December 31 2020

Dear UTAS reviewers

Thankyou for reading my submission which is focused on the failure of assisted suicide laws in overseas jurisdictions to protect the vulnerable.

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An outline of my submission is:

Section A Cases 1-9 from overseas jurisdictions where assisted dying laws are alleged to have been breached or failed to protect the vulnerable

B. Montana considering rescinding MAID law

C. The case of the DELTA HOSPICE where a facility is not allowed to conscientiously object to provision of assisted dying in Canada.

D. Policy statement of the US National Council on Disability on MAID (attached)

E. Progressive expansion of eligibility criteria for assisted dying in overseas jurisdictions

F. Government sanctioned legal suicide – a comment and dilemma for clinicians

G. Canada and MAID – problems

H. Victoria and VAD -problems

Summary

SECTION A

It is sometimes inaccurately stated that there are no known cases of allegations of breach of safeguards or failures of protections in overseas jurisdictions that have legal physician assisted suicide /MAID /VAD.

Data in such cases can be hard to find as the subject in the case is deceased. Who can take the lead in pursuing a safeguard breach in this setting? Details of such cases can also be kept confidential due to privacy concerns.

I document the following cases where concerns or allegations about breaches or failures of euthanasia laws have been widely available in the international media in print or online.

1. THE CASE OF MR ALAN NICHOLLS-CANADA

This man's case was well covered by the Canadian media in 2019 and these can be found on google. He was a 61year old man who was single with no children and who lived alone. He had a history of a brain tumour as a child. He had siblings with whom he had contact. He had previously worked as a janitor. For 10 years since the death of his father he had suffered from depression. He was found by a neighbour after a collapse and was found to be dehydrated and malnourished. He was taken to a hospital in British Columbia Canada. One month (just 30 days later) later he died by lethal injection in hospital despite the objections of his siblings. His family who visited him in hospital say that he was a vulnerable person who could have functioned well back at his home with increased support services. The family state that in their view he was depressed and lacked decision making capacity and they say he had no illness or condition that meant that his death was reasonably foreseeable. They were told nothing by the hospital due to confidentiality and the hospital maintained that the patient was competent to consent to MAID and that the family had no right to intervene. The MAID went ahead with family present and the family has lodged a complaint with the British Columbia Department of Health. The cause of death on his death certificate stated MAID, stroke and frailty.

CONCERN:

Family claim man INELIGIBLE FOR MAID (depressed, unable to consent, did not have a life-limiting serious illness)

OUTCOME – Hospital won't respond to media questions because of privacy

Family lodge complaint with BC government – no known response

HIGHLIGHTS: No clear route for complaints to be responded to or processed. Canadian government is not interested, not accountable, does not want to know, answerable to no-one.

2. THE CASE OF MR ROGER FOLEY-CANADA

Many articles confirm the details of this man's case and can be found on google. This man in his 40s, a former bank manager, has cerebellar ataxia a neurological illness that causes physical disability that makes him fully physically dependent needing fulltime care. He requested that health authorities in Ontario Canada provide him with self- managed at home care services. They declined and offered him medical assistance in dying instead (MAID) i.e., euthanasia. This would be much cheaper than providing care. He has an audio recording of the offerings of MAID. He has launched a court case (that remains active to this date) against the hospital, the Ontario Health Ministry, the province of Ontario and the federal government of Canada stating that these have abused him as a disabled person by offering him death by MAID rather than trying to assist him with his life, when he had made it very clear that assistance to live was what he wanted. He is concerned that this has happened to other disabled people.

CONCERN:

Coercion of a disabled man by government staff to use /access MAID despite him requesting assistance to live

OUTCOME:

Mr Foley now has the home care arrangements that he wanted but continues to articulate concerns about poor treatment of the disabled in Canada

His court case is ongoing against the Ontario government

HIGHLIGHTS: Vulnerability of disabled to coercion about MAID and the difficulty in proving this – if Mr Foley did not have the audio-recordings.

3. REPORT- UN First Rapporteur on the Rights of Persons with disability Ms Cataline Devadas Aguilar

This lady is a lawyer and human rights activist and she visited Canadian cities meeting with government and disability groups in April 2019.

She wrote a report, a part of which referred to MAID in Canada.

"I am *extremely concerned about the implementation of the legislation on medical assistance in dying from a disability perspective*. I have been informed that there is no protocol in place to demonstrate that persons with disabilities have been *provided with viable alternatives* when eligible for assisted dying. I have further received worrisome claims about persons with disabilities in institutions *being pressured to seek MAID*, and *practitioners not formally reporting cases* involving persons with disabilities. I urge the federal government to investigate these complaints and put into place adequate safeguards to *ensure that persons with disabilities do not request assisted dying simply because of the absence of community-based alternatives and palliative care".*

(access her full report on website – inclusionCanada.ca)

CONCERN:

Disabled in Canada not provided with alternative supports to live instead of assisted dying and can be pressured to access assisted dying

Doctors may not be reporting cases of MAID involving those with disabilities

OUTCOME – no public response from the Canadian government

HIGHLIGHTS: significant concerns of the Canadian disability community about the vulnerability of the disabled to be pressured into MAID

Non response of the Canadian govt to concerns expressed –no accountability, not interested, don't want to know.

4. THE CASE of MR SORENSON EUTHANASED IN CANADA

Mr Sorenson was an 83-year-old man with a history of chronic obstructive airway disease. He had been married for 48 years. He had been assessed by a number of MAID providers over a period of time, some of whom determined he was eligible for MAID and others who said that he was not. As two eligible and independent assessors determined him to be eligible for euthanasia in Canada the procedure was scheduled. His wife Mrs Sorenson 82 years old objected to his application for MAID and applied to the Supreme Court of Nova Scotia in Canada to have his access to MAID permanently blocked. Her contention was that the conflicting assessments of his eligibility meant that he should not be able to proceed. She sought the courts to undertake a role in reviewing the various doctors conflicting assessments in determining MAID eligibility.

Ultimately the case of Mrs Sorenson was dismissed and it was determined that courts have no role in reviewing MAID eligibility assessments – including capacity assessments. These assessments are entirely up to doctors and nurses. During the court hearings the couple separated. After the court finding Mr Sorenson was euthanised.

CONCERN:

Man, ineligible for MAID because of conflicting medical assessments

Sought court assistance and review

OUTCOME:

Two assessors say he is eligible so he is eligible for MAID

Court has no role to review or interrogate doctors about their MAID assessments

HIGHLIGHTS:

Doctors have unfettered power when making VAD /MAID assessments and their opinions and assessments will NOT be questioned.

Doctor shopping means that persistent patients may find an assessor who deems them eligible eventually

5.THE CASE OF THE WOMAN WITH DEMENTIA DRUGGED AND FORCIBLY EUTHANASED IN HOLLAND

In Holland a woman in her 70s expressed a wish that when her dementia deteriorated, she would like to die “when the time was right. “Then in 2016, four years after diagnosis the woman in the presence of her family at her nursing home had a sedative placed in her coffee and then when she woke up and resisted at the request of the doctor, she was restrained by family members and euthanised by lethal injection given by the doctor. The doctor was criminally prosecuted for manslaughter. The doctor was later found to not have broken any law, having acted “in good faith on the patient’s personal request years earlier in her “living will”

This case was one of the first criminal investigations since 2002 when Holland legalised euthanasia.

Since this verdict Holland has more recently approved the forced euthanasia of people with dementia if they earlier ask to be killed before they later become incompetent.

(APnews by Maria Cheng April 20 2018)

CONCERN:

Doctor forcibly euthanised patient against her consent at the time of the procedure

Doctors can practice involuntary euthanasia

OUTCOME:

Earlier competent consent meant doctor had acted in good faith so NOT GUILTY.

Now formalised in Holland that forced euthanasia of demented patients is fine if they have given previous consent.

HIGHLIGHTS:

Doctors willing to move ahead of established practice boundaries in their practice and commitment to the principle of euthanasia

Progressive expansion of conditions in Holland under which people can be euthanised. Fine to euthanise and restrain a previously consenting patient even if they later say they have changed their mind or resist.

6. THE CASE OF THE DEPRESSED WOMAN EUTHANASED WITHOUT FAMILY KNOWLEDGE IN BELGIUM

Tom Mortier is taking the case of his mother Mrs De Troyer to the European Court of Human Rights to challenge Belgium's euthanasia law- saying it has gone too far. She was euthanised for untreatable depression in 2012 by a medical oncologist Dr Wim Distilments who has no qualifications in psychiatry. She did not have cancer but had a 20-year history of depression. The doctor met Mrs De Troyer only for euthanasia and consulted with two other doctors on the case who were also euthanasia doctors and his own associates and these also had no previous involvement with her care. The patient's own doctor of more than 20 years had denied her request to be euthanised in 2011. But after she donated 2500 Euro to the End-of-Life Information forum (an organisation co- founded by Dr Distilmens) he carried out her request to die. Dr Wim Distilmens, the doctor involved in the case is President of the Belgian government's commission to investigate any failures of the euthanasia law and has been the head of this since the commission started. Son Tom Mortier maintains his mother was upset at the breakup of a relationship and disliked her physical distance separation from her family. Her family was not notified of her plans for euthanasia until after she had died.
At least 8 of the 16 people on the Belgian commission are doctors who perform euthanasia or are euthanasia advocates.

Details have become available that in this case the interval between death and the request was 58 days - a short time for a woman with complex and longstanding depression. As the decision of the commission was unanimous Distilmens voted to approve his own decision to euthanise this lady. As a member of the commission and given his involvement on the case Dr Distilmens should not have reviewed his own case. The patient's forms stated all treatment attempts had been exhausted and

that her unbearable psychological suffering could not be cured. However, the lady received no other therapy for her depression.

(European Centre for law and justice by Priscilla Kulczyk 2018) eclj.org). Also(bioedge.org)

CONCERNS:

Patient was ineligible for euthanasia as did not have incurable depression and received no other therapy.

Doctor involved was not a specialist in psychiatry and was inexpert to make this assessment.

Doctor received a financial inducement to euthanise the patient.

Doctors assessments of the patient were not independent of each other

Doctor on the commission reviewed and approved his own decision to euthanise the patient retrospectively.

OUTCOME: The findings of the European Court of Human Rights are awaited and expected by mid-2021

HIGHLIGHTS:

Shows why MAID assessments should be undertaken by a specialist in the underlying condition

Shows how patients can doctor shop until they get the euthanasia assessment they want.

Shows how review boards may not be independent and can be staffed by people who support assisted dying (the same has occurred in Victoria – limiting any scrutiny)

Shows how forms can list inaccurate information and usually this will never be reviewed and discovered.

9. THE CASE OF THE WOMAN WITH AUTISM EUTHANASED IN BELGIUM

This case was also referred for criminal investigation at the request of the patient's family.

Ms Tine NY's 38 was euthanised in 2010 for autism. Three doctors were reported for criminal prosecution relating to her death.

She had suffered depression and heroin addiction when younger and had made suicide attempts in the past. She had not had psychiatric treatment for 15 years prior to being euthanised. The diagnosis of autism was made 2 months before her death.

The family report the patient was upset after a relationship breakdown and did not have an unbearable and untreatable condition as required by Belgian law. They stated doctors had not tried to treat her mental illness and she was not incurably ill.

In Jan 2020 the three doctors who had been charged with manslaughter by poisoning were cleared. They had faced life imprisonment.

In September 2020 the Court of Cassation quashed the ruling of the Court of Ghent in regards to the administering Doctor and GP Dr Van Hove's involvement in this case. He will go for trial again in relation to this case. He is a GP and this case was his first case of euthanasia for mental ill health.

(vrt.be 15 sept 2020)

(apnews.com Maria Cheng no 28 2018) (www.bbc.com)

CONCERN:

That patient was not eligible for assisted dying as she did not have an untreatable condition and had received no other treatment.

OUTCOME:

Manslaughter charges against the 3 doctors were dismissed by the jury. Further proceedings have now been launched against the administering Dr Van Hove.

HIGHLIGHTS:

The difficulties of a non-specialist assessing a case for euthanasia especially where mental ill health is involved.

The vulnerability of those with mental illness in applying for assisted dying .

SUMMARY -These cases are just the TIP of the ICEBERG in terms of documenting concerns about and failures of assisted dying legislation overseas. These cases have made international media attention to receive the light of day. How many more concerns have been brushed aside or been hidden? Problems demonstrated include : the depressed and disabled being vulnerable to coercion and wrongful deaths, the two doctors assessments not needing to be independent or ever be re-assessed or reviewed(unfettered power), review boards and commissions being full of pro – assisted dying advocates which limits their real review capability , financial inducements of doctors, doctor shopping , nowhere for complaints to be received , processed and responded to short of criminal proceedings which are difficult and costly to undertake ,especially as the victim is deceased.

SECTION B

REPEAL OF MAID LEGISLATION IN MONTANA USA - TO BE A FIRST?

The US state of Montana legalised MAID in 2009 when its supreme court ruled that it should not be prohibited. Since then, a number of bills have attempted to repeal this legalisation but have failed. Now bill LC2844 is s further attempt to rescind MAID in Montana. With conservatives now in control of the legislature and governorship in Montana this bill may pass. This would be a first for a US state to rescind a MAID law. (twitter: Thaddeus mason pope December 2020)

SECTION C

THE CASE OF DELTA HOSPICE IN BRITISH COLUMBIA CANADA

When a facility is nor permitted to conscientiously object to the provision of MAID.

In Canada religious hospitals and hospices are not mandated to provide MAID but must organise appropriate transfers of care for MAID. One hospice the Delta hospice is not a faith-based hospice but has a board that rejects the provision of MAID as being inconsistent with its ethos of care not killing. It states that there are other facilities nearby where MAID can be performed. The land the hospice is on is owned by the provincial government and most operating costs are covered by the provincial government. The hospice has been involved in a protracted dispute with the government over its refusal to provide MAID. This has received prominent running media commentary. Currently the facility has been advised that it will be completely defunded if it does not provide MAID by February 2021.

CONCERN:

-This shows that there is no right for conscientious objection to MAID by non-faith-based organisations /hospices in Canada and that these will be defunded and closed.

(google hospice name for multiple media stories)

SECTION D

REPORT BY US NATIONAL COUNCIL ON DISABILITIES (report attached – see summary section)

A US national disability report by the US National Council on disability (NCD) that was produced in October 2019. The report is titled- the Dangers of Assisted suicide. All US national disability groups with a position on PAS/E are opposed to it . The NCD has a position of opposition to legalisation of PAS. Its executive summary states **"AS puts those most vulnerable at risk of deadly harm. The risks of abuse are significant and safeguards are not effective**"

Diane Coleman Founder and President of "Not Dead Yet "a North American Disability advocacy group said "PAS /E has been marketed to the public as a step toward increasing individual freedom but choice is an empty slogan in a world full of pressures on people with chronic illness and disabilities".

In Australia our own Disability royal commission in late October 2020 has produced an interim report that concludes that those with disability experience attitudinal , institutional and communication barriers to achieving inclusion in Australian society. Much needs to be done to ensure their human rights are respected. There is abuse, neglect and exploitation of those with disability in Australia - in schools work, the community, at home. in hospitals, courts and NDIS services . They have poor access to services , have a lack of advocacy , limited ability to complain , and lack of funding.

So, if these have a qualifying illness it is easy to see how they are vulnerable to coercion with respect to PAS/E. Ableism is discrimination of able-bodied people. One could ask – how could anybody want to live like that ?

SECTION E

PROGRESSIVE EXPANSION OF ELIGIBILITY CRITERIA OVER TIME FOR EUTHANASIA OVERSEAS

I choose to avoid the term of slippery slope for clarity and precision.

Euthanasia laws over time can change by amendment or replacement or by being interpreted differently. In these ways' expansion of eligibility criteria and erosion of safeguards can occur. An example of the later is that in late 2020 the Dutch Health minister De Jong announced an intention to permit PAS/E for Dutch children aged >1 <16.The law will not be amended but there will be an exclusion for punishment for doctors who engage in the practice. ELIGIBILITY EXPANSION

In BELGIUM and HOLLAND euthanasia of children (in Holland currently < 1year of age and >16+) and for reasons of mental ill health alone now occur whereas these groups were not eligible 20 years ago when PAS/E first started there. ELIGIBILITY EXPANSION

In HOLLAND a bill for those over 75 who are tired of life is before the parliament. If approved this will be an ELIGIBILITY EXPANSION.

CANADA legalised medical assistance in dying (MAID) in 2016 (Bill C 14). Now in 2020 it is examining Bill C7 which amongst other things extends PAS/E to those whose deaths are not reasonably foreseeable i.e., to those with an unlimited life expectancy, who meet the other eligibility criteria. Bill C7 has already passed the lower house of the Canadian parliament and has gone to the senate. If approved this will be a significant ELIGIBILITY EXPANSION after just 4 years.

In OREGON, USA their assisted suicide legislation has been in operation for over 20 years. In the last year an amendment allowing the waiving of the 15-day waiting period was approved. This is LOOSENING OF A SAFEGUARD.

So, it is CLEAR that in a number of overseas jurisdictions the laws relating to VAD/MAID (or their interpretation) have expanded eligibility with time and/ or safeguards have been loosened.

SECTION F

GOVERNMENT SANCTIONED LEGAL SUICIDE

Australia goes to significant effort and expense to prevent suicide in this country. Recent suicide rates have risen in most states including Tasmania especially in youth, Indigenous and veteran communities. Suicide is defined in the dictionary as a person who kills himself or herself. VAD can interchangeably be called Physician assisted suicide despite some claiming that this is upsetting due to the negative connotations of the word suicide. It remains factually accurate.

The American Medical Association has examined the terminology and opined that Physician assisted suicide /euthanasia most accurately describes the practice not MAID or VAD which it opines are euphemisms. VAD is not just for the dying and some cases deemed suitable for VAD might live for years. This has been shown in Oregon where some have ingested the lethal substance after more than 3 years.

There is a contradiction in message when a government prevents suicide in some while providing the doctors and the means to provide suicide to others. The general public and medical staff are aware of this contradiction.

In large cancer units sadly suicide attempts are not uncommon. These have happened in Victoria in the last 12 months despite legal VAD.

If a person who attempts suicide has cancer or other illness and meets VAD eligibility criteria does a nurse or doctor:

A/ increase supports and attempt to get the person to revalue their life and change their outlook? This is the conventional approach. Or

B/ Validate their hopelessness and worthlessness and call the VAD navigator to arrange their VAD procedure?

These are the dilemmas that medical staff and families will have to sort due to legal VAD.

SECTION G

MAID on the ground in CANADA (article attached) -PROBLEMS

A recent publication in the World Medical Journal by three Canadian palliative care experts outlines their views on how things have gone. (World Medical Journal, Herx and Scott 2020 pages 28-37. The normalisation of euthanasia in Canada- the cautionary tale continues)

It's noted by these 3 authors that over time in Canada that:

-there have been less restrictive interpretations of eligibility criteria and that individuals have been euthanised for arthritis, dementia and frailty.

- euthanasia deaths are now serving as a growing source of organ and tissue donations in Canada.

- the practice is normalising as demonstrated by educational materials that describe how to make kids comfortable with the practice. The information states "if adults normalise MAID then the kids will as well." Its suggested to show the kids the equipment – the tray with things that will "help your loved one to die."

-there are mounting concerns that some are offered PAS/E because of lack of access to care and long-term disability supports.

-some consider MAID an answer to a perceived poor quality of life of lack of health care resources.

-assessors are often colleagues belonging to a small community of medical provider (so not really independent).

-people can access any number of providers to see if they can be approved for MAID (raising concerns re doctor shopping).

-the authors report experiences of patients who lack decisional capacity and yet have still been euthanised despite those concerns being documented and raised with MAID providers. (no accountability)

-details of deaths are only reviewed retrospectively.

- MAID provision is much cheaper that the cost of providing care for the patient.

-some patients conflate PAS/E with palliative care and so refuse to engage with palliative care for fear of their death being hastened by the palliative care team.

-when a patient requests MAID there can be a tendency to call the PAS/E team rather than to assess and provide the patient with what palliative care has to offer.

-there is an awareness of the availability of palliative care but no mandatory consultation. They note that a number seeking MAID reject palliative care involvement and may die without having a trial of excellent palliative care. These can often be quite symptomatic while awaiting their MAID procedure.

-there is lobbying for MAID to be available in every palliative care unit in the country even though it is rejected as being part of palliative care by all the international palliative care societies.

-some hospice societies who do not wish to offer MAID are being mandated to provide it or face closure.

-hospitals and faith-based institutions are criticised for transferring patients out of their facilities to access MAID when they refuse to have it performed on their premises.

-concerns about burnout and stress in palliative care specialists from their forced engagement with the practice that goes against their convictions and causes them distress are rising.

-there are concerns about a potential loss of palliative care physicians from the workforce at a time when more are needed.

-**The authors conclude that the legalisation and normalisation of MAID in Canada has had serious negative effects on Canadian medicine and Canadian society as a whole.**

SECTION H

PAS/E in VICTORIA – PROBLEMS

According to the Victorian government all is fine with PAS/E in Victoria. The media reports on beautiful peaceful deaths surrounded by loved ones.

There is another side.

Relatives of some patients accessing PAS /E are upset and remain upset by their relative's choice.

As in Tasmania it is suggested but not mandated to inform relatives. In Victoria some relatives including spouses have been deceived and believe that their relative died naturally.

Some are concerned that there is a distraction from best medical care for the patient by diverting the patient down a VAD pathway where patients can receive suboptimal palliative care which can be a form of medical neglect.

The program has been costly – estimates of $6 million dollars in the first year to date have been circulated. There is a VAD review board with approx. 10 members, multiple VAD navigators and a hospital pharmacy service. VAD medication is free for all. Initially for 12 months a separate VAD Implementation board oversaw implementation with another 10 staff.

Grants are provided to fund patient access to private consults and transport for VAD consults. VAD pharmacists drive anywhere in the state to deliver VAD medication to patients. If struggling palliative care patients need assistance to access pain medications - there is no such assistance.

At many palliative care services staff are divided on the issue which undermines a cohesive functional service that provides care for all patients. Some formerly good colleagues barely speak because of conflict related to this issue. Some palliative care specialists are considering leaving the profession .

Few doctors want to be involved .

One doctor Cam McLaren (who is a board director of Dying with Dignity Victoria) has openly stated that he assisted 100 Victorian patients to access VAD. In the first year only 124 patients accessed VAD. He has openly told the medical magazine Australian Doctor – " if I go under a bus the entire Victorian program would grind to a halt." He has spoken of a colleague who has assisted 60 patients . Curiously this data was omitted from the recent Victorian report on VAD in the first 12 months.

No -one knows where a complaint about the process should be lodged and cases are only reviewed after death if at all .

There are many reports of a long time to death ten or more hours which is concerning for patients and family who can be left on their own, and this highlights that the patient and family are not always obtaining the quick easy death that they expect.

Palliative care services remain poorly funded and resourced in most if the state- especially regionally. Services received about an extra 10% of the funding increases requested from the Victorian government.

OVERALL SUMMARY

The data presented suggests that it is not possible to legalise assisted suicide without exposing many more vulnerable people to the risk of harm and wrongful death.

Paul Keating rightly stated "the bald utopianism to claim that safeguards can guarantee protection of the vulnerable depressed and the poor. No law and no process can achieve that objective. "

The vulnerable (the depressed and disabled and the elderly) who should receive protection can and have been placed at risk and wrongfully euthanised with assisted dying legislation. Palliative care services are divided, medical treatments are withheld, few doctors want to be involved, progressive expansion of eligibility criteria has occurred overseas and suicide prevention attempts have been contradicted.

In this process emotional stories of unquantified numbers of so called "bad deaths" have meant that palliative care efforts have been undermined and people are wrongly told and taught to be fearful of their deaths which almost always occur naturally peacefully or if complex can be well managed by specialist palliative care services if the assistance of these is accepted.

Assisted suicide legislation is inherently unsafe and safeguards fail. A number of other harms to the medical profession and society in general occur. This legislation is about far more than the individual and his or her choice.

Vulnerable people should not die and others suffer harms so that a tiny few can "control "and "choose" the timing and manner of their deaths.