VOLUNTARY ASSISTED DEATH

THE PROMISE VS THE REALITY

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INTRODUCTION

On 7 August 2019, the Health Minister, Roger Cook introduced into the WA Parliament the Voluntary Assisted Dying Bill promising that it "provides a safe and compassionate approach to voluntary assisted dying and a workable legal framework".

The Minister tabled a report of 102 so called "safeguards".

That is the promise.

The reality is that the Report seeks a profoundly radical change to end of life care in WA, with:

- **No evidence to guarantee it will always be voluntary**
- **No evidence to guarantee it will be completely safe or effective.**

Assisted suicide is a "cheap solution" that would make it much harder for tens of thousands of West Australians to access the best possible end-of-life care.

A PEACEFUL DEATH?

THE CLAIM

The WA Expert Panel Report claims that Assisted Dying is for those few who are at the "end of their life and suffering" (page 1).

THE REALITY

Experts in Palliative Care agree that, with best practice palliative care, experiencing unrelievable pain is extremely rare. This includes testimony from Associate Professor Daryl Jones, Austin Health; Associate Professor Peter Hunter, Alfred Health; Dr Michelle Gold and Dr Natasha Michael.[1]

Pain is not even in the top five reasons why people request assisted suicide. In Oregon, "losing autonomy" (95%) and "decreasing ability to participate in activities" (96%) far outrank pain as reasons.[2]

The priority should be ensuring all West Australians have timely access to the care they need to control pain and alleviate their suffering, not Assisted Suicide.

THE PROMISE

The Minister's promises that Assisted Dying offers a compassionate and safe death.

THE REALITY

Assisted Dying does not guarantee a safe, or pain free, death.

Stories from overseas show the painful truth about the Assisted Dying process.

In Oregon a longitudinal study found 3% of assisted suicides had complications.[3] Most recent Oregon data shows a known complication rate of 4.2% of total assisted suicides: but this is not assessed in 62% of cases. 4% may not seem a large number, but it is about the same percentage of deaths (~4%) that 'Dying with Dignity NSW' report to die in "extreme pain"[4] to call for legalised Assisted Suicide.

In the Netherlands, a retrospective analysis showed that 7% of people experienced unexpected side effects, including regaining consciousness, vomiting, gasping for breath and seizures.[5]

The longest death recorded in Oregon has been 104 hours (4 days and 8 hours).[6]

In 2005, Oregonian lumberjack David Pruitt woke up after three days of a barbiturate induced coma, and asked his wife why he was not dead. He survived for 14 days before dying naturally from his cancer.[7]

TRAUMA FOR FAMILY AND FRIENDS:

Research from Switzerland has found evidence of post-traumatic stress disorder and "complicated grief" in families after witnessing an assisted suicide.[8]

IT IS VOLUNTARY?

THE PROMISE

A key promise of the WA Government is that, with all the safeguards and recommendations, all Assisted Deaths in Western Australia are guaranteed to be voluntary.

THE REALITY

There is nothing in the WA Bill which demonstrates that the so called 102 safeguards guarantee it will be truly voluntary.

The Parliamentary Committee Report and the Expert Panel Report ignore evidence of involuntary euthanasia in other jurisdictions, despite these jurisdictions having similar safeguards to ensure "voluntariness".

Doctors in WA will be able to suggest assisted suicide to clients. This was rejected in Victoria and opens the door to subtle coercion by well-meaning but misguided medical professionals, such as those who are not fully aware of palliative care options.

The Netherlands: In 2015 there were 431 cases of euthanasia without explicit request, representing 6.06% (or more than one out of sixteen) of all euthanasia deaths.

More than 1 in 200 (0.52%) of all deaths (other than sudden and expected deaths) of 17-65 year olds in the Netherlands are caused intentionally by euthanasia without an explicit request from the person being killed.

The Netherlands has been criticized twice by the United Nations Human Rights Committee for not taking the issue of involuntary euthanasia seriously.[9]

On 28 January 2017, a Dutch doctor drugged an elderly patient's coffee, and tried giving her the lethal injection while she was asleep. The woman woke and began struggling, and the family held the woman down as she was killed. Although the Dutch 'Regional Review Committee' – the equivalent of the proposed WA Voluntary Assisted Dying Review Board – ruled that the doctor had "crossed the line"[10], they did not press charges, concluding that the doctor has acted "in good faith".[11]

THE PROMISE

The WA Parliamentary Committee Report informing this Bill wrongly argues that the Oregon process works effectively.

THE REALITY

In Oregon, an elderly woman with dementia received lethal drugs because her daughter (described by one physician as "somewhat coercive") kept doctor shopping until she found a doctor willing to overlook the dementia and prescribe them.[12]

In Oregon a physician injected an unconscious patient with a paralysing drug to cause death. These have led to no prosecutions although all the law's "safeguards" were ignored.[13] And in WA, inadequately trained Nurse Practitioners will be able to give the lethal drug.

In Oregon, as in the proposed West Australian model, all records are based on what is reported by the doctors involved. In most cases, there will be no report of the circumstances of the patient's death – whether there were complications, whether there was undue influence, or whether the patient had legal capacity at the time of death.

THE SAFEGUARDS – A CLOSER LOOK

The Bill proposes 102 safeguards but many of these are explanations of procedure, not safeguards. There is no compelling evidence to suggest that this list will result in the safe legislation. It is the illusion of safety.

SAFEGUARD #4:
The person must be ordinarily resident in Western Australia. This will stop "suicide tourism".

REALITY

Like the other safeguards, the sole responsibility of ensuring this safeguard lies with the physician, who will be presented with 100 points of identification. Physicians should not be expected to determine whether someone is "ordinarily resident" anywhere. To place this burden on them is unreasonable.

SAFEGUARD #6:
Must be diagnosed with a "disease, illness or medical condition that meets a specific and limited restrictive of criteria". Safeguard #7, restricted to those that will die within 6 months.

REALITY

Evidence from other jurisdictions[14], shows that there is a growing number of patients with conditions not generally accepted as "terminal" that are accessing assisted suicide.

This demonstrates that the safeguard does not work in other jurisdictions. Why would it work here?

The prediction of a life expectancy is notoriously difficult and inaccurate, even for highly experienced medical specialists. What we do know for certain is that people have lived well beyond a 6-month prognosis.

In Washington, 14% of the 835 recorded deaths under the assisted suicide law since 2009, have occurred 25 weeks or more after a prognosis of no more than 6 months to live.

In Oregon, there has been a similar experience. The record has been that a patient has ingested the lethal dose 1009 days (2 years 9 months) after a prognosis of "six months" to live.

Safeguards #6 and #7 also ignores the possibility of misdiagnosis.

After the death of Italian magistrate, Pietro D'Amico, 62, by assisted suicide, the family insisted on an autopsy. It was discovered that he did not have a terminal illness at all, despite being diagnosed by both Italian and Swiss doctors prior to undergoing assisted suicide in Switzerland.[15]

SAFEGUARDS #2-10:
relate to the "eligibility" criteria to access Voluntary Assisted Dying.

REALITY

Every one of these "safeguards" is solely reliant on the coordinating (and consulting) physician to accurately assess and diagnose the patient (sometimes in areas they do not specialise in) and explain to the patient possible outcomes.

The physician will then self-report that all of these safeguards have been met.

They will then submit this report to the Voluntary Assisted Dying Review Board, which does not have the capacity to "provide clinical oversight" and has no "investigative role". At no point of the process does a third party review the individual assessment.

This is not a safeguard, this is a checklist.

In Oregon, a minority of doctors (18%) are responsible for the majority (61%) of assisted suicides. These are often connected to the organisation Compassion and Choices, America's largest NGO advocating for euthanasia and assisted suicide. There is nothing in the Bill to stop doctors in Western Australia who have liberal views on euthanasia and assisted suicide providing liberal assisted dying services.

SAFEGUARDS #14, 21 & 22:
The patient must make three distinct, separate requests, one of them a written declaration signed by two witnesses. This promises to "clearly demonstrate a person understands the decision".

REALITY

The process requires only one official written document, signed by two witnesses. The other two "requests" are made directly to the two doctors.

There are no guidelines as to what these other "requests" must look like, they are just described as "verbal".

The only record of these non-written requests will be a document, filled out by the doctors. This document does not have to be reviewed by the patient, or anyone else. This document will be submitted to the Voluntary Assisted Dying Review Board.

As a safeguard to ensure "voluntariness" this does not work, as in unclear cases, neither lay witnesses nor most doctors are sufficiently qualified to assess decision-making capacity.

Oregon also has the requirement that a person sign a written declaration, yet studies by Hendin and Foley show there is statistical evidence of "suspect coercion and lack of psychiatric evaluation". Again, the advice to the Government by the Expert Panel does not recognise this risk.[16]

SAFEGUARDS #26-29:
The patient must be assessed by two doctors – called the coordinating doctor and a consulting doctor. They must meet "specific registration and experience requirements".

REALITY

Inaccuracy in prognosis is the rule, rather than the exception.

A study on the prognosis relating to central nervous system cancers found that:

> ***"All physicians had individual patient survival predictions that were incorrect by as much as 12-18 months … Of the 2700 predictions, 1226 (45%) were off by more than 6 months and 488 (18%) were off by more than 12 months"***[17]

Not some, not rare, but ALL.

This is hardly a comfort.

SAFEGUARDS #30:
Requirement to provide specific administering information to the person.

REALITY

Neither doctor is required to have any expertise in Palliative Care. Therefore, they cannot be realistically required to “properly inform” patients of their Palliative Care options and outcomes.

SAFEGUARDS #32:
A doctor "must refer the person for further assessment if unable to determine if the person has decision-making capacity"

REALITY

Expert mental health professionals will admit that they cannot assess a person's mental capacity, much less determine whether a request for assisted suicide is "rational" or the result of a mental illness:

In a study of 321 psychiatrists in Oregon only 6% were very confident that in a single evaluation they could adequately determine whether a psychiatric disorder was impairing the judgment of a patient requesting assisted suicide[18].

Northern Territory: The only jurisdiction which has required a psychiatric assessment for each case of euthanasia was the Northern Territory. However, this system signally failed to adequately identify depression, demoralization or other psychiatric issues which may have been treatable in four persons killed under the Rights of the Terminally Ill Act 1995 (NT).

Considering all the warnings given to the Panel from those representing vulnerable groups – the mentally ill, the depressed, people with disability and people at risk of elder abuse – these "safeguards", which are little more than paperwork and a checklist, are woefully inadequate protection for those who may be pressured into Assisted Suicide.

CAN THE VULNERABLE BE PROTECTED?

THE PROMISE

"Australian and international inquiries demonstrate that the vulnerable can be protected.", Speech of Minister Cook 7 August 2019.

THE REALITY:

What WA is doing constitutes a profoundly radical change to the provision of end of life care. For the first time in WA, state assisted suicide and euthanasia of a patient will be sanctioned. The Government gives the impression that the more "safeguards" it proposes, the "safer" it will be. But the 102 safeguards are just tick boxes of a radical social agenda – not considered medical practice. The more they add to the list the less convincing they become.

1 **Oregon**, along with **Vermont, Washington, California** and **Colorado** require a 15-day "cooling off" period between first request and second, whereas the Bill mandates only 9 days before the third request.[19] Why does WA offer a weaker safeguard than every US state?

2 **Canada** requires patients to fill out a form 48 hours prior to self-administering the drug[20]. Western Australia does not. In this way, there is no safeguard between obtaining the lethal dose and taking it, so there is no way of knowing with certainty whether the person ingests the dose voluntarily.

3 **The Netherlands**, even though it has far weaker safeguards in other respects, has a mandatory Coroner's reporting of assisted suicide to determine if there is any evidence of abuse[21]. The Expert Panel (p.20) decided to ignore the advice of Principal Registrar of the Coroner's court and recommend that "A death that occurs through voluntary assisted dying should not be a reportable death for the purposes of the Coroners Act 1996 unless the death is referred to the Coroner by the voluntary assisted dying oversight body." Why would this safeguard recommended by the Coroner's Court be rejected?

4 In **The Netherlands** a "doctor should be present when euthanasia or physician-assisted suicide is carried out" in case of complications.[22]

5 The West Australian Report does not require this. In fact, it is modelled on Oregon's law that only has a doctor present for 15.7% of suicides up till 2014, and less (10.1%) in 2016[23]. This means there will be no doctor on hand to provide expert care if the Assisted Suicide does not go to plan. Because there is no Coroner's report, it is possible that the patient will die more slowly and painfully, and there will be no record of it. In that sense, this is less safe than the **Netherlands'** approach.

OVERSIGHT

THE PROMISE

The Bill establishes of a Voluntary Assisted Dying Review Board (Safeguards #96). Physicians must report to the Board after each request for assisted suicide, regardless of the outcome (Safeguards #77).

THE REALITY

The Board has no judicial authority. It is not a "complaints body" and it does not "provide clinical oversight or act as a professional disciplinary body". It has no "power to veto requests" or "arbitrate appeals" and it does not have an "investigatory role". So, it cannot challenge or question a request for assisted suicide. The Board can only collect data.

This is not a safeguard, and does nothing to enhance standards of clinical care.

DID YOU KNOW? There is no safeguard to ensure the voluntary consumption of the drug, only the voluntary request. There is no protection for the terminally ill person who is forced to take the lethal dose against their will. Their death would be marked as "natural" and there would be no investigation.

DO WEST AUSTRALIANS WANT IT?

THE PROMISE

The Report promises that Assisted Dying will give West Australians the choices they want. Public opinion polls show support ranging from 70% to 85%.[24]

THE REALITY

Polls can be a misleading way to assess public sentiment on complex issues. Public support often falls when people hear arguments against assisted suicide, sometimes by as much as 30%.[25] Public opinion also shifts markedly and decisively, depending on the phrasing of the question.[26]

There have been many cases in recent history where opinion polls do not match the outcomes of a vote. In Oregon and Washington, assisted suicide only passed with a slim majority (51% and 58%), even though polls were showing support of around 80%. In Massachusetts, public opinion shifted from 68-20 pro to 51-49 against in a 2012 referendum.

CONCLUSION

What do West Australians really want?

The 2015 Auditor-General's report Palliative Care, found that only a very small proportion of the Australians who recorded their preferred place of death (home), were able to do so.[27]

The Grattan Institute said that "dying in Australia is more institutionalised than in the rest of the world".

> ***"…Community and medical attitudes plus a lack of funds for formal community care mean that about half of Australians die in hospital, and about a third in residential care. Often they have impersonal, lingering and lonely deaths."***[28]

> ***"People want to die comfortably at home, supported by family and friends and effective services."***[29]

Palliative Care Australia, Australia's peak body with regard to end of life care, has linked these experiences with the public's interest in euthanasia.[30]

What West Australians really need is:

- Fair, early and universal access to expertly-delivered, high quality Palliative Care;
- The opportunity to die in the place of their choosing;
- Education about Palliative Care's capabilities;
- Opportunities to discuss death and the way in which they would prefer to die; and
- Greater support for carers.[31]

Let us recognise that there is enormous room for improvement in the West Australian Palliative Care System. And let us commit to the early and effective provision of palliative care, which aims to relieve suffering in all its forms.

Until we can be sure that each West Australian has all of the above, we should not consider Assisted Suicide or Euthanasia a justifiable option.

Assisted Suicide is a false panacea, that will undermine the provision of excellence in end of life care for the 14,000 West Australians who die each year.

Wrongful deaths are inevitable in systems of euthanasia and assisted suicide, as true safeguards are simply impossible to construct. To quote former Prime Minister Paul Keating,

> **"This claim (of adequate safeguards) exposes the bald utopianism of the project – the advocates support a bill to authorise termination of life in the name of compassion, while at the same time claiming they can guarantee protection of the vulnerable, the depressed and the poor. No law and no process can achieve that objective."**[32]

To be clear, the legalisation of assisted suicide and euthanasia represents the crossing of a rubicon we should do all we can to avoid. It is fraught with the risk of wrongful death, for which no number of questionable safeguards can provide sufficient protection. It undermines the notion of choice and autonomy by exerting subtle pressure upon the most vulnerable in our community. In the jurisdictions where it is legal, it has undermined the resourcing and importance of palliative care.

The assisted suicide this bill seeks to make lawful is neither compassionate nor safe.

ENDNOTES

1. Associate Professor Daryl Jones (5 August 2015) Transcript of Evidence to the Parliamentary Committee on End of Life Issues. p 24; Associate Professor Peter Hunter (15 October 2015) Transcript of Evidence. p 55; Dr Michelle Gold (15 July 2015) Transcript of Evidence, pp. 56-57; Dr Natasha Michael (16 September 2015) Transcript of Evidence, pp. 9-10.
2. Oregon Public Health Division, 'Oregon Death With Dignity Act: 2018, Data Summary', p. 12.
3. K Hedberg et al (2003). 'Five Years of Legal Physician-Assisted Suicide in Oregon'. New England Journal of Medicine. March 2003, 348. http://www.nejm.org/doi/full/10.1056/NEJM200303063481022, pp. 961-964.
4. Dying with Dignity NSW, 'Assisted Dying: Setting the Record Straight', p. 12.
5. J Groenewoud et al (2000). 'Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands'. New England Journal of Medicine; 2000; 342, DOI: 10.1056/NEJM200002243420805, pp. 551-556.
6. Oregon Public Health Division (2017), 'Oregon Death With Dignity Act: Data Summary 2016', p. 11.
7. Seattle Times (2005). 'Oregon man wakes up after assisted-suicide attempt'. 4 March 2005, http://www.seattletimes.com/nation-world/oregon-man-woke-up-after-assisted-suicide-attempt/.
8. B Wagner, J Müller, and A. Maercker (2012).'Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.' European Psychiatry 27.7: 542-546.
9. UN Human Rights Committee (HRC), 'Concluding Observations: Netherlands', 27 August 2001, CCPR/CO/72/NET and again 'Concluding observations of the Human Rights Committee: Netherlands', 25 August 2009, sCCPR/C/NLD/CO/4.
10. Response of the Regional Review Committee (2016) https://www.euthanasiecommissie.nl/uitspraken-en-uitleg/d/dementie/documenten/publicaties/oordelen/2016/niet-gehandeld-overeenkomstig-de-zorgvuldigheidseisen/oordeel-2016-85.
11. Guilia Crouch, 'Female Dutch Doctor drugged patient's coffee'. Daily Mail. 28 January 2017. http://www.dailymail.co.uk/news/article-4166098/Female-Dutch-doctor-drugged-patient-s-coffee.html?offset=0&max=100&jumpTo=comment-175426032#comment-175426032.
12. H. Hendin and K. Foley (2008). 'Physician-Assisted Suicide in Oregon: A Medical Perspective' Michigan Law Review http://repository.law.umich.edu/cgi/viewcontent.cgi?article=1374&context=mlr. Pp. 1613-39; 1626-7.
13. Disability Rights Education & Defence Fund, 'Some Oregon and Washington State Assisted Suicide Abuses and Complications'. https://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-and-complications/.
14. P S Kouwenhoven et al (2013). 'Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach.' Palliative Medicine 27.3: pp. 273-280.
15. 'Aided suicide in question after botched diagnosis', The Local, 11 July 2013, https://www.thlocal.ch/20130711/assisted-suicide-in-question-after-botched-diagnosis.
16. Hendin and Foley op cit.
17. MS MacKillop and CT Quirt (1997). 'Measuring the accuracy of prognostic judgements in oncology'. Journal of clinical epidemiology, Jan: 50 (10): pp. 21-9 http://www.sciencedirect.com/science/article/pii/S0895435696003162.
18. Linda Ganzini et al., 'Attitudes of Oregon psychiatrists toward physician- assisted suicide', American Journal of Psychiatry 1996; 153:1469-75, http://ajp.psychiatryonline.org/doi/abs/10.1176/ajp.153.11.1469.
19. Oregon, 'Death With Dignity Act', 1997; Washington, Death With Dignity Act, 2009; Vermont, Patient Choice at End of Life Act, 2013; California, End of Life Option Act, 2016.
20. Canada, Medical Assistance in Dying Act, 2016, http://laws-lois.justice.gc.ca/eng/AnnualStatutes/2016_3/FullText.html.
21. The Netherlands, Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002, 8.

22. Ibid.
23. Oregon Public Health Division (2016), 'Oregon Death With Dignity Act: 2015 Data Summary', p. 4.
24. Dying with Dignity NSW (2007). 'Assisted Dying: Setting the Record Straight'. www.ASSISTED-DYING-Setting-the-record-straight-Final-10_7_17-Web%20(2).pdf , pp 4;9.
25. ComRes (2014) 'Assisted Suicide Poll'. http://www.comresglobal.com/wp-content/themes/comres/poll/Care_Assisted_Suicide_Poll_July_2014_(with_summary_table).pdf; See also Abingdon Research, Quebec (2013). 'Medical Aid in Dying Survey' http://www.lifecanada.org/images/National%20Polls/Life_Canada_-_Results.pdf, p. 25.
26. L Parkinson et al. 'Cancer patients' attitudes towards euthanasia and physician-assisted suicide: The influence of question wording and patients' own definitions on responses.' Journal of Bioethical Inquiry, 2005, 2(2), pp. 82-89.
27. Victorian Auditor General's Office (2015). Palliative Care. https://www.audit.vic.gov.au/sites/default/files/20150415-Palliative-care.pdf, p. 17.
28. Ibid.
29. Ibid.
30. Palliative Care Australia, 'Submission to Parliament on End of Life Choices'. https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_376_-_Palliative_Care_Australia.pdf.
31. Victorian Auditor General's Office, Palliative Care, pp. 12-25.
32. https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html