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13 May 2018

Joint Select Committee on End of Life Choices
Parliament House
4 Harvest Terrace
West Perth WA 6005
Via email: eolcc@parliament.wa.gov.au

RE: **Response from Andrew Denton, director of Go Gentle Australia, to request from the Hon Nick Goiran to supply comment on submission #391 provided to the Committee from the WA Branch of the Royal Australian and New Zealand College of Psychiatrists.**

Dear Mr Goiran,

Thank you for your request for a response to the submission to the Joint Select Committee provided by the WA Branch of the Royal Australian and New Zealand College of Psychiatrists.

In summary, Go Gentle does not support mandatory psychiatric assessment for VAD. We do, however, support legislation which mandates that a psychiatric assessment is considered where decision making capacity is in doubt

To elaborate further we would like to provide comment on submission #391 in the following areas:

1. **Whether or not Psychiatric Assessment of Patients Seeking VAD should be Mandatory.**
2. **The Risks of Conflating 'PAS' with Suicide.**
3. **The Need to Resource Palliative Care and Mental Health Resources as a Priority.**
4. **Further Recommendations by the WA Branch of the Royal Australian and New Zealand College of Psychiatrists.**

1. Whether or Not Psychiatric Assessment of Patients Seeking VAD should be Mandatory.

In their submission, the WA Branch states that they 'strongly support':

> *"a framework which mandates consideration of psychiatric assessment of patients whose decision making capacity is in question regarding a PAS request"*

Go Gentle also supports this framework, as we did in Victoria, where the *Voluntary Assisted Dying Act (2017),* mandates that a person seeking VAD can only be eligible if they have:

> *'Decision-making capacity in relation to voluntary assisted dying'*[1]

The Act stipulates that two medical practitioners – the Co-ordinating and Consulting Medical Practitioners – must, at a minimum:

> '*hold a fellowship with a specialist medical college; or be a vocationally registered general practitioner'*

And that, additionally they:

> *'must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires).*
>
> *Either the co-ordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed'*

Furthermore, neither medical practitioner can complete a first assessment of a patient requesting VAD until they have completed approved training in assessing capacity. Medical practitioners are then required by law to refer a patient for specialist opinion if either are:

> *'unable to determine whether the person has decision-making capacity in relation to voluntary assisted dying as required by the eligibility criteria, for example, due to a past or current mental illness of the person, the co-ordinating medical practitioner must refer the person to a registered health practitioner who has appropriate skills and training, such as a psychiatrist in the case of mental illness'*

Capacity, under the Act, is decision specific and may be influenced by not only mental illness but loss of cognitive capacity for a range of reasons hence an opinion by an appropriate specialist in relation to decision making capacity may be required. This may be a psychiatrist geriatrician or neuropsychologist depending on the question regarding a person's decision making capacity.

[1] VOLUNTARY ASSISTED DYING ACT 2017 (NO 61 OF 2017) - SECT 4 Meaning of decision-making capacity

The Act goes on to define decision-making capacity in relation to Voluntary Assisted Dying ('VAD') as when the person making the request is able to:

> *'(a) understand the information relevant to the decision relating to access to voluntary assisted dying and the effect of the decision; and*
>
> *(b) retain that information to the extent necessary to make the decision; and*
>
> *(c) use or weigh that information as part of the process of making the decision; and*
>
> *(d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means'*

Importantly, the Act states that:

> ***'a person is presumed to have decision-making capacity unless there is evidence to the contrary'***[2]

It is worth re-visiting the key reasons why Victoria's *Voluntary Assisted Dying Act* did not legislate for mandatory psychiatric assessment:

a) Decision-making capacity is already assumed, and protected, in other end-of-life decisions by patients.

In Australia, there is no requirement for psychiatric assessment if a patient declines treatment, including life sustaining treatment. This happens very regularly and is entirely the decision of the patient provided they are an adult. Not respecting someone's refusal for treatment would be assault - it is treatment without consent.

Two senior Victorian psychologist who strongly support Victoria's *Voluntary Assisted Dying Act* are Professor David Copolov and Associate Professor Steve Ellen. They write:

> *'the processes and safeguards in the VAD legislation, combined with routine clinical care currently in practice in Victoria, will ensure that people requesting VAD will be assessed for their capacity, and that VAD will not be available to people who fail the capacity test'*

[2] The Act, as legislated, was supported in relation to assessment of capacity by the Victorian Branch of the RANZCP. This was flagged in the RANZCP's earlier, February 2016, Position Statement 67 on Physician Assisted Suicide,:

"The need for psychiatric assessment and treatment should be considered for patients who request PAS of their doctors"

Assoc. Professor Ellen, who has had decades-long experience in General Hospital Consultation Liaison Psychiatry, before being appointed as Head of Psycho-oncology at the Peter MacCallum Cancer institute explained in correspondence to Go Gentle where the law stands on mandatory psychiatric assessment in relation to refusal of care (a decision which has the likely foreseeable consequence, in someone who is terminally ill, of death):

> *'I'm not aware of any mandatory psychiatric assessments for people refusing care. All psychiatric assessments follow clinical need, however individual hospitals may impose guidelines, or even protocols, for their clinicians. The only time a patient has a* ***mandatory*** *assessment (excluding court ordered assessments) is if a patient has evidence of a* ***mental illness, plus ideas of self-harm (such as suicidal plans), and is refusing mental health care (they must meet ALL three criteria)****, then they have a compulsory psych assessment (required under the various state mental health acts). This would NOT be the case for refusing treatment, UNLESS they appeared to be mentally ill. So, the psych assessment is ONLY compulsory if there is evidence of mental illness'*

Professor Copolov, Professor of Psychiatry at Monash and at the University of Melbourne, explains further:

> *'If a person is deemed by his or her treating doctor to have intact decisional capacity and refuses treatment or food and fluids, then that person's wishes must be adhered to. The guidelines state that in the circumstances that "a health practitioner cannot determine whether or not a person has capacity to make the decision, the person* ***may*** *(my bolding) be referred for a relevant specialist assessment" -ie it's not mandatory to do so'*

Judicial decisions of the Supreme Courts of NSW (CJ McDougall), WA in the case of Rossiter, and SA (J Kourakis) have all -(confirming decisions in UK, US, and NZ courts - determined the right of competent persons to make these decisions without mandatory psychiatric assessment, and all confirmed that such action was not suicide, and that such persons should be considered to be dying, and provided with the same palliation of any suffering and/or distress as any dying person.

b) Existing mental health legislation already guides doctors in relation to capacity.

In his correspondence to Go Gentle. Professor Ellen emphasized the following:

> *'The psych assessment [in Victoria's VAD Act] is ONLY compulsory if there is evidence of mental illness' – and this law already exists throughout Australia in the various mental health acts, so there is no need to repeat it in any assisted dying legislation'*

In supplying the framework for Victoria's *Assisted Dying Act* – and after widespread consultation across the medical community, including with the Victorian Branch of the RANZCP – the Ministerial Advisory Panel concluded the following:

> *'Legislative tests for capacity currently exist in the Medical Treatment Planning and Decisions Act 2016, the Mental Health Act 2014, and the Powers of Attorney Act 2014.*
>
> *The Panel considers that the four-part decision-making capacity test in the Medical Treatment Planning and Decisions Act should be used to assess an adult's decision-making capacity in relation to voluntary assisted dying. The Act is contemporary, having been passed in 2016, and is generally regarded as appropriate to test decision-making capacity for a wide range of medical treatment decisions. In addition, use of this test takes into account feedback received during the consultation process that having one test that applies across a range of medical interventions is likely to achieve consistent application by medical practitioners.'*

c) Benefits of existing longitudinal relationships between doctors and patients.

Go Gentle supports the view, expressed to the Joint Select Committee by the WA Branch of the Royal Australian and New Zealand College of Psychiatrists, that:

> *'proper assessments are best undertaken by clinicians with the benefit of extended interactions over a significant period of time with the individual in question'*

In many cases, this may not be a psychiatrist. As Drs4VADChoice pointed out in their submission to the Joint Select Committee, general practitioners can be:

> *"best placed to assess the patient's mental state and decision-making capacity due to their longitudinal relationship with the patient and the routine use of this assessment in all health care decisions that patients make. There should be no need for a mandated psychiatrist review."*

Proponents of mandatory psychiatric referral express concern that non-psychiatric physicians may miss some mental illnesses. Whilst this does occur in busy clinical settings where capacity and consent are not under scrutiny, under the Victorian *Assisted Dying Act,* where capacity and consent are explored by two separate experts who have been trained in their assessment, this concern is misplaced.

In truth, by mandating a level of scrutiny not previously encompassed in law, such legislation will improve the capacity to detect mental illness in the terminally ill. Clinicians will be more vigilant in determining if it is present and, if detected, patients will be referred for psychiatric assessment and, if appropriate, care.

d) Mandatory psychiatric referral has the potential to be unnecessarily burdensome to a dying patient seeking relief from unbearable suffering.

The Victorian Ministerial Advisory Panel felt that given the view of RANZCP and after feedback from nine months of consultation sessions across the medical community, to add a further consultation to a process that was already rigorous for a person who is dying a of an advanced, progressive, incurable disease, illness or medical condition, was not consistent with the compassionate nature of the legislation and was unnecessary unless there was a question of impaired decision making capacity.

2. The Risks of Conflating 'PAS' with Suicide.

In their submission, the WA Branch states that:

> *'Australia's oldest citizens, those aged 80 and above, are the age group most likely to die as a result of suicide (ABS, 2012). This has led to a misconception that suicide in older people is largely driven by suffering associated with chronic, debilitating or terminal illness (Mckay 2014), whereas the aetiology of suicide is complex and usually multifactorial (RANZCP, 2016)*
>
> *The WA Branch is concerned that this misconception may lead individuals to erroneously conflate suicide with PAS. While the latter may be an understandable choice in the context of unbearable suffering, suicide is a tragic outcome for individuals who suffer from mental illness. Given the disastrous consequences for the individuals, families and communities of those who suicide, or attempt suicide, it is imperative that the implementation of PAS be accompanied by stringent safeguards to ensure that older people considering suicide are not given access to PAS, as well as an expansion of suicide prevention programs to target older persons (RANZCP, 2017)'*

Go Gentle agrees that the implementation of a VAD law should carry with it stringent safeguards so that only those who are clearly dying can have access to such a law. This is why we are strongly in support of Victoria's *Assisted Dying Act*, which carries more safeguards than any other such law written in the world.

And Go Gentle shares the WA Branch's concerns that people may:

> *'erroneously conflate suicide with PAS'*.

In combatting this, we believe the RANZCP has a crucial role to play as they are a contributor to this conflation.

Throughout their submission, despite acknowledging that Voluntary Assisted Dying may be an '*understandable choice in the context of unbearable suffering*', they use the term 'PAS' – 'Physician Assisted Suicide'.

That there is a distinct difference between the two is acknowledged by their Chair Dr Elizabeth Moore who, in evidence to the Joint Select Committee, said that:

> *'When a person is not expected to live for a certain amount of time, that they have unbearable pain or suffering, I think this is a very different scenario from actually saying that the person wants to suicide [in the sense meant when] talking about suicide prevention'*

Western Australia's Chief psychiatrist, Dr Nathan Gibson, also emphasised this distinction in his appearance before the Committee:

> *'Can I just say that, like the college of psychiatrists, I do not support physician-assisted suicide, but that is a different kettle of fish to voluntary-assisted dying'.*

We agree with Dr Moore and Dr Gibson: Suicide is distinct from voluntary assisted dying.

The first – suicide - is an irrational impulse, acted on in secret, in response to a problem that, with treatment, could most likely be fixed. The second - – voluntary assisted dying - is a rational response, taken in consultation with doctors and family, to a condition that cannot be fixed.

This difference was clearly understood by the Chief NY medical examiner, Charles Hirsch, when investigating the deaths of office workers who jumped from the Twin Towers on 9/11. Faced with a terrible choice – a slow, agonizing death by fire, or a quick death by jumping – many chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as 'suicides'.

In correspondence to Go Gentle, Associate Professor Steve Ellen explained the confusion that such conflation can cause:

> *'The term suicide causes enormous confusion. Whilst strictly speaking the definition is 'the act of intentionally causing one's death" and so strictly speaking assisted dying IS suicide, the term causes confusion, especially amongst politicians! Most suicidal behaviour, and most suicide, is caused by mental illness. The figure thrown about is 85 – 90%. The rest is people taking their life due to some other factor (like terminal illness) in the absence of mental illness. As a consequence, many people use the term 'suicide' to mean taking one's own life BECAUSE of mental illness, and when they refer to assisted dying they use terms like euthanasia.*
>
> *So, in clinical situations, if someone wants to end their life by refusing care (food or anything else) we DON'T usually call it suicidal behaviour (unless it's due to mental illness) – we would just call it 'refusing treatment' as there is no active act of trying to end life. If they actively want to end their life because of illness, without mental illness, we'd call it euthanasia. If they want to end their life because of mental illness/distress we call it suicide. The anti-VAD lobby love calling VAD suicide because it conflates VAD with mental illness, confuses politicians, and allows them to call for*

all sorts of extra hurdles – the extra hurdles are not necessary when we have a decent mental health act (that outlines conditions for mandatory psych assessment & treatment in suspected mental illness) and a decent medical treatment act (that defines consent).'

To avoid this continued confusion we urge that, in future, the RANZCP no longer uses the term 'Physician Assisted Suicide', and that they select their terminology with greater care and in a way which more accurately reflects their own understanding of the difference between suicide and Voluntary Assisted Dying.

3. The Need to Resource Palliative Care and Mental Health Resources as a Priority.

In their submission, the WA Branch recommends that:

'palliative and mental health services are properly resourced as a priority.

Go Gentle strongly supports greater resourcing of palliative and mental health care at the end of life. However, we do not see these as separate from, a more urgent priority than, or in opposition to, Voluntary Assisted Dying.

The aim pf palliative care (as supported by mental health care) – as with Voluntary Assisted Dying – is not to help people die. It is to help people to live as well as they can while they are dying.

Both are palliative. In light of the reality that approximately 4-5% of patients are beyond the help of palliative care – and the darker reality that has been brought to light now by coroners in Victoria, South Australia, and Western Australia, that some of those patients are committing brutal suicides, leaving behind great damage – it is imperative that all areas of palliative care, including VAD, be given equal priority.

This is not - and never has been - a binary conversation. As the Victorian inquiry found, assisted dying sits on the spectrum of end-of-life care alongside palliative care, advanced care directives, and refusal and withdrawal of treatment.

In support of this, Go Gentle's submission to the Joint Select Committee, (part B, Section 7 **'Palliative Care vs Assisted Dying; a False Binary' – p. 35**) details the landmark judgement handed down by the Victorian Civil and Administrative Tribunal, in the case of Syme v Medical Board of Australia in December 2016.

Dr Syme brought his case to the tribunal after the Medical Board had sought to prevent him from engaging in:

> **'the provision of any form of medical care, or any professional conduct in his capacity as a medical practitioner that has the primary purpose of ending a person's life.'** [3]

The Medical Board had taken this action after learning that Dr Syme had offered to supply the illegal drug Nembutal to Bernard Erica who was dying of throat and tongue cancer.

In finding in favour of Dr Syme, the tribunal supported the following:

1. The right of any individual of sound mind to seek reassurance that they will be able to, if they wish, control the manner of their dying.

2. The palliative effect on a patient, knowing that they are dying; and

3. That the reassurance of the promise or actual possession of the drug does not, from the patients' perspective, place them at any risk.[4]

There is abundant evidence from Oregon to demonstrate that providing legal, regulated access to life-ending medication has strong palliative power and likely helps *prolong* life.

Statistics from the last 20 years from the Oregon Department of Health show that more than 30 per cent of terminally ill patients who are written a prescription for life-ending medication under their Death with Dignity Act, ultimately choose not to take it.[5]

<u>The VCAT hearing was the first time in Australia that Voluntary Assisted Dying has been judged in a legal setting. Its palliative value – and the right of a dying patient to seek such palliation – were unanimously upheld.</u>

(You can read the full judgement here.)

Professor Ian Maddocks, Australia's most senior palliative care physician, confirms that Voluntary Assisted Dying and palliative care are both about palliation:

> **'They have similar aims in relief of distress, and need to espouse similar approaches of compassion, lack of haste, involvement of family, transparency, clear consent, open reporting … The existence of such a law would have made me a better palliative care physician.'**

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[3] Rodney Syme in 'Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150', Victorian Civil and Administrative Tribunal Administrative Division, Review and Regulation List, VCAT Reference No. Z164/2016, 97(c), 21-23 November 2016 (Hearing), 20 December 2016 (Date of Order), p. 4, viewed 21 July 2017, link to document file here <https://tinyurl.com/y88ac64f>.

[4] 'Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150', Victorian Civil and Administrative Tribunal Administrative Division, Review and Regulation List, VCAT Reference No. Z164/2016, 97(c), 21-23 November 2016 (Hearing), 20 December 2016 (Date of Order), p. 44, viewed 21 July 2017, link to document file here <https://tinyurl.com/y88ac64f>.

[5] Oregon Public Health Division, 'Oregon Death with Dignity Act: 2015 Data Summary', Oregon Health Authority, 4 February 2016, p.2 viewed 21 July 2017, <http://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>.
"Since the [Oregon] law was passed in 1997, a total of 1,545 people have had prescriptions written under the DWDA, and 991 patients [64%] have died from ingesting the medications."

In the debate around Voluntary Assisted Dying in Australia it is possible to find a list of statements about priorities in end-of-life care similar to those from the WA Branch: “Palliative care needs to be fully resourced before we discuss assisted dying,” “the lives of people with disability need to be fully supported before we discuss assisted dying’, ‘mental health services need to be better before we discuss assisted dying”.

Which raises the question: Where does the bar have to be - at what level of subjective perfection - before it's ‘OK’ to consider assisted dying as part of end-of-life care?

Do we just ignore the testimonies of families who have watched – and continue to watch - their loved ones die in agony? (I attach a PDF of **The Damage Done** which contains many such testimonies.)

Do we continue to look past palliative care’s own statistics that around 4-5% of their patients are beyond their help?

Do we continue to look past the weekly, violent, suicides of our terminally and chronically ill?

Do we continue to turn a deaf ear to the police and ambulance officers who testified in Victoria, and now Western Australia, about the impact on their members of having to attend the aftermath of those suicides?

Do we continue to turn a blind eye to doctors having to break the law in order to help patients who are dying beyond endurance?

Do we shelve the testimonies of nurses from around Australia about the distress being caused when patients beg for help to end their suffering – requests to which they have no meaningful response?

This needs to stop being a binary conversation. Dying people need help of many kinds. For many, it will be what palliative care and others can offer. For a small percentage it will be the help that assisted dying choice offers. They are both in the same conversation and until we accept that, the litany of horrors heard by the Victorian, and now Western Australian, Select Committees - and listed in **The Damage Done** - will surely continue.

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4. Further Recommendations by the WA Branch of the Royal Australian and New Zealand College of Psychiatrists.

In their submission, the WA Branch recommends the following:

- *The establishment of a Clinical Reference Panel on end of life choices .*
- *Allow time for comprehensive consultation on end of life choices.*
- *Sensitivity to the needs of vulnerable populations during end of life choices discussions.*
- *The right of medical practitioners to choose their degree of involvement in Physician Assisted Suicide*

Go Gentle supports all these recommendations and notes that the core of any Voluntary Assisted Dying Law is that it is voluntary – for medical professionals as much as it is for patients.

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Mr Goiran, thank you for the opportunity to respond to the WA Branch's submission. It raises many important points and I am pleased to be able to share Go Gentle's perspective on them.

I would be happy to discuss further these, or any other, matters pertaining to a VAD law in WA. As I said in my appearance before the Joint Committee, I strongly believe that the only way for legislation to be properly written is for there to be full and frank debate.

Sincerely,

Andrew Denton
Director, Go Gentle Australia