSC René Cassin, Pierrefonds

➤ Les Chuchotements de l’Âme, National Film Board and Théâtre Gesù, play created & produced by caregivers, 25-02-07

➤ ‘The Caregiving Experience: Navigating New Water’, Heart and Stroke Health Day, The Divisions of Cardiology and Neurology, Jewish General Hospital, June 4, 2003.

➤ ‘Helping Caregivers Hire Private Help’, A Panel Discussion for Family Caregivers and Professionals, Caregiver Support Centre, CLSC René Cassin, May 1, 2003.

➤ ‘Increasing the Quality of Life for Stroke Survivors and their Caregivers’, Professional Development Workshop. Address. McGill University Health Centre Stroke Network November 15, 2002.

➤ Moderated the conference of stress ‘Need to relax Are you a caregiver?’ Nov. 2, 2005, Advisory Committee to the Caregiver Support Centre of CLSC René Cassin.

MEDIA.

➤ Vita (titre provisoire) version québécoise du magazine canadien More, -Suzanne Décarie, novembroujanvier 2008-9, S’occuper d’un parent ;âgé : comment s’en tirer quand on travaille.

➤ St-Laurent News, Aug. 10, 2008, Bon pied, bonne santé, Pascal LeBlanc

➤ The Suburban, Oct. 31, 2007, ‘Taking Care of your own’, Irene Chwalkowski

➤ National Film Board filming of RAANM’s creation and production of Les Chuchotements de l’Ame, Théâtre Jésus,

➤ CTV Pulse (interview) Aug. 30 2005.

➤ CJAD Tommy Schurmacher, Nov. 2 2005 panel,

➤ RDI – Le Point (interview) Céline Galipeau 2004,

➤ CTV Pulse (interview) Ann Lewis, November 29, 2001,

➤ Radio Edmonton, 2001,

➤ Gazette, Jan. 7 2004, ‘Paid Leave to Lighten Caregiving Burden’, Cheryl Cormacchia,

➤ Gazette, Oct. 27 2003 ‘Giving Back to Our Parents’, Susan Schwartz,

➤ Gazette, Nov. 15, 1999, ‘Tiny Turnout Feared for Poll, Jeff Heinrich,

➤ St-Laurent News May 29, 2005, ‘Ca Bouge en Santé’,

➤ St-Laurent News, Dec 8 2002 ‘S’exprimer à travers les toiles’,

➤ St-Laurent News, Nov. 7, 14 1999, Vol 48 no. 45 & 46 Re elections

I knew Who I was This morning But I've Changed a Few Times Since Then.



MEMOIRE

There is no more important decision that one will ever make.
To decide to end one's own life, or that of another!

If it is an incorrect decision it is irrevocable!

INTRODUCTION

This particular debate on end of life care focuses more narrowly upon that substrata of the vulnerable who are mentally ill and incompetent. It forms part of a continuing spectrum of discussion where systemic thinking is required to address the more fundamental question:

How do we as a society aim to care for our most vulnerable citizens: how do we aim to treat their diseases; to relieve their suffering, to provide compassionate end of life care and how to provide quality long term care?

Since the law's inception in 2014, questions have been continuously evolving. The many amendments attest to this dynamic search. All who are participating in this consultation, seek

- to define what is ethical, humane, and merciful
- to establish systems that manage and uphold the principles as defined
- to reconcile the impact these decisions will have upon resource availability and determine priorities systemically

These are monumental and difficult decisions. We are just learning to appreciate their implications and we must remain vigilant.

I am presently witnessing some weaknesses in the so called 'safeguards' of a MAID request unfolding at this moment in time in another province. These ongoing experiences have prompted me to write this memoire.

I am living through some of the very same issues we will be debating and soon codifying into law. These experiences form the focus of my reflection and constitute the main thrust of my memoire. They will deal predominantly with the situation of 'Lucie' and the neurodegenerative Alzheimer's disease which presents one distinct set of challenges of the many this Commission will seek to address. I will briefly address a few other concerns not related specifically to the case of 'Lucie'.

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I

THE CASE OF 'LUCIE' AND THE NEURODEGENERATIVE ALZHEIMER'S DISEASE - INCLUDING REFLECTIONS BASED UPON OBSERVATIONS OF A VERY REAL MAID CASE UNFOLDING IN ANOTHER PROVINCE

TIMELINE OF PATIENT FROM PRE-DIAGNOSIS OF ALZHEIMER'S DISEASE TO EXECUTION OF MAID REQUEST

- PRE-DIAGNOSIS CIRCLE OF CARE HEALTHCARE PROFESSIONALS
- DELIVERY OF THE DIAGNOSIS OF ALZHEIMER'S DISEASE
- REQUEST FOR MAID
- ASSESSMENT PROCESS
- SAFEGUARD PROCESS
- EXECUTION OF MAID REQUEST

■ **ASSESSMENT PROCESS and issues**

I will begin with the Assessment process and loop back later to pre-diagnosis and diagnosis delivery in the timeline. I want to demonstrate how the actions of the health professionals in the circle of care at pre-diagnosis and at diagnosis can affect suicide ideation and impact everything on the timeline. Particularly for the vulnerable patient, the circle of care health professionals should manage a continuum of care with an integrated approach based on best practices including prevention. I feel that for the most part at the current time, our healthcare system does not perform at best practice level nor offer integrated care and its likelihood in the near future looks dismal.

IN GENERAL - PREAMBLE

Patients situations are always more complex that any attempts to classify them.

The prudent thorough investigative analysis that will be required to assess these requests, on a case by case basis, in such a current fragile resource stretched healthcare system as our own, I fear will leave the vulnerable not adequately protected.

The complexities may generate too significant a monopolization of resources to properly address them. (one case file from annual report of euthanasia in the Netherlands generated...20 GP discussions, 3 Psychiatric sessions, another psychiatrist assessment for expertise-p53)

Quebec has never seen hospitals as understaffed as now. 1 hospital in three has a budget deficit and CHSLDs are still understaffed. At least one hospital is closed and across Quebec many emergency rooms are farther above capacity than ever before. Nursing shortages have never been so profound and relying on private sourcing has just cost us another 500M\$ to the annual 500M\$ we spend each year. Job vacancies in healthcare have risen by nearly 40% since last year. This will impact the system and reverberate through it on many levels. July 30 Dr. Tam warned us that once again healthcare capacity could be exceeded due to the Delta variant if not enough Canadians are vaccinated. Even pre COVID status quo resource level is far from realistic to ethically realize and manage the proposed assessment procedures and the added safeguards required for protecting our most vulnerable clientele for MAID requests. 400,000 Quebec citizens await assignment to a family doctor. The federal parliamentary budget officer says an additional 13.7 billion will be required just to help remedy long term care. The annual funding for an aging population and inflationary pressures on wages will rise by more than 4% per year. Our healthcare system in Canada is ranked second to last among 11 high income countries. The Netherlands came in 2nd. If you only compare universal healthcare countries 2020, Canada has some of the lowest numbers and longest wait times. (Fraser Institute) 24th of 28 for no of Psychiatric beds, 25th for acute beds, 26th for no. physicians, 14th for in patient suicide among patients diagnosed with mental disorders.

.....

Why is mental illness alone necessarily a separate case from mental illnesses and another disease? Alzheimer is a neurogenerative disease. What if there is mental illness and Alzheimer? What if there is iatrogenic induced depression accompanying the diagnosis of Alzheimer or any other grievous and incurable disease diagnosis? **Depression is classified in both ICD-11 and DSM-5 as a**

mental illness. When there are comorbidities there is an obligation of the assessor to consult someone else with 'expertise' under Canadian MAID law.

Each scenario certainly has unique considerations and generates a distinct set of challenges. Severe unrelievable psychological suffering is a criteria for many of the MAID requests and particularly those clientele this Commission addresses.

Some of these differences in classifications relate to issues of competency or waning competency but I believe capacity can be compromised no matter the type of incurable disease diagnosis. Perhaps other classification issues relate to defining 'advanced' or in the case of mental illness, 'decline' may be the problematic concept. Is it a process or a state? Either way, currently it defines part of one criteria.

Across the country the classifications are different. Was Yves Monette's case different from Alzheimer's? It too was a neurodegenerative disease. Canada classifies them the same and not per se as a mental illness. You are treating Alzheimer's disease in the context of this Commission alongside mental illnesses.

Across countries more differences are found. European countries differ from Canada in the extent to which they **allow for psychological suffering to be self-assessed.** (Health Law Institute, Dalhousie University). They seem to require more visits and a greater frequency of assessments by all involved than Canadian standards do. Quebec is a step ahead of Canada I believe in that it requires Doctors to perform all assessments.

2017 statistics showed 4.6% of all deaths are MAID deaths in Benelux countries who base requests on suffering rather than proximity to death; 2% of all deaths in Canada, .3% in US however in the US only the terminally ill have access to euthanasia and the US permits only self administered MAID.

In Canada this year, 2021, we have seen an increase in MAID requests already compared to last year per a Right to Life report. 2019 stats from the First Cdn Annual MAID 2019 report points to increases as well. 3.3% of all deaths in

Canada are MAID deaths. One has to ask whether the new MAID law, COVID, the state of longterm care, the unavailability of supports are contributing to the rise, or is it the aging of the population? However it is not in the oldest age groups where the requests for MAID are the greatest.

Psychiatrists have been consulted in MAID cases only 6.2% of the time and yet severe psychological depression may impact on competency and capacity for certain health care decisions as per several abstracts written by various psychiatrists. **The assessment of depression and capacity and competency is handled differently across our country and I might venture can suffer as a function of the assessors' field of experience, expertise and specialization or lack thereof. It may suffer as a function of the fee schedules in place or lack thereof and it may suffer due to possible time constraints and lack of resources.**

From the 'Medical Assistance in Dying: Implementing the Framework' document: **'In the event of comorbidities, assessors must consult with a practitioner with expertise in the medical condition** that is

- Most responsible for the patient's suffering
- The reason for the patient's request for MAID' and

Elsewhere they state

- The condition that is causing the person's suffering is a broader concept than the person's medical condition. In most cases, the condition causing the unbearable suffering will be the serious and incurable illness, disease or disability . However it can also be
- their state of advanced decline in capability
- their generalized pain associated with their multiple morbidities
- A broader concept involving psychological, existential or psychosocial suffering that flows from their
state of decline or
illness, disease or disability.

The assessor needs to assess the greatest source of suffering to determine what 'expertise' is required.

MORE SPECIFICALLY

ASSESSMENT AND SAFEGUARDS WHERE DEATH IS NOT REASONABLY FORESEEABLE AS IN THE CASE OF AN ALZHEIMER DIAGNOSIS.

Frequently when one receives a diagnosis of Alzheimer's disease, it is at the early stages. Depression is commonly experienced upon receiving an Alzheimer diagnosis and fear, anxiety, insecurity and hopelessness are exacerbated when necessary support services are not yet discussed or available and in place. If isolated socially, this can often leave a person focusing all of their time, day after day , hour after hour, on fear and despair as the ground under them begins to slip away. Many morbid thoughts including dying turn over and over in one's mind. The level of anxiety and depression can obscure a person's ability to reason propelling them to hasten death. Competency, capacity to decide MAID in a state of crisis is at issue. Diagnosing and treating depression properly factor into the MAID assessment.

CRITERIA

Typically, the advanced state of decline criteria for MAID cannot yet be met when the diagnosis is early and for mild Alzheimer however a request for MAID most likely will be filed. How do you define an advanced state of decline, how do you define that loss of capacity is imminent? If you pick an early date, the minimum, 90 days, when perhaps the advanced state of decline has not arrived, how can you proceed with the request, what can the assessor measure and evaluate?

They say **advanced state of decline is clinician determined but I think we need more transparency and guidance in the definition.** Certainly more precision afforded than the Ontario Maid Provider Handbook (see Clinical Frailty Scale, palliative performance scale)

Another significant criteria concerns the unbearable unrelievable psychological suffering. One is forced to ask is its source the Alzheimer's disease or the perception of the Alzheimer disability in our society or the perception of that disability in our current healthcare system, or the depression about impending loss or regret or iatrogenic harm possibly surrounding it?

The MAID Assessment form itself is vague although it asks this question regarding capacity to consent and depression: 'Can untreated depression be ruled out as a primary cause of the request? Yes or No...'

I think the question should read: Can depression, treated or not, be ruled out as a primary cause of the request? Is this a depression newly diagnosed or is there a more significant history of clinical depression prior to the diagnosis of the grievous disease? How is treatment defined? Is it only meds and are they adequate? Could psychotherapy be beneficial? Are there anxiety disorders as well? Can it be ruled out as a primary cause of a hastened request and date?

Enduring psychological suffering that is intolerable...**is that all the time or some of the time...how to determine and measure this needs to be better defined for transparency, timely accountability.**

Which assessors' expertise resides in the medical source of the person's suffering? Who will be consulted. Even Canadian standards for MAID require at minimum, and it certainly is minimum, that someone with expertise, not even a specialist, be consulted by assessors if they do not have expertise or if there are comorbidities. The quality of expertise defined and required is exceedingly low and substandard. Some transparency is required for such a crucial life and death decision for all concerned including family members.

'To have expertise in a persons' illness, disease or disability a registrant is not required to have a specific certification or specialist designation. **Expertise could be obtained, for example, through training or previous experience with patients with a similar condition.'** From Ontario Maid provider handbook. Can we see the training requirements, can we verify the previous experience? This is the most significant of all decisions that an individual can make and much resides upon the assessors' prowess.

The qualifications needed for all assessors but particularly for this Commission's type of patient should include the following:

- 1 psychiatrist-1 psychologist in addition to the 1 specialist in the disease that precipitated the request. This is critical in my mind for every single request to deal with depression and psychological suffering, no matter the source: clinical antecedents, iatrogenic induced or the unrelievable psychological suffering criteria. They are best suited to detect , evaluate and best suited to know how to treat it. This is particularly relevant for whom we consider here today where unrelievable psychological suffering is in many cases a harsh enduring reality.

Time is of the essence of course and a window of opportunity may be lost particularly if a MAID request date is selected at the 90 day minimum.

In CPSO Advice to the professionals: Medical Assistance in Dying May 2021, 'The federal government has noted that the federal legislation does not specify a timeline within which the referral to these services and or treatment must take place. If the individual expresses interest in accessing services and or treatments which may relieve their suffering, but it will take significant time to access them, the federal government advises MAID providers to take **great care in assessing the voluntariness and informed consent of the individual's request for MAID if they proceed as a result of the length of time it is taking to obtain those other services and or treatments.**'

It should further read that the knowledge of the delays and treatment time may even deter an expression of interest and affect voluntariness and informed consent! I think the proper Assessor must make sure this is not the case and document those efforts to the file and family.

This is an important statement. It concedes and acknowledges that the healthcare system accessibility to services can significantly affect patients and their request for MAID. Healthcare Canada cautions the assessors but I fail to see how this **is useful, measurable or accountable in a timely and transparent fashion. The assessor may not even report same if they so choose as there are no controls. Far greater precision and clarification is required than 'great care'.**

We are here at this Commission because we want to recognize the psychological suffering of mental illness of the most vulnerable, the incompetent, inapt, and

others so let us begin by recognizing the need to treat it where treatable and ethical prior to a MAID request and let us recognize our failure to treat it.

This delay may provide an argument for the descriptive type advance directives or hybrid directive. They may choose to avoid counselling on this basis. The artificial selection of a date also puts an additional pressure on patient even if it was designed to avoid it. No one knows how to pick when faculties will be too compromised, so some go for the minimum. It does seem though that the patient is the assessor.

The caveat that 'suffering be relieved under conditions you consider acceptable' is very large in Canadian MAID and one must ask is it truly 'useful'. This may testify to the right of self determination but is it protective of the vulnerable? In European countries, if the assessor is not convinced the suffering is intolerable, the person will be found to be ineligible for MAID. In Canada they can also conclude this but **oftentimes assessors find it easier not to conduct a prudent investigative query, nor seek information out nor suggest treatment and simply rubber-stamp the Request.**

'Do I know if my patient is suffering from "enduring psychological distress"? One of the key considerations with regard to assessment of enduring "psychological distress" is assessment of the impact of affect (such as anxiety and/or depression) and cognitive functioning on the capacity to make an informed decision. It is well understood that cognitions and affect can impact significantly on competence to make an informed decision. **Speaking to the patient's family can sometimes provide useful information.** In some cases, an objective assessment of an affective state (**by a psychiatrist or registered psychologist with expertise in this area**) can provide clarification.' Once again, there is no transparency or accountability that this is done and it should read **entire concerned family** as some family members may have more relevant information than a primary caregiver?

To grant a MAID request early on would mean that they confirm the presence of an advanced state of decline that is irreversible as well as grievous psychological suffering. According to the Canadian Psychological Association, **this grievous psychological suffering is treatable**.

I think much can be gleaned from the recommendations of the Canadian Psychological Association brief submitted in the consultations leading to the formulation of the Canadian Maid Law. I have included them a little further on in the memoire.

COMPOUNDED COMORBIDITY CASE ASSESSMENT - MY LUCIE CASE

Now what if you have a history of mental illness, a clinically depressed highly anxious person who has been on medication for decades and who receives a diagnosis of Alzheimer? Here more than ever the aforementioned recommendations become imperative.

'Whatever we plant in our subconscious mind and nourish with repetition and emotion will one day become reality.' The clinically depressed already have thickened neural pathways all set to fire to the gloomiest of scenarios. Add to this mix a devastating diagnosis and isolation, these new harsh realities fans the hopelessness and anxiety which builds hour after hour, day after day to dangerous levels exacerbating memory loss and propelling them into crisis, too emotional to reason. Desires to hasten death fixate early on before some modicum of supports and counselling are in place. Oftentimes the mentally ill are socially isolated and have not the resources to help themselves and are less proactive at the best of times hence the importance of guidance and assistance in every guise imaginable. In the context of COVID how can anyone proceed with any MAID request!

A reasonable presentation may be proffered to the assessor in a one hour time slot who is not privy oftentimes to all timely info nor the undercurrents of despair and anxiety and panic at home.

Will the assessors even see it at all? I am not even sure they will read the whole medical file. I am not even sure they will probe to find out. I am not sure they will visit frequently enough or better still have some unscheduled visits to ascertain the true picture. The person sounds competent and clear headed in the office so. There are comorbidities but the depression is treated I do not feel I need to consult or I consult with another doctor with 'expertise' that may be far too limited, is fine by me...my job is done here. IN 2017 \$40 PER 15 minutes capped at 90 minutes for first assessor and 75 minutes for the 2nd assessor. \$200 for euthanasia. Many doctors refuse to perform MAID because of poor remuneration issues.

BRIEF FROM CANADIAN PSYCHOLOGICAL ASSOCIATION

The following extract is from the brief prepared by the **Canadian Psychological Association**, prior to the final amendments and speaks to many of these issues:

- '4) There is concern that clinicians who communicate a professional opinion to a client that one's disorder is irremediable, or that the client is beyond help, may be contributing to iatrogenic harm, may be incorrect, and may dangerously impede that individual's sense of hope. **Hope plays a critical role in psychological treatment** (e.g., Moore, 2005; Snyder, Wrobeliski, Parenteau, & Berg, 2004), and **hopelessness (which research suggests is more like pessimism than absence of hope) is strongly and significantly associated with psychological despair, the wish to hasten death**, suicide ideation, self-injury, and risk for death by suicide (Brown, Beck, Steer, & Grisham, 2000; Heisel & Flett, 2005).
- 5) **Suicide ideation and the wish to hasten death can be remedied. Research supports the effectiveness of psychotherapy (alone or in combination with medication) in reducing or resolving suicide ideation among individuals with an active mental disorder** (e.g., Bruce et al., 2004; Heisel, Talbot, King, Tu, & Duberstein, 2015; Szanto, Mulsant, Houck, Dew, & Reynolds, 2003). **The desire to hasten death among individuals with terminal illness can also be transient and ambivalent** (Chochinov, Wilson, Enns, Mowchun, Lander, Levitt, & Clinch, 1995) **and is sometimes treatable** (Breitbart et al., 2015). **Although the desire to undergo MAID can certainly**

be stable over time (Wilson et al, 2007), requests are sometimes rescinded (Li et al, 2017).

- 6) Risk factors associated with suicidal ideation, such as lack of interpersonal relationships, social isolation, and stigma are more prevalent among persons with a mental disorder compared to the general population (e.g., Rüscher, Zlati, Black, & Thornicroft, 2014; van Orden et al., 2010). **Thus, the role of external factors should be considered to determine their influence on decision-making capacity and whether associated suffering can be treated or managed.**
- 7) In many instances **failure to reduce suffering associated with mental disorders stems from social conditions limiting access to evidence-based treatments.'**

.....
Let us now loop back to pre-diagnosis and diagnosis delivery in the circle of care surrounding the patient, to look at this systemically. At these stages in the timeline, suicide ideation could have been attenuated avoiding a need for MAID altogether or facilitating it because a state of crisis is not permitted to escalate to affect capacity.

■ **PRE-DIAGNOSIS IN NETWORK - CIRCLE OF CARE (PARTIAL COVID CONTEXT)**

Medical file, gp, nurse practitioner, pharmacist

The Circle of care depends upon the medical file and what is brought to it by the patient, concerned family members and due **diligence in documenting same to the file**. Less gets into the medical files these days when doctor visits are no longer **prevention oriented, problem oriented only** and **limited to 15 minutes**. Is the **file read, is it reviewed periodically?**

My Lucie has a long history of clinical depression and a significant history of related complications that punctuated her medical history. Concentration and focus was becoming problematic. In the past it was generally associated with going off the medications. As I spoke with Lucie daily I could see the COVID confinement had resulted in the loss of the only friend and only social activity and major stimulation Lucie had. There was less contact with family. Lucie's morale was terrible and the isolation unbearable.

No discussions about medications took place. Some concern for her already fragile mental state during COVID and some supports should have been suggested to appease anxiety and address depression. A request for Alzheimer evaluation with a geriatrician was ultimately proposed.

■ **DIAGNOSIS DELIVERY IN NETWORK - CIRCLE OF CARE EXPANDS GENERALLY**

Medical file, gp, nurse practitioner, pharmacist, geriatrician, clinical trial doctor,
Test administered by nurse practitioner I believe, geriatrician proceeded and perhaps tested as well.

FIRST DIAGNOSIS DELIVERY 2020 SEPTEMBER (COVID CONTEXT).

Without a family member present, over the telephone only, the geriatrician informed my Lucie of this devastating diagnosis, having never met my Lucie and knowing another family member could have been present. My Lucie fired geriatrician.

WHAT TRANSPIRED BETWEEN FIRST DIAGNOSIS AND 2ND IN MARCH

Poor eating habits, loss of weight, minor surgery which produced excessively levels of high anxiety for my Lucie. Overall anxiety was high as my Lucie had been worrying since September diagnosis about the possibility that the diagnosis was correct, in isolation all alone during COVID with no distractions no stimulation. This anxiety contributed to more memory loss itself and more consolidation about the diagnosis due to the repetitive uninterrupted narrative. This was akin to lighting a match to kindling and kerosene. Some in the care circle were advised of these signals of anxiety but still no one addressed medications, and my Lucie had gone off them since November having read somewhere they may contribute to Alzheimer's disease. There were other signals of high anxiety, some of which may not have got to clinician I cannot be sure. This is why **I believe all concerned family members should consulted. I believe one should be proposed counselling immediately when delivered any incurable disease diagnosis with frequent followup, particularly for someone with such a history of anxiety and depression!**

SECOND DIAGNOSIS DELIVERY MARCH (COVID CONTEXT)

Same geriatrician was rehired. Anxiety kept increasing and fear and emotions were getting out of control. Early Alzheimer was once again diagnosed. I requested to be on phone call but questionably got on with only 5 minutes left. I was unable to address anxiety. I only got 2 questions in. A referral was made to participate in clinical trial for early Alzheimer's disease. Finally medications were re-prescribed as my Lucie had been off them for 5 months.

Panic set in now at a second confirmation of diagnosis. My Lucie began focusing on death and suicide ideation while beginning the tests to qualify for clinical trial. Patient and others of significant import in my Lucie's life, discussed MAID which due to circumstances could be **construed as influential**. My Lucie started preparing for death rather than start proactive actions....Planning to relieve burden for others was major concern and arrange for death all the while highly anxious. The **focus on death, tempering the hastened desire to end one's life, taking one out of crisis mode all could have been attenuated in my opinion with proper counselling and followup after the first diagnosis and once again this was overlooked at 2nd diagnosis, as it was again after the next diagnosis and again when it got into the assessor's hands. Sending an occupational therapist right away to help to anticipate and arrange for supports would have been therapeutic and helpful.**

THIRD DIAGNOSIS DELIVERY (COVID CONTEXT)

One anxiety attack prompted getting companion in a few days a week.

Assessments were made in clinical trial. JUNE a Tao tangle pet scan result confirmed a diagnosis of early Alzheimer. I was never informed of cessation of interest in study. By now most medical info was no longer forthcoming as I had questioned the assessment process which was perceived as opposing the request. Tension in family dying days...tragic and avoidable if assessors had reached out to all concerned family members.

My Lucie was so anxious that any noise, including the sound in my earphones in another room, could disturb her and keep her awake. I experienced this once in the past and when the COVID border restraints were lifted and I had had both

vaccines, I went to stay with her. Why no counselling has been proposed is not looking after the vulnerable.

The Doctor who was doing the clinical trial recommended that Lucie's antidepressants should be increased. The Alzheimer Drug had been prescribed perhaps at 2nd diagnosis, I cannot remember.

Missing in this care circle was prevention and frequent follow ups. Did anyone check her regularly for all the intensified signals of anxiety depression, to ensure stimulation, medications were taken, eating well, exercising ? When no medications were verified until March and only by the geriatrician I feel this is negligence. This was also during COVID.

Communication must improve and all the shared info should be discussed with team members like the SIPA Initiative of Dr. Howard Bergman of the Jewish General Hospital Montreal in the 2000s. During COVID, at a minimum, FaceTime calls should be used when communicating an Alzheimer diagnosis to a client.... No supports organized. Left to client and others to inform themselves at Alzheimer centre for some activities. When she was fired, was this signalled to the GP. Did the GP do anything, question the geriatrician or my Lucie , etc. Did the geriatrician signal to the care circle that another family member was interested in client and had permission of patient to be present with medical info and call that was shared?

Team should include a nutritionist, an ergo therapist for aerobic exercise, and where is neuroplasticity in this? All these elements are highly recommended for Alzheimer care. Why did we spend money on finding this out if we don't use it or recommend it or have it available? While such a team will prove costly, it is of short duration (at the present time) and may slow the progression perhaps as much as costly clinical trials will here in Canada , as Aricept does or as well as the recent and highly contested US FDA approved Alzheimer drug might.

An occupational therapist visit was only suggested by a social worker mid July and not acted on it yet. The aids could have and could contribute to a functional and secure morale boosting sense of autonomy. On 2nd zoom call of August, social worker did not verify if it was done. **You must assess presence and responsiveness of caregiver or substitute** otherwise you are not being prudent and protecting the vulnerable.

Should pet scans be mandated prior to a MAID request for Alzheimer's request as that really is the only way to really confirm Alzheimer's or will they only be used for clinical trials for early dementia? Of course the costs are prohibitive and we are ranked 18th out of 28 countries for availability to same.

■ MAID REQUEST

From the looks of things this network does not communicate with each other or really care about the vulnerable patient so I rather doubt the assessor has all this information or if he has, he has not read it or does not care because in one hour he declared Lucie competent.

Is their salary capped at 90 minutes, 2nd assessor at 75minutes? In 2017 there was not much satisfaction of that. I sure hope that does not include the medical file reading , etc. Some BC doctors who seemed to care said it was very time intensive and wanted more remuneration. In the Netherlands providers are paid \$2200 , 5 times higher and get the day off after assisting a death according to Catherine McIntyre, July 12, 2017, Maclean's.

'Many provinces have no specific fee schedule for physician remuneration and some nurses often paid by salary provide MAID outside regular office hours without compensation.'from First Canadian Annual report on MAID 2019.

What temporary amendments have been made due to COVID-19, and for how long will these amendments remain in effect? The temporary changes made due to COVID-19 include the following:

- Both practitioners can conduct the assessment by telemedicine.

- Capacity assessments can be done either in-person or by video-enabled telemedicine. **I think this is far too important to subject to risk 3rd party influence and you may miss vital body cues , etc.**
- These are temporary amendments which will be re-evaluated once the public health emergency abates. Social worker did her 2 consults virtually. There was no reason to in July and August of 2021 and it is a growing tendency now.

If for any reason the assessors do not concur in my Lucie case, the breaking of this expectation about the chosen date for my Lucie will be poorly received, almost tragic now. **It should never be concluded or affirmed at first assessment, after all it is in theory a process.** If this was not done, the patient and primary caregiver certainly believe so. Has the social worker picked this up in her 2nd of 3 talks? The assessor has not as he has only seen her once!

My Lucie's date selection was also based on a calculation of the waning effect of Alzheimer drug..at the minimum 7 month window. Does anyone know this in the file? This is something that should be better explained. **Date selection reasons should be documented in file.**

Patients who had professions in life who did assessments themselves, know how to answer! At home, the emotions and anxiety level may be quite concerning. No one has the whole picture in this file and it should not happen again to anyone who is so vulnerable.

No one in this file has asked about other family according to primary caregiver. No attempt was made to contact a 3rd family member who wrote concerns to assessor, and no attempt was made to contact me. My request to meet with social worker was not followed up by her.

TIMING IS CRITICAL FOR ASSESSMENT AND SAFEGUARDS.

- **Revisiting and frequent visits are necessary**

- **to get complete picture of patient's situation. It can reveal true psychological profile and emotional states that frequently take time to ascertain and are oftentimes hidden behind a functional facade presented in an interview.**
 - Summer 2021 there is no reason the social worker cannot come on scene. **I would even try to do unscheduled visits.**
- **because much mental illness is erratic**
- **to better understand refusal or the perception of refusal. This is very important for other cases of mental illness and those with communication issues.** Patterns of rejection may be misunderstood and can change. When an aphasic person displays behaviour misperceived as anger and opposition, their wishes may be misunderstood and may not be treated in our hospital system, or worse in the context of a MAID request or refusal.
- I know behaviour from my Mother was misperceived on two occasions and in two different hospitals in two different provinces. She was recovering from hip replacement when she was 91 and both times when physiotherapy was performed in very public exposed places she protested and tried to turn around in her wheelchair, grabbing doorways, raising her voice. Although I had been given the talk, both physios who persisted one last time before concluding she could not be rehabilitated or could not be offered rehab (differences in hospitals) found it was just about her pride. When alone in a more private place she responded and learned to walk again.

This is important for Lucie but also for other **patients who have had strokes** .Do you really want to take away someone's life based on your perception . If you try again maybe things will be different.

As Dr. Felix Pageau said in his brief when dealing with the most distressed Alzheimer classification, that they try anti-pain medications, antipsychotics or treatments adapted to dementia, sometimes even palliative sedation intermittently. Removing them as they go along if they do not work. Impossible to do, he said, with MAID as there is no coming back! However I also agree that extensive efforts to preserve life at this point are not to be initiated.

Just like Alice in Wonderland, not only are the moods and identities different of the patient overtime, treatments change and different people including doctors have better skills and at different times are more effective. Revisiting and revisiting can spell all the difference in the world!

I also had a friend who had a stroke who heard people discussing whether to let her die by her bedside unable to signal anything. What mental terror that must have been! She survived and though dependent upon a caregiver for help with basic needs daily for life (up to now), she has laughed, loved, had a child, became an active advocate for patient rights notwithstanding the difficulty she has to talk, to travel in her electric wheelchair , to wait for transport , to wait for home care, etc.

I would not cap how frequently the psychiatrists or psychologist in mental illness or whomever perform the assessments and I would not cap how the second assessor, who is supposed to make sure all is truly comprehended, does either. They need to visit many times and make multiple attempts.

I think they should record all assessments and interviews. Names could be redacted in hard copy.

According to a Doctor interviewed about MAID in 2017, 'most providers need to meet with their patient a couple times before the procedure. They need to review their medical history, which in many cases is lengthy and complicated, involving several specialist and care providers. They need to counsel the family, sometimes for hours and over multiple visits if some member oppose the procedure or feel conflicted. ..., etc.' The article went on to document how **It's no secret that fee codes influence the kind of care patients receive.**

Although the forms seem to suggest differently, self determination protects the apathetic assessor and fails to protect the vulnerable. Assessors find it easier to not conduct a prudent investigative query, not seek information

out again and again nor suggest treatment and simply rubber-stamp the Request.

According to First Annual Report on Medical Assistance in Dying in Canada 2019 stats report:

1271 practitioners . Specialty 65% per Family medicine, 1.2% psychiatry. Palliative and nurse practitioner both around 7-9%.

Consultation with other: mostly nurses 46.7%, only 6.2% psychiatrists

The report generates some questions that may generate important future considerations:

10.4% of requests Neurological conditions..interesting to see this next year.

65-70 is age most requested.Why do older less request it less! Maybe the suffering is not as profound as expected after 65-70. Of course could be less competence or capacity over 65-70 !

That some physicians have done 10 plus procedures is the frequency perhaps reason to compare assessment styles or further subdivide data into types of ailments and no of requests for ailment ie. Cancer generally has more physicians performing more requests so some **more sophistication in data compilation may be required to make data more meaningful info.**

Of 7336 requests, 571 declined, 5389 deaths performed 263 withdrew patients could meet more than one of criteria.

Reasons for ineligibility

Not capable decision health 32.2	Not experiencing suffering intolerable to them17.7
Death not reasonably foreseeable 27.8	Not provide informed consent 17.0
Not in advanced state of irreversible decline in capability 23.5	Not serious incurable 13.3
Request not voluntary 1.6	

In 2019 SASK 42.4%, AB 3.9% . ON .5% speciality of maid provider psychiatrists. Is the maid provider the maid assessor, I am not sure? Once again the data can help us if better defined to answer such questions as to why in SASK is the specialty of maid provider predominantly a psychiatrist?

GOVERNMENT AND TACIT DISCRIMINATION -VALUES-CONTRADICTIONS

We know some of the reasons Lucie wants to end her life, but what should it mean to the government?

From the First Annual Report on Maid:

Loss of ability to perform Activities of daily living 78.1	Able to engage in meaningful life activities 82%
Loss of dignity 53.3	Inadequate control of symptoms other than pain 56.4
Burden on family friend caregivers 34.	Loss of control of bodily functions 31.9
Isolation or loneliness 13.7	Poor loss of quality of life 3.7
Anxiety emotion fear existential suffer 4.7	Loss of control autonomy Independence 4.1
Other .6	

Some Alzheimer's disease candidates for MAID wish to end their life because they do not want to be like Alzheimers they have seen... or cannot imagine not remembering family members, or other things such as depending on others for hygiene and food and the basics. This is called aging with a disability but basically it is a value and a perception of this person regarding a disability.

If the state of disability is the value by which the patient determines their request MAID I think that it is clear that by acquiescing to such a request is akin to discriminating against persons with disabilities. By actively participating in the medically assisted dying is tacitly supporting their value of discriminating on the basis of a disability.

When a PAB who is black or is a man and a senior does not want to be cared for by them for their prejudices, what does our system do? Well, although recruiters from government health facilities request white staff once a month EPPSQ , or like the case in St Eustache, generally they do not and are not supposed to. Guilbault said patients with cognitive issues handling services for people of a certain profile creates a difficult situation and has a lot of empathy, but hiring on race or sex is against the law which also prohibits discrimination based on someone's disability.

Not wanting to feel like a burden on their family but we are not here to manage their legacy or their children's time and life choices. **Tacitly agreeing to perform MAID for these reasons extends healthcare far beyond its field of expertise and demonstrates government tacit approval of these and other values.**

Furthermore when death is not foreseeable, it is yet at an early stage to conclusively state that the quality of life is one which is intolerable at some future date, it is impossible at this point in time to determine this for oneself.

This is inconsistent with self determination. If we cannot know the state in advance of it..not real self determination. Unbearable suffering at a future date is an unknown!

Judged from without be it an assessor, a team of assessors in a hospital, a caregiver, wishes and suffering are hard to determine and bias is always a risk. Caregivers argue that there are well documented states for Alzheimer, but it is still as seen from the outside. Also one must assess the caregiver. An attribute of loyalty and long dedication are not necessarily favourable as caregiver fatigue can set in and colour decisions with bias. Timing is important for everyone involved! Bias has to be evaluated everywhere and often when so important a decision is being made. In determining teams of assessors in a hospital all efforts to minimize bias must be made. CPA Brief discusses prevalence of bias.

BRIEF FROM CANADIAN PSYCHOLOGICAL ASSOCIATION

A CPA Survey on MAID produced variable results that also suggest **that approaches to discussing alternatives to MAID, required for Consent, are not so straightforward.** These specialists’ increased sensitivity to same permits the assessor to more accurately conclude whether the client has truly understood the alternatives and still choose MAID.

- ‘Dementia is now more widely acknowledged as a life-limiting illness, although whether it is a ‘terminal’ condition (i.e., causes death) continues to be disputed (Sachs et al., 2004).
- There is a widespread prevalence of stigma, both in Canada, where more than one-third of people admit to being uncomfortable socializing with someone who has dementia (Ubelacker, 2018), and globally (e.g., Milne, 2010; Swaffer, 2014). Research confirms that health professionals are not immune from negative stereotypes about dementia (e.g., Gove, Downs, Vernooij-Dassen, & Small, 2016).
- Inadequacies in supportive care for dementia, including symptom management and end-of-life care, have been documented in Canada and globally (see Hunter et al., 2015, for review), and may contribute to beliefs that dementia implies suffering (Swaffer, 2014).
- Research also supports the idea that those who have greater familiarity with specific conditions, such as dementia, also have more positive attitudes (e.g., Angermeyer & Deitrich, 2006). Thus, at least some of the variability in the survey results may be explained by socially derived negative expectations about dementia, and by varying levels of personal experience with the disease.’

CONSENT CRITERIA-VOLUNTARY INFORMED

From First Annual Maid Report Table 6.3 Is it a voluntary request not as result of external pressure. If yes why . Many practitioners consulted with others.

99.1 consultation with patients	58.5 consultation with Family
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43.9 reviewed medical records	Consultation with other Health or social service 40.7
Knowledge of patient from prior 14.9	Other .3

Canada seems to recommend in the Medical Assistance in Dying: Implementing the Framework: 'Practitioners may wish to **encourage the patient to share their intention and involve their family or loved ones in discussions about receiving MAID.** This way, family and friends will be aware of the patient's wishes and more likely to respect them. However Health law, medical ethics or medical practice is a provincial matter.'

Here again some investigative prudence must be undertaken. **Does the patient have a caregiver or person who can exert an inordinate influence upon their decision making? Do they have something to gain? What is there to address the many typical forms of senior abuse and manipulation which can be subtle. Some clarification and transparency is necessary and although 60% of assessors consulted with other family members this should increase.**

As MAID must be a voluntary request not made as a result of external pressure, one might ask what constitutes external pressure and can the aforementioned social mores and stereotypes, poor services and ignorance be construed as forcing one's hand. Canada admits to same as previously discussed.

To satisfy informed consent criteria one must discuss alternatives available and truly understand them.

The Canadian Psychological Association states: 'Understanding should include an awareness of all available treatment options including palliative care interventions, and where there is the presence of **a concurrent mental disorder**, the availability of psychological, medical, social, and where relevant, spiritual care.' Kolva, Rosenfeld, Brescia, and Comfort (2014) underscore the importance of ensuring that **assessment of decisional capacity in patients with terminal illness is comprehensive and extends beyond the use of global measures of mental status or a diagnosis of a mental disorder.**

We must be sure providing alternatives is not simply the perfunctory checking off from a list of services available but rather seeks to provide an understanding and probing of the client's perceptions of alternatives

Are we understanding the stereotypes regarding the alternatives we propose to the patient and seeking to re-educate if incorrect? Have we even asked? Do we seek to re-educate? Alternatives change over time, they are vastly different offerings, To really 'understand' you have to re-educate or conclude no real understanding of the alternatives. My Mother rejected one environment for a day program but she loved and accepted another morning program, ie If we take an alternative ie, longterm care residence, is there anyone to really help understand the options and that they change over time? You almost need a tour particularly after COVID.

The Covid reporting on horrific conditions could not have helped either any expectations for pleasant long term care homes. Family is oftentimes expected to explore options and alternatives but what if they do not? What if there is no family?

EXECUTION OF REQUEST - IS IT REALLY A PAINLESS DEATH.

As already presented in Senate, according to Dr. Joel Zivot, said autopsies of prisoners who are executed in the US suggest that it could be exceedingly painful and akin to a drowning death and the last paralytic can act to hide that to observers. **Perhaps a request could be made for a certain number of autopsies to be performed to ascertain if indeed MAID is painless and merciful? If it is possibly brutal or unknown then that should be part of assessors discussion with patient when receiving the MAID request however I would suggest only when patient is not in crisis as for all other coroner details and morgue, funeral arrangements.** The arrangements and planning is not therapeutic if done too early prior to counselling for high anxiety and depression.

II

THE PROBLEM OF NO TRANSPARENCY AND TIMELY ACCOUNTABILITY-REPORTING MECHANISMS

'Objectives: The regulations set out in the federal monitoring regime would support public accountability and transparency.' **Can the patient's family ever request a copy of MAID request and assessment?**

'If Health Canada or a provincial or territorial designated recipient, became aware of failures to apply the eligibility requirements or safeguards in the Criminal Code, failures to report, or continued or egregious omissions in reports, a situation could be referred to law enforcement.' **The timeliness is questionable. Furthermore, the complaint process is nowhere to be found easily, if at all. Absolutely no transparency and accountability as far as I can see.**

I was told by the medical assistance in dying care coordination service supervisor that the compilation of statistics at death provides that accountability and transparency....Those kind of checks and balances are rather useless!

Then she suggested writing to Circle of care any information you find relevant. **As they are under no obligation to answer you, even though it is recommended that they speak with family members, what transparency exists here to reassure everyone safeguard process is being followed adequately and that your concerns have been considered? There is no assurance that it is dealt with and even submitted into file. It may never be reported to StatsCan and if family never has access to copy, no one will never know.**

Who was witness, what are the assessors' qualifications and experience, their names, that of social worker. Not all family members are privy and not necessarily because the patient denies access.

Stats on expertise of second assessor should be kept for Annual Maid Reports.

Care Alerts should be documented in stats Canada reporting if they are not.

Assessments should be taped. Let 2nd assessor access the first Assessment interview and all thereafter. Ideally should meet 2nd assessor in person.

III

TEMPORARY MORATORIUM ON REQUESTS FOR MAID OF MENTALLY ILL DUE TO PSYCHOLOGICAL SUFFERING EXACERBATED BY COVID

For all mental illness cases and all who have received devastating diagnosis and may possibly have fallen into severe depression, they should first be offered treatment before any MAID request can proceed. A moratorium on requests until Covid is over and until its even greater devastating long lasting impact on the mentally ill has been addressed would be the responsible thing to do.

For more than a year, the isolation, lack of stimulation, exacerbated many mental illnesses. Despair never seems to be the right place to make a decision. Month after month day after day hour after hour, minute after minute...in isolation, no distractions no stimulations to break the constant misery.

Furthermore the intensive media attention considering senior abuse etc and health care failure and long term care atrocities amongst others cannot inspire confidence but further erode the trust and sense of hope and possibly enter into decision making. This has been as pervasive and intensive during the past 2 years as was their isolation and loneliness. All these factors contribute significantly to the problem and psychological suffering..and perhaps an unduly hastened desire to request MAID.

A Survey taken by the National Institute on Aging in July 2020 found that almost 100% of those asked had no current interest in going to a longterm care facility and as many as 70% said that decision was influenced by pandemic. The 15000 long term care deaths represent more that half of all Canadian Covid death toll.

IV

A POTENTIAL POLITICAL CONFLICT OF INTEREST

- If many Health care professionals believe most mental diseases and suffering are relievable and curable (debated but possible)

- If many Health care professionals believe the lack of timely and appropriate government managed resources are responsible for much of the unbearable non alleviated suffering, (debated but possible)
- If government assesses competency on a case by case basis for Health care decisions, for Financial decisions but **not** for electoral decisions

Then a serious ethical question emerges which speaks to selective practices, discrimination, and could also have criminal implications.

Many inapt and mentally ill persons do not have the right to vote in Quebec elections. Healthcare is under provincial jurisdiction. The question of mental competency is oftentimes broached on an individual basis on a spectrum as regards financial decisions as regards health decisions and perhaps it should proceed regarding political decisions as well. Federal law permits those under curatorship to vote. Quebec law prohibits same.

For those who have been stripped of their right to choose representation a potential conflict of interest arises and could usher in a potential abuse of power if unchecked. It also constitutes a discriminatory practice.

'I mistreat you by not providing adequate services , I do not give you an opportunity by vote for you to voice your dissatisfaction and vote me out of office. I do not even assess your competency to vote as I do for other very significant acts. Notwithstanding, I may even allow you to decide MAID or AMR , whether you are competent or not by this new law. By allowing your death, it may serve to lower healthcare costs in the long run, It may serve to eliminate the source of criticism and dissension for political purposes of remaining in power. If organ donations get into the picture the appearance of impropriety exists at a minimum, and may not be long that Quebec will be perceived of forced organ harvesting! Or more professionals like the anaesthesiologist of Cite de la Sante who performed euthanasia improperly..no MAID, no palliative care bed. Beds are short one day, who is to say ! Add media suppression or media partnership which is more and more a reality alongside the very short news cycles that allow for no accountability like the ambulance technician directive.

But to give one the right to vote just to give them the right to die may also be inappropriate. It also opens up debate of the appropriate barometer or standard to be held up for assessing capacity to choose a candidate as

- there is debate that many electors do not base their decisions on the understanding of the issues
- there is debate that many may vote on an emotional basis,
- there is debate that many may simply vote along historical family traditions

V

OUR MOTIVATION-ATTITUDES-SOCIAL PSYCHOLOGY

As long as there is inadequate care and negligence that is tolerated by any of us, and as long as there are laws such as MAID that facilitate the cessation of life, there will be less motivation and impetus to do the restructuring of society, medicine, Pharma and healthcare necessary to transform and imbue treatments and longterm care with humanity and dignity.

These quick fixes serve only to maintain the current poor health care system management and priorities as well as the current poor government management and priorities. Some might even go so far to say that MAID provides a cost benefit insofar as it will eliminate the high costs of longterm care for our fragile health care system. According to the Canadian Medical Association, assisted dying could cut health care costs by at least \$34.7 million and up to \$138.8 million a year! (2017 statistics..with expansion to MAID and more aged no doubt this will rise) Our current annual costs for healthcare are \$265 billion.

Is it a coincidence that this is occurring at a time in our history when demographics show longevity is increasing, an aging population?

Expensive research to develop new treatments for disease are continually being developed, and costly programs to that end such as ie. Mobile ECMO units, drone defibrillator delivery , and drugs etc , constitute great successes that increase life expectancy for so many. **However investing in quality of life programs and care for this increased lifespan afforded us has to be part of the equation or it does not make sense.** In fact it becomes cruel and abusive

and all who contribute to prolonging life without ensuring good quality of longterm care and other support services for the vulnerable are indirectly responsible. Many professions recognize this and participate as well in advocacy. To live and function in a silo without regard for the ramifications of our actions upon others is unworthy of any of us.

Are industrialized and rich countries incapable of looking after their frail and sick with dignity, comfort and joy? Ours, and many other countries' COVID experience has exposed this. How we treat our seniors in our longterm care system and others with disabilities by a lack of support services out there is far from exemplary! After the first wave of COVID, some provinces ,when resources were **not** short and protocols deciding who would receive care and who would not were **not** required, nevertheless ordered ambulances not to resuscitate seniors from cardiac arrest while pregnant women and children were. In the **anticipation** of shortages, orders were given to not send CHSLD clients to hospitals knowing that care capabilities in those facilities would not be in some cases adequate.

If we continue to ignore quality of longterm care and support services, will we encourage **more** end of life decisions being taken? Will more vulnerable people argue that 'their psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable' is in largest part due to the further degradation of longterm care and our health care system's inability to care for people in dignity. We invent instead 'dying with dignity' and this option looks better and better to seniors when **being cared for and living in dignity should be the most humane option which is neither enforced, prioritized or adequately funded.**

And we must all begin to advocate for funding quality of life supports and dignity in longterm care as much as we do for research to relieve suffering and disease and prolong life, which means our the HC system as well as our governments and all citizens will have to prioritize differently if we wish to keep our humanity.

You say the opinions and questions have evolved in society about this but I believe by a very limited group. Most of the population will read the headline, identify with one issue that resonates and that is enough to propel a trend enter into mindset and influence decision making. 282 participants and the groups of professionals for the most part represent very little citizen representation. I do not think up to this Commission the Alzheimer Group has contributed a brief although they did during Canadian MAID consultation.

Where are other ministers on this portfolio? Will the deputies and Ministers see that this is not just a healthcare issue? The restructuring called for to make our system functional and up to par calls for major restructure and may involve other portfolios and ministries. We have all been there before but notwithstanding all the efforts since the 80s, we are no further ahead! Medical advances yes but on many fronts such as longterm care and supports for disabilities we are no further ahead. The **National Institute on Aging says discussion on home-care vs longterm care funding may be more important a discussion to commence.**

CONCLUSION

I have focused particularly on 'Lucie' and the neurodegenerative disease of Alzheimer's when death is not foreseeable and with comorbidity of depression. Some of these issues apply to all types of clientele targeted by this Commission as well as others from previous consultations.

I feel that many MAID assessments fail to protect our most vulnerable and we must ensure we take all corrective measures at our disposition to change that immediately. I believe our standards are not set high enough to proceed humanely to so critical and irrevocable an action and therefore many MAID assessments will fail to protect our most vulnerable. I also believe that the precarious state of our Health Care system will prevent the prudent investigative analysis these assessments will need.

They fail because of the assessors' field of experience, expertise and specialization or lack thereof. They fail perhaps even as a function of the fee schedules in place or lack thereof. They fail as a function of time constraints and lack of resources.

THEY HAVE THE WRONG PEOPLE PERFORMING THE ASSESSMENTS

- I suggest that assessors include the following: 1 psychiatrist-1 psychologist in addition to the 1 specialist in the disease that precipitated the request. This is critical in my mind for every single request to deal with depression and psychological suffering, no matter the source: clinical antecedents, iatrogenic induced or the unrelievable psychological suffering criteria. They are best suited to detect, evaluate and best suited to know how to treat it. This is particularly relevant for whom we consider here today where unrelievable psychological suffering is in many cases a harsh enduring reality and where it is a major criteria. Psychiatrists todate have only been consulted 6.2% of the time.
- Depression is classified in both ICD-11 and DSM-5 as a mental illness.

When one receives a diagnosis of Alzheimer's disease, or any incurable disease for that matter depression is commonly experienced. The depression may be quite severe. For some panic, anxiety, suicide ideation enter into the mindset

propelling them to hasten death. Competency, capacity to decide MAID in a state of crisis is at issue. Diagnosing and treating depression properly factor into the MAID assessment.

The Canadian Psychological Association brief confirms that

- **this grievous psychological suffering is treatable**; that suicide ideation and the wish to hasten death can be remedied; that social isolation influences decision making and capacity; and social conditions that limit access to treatments accounts for failure to reduce suffering associated with mental disorders.
- The European system does not allow psychological suffering to be self-assessed
- In Canada this is sometimes done but with self determination and 'suffering that cannot be relieved in ways that are acceptable to me' a caveat so large that oftentimes it is far easier not to conduct a prudent investigative query, nor seek information out nor suggest treatment and simply rubber-stamp the MAID Request.

THESE ASSESSMENTS FAIL BECAUSE CRITERIA IS DEFINED SO POORLY WITH NO TRANSPARENCY AND ACCOUNTABILITY WHICH LEAVES THE VULNERABLE UNPROTECTED

- Question on MAID form regarding depression is too simplistic
 - 'Can untreated depression be ruled out as a primary cause of the request? Yes or No...' I think the question should read: Can depression, treated or not, be ruled out as a primary cause of the request? Is this a depression newly diagnosed or is there a more significant history of clinical depression prior to the diagnosis of the grievous disease? How is treatment defined? Are the meds adequate? Is psychotherapy ongoing or recommended? Are there anxiety disorders as well? Can it be ruled out as a primary cause of a hastened request and date?
 - Enduring psychological suffering that is intolerable...is that all the time or some of the time...how to determine and measure this all needs to be far better defined for transparency, accountability and proper assessment purposes.
 - 'Expertise could be obtained, for example, through training or previous experience with patients with a similar condition .' Ontario Maid provider handbook. What are the training requirements and the previous

experience? This is the most significant of all decisions that an individual can make and much resides upon the assessors' prowess. Standards must be elevated as suggested earlier and remain transparent for all involved.

- 'advanced state of decline' is clinician determined. Here too we need more transparency and a clearer definition than is afforded by the Ontario MAID provider handbook.
- 'great care in assessing the voluntariness and informed consent of the individual's request for MAID if they proceed as a result of the length of time it is taking to obtain those other services and or treatments.'
 - It **should** read that the knowledge of the delays and treatment time may even deter an expression of interest in possible treatments and affect voluntariness and informed consent! The proper Assessor must make sure this is not the case and document those efforts.
 - The Canadian Government stipulation is not useful, or measurable or accountable in a timely fashion. The assessor may not even report same if they so choose as there are no controls. 'Great care' must be clearly defined in a transparent way that documents how, to better protect the vulnerable.
- Required or desired treatment may be an argument for the descriptive advance directives or hybrid directive which I believe is better for patient.
 - Decline is unpredictable and the **description** 'when such and such happens', may be more humane and effective for early Alzheimer clients' death date selection.
- how assessors will determine if a mentally incompetent can understand a certain medical act also needs great precision and clarity. It must be persuading to an unbiased team. The ability to determine capacity to vote may be required concurrently.

THEY FAIL DUE TO REMUNERATION

- no caps , incentives such as day off, better remuneration like Europe

THESE ASSESSMENTS FAIL FROM LACK OF PRUDENT INVESTIGATIVE ANALYSIS, CONDUCT AND LACK OF ACCOUNTABILITY

- Revisiting and frequent visits are necessary to get complete picture of patient's situation. It can reveal true psychological profile and emotional

states that are frequently hidden behind a professional facade presented in an interview.

- I would even try to do unscheduled visits.
- Mental illness is erratic. Repeated visits are critical to better understand refusal or the perception of refusal and particularly where communication problems exist, aphasia, etc. See example p.24 with my Mother.
- Like Alice in Wonderland, not only are the moods and identities different for the patient overtime, treatments change and different people including doctors have better skills at helping, at different times are more effective. All this can spell all the difference in the world!
 - Patients who did assessments themselves know how to answer and caution must be exercised as in cases of family consisting of an only child
 - Assessors should never conclude or affirm at first assessment, that patient's request will be accepted
 - The reasons for choosing a particular date for MAID should be documented and revisited periodically.
- 60% of the time there is consulting with family members to help ascertain voluntary consent
 - Speaking with family is also encouraged to help the family deal with decision. This should be both transparent and verifiable that it is attempted.
 - Does caregiver exert an inordinate influence upon decision making and do they have something to gain? How do they assess the many typical forms of senior abuse and manipulation which can be subtle. Clarifications and transparency are required here.
- Comorbidities require a consult with someone with expertise. Who is it, when is it, what was concluded? Will anyone besides Stats Can know if ever they will? I think the family should and in real time.
- Complaint process is non existent or very hard to find and should not be.
- Permitting capacity assessments by video-enabled telemedicine risks 3rd party influence and possibly vital body cues
- More sophistication in data compilation is required for more profound analysis by StatsCanada

- Recording assessors' assessments would prevent or clarify misunderstanding or misdirected efforts
- In order for 2nd assessor to assert 'fully understanding the alternatives', to fulfill mandate and safeguard, prudent investigative approach required as well as re-education to correct incorrect stereotypes should proceed.
- Assessments done by a team for incompetent patient have to be as unbiased as possible. Evaluation teams can hire a psychiatrist outside of hospital network and rotate. This way relationships, finances factor in as little as possible. Maybe someone from protection de malade observing or another qualified outsider can be enlisted.
- Advance requests: CCA (Canadian Council of Academies) suggest 'formal counselling' for people who wish to draft advance request for MAID This is desirable as is mandatory updating of a registry of advance requests. If formal counselling is proposed here surely when making a MAID request it should proceed without saying.
- I still think everyone at all times has to respond to a gesture perceived to be a refusal to proceed with MAID or euthanasia, no exceptions

LOOK AT THIS SYSTEMICALLY, THEY EVEN FAIL TO PROTECT VULNERABLE BEFORE THE ASSESSMENTS.

If the circle of care health professionals manage a continuum of care with an integrated approach based on best practices including prevention, proper medication, then stress, anxiety and suicide ideation may be reduced either avoiding the need for MAID altogether or facilitating it because crisis is not allowed to escalate.

- 15 minutes problem focused visits for seniors far from adequate. Diligence applied in documenting, reading and reviewing files.
- Counselling should first be encouraged and initiated at this stage for anyone who receives a grievous incurable disease . This can attenuate suicide ideation early on and is far more ethical and humane whether there is a MAID request or not.
 - frequent follow ups, as well as an occupational therapist should be dispatched rapidly.

- Communication must improved and all info, shared and discussed with with team members like the SIPA Initiative of Dr. Howard Bergman of the Jewish General Hospital Montreal
 - team should include a nutritionist, someone to monitor aerobic activity and train neuroplasticity. All elements are highly recommended for Alzheimer care. If we spend money developing all this we must make it available, recommend it and use it.
 - During COVID, at a minimum, FaceTime calls should be used when communicating an Alzheimer diagnosis to a client with a family member present unless otherwise specified and only if in person delivery is not possible.

MORATORIUM OF MAID DURING COVID AND UNTIL TREATMENTS FROM ITS RAVAGES BEARS FRUIT AS IT STRONGLY INFLUENCES MAID REQUESTS.

- That COVID has adversely affected those with mental health problems, as well as opinions of desirability of longterm care is self evident . Both of these facts can impact upon MAID decisions in a detrimental fashion. See Survey National Institute on Aging in July 2020.

ENSURE DEATH NOT PAINLESS

- autopsies should be performed to ascertain if indeed MAID is painless and if so, disclosed by assessor at appropriate time along with all other death arrangements

POLITICAL CONFLICT OF INTEREST

- Government overtly advocates discrimination against disabled by not evaluating on case by case basis right to vote as they do for financial competence and health decision competence. All questions should be disclosed that evaluate competency in each domain
 - By allowing such a death request to proceed without according a right to vote, may serve to lower healthcare costs in the long run, eliminate criticism and dissension for political gain and be perceived as conflict of interest.

SOME ETHICAL AND PUZZLING CONTRADICTIONS THAT NEED TO BE RECONCILED IN MAID POLICY IN ORDER TO PROCEED

- If the state of disability is the value by which the patient determines the request for MAID, then the government by acquiescing to such a request by

actively participating in MAID is akin to discriminating against persons with disabilities. They tacitly support that value. The case where the government agencies hired white PABs for dealing with the vulnerable's prejudices Guilbault though empathic, qualified that hiring on race or sex is against the law which also prohibits discrimination based on someone's disability.

- Another value cited is not wanting to feel like a burden on family but we are not here to save money for families, manage their legacy or their children's time and life choices. By tacitly agreeing to perform MAID for these reason overextends healthcare far beyond its scope and demonstrates government support for same when resources are scarce and more effectively spent elsewhere.
- Government overtly advocates discrimination against individual by not evaluating on case by case basis political competency as they do for financial and health decision competency.
- 'advanced state of decline". An early dementia request for MAID offers little for the clinician to evaluate.
- Furthermore when death is not foreseeable, it is yet at an early stage to conclusively state that the quality of life is one which is intolerable.
- Inconsistent with self determination if we cannot know the state in advance of it. Unbearable suffering at a future date is an unknown!
 - Although the MAID reporting forms seem to suggest differently, self determination protects the apathetic assessor and fails to protect the vulnerable. It is easier to rubber-stamp requests. The psychologically ill assess themselves psychologically,
 - Although self determination is a right in the end of Life Health Care act, it must be remembered that healthcare is not a 'right ' either in the charter of Quebec or that of Canada. I cannot imagine that this does not violate one of the 7 principles of fundamental justice
 - Self determination is not so sacrosanct as we make it out to be: vaccine passports, restraints of all kinds: physical, chemical or environmental, influence of all sorts. Health workers, teachers and others who may soon be forced to be vaccinated. Recommending or using counselling like a vaccine passport (no counselling, no MAID) could even be construed to be

a protection , like a restraint, for the psychologically ill who are choosing death, or harming themselves.

- Notwithstanding this there is no obligation to perform these medical healthcare acts, or any other, with taxpayer funds as all provincial jurisdictions state, 'resources permitting.' With all these deficits and shortages and the additional costs to truly have teams who assess prudently, is this not contradictory? Do resources truly 'permit'?
- Irremediable psychological suffering a criteria which is treatable is not treated.
- Prevention and integrated health care is advocated and budgeted for but not implemented.
- Any kind of request for euthanasia, any type of client, should get the same treatment whether filed as a part of power of attorney, mentally disabled under curatorship or otherwise regarding changing their mind at death and healthcare professionals should respect same. Overtime better treatments and cures may be developed. A team that evaluates in favour of life and disregards advance requests, should not be sued should be made law, even if this concerns religion.
- cures for incurable disabilities may suffer if cases opt for death.

WHAT IS LIKELY TO HAPPEN

All these contradictions - a veritable Pandora's Box. It is too full of contradictions, too risky, too subject to error and bias, too costly to assess properly and to correct for bias. **The prudent thorough investigative analysis that will be required to assess these requests, on a case by case basis , in our current fragile resource stretched system I fear will just not get done and leave the vulnerable not adequately protected.** Let's focus on what is needed to live in dignity and get that right before using resources with such high risks management costs.

- Quebec has never seen hospitals as understaffed as now. 1 hospital in three has a budget deficit and CHSLDs are still understaffed. At least one hospital is closed and across Quebec many emergency rooms are farther above capacity than ever before. Nursing shortages have never been so profound and relying on private sourcing has just cost us another 500M\$ to the annual 500M\$ we spend each year. Job vacancies in healthcare have risen by nearly

40% since last year. Our 'Guardian Angels' psychological stress is higher than normal. Our COVID engorged waiting lists for surgeries are dangerously long. All this impacts the system and reverberates through it on many levels. July 30 Dr. Tam warned us that once again healthcare capacity could be exceeded due to the Delta variant if not enough Canadians are vaccinated. Even pre COVID status quo resource level is far from realistic to ethically realize the proposed assessment procedures and the added safeguards required for protecting our most vulnerable clientele for MAID requests. 400,000 Quebec citizens await assignment to a family doctor. The federal parliamentary budget officer says an additional 13.7 billion will be required just to help remedy long term care. The annual funding for an aging population and inflationary pressures on wages will rise by more than 4% per year. Our healthcare system in Canada is ranked second to last among 11 high income countries. The Netherlands came in 2nd. If you only compare universal Health care countries 2020, Canada has some of lowest numbers and longest wait times. (Fraser Institute) 24th of 28, for no of Psychiatric beds, 25th for acute beds, 26th for no. physicians.

- We have waiting times for palliative care. We waste funds building units averaging 750,000\$ instead of reasonable ones for seniors in political haste to address our COVID exposed long term care neglect. To set up more systems, devote more personnel, more evaluations and meetings we do not have the resources. It will further impact shortages, or more likely than not, it will not be done as thoroughly as we talk about. The CMA is holding 3 conferences before their annual general meeting to Rethink Healthcare Summit 2021 but particularly longterm care and supports have not improved since the 80s,

THIS IS WHY IT IS NOT LIKELY ASSESSMENTS WILL BE DONE PROPERLY AND THERE IS ALSO A RISK OF THE FOLLOWING

- We have demonstrated in the past a discrimination towards seniors and vulnerable without consequences and accountability which may incite professionals like the anaesthesiologist of Cite de la Sante who performed euthanasia improperly..no MAID, no palliative care bed. If beds are short one day, who is to say! Much like anticipating shortages when we ordered ambulance drivers not to resuscitate seniors or CHSLD patients not to be

transported to hospitals. Add media suppression or media partnership which we witness nowadays along with very short news cycles that allow for little to no accountability.

Our 2084 will prove far more dystopian to George Orwell's 1984: no longterm or home-care, a new order where only 'meaningful' lives proceed and maybe the state will define that by then as they already acquiesce to others' definitions!

WHAT SHOULD HAPPEN



I recommend distancing ourselves from this expansion of the MAID law and investing more in life and supports for mental illness and palliative care for dying which will remain challenging to finance.

If you have a chance please take the time to Watch BJ Miller - What Really matters at the end of Life utube Ted talk. He is a hospice

and palliative care doctor who got into this work because he came close to death.

I cannot imagine the horror of living in a continual vortex of fear and paranoia and mental illness: the internal violence, the continual episodes of getting readmitted to hospitals, prisoners in imaginary cages, the languishing on heavy drugs. Or recently the Abel story that has come to your attention. This is all very sad and terrible. Symptoms can be managed to some extent and the quality of life looks terrible to us. These are hard things to witness, harder still to judge if we are doing the right thing but **ever so irrevocable and tragic if we do not.**

I in no way wish to trivialize the 'pain' or suggest the source of psychological suffering is loneliness suggested by the following excerpt. Rather I do feel that such a great part of the problem is due to inadequate supports of all kinds and the real tragedy is that we save so few because of this.

Died in the church and was buried along with her name
Nobody came
Father McKenzie
Wiping the dirt from his hands as he walks from the grave
No one was saved
All the lonely people (ah, look at all the lonely people)
All the lonely people (ah, look at all the lonely people)
Where do they all belong?

Source: [LyricFind](#) Songwriters: John Lennon / Paul McCartney Eleanor Rigby lyrics