



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

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REGARDING :

Inquiry into End of Life Choices in the ACT

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Dear Committee Members,

Please refer to the attached submission for this inquiry.

Yours sincerely,


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Submission for

Inquiry into End of Life Choices in the ACT

23 Mar 2018

Dear Committee members,

I am making this submission in a private capacity, as an ACT resident and a member of the public, but also as a healthcare professional with over 16 years' experience as a medical practitioner. I currently practice in the hospital sector as a specialist in the fields of Infectious Diseases and Clinical Microbiology. My previous experience includes working for varying periods as a specialist trainee in the areas of Medical Oncology, Haematology, Geriatrics, Neurology, Respiratory Medicine, Nephrology, Cardiology, Intensive Care and Emergency Medicine, all of which are areas where end of life issues are frequently addressed. There have been many instances where I have been involved in end of life discussions and decision-making, both with patients and their family members. I have, over the course of clinical practice, encountered patients expressing the wish to die or, much less frequently, requesting to have their lives ended by intentional medical intervention.

Practices utilised to assist a person to exercise their preference in managing the end of their life

From personal experience, I often encounter situations where patients with a life-threatening illness have not thought seriously about end of life decisions, and neither have their family members. Many of these persons have not expressed to their family members or surrogate decision-makers, either verbally or in written form, their wishes regarding treatment goals and limitations, especially with regard to escalation of management to include intensive care management (e.g. with artificial ventilation). In ACT public hospitals, this is addressed by discussions initiated by clinical staff soon after admission. These are documented on forms such as those attached to this submission, leading to written treatment orders aimed at meeting 'Goals of Care'. However, many such discussions occur in acute emergency situations which are not optimal for carefully considered decision-making by either patients or their families.

I believe that there is a greater need in the ACT for the public to be educated on end of life decision-making and be encouraged to discuss this with their families, surrogate decision-makers and their regular General Practitioner or medical carer *prior to* illness crises which precipitate emergency hospitalisation.

Having had multiple encounters with dying patients and their families, it is my opinion that the public also needs to be provided with more information on palliative care services and strategies

available at the end of life, especially home-based palliative care. Many **do not have an understanding of what palliative care can offer**, and therefore do not make well informed end of life choices.

Motivations for accessing assisted dying

In public discussion, a commonly cited reason for legalising assisted dying is that this provides a mode of relief for those dying with excruciating pain that cannot be otherwise relieved. But how often is this the main reason for accessing assisted dying? Data from Oregon, USA, where Physician Assisted Suicide (PAS) is legal, show that only 26% of patients receiving PAS cited pain as a significant concern in their decision making (Table 1).¹ **The most common key reasons for accessing PAS were loss of autonomy (91%), loss of ability to engage in activities making life enjoyable (90%) and loss of dignity (76%), not uncontrolled pain.**

It is important for the public and for legislators to understand these key motivations before embarking on the process of deciding whether and how to legislate for assisted dying.

Oregon Patients receiving Physician Assisted Suicide – 1998-2017		
End of life concerns	(N=1,275)	
Losing autonomy (%)	1,154	(90.9)
Less able to engage in activities making life enjoyable (%)	1,137	(89.5)
Loss of dignity (%)	865	(75.7)
Losing control of bodily functions (%)	579	(45.7)
Burden on family, friends/caregivers (%)	554	(43.7)
Inadequate pain control or concern about it (%)	327	(25.8)
Financial implications of treatment (%)	47	(3.7)

Source : Oregon Death With Dignity Act 2017 Data Summary

Table 1 : Main End of Life Concerns in Patients receiving PAS

Risks to individuals and the community associated with voluntary assisted dying

Potential threat to patient autonomy and risk of involuntary death by euthanasia or PAS

Given that the data from Oregon show that the most common considerations for accessing PAS have to do with individual perceptions of losing autonomy, enjoyment and dignity, it can be argued that **patients may potentially be psychologically manipulated by others (intentionally) or influenced by others (inadvertently) into requesting euthanasia/PAS**. This is important because a reasonable proportion of patients felt that being a burden to caregivers was the main concern involved in their decision to access PAS. Usual safeguards may not be able to detect

these subtle undue influences on a patient's decision-making process. In my clinical practice, I have personally witnessed how communications between family members and a sick or dying relative can profoundly and adversely influence their perception of themselves and the value of their life, even in those without clinical depression.

The risk of involuntary euthanasia exists. In the Netherlands (where euthanasia and PAS is legal) in 2005, ***over 500 patients were estimated to have had their lives ended by their physician without explicit consent.***² In Belgium from 2005-2006 (where euthanasia and PAS is legal), a study of 1644 non-sudden deaths revealed that 22 deaths occurred by euthanasia or PAS with explicit consent, but that ***26 deaths occurred by lethal drug administration without consent.***³ In these countries, despite the presence of regulatory safeguards, it is unclear how deaths without consent can be effectively avoided.

Another safeguard which has been applied in some jurisdictions, such as Oregon, is that patients of concern must be referred for psychiatric assessment before euthanasia/PAS is carried out, just in case depression has been a contributor to their decision to request termination of life. In the Netherlands, a study of terminally ill patients with less than 3 months to live showed that those with depression were 4 times more likely to request euthanasia/PAS than those without depression.⁴ In Washington, USA, 55% of patients requesting euthanasia/PAS had severe depression or depressed mood.⁵ Although Oregon regulations require referral of a patient requesting PAS to a psychologist or psychiatrist if concern exists that the patient has a psychiatric disorder, including depression, that may impair judgment, ***a study showed that 3 of 18 (17%) of patients who received PAS had depression but yet none of them had formal psychological/psychiatric assessment before the lethal drug was prescribed.***⁶ This calls into question the efficacy of safeguards, no matter how stringent they may seem.

Expansion of assisted dying access to groups not originally targeted by legislation

Once legalised, there may be the risk of a gradual increase in the groups of people who are accessing assisted dying, either through changes in the law or else through a change in practice within the limits of a broad interpretation of existing laws.

The Belgian Parliament legalised euthanasia for adults in 2002. However, by 2013, the ***law was changed to allow terminally ill minors to choose euthanasia.***⁷ In September 2016, the first minor was euthanised under the new laws.⁸

In Canada, medical assistance in dying (MAiD) was permitted by law in 2016 for persons at least 18 years of age with a serious and incurable illness, disease or disability and in an advanced state of irreversible decline in capability. However, the Act allowing euthanasia and PAS had provisions for establishing one or more independent reviews relating to ***requests by mature minors for medical assistance in dying, to advance requests and to requests where mental illness is the sole underlying medical condition.***⁹ These steps are aimed at subsequently broadening access to assisted dying.

In the Netherlands, amongst other criteria, provided that the physician is satisfied that the patient's suffering is unbearable and that there is no prospect of improvement, and the physician has discussed the situation with the patient and come to the joint conclusion that there is no other reasonable solution, euthanasia is allowed under the Termination of Life on Request and

Assisted Suicide (Review Procedures) Act, which came into force in 2002.¹⁰ There is no explicit need for a terminal illness to be present, although most cases have been cancer patients. In recent years, interpretation of the criterion for unbearable suffering with no other solution has resulted in **increasing cases of euthanasia for psychiatric disorders** (Figure 1).¹¹ A separate study analysing Dutch cases from 2011-2014 noted that the *granting of euthanasia/assisted suicide requests for psychiatric disorders appeared to involve considerable physician judgment, usually involving multiple physicians who did not always agree (and sometimes without independent psychiatric input) but the Review Committees generally deferred to the physicians performing the euthanasia or assisted suicide*.¹² This is certainly a worrying trend in a vulnerable population.

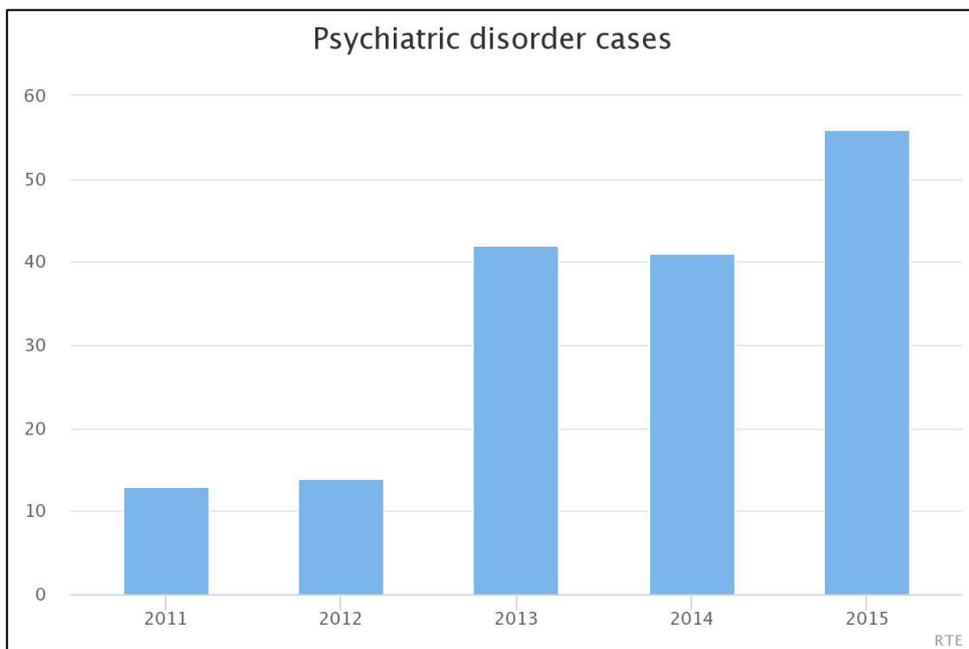


Figure 1: Cases of Euthanasia and Assisted Suicide for Psychiatric Disorders in the Netherlands

Potential adverse impact on societal views and practice of suicide

Legalisation of assisted dying may potentially lead to increasingly conflicting and confused views in our society regarding suicide in general. While not illegal, suicide is generally considered an adverse event which ought not to occur and, therefore, its prevention is something which our society generally accepts and which the government advocates (e.g. through the ACT Health 'Let's Talk for Suicide Prevention').¹³ Suicide prevention is also important nationally, where suicide prevention organizations like Lifeline exist. By legalising euthanasia or PAS, we may be perceived by vulnerable, psychologically troubled persons to be a society holding double-standards with regard to suicide.

More worrying is some data which seems to show at least an **association between legalising PAS and overall suicide rates**. One study, comparing US states which legalised PAS with those that did not, found that legalising PAS was associated with a 6.3% increase in total suicides.¹⁴ The

exact reason for this is unclear, but social contagion effects, where a person's actions influence other peoples' actions, have been postulated.¹⁵ In many cases, I believe the overall impact of legalising euthanasia and PAS on society at large has not been deliberately or rigorously studied or even measured well.

Mistakes in diagnosis or prognosis leading to assisted death

Even with modern technology, doctors cannot accurately diagnose terminal illness or estimate the time to death in every case.

When considering medical conditions causing critical illness, one study of discrepancies between clinical and autopsy diagnosis reveal that ***post-mortem findings are in complete agreement with pre-death diagnoses in under half the cases.***¹⁶ In critically ill patients, another study showed that only 31% of cases had complete agreement between pre-mortem and post-mortem diagnoses.¹⁷ Another study showed that in 10% of cases, the patient would have been expected to live had a correct clinical diagnosis been made.¹⁸

The very real possibility of wrong diagnosis leading to death is illustrated by the case of Pietro D'Amico, a 62-year-old magistrate from southern Italy, who ended his life by assisted death at a clinic in Basel, Switzerland. The father-of-one took the decision after a wrong diagnosis of life threatening illness from Italian and Swiss doctors. An autopsy carried out by the University of Basel's Institute of Forensic Medicine found that D'Amico was not suffering from a life-threatening illness at the time of his death.¹⁹

Even in situations where a diagnosis has been made seemingly accurately, an incorrect prognosis may be provided. Take, for example, the illustrious physicist Stephen Hawking, who recently died, aged 76. He was diagnosed with amyotrophic lateral sclerosis (a form of motor neurone disease) at age 21, and was told he had only a few years to live. Yet, he defied expectations to outlive his prognosis by many decades.^{20,21} The world of theoretical physics would be much poorer off if he had chosen assisted dying (had it been available) in the first few years after diagnosis, based on an incorrect prognosis.

A recent review of clinical studies that reported clinicians' prediction of survival (time to death) in advanced cancer patients showed that ***clinicians' prediction of survival is often inaccurate.*** Clinicians in 5 studies underestimated patients' survival whereas clinicians in 12 studies overestimated survival.²²

Since decision-making for assisted dying is influenced both by diagnosis and prognosis, patients may potentially choose assisted death based on incorrect information. ***Because assisted dying is an intervention which, once completed, is not reversible, much greater certainty needs to be attached to the diagnosis and prognosis of diseases, both of which may not be achievable currently.***

Conclusion

I believe that there is a greater need in the ACT for the public to be educated on end of life decision-making and be encouraged to discuss this prior to illness crises which precipitate emergency hospitalisation. This includes provision of more information on palliative care services and strategies.

With regards to the legalisation of assisted dying, I believe that the potential risks are likely to outweigh benefits. No safeguards are foolproof. I submit that the legalisation of voluntary assisted dying would not be in the best interests of the ACT community.

Yours sincerely,

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Goals of Care Discussion Record		Affix label here	
Date:	Time:	Location:	
Name and designation of person leading discussion *SDM= substitute decision maker	People present for the discussion (please include names and relationship to patient/resident) Patient: _____ SDM*/Enduring Guardian: _____ Others: _____		
Summary of patient and/or substitute decision-maker/family understanding of condition/situation: Prompt: "Can you tell me what you understand the situation to be in relation to your current illness"			
Summary of information provided to the patient/substitute decision maker/family:			
Summary of goals of care (i.e. medical, social, emotional, spiritual) arising from the meeting:			
	MOLST Completed? (Please Circle Response)	YES	NO
All the following MUST sign this record	Name	Signature	Date
Patient or person responsible			
Person recording discussion			
Medical Officer			

Please complete additional information overleaf

Information provided to patient/person responsible/family at meeting:
Pamphlets:

- Medical Orders for Life Sustaining Treatments (MOLST Consumer Brochure)
- Advanced Care Planning

Fact Sheets:

- Guardianship
- Person responsible

Other Information

1.
2.
3.

Note: Additional clinical information for situational awareness should be documented in clinical record

Information provided by:	Name	Signature	Date

Additional information provided:

- 1..... Provided by:..... Date:
- 2..... Provided by:..... Date:
- 3..... Provided by:..... Date:
- 4..... Provided by:..... Date:
- 5..... Provided by:..... Date:

MEDICAL ORDERS FOR LIFE SUSTAINING TREATMENT (MOLST)

Unit Record Number:

--	--	--	--	--	--	--	--	--	--

Family Name: _____

Given Names: _____

Date of Birth:

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Age:

Gender:

This is a Standing Medical Order based on a discussion regarding the person's Goals of Care (see Goals of Care Discussion Record), medical condition as recorded in medical notes and anticipated prognosis. The MOLST must be completed/reviewed by Medical Officer every admission and as required.

If any section is not completed full intervention should be assumed until clarified with patient or Substitute Decision Maker

Every Patient Should Receive Full Attention to Comfort

A
Select one box

CARDIOPULMONARY RESUCITATION (CPR): For a person in cardiac or respiratory arrest

- Attempt CPR to prolong life Do not attempt CPR - allow natural dying

When not in cardiopulmonary arrest, follow orders B, C and D (below)

B
Select one box

LIMITED USE OF LIFE SUSTAINING TREATMENT

- No Limitation to treatment** - The current goal of care is CURATIVE or RESTORATIVE. Use all treatments aimed at prolonging life.
- Use Limited Life Sustaining Interventions** Use medical treatment, IV fluids, medication and cardiac monitor as medically indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation for person's irreversible condition/s. **Avoid** admission to critical care units if possible. Includes care as described in the "allow natural dying" section below.
- Allow natural dying - use comfort measures** Use medication by any route (subcutaneous or oral preferred), positioning, wound care and other measures to relieve distressing symptoms, pain and distress. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Do not admit to critical care unit.**

ORDERS FOR SPECIFIC MEDICAL INTERVENTIONS

C
Select one box

ANTIBIOTICS

- Use antibiotics by whatever route necessary to prolong life, where this is medically supported.
- Use antibiotics by whatever route necessary to promote comfort and relieve distress only.

D
Select all applicable boxes

ARTIFICIALLY ADMINISTERED NUTRITION & HYDRATION

- Do not use artificial nutrition treatment (Naso-gastric or PEG feeding).
- Do not use intravenous fluids (IV) - Use subcutaneous (S/C) or oral routes only.

Informed and agreed to have a MOLST order written

M1

Persons involved in decision-making related to these MOLST

- Patient Enduring power of attorney/substitute decision maker/ guardian Other

Name: _____ Contact number: _____

CONSENT

M2

Medical Officers Signature

Doctor's Name (Print): _____ Designation: _____

Signature: _____ Date: _____

Contact Number: _____ Consultant Responsible Informed: Yes No

REVIEW

M3

MOLST form reviewed by Medical Officer

Date/Initial

Date/Initial

Date/Initial

REVOKE

M4

REVOKING THIS MEDICAL ORDER

If medical orders for life sustaining treatment change, the treating doctor must **cross through these orders and write VOID** in a clearly legible format. A new MOLST form must be completed with revised orders

Name of person voiding form:

Signature: _____ Date: _____

Unit Record Number:

--	--	--	--	--	--	--	--	--	--

Family Name: _____

Given Names: _____

Date of Birth:

--	--	--	--	--	--	--	--	--	--

Age: Gender:

MEDICAL ORDERS FOR LIFE SUSTAINING TREATMENT (MOLST)

NOTE:

The following patients should be considered for appropriate **LIMITATION OF LIFE PROLONGING MEDICAL TREATMENT** and goals of care, medical condition and anticipated prognosis discussed with them and their family/person responsible:

2. Any patient for whom such therapy carries a far greater risk of complications than possible benefits.
3. Any patient who appears to have decision-making capacity and who states that they do not want to have certain or all, life-prolonging treatments.
4. Any person who has an **Advance Care Directive** or whose legal substitute decision-maker states that they do not want life prolonging treatments.

Guidelines for using the MOLST - An Eight Step Framework

STEP 1: Assess and prepare

- Undertake a clinical evaluation of the patient - history, presentation, capacity
- Utilise the Palliative and End of Life Screening tool to determine if there are unmet end of life care needs
- Identify if the person has an Advance Care Directive
- Identify who is the patient's substitute decision maker/guardian/Person Responsible and contact them

STEPS 2 - 5: Communicate and agree goals of care

2. Begin with an enquiry into what the patient/family/person responsible already knows
 - a. About their condition and prognosis
 - b. About the patient's values and beliefs
3. Provide any new information about the patient's medical condition from the medical team's perspective
 - a. Provide information in small amounts, give time for response
 - b. Seek a common understanding - understand areas of agreement and disagreement
 - c. Make recommendations based on clinical experience taking into account patient's condition and values
4. Try to reconcile differences in terms of prognosis, goals, hopes and expectations
 - a. Seek common ground
 - b. Use conflict resolution when necessary
5. Respond empathetically
 - a. Acknowledge the patient's/family perception and concerns
 - b. Legitimise
 - c. Explore (rather than offering premature reassurance)
 - d. Empathise
 - e. Reinforce commitment and non-abandonment

STEPS 6 - 8: Document

6. Use MOLST to guide choice and finalise patient/family/responsible person wishes
 - a. Review the key elements with patient/enduring power of attorney/guardian
 - b. Apply shared, informed medical decision-making
7. Complete and sign MOLST
 - a. Obtain verbal or written consent from patient or substitute decision-maker
 - b. Document conversation in the medical record

The Consultant or Medical Specialist responsible for the patient's care, or their designated delegate (CMO, Registrar or Senior RMO) in discussion with Specialist completes and signs the MOLST form. **This responsibility must not be delegated to a medical intern/junior RMO**

8. Review and revise as required - when patient's goals of care, condition or prognosis change