



1. INTRODUCTION

Purpose of submission

- 1.1 This submission to the Joint Select Committee on End of Life Choices (the Joint Committee) is made by Dying With Dignity Western Australia Inc (DWDWA), pursuant to an invitation dated 15 September 2017 from the Chair of the Joint Committee, Ms A Sanderson, MLA.
- 1.2 It responds to the Terms of Reference of the inquiry which is to be undertaken by the Committee, following its establishment by the Parliament of Western Australia on 23 August 2017.

Who we are

- 1.3 DWDWA is an incorporated association. It was incorporated in 1984 in Western Australia, as The West Australian Voluntary Euthanasia Society (Inc.) (WAVES), and changed its name in 2016.

Our purpose and objectives

- 1.4 Our stated purpose or mission is to bring about such changes to Western Australian Statute Law and to medical ethics as will allow a person to receive medically-assisted euthanasia under circumstances specified by him, or her, when legally competent to make such a choice.
- 1.5 Our objectives include the promotion to the Western Australian community of our purpose or mission, and to procure the passage in the Western Australian Parliament of a Bill allowing, with appropriate safeguards,

“voluntary euthanasia” (defined as meaning a peaceful death facilitated by another party, such action being consequent on the subject’s freely made request while legally competent to make such a decision).

Our primary submission

- 1.6 DWDWA very much welcomes the establishment of the Committee by the Parliament of Western Australia. It is right and proper that an issue so centrally important to the lives of all living in this State should be carefully considered, with opportunities given for submissions on the relevant facts and on appropriate terms for legislation. As noted by the Chair of the Victorian inquiry at the commencement of his Foreword, death and taxes have long been seen as the two certainties of life. Politicians have always in living memory formed views and crafted laws on taxes; but have proved to be reluctant in doing the same regarding death.
- 1.7 It is apt that the inquiry is described (by the Parliament) as being “into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices”. This description employs several key terms that go to the heart of the matter. For convenience, we will refer to such laws as VAD laws.
- 1.8 Emphatically, we submit that there **is** such a **need**, one that has been unmet for far too long, even in the face of sustained and overwhelming public support for such laws.
- 1.9 Such laws, we submit, must **allow** (and not compel or pressure) citizens and residents to (themselves) **make** decisions (which indeed should be **informed**) regarding **their own** end of life **choices**.
- 1.10 We cannot do better than quoting the submission made to the Victorian inquiry by our former president, Ranjan Ray¹:

¹ Set out at p 196 of the Victorian report

‘At present in most jurisdictions in this country any person, suffering more than he/she wishes to bear can refuse to accept any treatment and virtually commit suicide. It is surprising that we as a community can watch the patient slowly die but cannot help to bring a swift end to that life ... To me that is not compassion, it is cruelty.’

- 1.11 While certain limiting criteria will be required for legislation to operate with “safeguards”, and certainly reporting requirements to ensure transparency should be included, nevertheless, we submit, such limitations should be confined to those that are reasonably necessary to ensure that the individual’s wishes regarding their end of life are given primacy. These matters are dealt with later in this submission.
- 1.12 It is basic and important to our submission that we sincerely ask all members of the Committee to approach their consideration of the powerful questions before them in the spirit that, while these questions obviously have an important moral dimension, they are not religious questions, and in the interests of the community as a whole, deserve not to be determined or even heavily influenced by matters of personal religious belief or doctrine.
- 1.13 DWDWA submits that the process in which we are all involved is a secular one, which calls for careful, dispassionate and respectful discussion and examination of the evidence. In essence, we ask that **facts**, and not **faith**, be the determinants.

Nature and limits of this submission

- 1.13 DWDWA is a group rich in support and in membership, but not in resources. It has no paid staff, no office, and few members with the physical and technical capacities to prepare a comprehensive written submission. Accordingly, this submission has to be strictly limited in its length and breadth, and especially in terms of research undertaken.

- 1.14 Nevertheless, it attempts to make sensible reference to legislative models adopted in various overseas jurisdictions and the subject of consideration in various Australian parliaments. It is noted particularly that currently both the Victorian and New South Wales parliaments have before them draft laws to permit voluntary assisted dying. Those Bills, being the product of thorough and comprehensive inquiries and consideration, will no doubt be of very great assistance to the Joint Committee.
- 1.15 For our part, DWDWA has found the submissions to, and the report of, the Victorian parliamentary inquiry into end of life choices, to be highly relevant and useful in addressing the need for broadly similar law reform in this State. The Victorian committee took submissions from many interested persons and bodies in Melbourne and various other places in Victoria. No doubt this committee will do likewise. The Victorian inquiry also had the benefit of hearing from people familiar with the operation of relevant laws in The Netherlands, Switzerland, Canada (including Quebec as well as federal laws), and Oregon. Its report is most comprehensive, thoughtful and balanced.
- 1.16 It may be noted also that the first three of the four terms of reference of this inquiry are identical to the Victorian inquiry's terms of reference.
- 1.17 DWDWA has neither the wish nor the resources to attempt to "reinvent the wheel" by recapitulating, teasing out, and minutely considering and revising the Victorian findings and recommendations. Rather, as the foundation of its submission, it commends and adopts the Victorian report (subject of course to the further matters raised below in our submission).
- 1.18 Finally, we record that DWDWA looks forward to being able to present oral submissions to the inquiry, in order to further address particular aspects of the terms of reference with which it might be able to assist the Joint Committee.

2. FIRST TERM OF REFERENCE:

“[To] assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way in which they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care”

- 2.1 DWDWA is aware that a group of medical practitioners with expertise and experience in medical practices relating to chronic and terminal illnesses, palliative care and end of life management, and who generally support the introduction of laws to permit voluntary assisted dying, are preparing a submission to the Joint Committee.
- 2.2 By reason of our very limited resources, we are not in a position to ourselves advance data or qualified opinions about those medical practices, but instead we rely² on the submission of DWDV to the Victorian inquiry (written by Dr Rodney Syme), which refers to a number of authoritative reports and articles regarding current medical practices (and there is no reason to believe that there are any significant differences between Victorian practice and that in this State).
- 2.3 Further, we wish to record that our members have the following very clear impressions, formed during their long lives, that:
- 2.3.1 palliative care services generally are excellent and caring (but have various limitations, some of which are mentioned below), however these services require greater resources;
 - 2.3.2 many doctors do in fact provide assistance to patients in the last stages of illness, by deliberately hastening death (often relying on the opaque and dishonest doctrine of ‘double effect’);
 - 2.3.3 however, the availability of such assistance is uneven, depending on luck and, probably, socio-economic status;

² See below at 2.5

- 2.3.4 it is desirable for all concerned that the provision of such assistance become transparent;
- 2.3.5 doctors and other health care personnel require legal protection in order to adequately care for their patients in the last phase of life; and
- 2.3.6 Western Australia, a truly vast State with a population highly centralised in a few locations, most especially Perth, has particular needs and difficulties that are not the same as those in Victoria or even in NSW, and accordingly special consideration needs to be given to the needs of people living in remote and regional areas, many of whom are indigenous and suffer from various hardships, and in particular the law to be introduced needs to cater for the limited availability of specialist care to such persons.

Victorian inquiry and report

2.4 We suggest that at least the following key findings of the Victorian inquiry³ would apply equally in Western Australia:

- 2.4.1 although most people wish to die at home, in reality most will die in hospital;
- 2.4.2 demand for palliative care is steadily increasing, and is expected to continue to do so, and further, palliative care patients' diseases and needs have increased in complexity, so that the palliative care sector is overburdened and needs better support;
- 2.4.3 despite the availability of good palliative care services, those who could benefit the most often receive care too late;
- 2.4.4 although the advance care planning process has proven benefits, there are low awareness and implementation rates for advance care plans; and

³ See Report at xix and xx, Executive Summary

2.4.5 prohibition of assisted dying is causing a significant number of people great pain and suffering, and leading some to end their lives prematurely and in distressing ways (described as “desperate and violent”)⁴.

DWDV and Dr Rodney Syme

2.5 DWDWA wishes generally to adopt the helpful and well-considered submissions made to the Victorian inquiry by DWDV. Those submissions were substantially contributed to by Dr Rodney Syme, a well-known and much-respected urologist and author. They particularly include Chapter 4, entitled ‘*Current palliative care limitations*’⁵.

2.6 While the whole of the chapter is important, we mention the following points:

2.6.1 Careful examination of the medical literature reveals the **extent of suffering in the terminally ill** (and the difficulty in measuring and relieving it):

2.6.1.1 Australia’s most eminent pain specialist said in 2010 that 10% of cancer pain was so difficult to treat at the end of life that some patients were given drugs to sedate them to unconsciousness, culminating in death over several days to a week;

2.6.1.2 The Australian Government *Palliative Care Outcomes Collaboration Study* (October 2014) records that only just over 50% of patients with moderate to severe pain become pain-free;

2.6.1.3 A Toronto palliative care physician with 30 years’ experience has said that: ‘*We used to say that palliative care*

⁴ The Victorian Coroner, individuals, and a senior police officer provided graphic evidence in this regard (see pp 197-200), and media and anecdotal reports in Western Australia are to similar effect

⁵ Found at pp 20 – 26 of the submission (being a paper written by Dr Syme)

would relieve all suffering, but that, of course, is nonsense. I've seen too much suffering to be glib about it any more'; and

2.6.1.4 Palliative Care Australia acknowledged in 2008 that it could not relieve all pain and suffering, even with optimal care.

2.6.2 **Terminal sedation** (perhaps more accurately termed *continuous palliative sedation*, the phrase adopted in the Victorian report), which in truth is a form of slow euthanasia, has become widespread, although the extent of its use is not acknowledged publicly (in fact, to the contrary, the palliative care industry has been assiduously arguing that its members never hasten death). Chapter 4 of the DWDV submission to the Victorian inquiry refers to the following pertinent facts (among many others):

2.6.2.1 A 1996 article in the Journal of Palliative Care reported the use of terminal sedation in 52% of palliative outpatients;

2.6.2.2 This process is associated with patient consent in only up to 50% of deaths (giving no opportunity to the patient to say goodbye);

2.6.2.3 Terminal sedation is justified for the treatment of 'refractory' or 'intractable' symptoms, however, this is determined by the clinician (alone), not the patient;

2.6.2.4 In order to demonstrate that hastening of death is not the intention, the treatment is slowly titrated to a level where consciousness is suppressed, and thus, in association with withdrawal of hydration, death inevitably follows – contrary to the imperative to provide maximal relief of pain and suffering as soon as possible;

2.6.2.5 The result is that suffering continues until unconsciousness ensues, which may take days;

2.6.2.6 This occurs despite the observations of a senior consultant that ‘*nothing short of deep unconsciousness could provide relief*’ and that ‘*inadequate sedation makes matters worse*’; and

2.6.2.7 A *Lancet* editorial (in 2000) stated there is concern that sedation as the best means of symptom control in the dying patient is under-used because of fear of terminal sedation (meaning, we suggest, fear of being charged with murder, a fear that exists despite the belief of many that there is no problem in Australia with hastening death where the intent is to relieve suffering).

2.6.3 Despite the availability and use of terminal sedation, it does not provide an adequate remedy in every case⁶:

2.6.3.1 Eminent British geriatrician and ethicist Professor Raymond Tallis reports the opinion of a palliative care physician that 15% of deaths are ‘bad deaths’⁷;

2.6.3.2 Palliative Care Australia acknowledges that patients make rational and persistent requests for a hastened death – 25% of his palliative care patients, for instance, according to Dr Roger Hunt; yet a prominent segment of the palliative care professional community ‘*almost without exception maintains that patients who receive state-of-the-art palliative care, including psychosocial and spiritual interventions, almost invariably cease and desist from their desire for a hastened death*’ (Ben Rich, 2014);

2.6.3.3 Associate Professor Alex Broom spent six months in a Catholic hospice, interviewing doctors, nurses and patients. He found among the patients virtually unanimous support for assisted dying, but the hospice was totally opposed. Hastened death was seen as a call for help; the patient ‘just needed more time’ to adjust; and their request was met by spiritual and social support. The assessment was that it was ‘not his time to go’. Assisted death was not

⁶ *Loc cit* (regarding the following propositions)

⁷ Referred to by Dr Syme in the DWDV submission to the Victorian inquiry, at p 22

part of care in that hospice, which has an ideological model of dying, based on religious contexts, according to Associate Professor Broom; and

2.6.3.4 Ian Maddocks, the first Australian Professor of Palliative Medicine, has stated that palliative care usually has adopted a confrontational position against voluntary euthanasia, while Ben Rich backs this statement with evidence of widespread concerns about the authoritarian streak observed in many in the hospice movement, who maintain a rigid and monolithic view of death (*'one size fits all; it's the hospice way or the highway'*).

2.6.3.5 Finally on this point, we refer the Joint Committee to the following comment by Ranjan Ray in his submission to the Victorian inquiry⁸, as we believe it to be succinct and accurate:

'Palliative care has improved by leaps and bounds and we all hope that it keeps improving, but it is not and never will be the answer to the distress and loss of dignity that the elderly fear and hope to avoid at the last stages of their lives.'

2.6.4 There is no reason at all to think that the extent and standard of palliative care would suffer from, or following, the introduction of legislation to permit assisted dying:

2.6.4.1 The 2011 *Report of the European Association of Palliative Care* stated:

'Palliative care is well developed in countries with legalised euthanasia/assisted suicide, or at least no less well developed than in other European countries. There is evidence of advancement of palliative care in countries with legalisation of euthanasia and/or assisted suicide. The idea that legalisation of euthanasia and/or assisted suicide

⁸ See the Victorian report at p 206

might obstruct or halt palliative care development thus seems unwarranted and is only expressed in commentaries rather than demonstrated by empirical evidence’;

2.6.4.2 DWDWA in fact positively and strongly supports the better resourcing of palliative care, which is very beneficial to many patients, and has set out to establish a strong working relationship with PCWA to that end.

Some supporting eminent medical opinions

2.7 Dr Syme, as a voice of experienced and reputable medical opinion, is hardly alone. A published paper from 2013, entitled “Doctors in support of law reform for voluntary euthanasia” (by Emeritus Professor of Medicine John O Willoughby MB BS, PhD, FRACP, Robert G Marr MB BS, MPH, FAFPHM and Emeritus Professor of Anatomy Colin P Wendell-Smith AO, MB BS (Lond), HonLLD, FRANZCOG) stated the following “**Facts** about the end of life” (our emphasis) as confirmed either by the authors’ own life experiences or by reference to peer-reviewed medical literature:

2.7.1 Dying may be associated with intolerable suffering and there may be a crescendo of suffering as death approaches;

2.7.2 Some suffering will only be relieved by death;

2.7.3 Some patients rationally and persistently request assistance to die;

2.7.4 Palliative care does not relieve all the pain and suffering of dying patients; and

2.7.5 Palliative care may include terminal sedation in order to relieve intolerable suffering.

2.8. The same authors categorically and simply stated, immediately thereafter, that “Accepting these facts leads to the **inevitable conclusion** that the

medical profession is **failing in its duty of care** for some patients at a time of need” (emphases added). This is precisely the position taken by DWDWA.

2.9 These eminent authors also state that they believe that the current situation, in which voluntary euthanasia is illegal, inevitably leads to optimal management being denied to some patients: some have unrelievable forms of pain, while others are forced to endure a wretched but ongoing existence. We observe that the problem could not be stated with more clarity.

2.10 Those stark propositions were further supported by the authors’ reference to the following statements extracted from the Australian Medical Association (AMA) Code of Ethics⁹:

2.10.1 Treat your patient with compassion and respect;

2.10.2 Approach health care as a collaboration between doctor and patient;

2.10.3 Respect your patient’s right to ... make his or her own decisions about treatment or procedures;

2.10.4 Remember the obligation to preserve life, but, where death is deemed to be imminent and where curative, or life-prolonging treatment appears to be futile, try to ensure that death occurs with dignity and comfort; and

2.10.5 Respect the right of a severely and terminally ill patient to receive treatment for pain and suffering, even when such therapy may shorten a patient’s life.

Mr Andrew Denton

2.11 DWDWA would also like to associate itself with the contents of the submission made to the Victorian inquiry by Mr Andrew Denton¹⁰. One of

⁹ Now found, in similar terms, in the November 2016 Position Statement on Euthanasia and Physician Assisted Suicide

¹⁰ Submission 969, entitled ‘Voices From The Frontline’

the purposes of his presentation was to bring to his audience the authentic voices of those at the frontline of the debate – doctors, nurses, activists, academics, lawyers, and, above all, those most affected by the absence of assisted dying laws – the dying and the bereaved.

2.12 His hope was to provoke a serious conversation about assisted dying, amongst the Australian public generally, but in particular, within Australia’s medical community, which, he was surprised to find “is often poorly informed about an issue on which they, nonetheless, claim to have strong opinions”.

2.13 It is a most helpful fact that Mr Denton, besides speaking to a large number of people in Australia falling within the groups he described, also had the benefit of speaking with well-informed people in Belgium, the Netherlands, and Oregon. Moreover, he spoke with people on both sides of the debate, and, clearly and thoughtfully, tested their various assertions.

2.14 For these reasons, and no doubt because of his erudition, his submission is highly persuasive. While Mr Denton is commendably careful in his research and consideration, his style is somewhat journalistic and conversational. It is in this way (and, as he says, by reference to the voices of those most affected) that he comprehensively debunks the various myths and pieces of disinformation that are commonly put against arguments for the legalisation of assisted dying, including the following:

- *All we need is better palliative care*
- *Can palliative care and assisted dying go together?*
- *The ‘slippery slope’ argument¹¹ (including ‘bracket creep’- ‘now they’re killing babies’)*
- *The elderly, disabled, and the otherwise vulnerable need to be protected from such laws*

¹¹ Note particularly the reference to the Judgment of Justice Lynn Smith of the Supreme Court of British Columbia (upheld unanimously by the Supreme Court of Canada), who found that there was no evidence from permissive regimes of a slippery slope.

- *The allegation that in Belgium there is a practice of ending patients' lives without request*
- *The trivialisation of death: how can we trust our doctors any more (following the passage of such laws)?*
- *The risk of 'suicide contagion'*
- *The rate of increase over time of people using laws permitting assisted dying*
- *The claim that laws permitting voluntary assisted dying mean, at least over time, that people come to see death as a 'right' – and that this has happened in the Netherlands.*

2.15 We suggest that each of these myths, being exercises in speculation at best and disinformation at worst, is conclusively dispatched by the empirical evidence of those who know – that is, people in jurisdictions with practical experience of the operation of laws of the kind that need to be introduced in this State, to give respect, autonomy and choice at the end of life, according to the wishes of the person whose life and death are in question.

2.16 It is also worthwhile noting Mr Denton's reference to data provided by the National Coronial Information System on the numbers and methods relating to elderly Australians taking their lives. These show "the dark reality" facing too many older Australians: in 2001 to 2012 coroners recorded 3612 deaths by suicide, and of those almost one-third were 80 years or older. On average, two octogenarians a week are killing themselves in this country. The most common method used is hanging.

Mr Andrew McGee

2.17 An article in *The Conversation*, by Andrew McGee (Senior Lecturer, Faculty of Law, Queensland University of Technology)¹² provides some interesting data on the numbers of people using assisted dying laws in places such as the Netherlands, Belgium, Luxembourg, Colombia, Canada and states of the

¹² March 2017, entitled *In places where it's legal, how many people are ending their lives using euthanasia?*

USA. which, like those marshalled by Mr Denton, put the lie to some of the alarmist nonsense peddled by the opponents of law reform in this area.

2.18 It referred to a peer-reviewed paper in the respected journal *JAMA*, which reported that:

‘Euthanasia and physician-assisted suicide are increasingly being legalized, remain relatively rare, and primarily involve patients with cancer. Existing data do not indicate widespread abuse of these practices.’

2.19 The authors of the paper stated that in 2015 0.39% of deaths in Oregon were reported as physician-assisted suicides, while in Washington the percentage was 0.32. Figures of course may vary between jurisdictions, for many valid reasons, including methodological ones, but we suggest that those just referred to serve to illustrate how wild and fanciful are many of the claims expressed by opponents.

Public support

2.20 Finally in this section of the submission, and although it does not strictly relate to this term of reference, we think it important to make the point that for many years there has been a very high level of public support for the legalisation of assisted dying.

2.21 In fact, we would describe it as a clamour, one which until quite recently many parliamentarians (unfortunately, and contrary to democratic principles) have not only failed to support, but which they have sought to quell by declining even to allow open debate in the parliament.

2.22 Australia 21 (a non-profit body, committed to an analysis of complex issues which bear on Australia’s future) prepared a report following a Roundtable meeting in January 2013. This was entitled “*The right to choose an assisted death: Time for legislation?*”

2.23 It noted (in the Executive Summary) that a very substantial majority of Australians have repeatedly expressed in public opinion polls their desire for law reform on these matters¹³. In the body of the report it was noted that a Newspoll (in 2012) of more than 2,500 people confirmed ongoing very high public support for legal access to physician-assisted dying in the face of intolerable end-of-life suffering that cannot be relieved. Respondents were strongly in favour (approximately 80%), across all age groups, religious affiliation and political affiliation.

2.24 This is but one of a myriad of examples of professionally conducted public opinion polls which consistently show similarly high levels of support for such legislative change.

¹³ It also concluded that there is now a large body of experience in a number of international jurisdictions following the legalisation of voluntary euthanasia and/or assisted suicide, which shows that appropriate safeguards can be implemented to protect vulnerable people and prevent the abuse that opponents of assisted dying have feared.

3. SECOND TERM OF REFERENCE:

“[To] review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions”

3.1 In addressing this crucial term of reference, DWDWA will firstly refer to a New Zealand paper that is of great general assistance, and then turn to the question of eligibility criteria, and to desirable mechanisms to ensure an adequate and transparent process for the provision of assistance in dying (the so-called ‘safeguards’).

Some useful research on terms of VAD legislation

3.2 In January 2016 Pam Oliver provided an interesting submission to the New Zealand Parliamentary Health Committee on Assisted Dying. During the previous two years she had undertaken, as doctoral research in the University of Auckland Law School, a comprehensive analysis of the safety and other issues related to implementing assisted dying laws, internationally; focussed on “identifying implementation issues and how they can be addressed through the laws to make AD [assisted dying] practices safer and more effective for all”.

3.3 She interviewed more than 90 people in six jurisdictions with legal assisted dying (including doctors, legislators, ethicists and researchers). Half of them had been directly involved in providing legal assistance in dying, some for up to 20 years. She also reviewed more than 300 research studies and other documents. Based on that research, she provided a summary (in tabular form) of essential safeguards that in her view should be included in such laws and regulations, to ensure safe provision of legal assistance in dying. She also prepared a draft ‘model’ statute (even including, as an explanatory note, a ‘general policy statement’ and a ‘Clause by clause analysis’, in the form taken by an Explanatory Memorandum in our parliament).

- 3.4 DWDWA commends this submission as a helpful tool in considering the desirable terms of legislation. Although it is not a wholesale comparison of different models (as to either eligibility criteria, or ‘safeguards’) it usefully draws together the author’s considered views following her substantial research.
- 3.5 Further, DWDWA generally agrees with Ms Oliver’s views as to what provisions are appropriate for the ‘safe’ provision of assisted dying.

Eligibility criteria

- 3.6 The eligibility or entry criteria surely present some of the more vexing questions for the drafting of appropriate legislation. As in the entirety of the debate, we ask the Joint Committee to dispassionately focus on matters of fact, rather than of faith or belief. However, we accept that the issue of eligibility criteria constitutes an area of discourse in which reasonable minds might come to different conclusions.
- 3.7 For example, how much emphasis should be placed on the individual’s own assessment of their condition, pain and prognosis? To what, if any, extent should the opportunity to access lawful assistance in dying be limited to those about whom it can be said with reasonable confidence that there is only a finite time left to live?
- 3.8 As touched on earlier, we firmly believe that the balance should be struck so as to maximise the weight to be attached to the right of a rational and informed person to make their own choices, and to minimise the restrictions imposed by society by limiting that right of choice to arbitrarily (and, it will follow, cruelly) drawn categories based on prognosis as to expected time to death.
- 3.9 Thus, we suggest that (as is common in relevant statutes) the determination of when suffering is unbearable, or cannot be relieved in a manner that the

person considers is intolerable, must be entirely in the hands of the patient. There can be no requirement that any other person (doctor or otherwise) be satisfied as to such matters.

- 3.10 Further, it is important that suffering be understood to include not only pain (as that concept might be casually understood), but also the existential and profound suffering that at times results from debilitating and long-term conditions. Pain, and suffering, must be viewed broadly, and empathetically, which may not be easy to do by those of us fortunate enough not to have been struck down by horror diseases and conditions. In other words, “pain” as a concept superficially used may not be the only or isolated reason for a person to deeply seek an assisted death. Existential suffering and a rational wish to have all suffering cease must be appropriately recognised in the law as powerful drivers.
- 3.11 In this regard, the Palliative Care Outcomes Collaboration at the University of Wollongong¹⁴ publishes interesting statistics on patient outcomes in palliative care. In addition to patient distress from pain, they recognise distress from fatigue, breathing problems, appetite problems, bowel problems, nausea and difficulty sleeping (see Tables 34 and 35 at pages 40 and 41 respectively).
- 3.11 Returning to the fundamental task of striking a balance, the committee may consider, on the other hand, that legislation should not permit assisted death to be provided to **any or all** informed and rational patient(s) (that is, with decision-making capacity) who consider(s) subjectively that their illness and its effects on them are such that they wish their life to end.
- 3.12 As in so many aspects of life, in the end this issue of boundaries on eligibility may come down to matters of fact and degree, and will call for the drawing of a line which will not completely satisfy many on either end of the debate spectrum, but which will represent a reasonable and sensible middle course.

¹⁴See <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow231313.pdf>

3.13 DWDWA submits that it would be unnecessary and unreasonably prescriptive to require— as the Victorian and New South Wales Bills do – that the relevant condition is expected to cause death within a certain stated (and short) time-frame¹⁵.

3.14 It is suggested that a reasonable balance can be achieved by limiting eligibility to, essentially, the conditions found in the Victorian Bill **other than** the ‘twelve months to death’ requirement (or any requirement that death will or is likely to occur within a specified time-frame). In other words, it would be sufficiently limiting, and would satisfy reasonable reservations that might commonly be expressed, if a person could access lawful assistance in dying if they met each of the following conditions:

3.14.1 afflicted with a disease, illness or medical condition; and

3.14.2 the disease, illness or condition

(a) is incurable

(b) is advanced

(c) is progressive

(d) will cause death, and

(e) is causing suffering to the person that cannot be relieved in a manner that she or he considers tolerable.

3.15 Limits of eligibility drawn in this way will mean that access to assistance will certainly be narrowly limited – more narrowly than many in the community would wish. Access would be possible only by persons with terminal conditions (those that are incurable and will cause death), that are getting worse (progressive), and that have moved very substantially along the path to

¹⁵ Clause 9 of the Victorian Bill requires that the person must be diagnosed with a disease, illness or medical condition that is incurable; is advanced, progressive and will cause death; is expected to cause death within weeks or months, not exceeding 12 months; and is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable. The NSW Bill (see Clauses 4 & 9) requires the person to have a ‘terminal illness’, defined to mean ‘an illness that will, in reasonable medical judgment, result in the death of the person within the next 12 months’.

conclusion (advanced). The final criterion (suffering that cannot be relieved) will be determined by the patient (as it must be, in any kind of scheme, including those envisaged by the Victorian and NSW Bills).

- 3.16 Crucially, the form of Bill for which we advocate not only draws the philosophically important line closer to autonomy and choice, and further from State control, but will allow assistance to the small but absolutely key groups of sufferers of terrible progressive, degenerative and disabling conditions which may take a number of years to kill (such as MND and MS). Such persons are proceeding to certain death, but on a slower trajectory than those caught within an arbitrary time-frame of estimated death. And yet their suffering may well be as severe, or even more so. Some patients experience unbearable suffering more than twelve months before the likely time of death. They must be recognised as deserving of dignity and choice in the manner and timing of their dying.
- 3.17 We submit that it is unacceptable and inhumane to require of such people that, despite their being fully informed and rational, and despite their understandably having reached a decision that their quality of life is unacceptable to them, they must await the utterance of a medical professional that finally their death looms as so imminent that it fits an arbitrary time-frame imposed by others.
- 3.18 Surely, it should be enough that such a person is established as suffering from a terminal illness, that is advanced, and is still progressing? Beyond those qualifying criteria, it should require no more than the person's own rational assessment of her or his suffering to open the door to a lawful and merciful path out of misery. Any further limitation is inhumane, and paternalistic in the extreme.
- 3.19 It should not be thought that every voluntary assisted dying (VAD) law or carefully drafted Bill includes a criterion that the person assisted is likely to die within a finite period, or even in an undefined time-frame (such as within

the “foreseeable future”, a concept considered by the Victorian ministerial advisory panel). For instance, the Oregon Death With Dignity Act (one of the laws often cited in discussion, and which is generally recognised as working well) turns¹⁶ on a simple definition, namely: ‘*An adult who is capable, is a resident of Oregon, and has been determined by the attending physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die*’.

3.20 Another example is the Tasmanian *Voluntary Assisted Dying Bill 2013*, which required that the person be suffering from a condition in its advanced stages, with no reasonable prospect of permanent improvement.

3.21 Even more striking is the direction taken by the Supreme Court of Canada in its ruling made in February 2015¹⁷, and which was founded on an examination of a very large range of research. A distinguishing feature of the Judgment, which will set Canada apart from approaches taken in many other jurisdictions, is that it does not stipulate that the legislation (which it required to be introduced) should be limited to cases of terminal illness. Rather, the legislation is to apply to people with **intolerable, irremediable suffering**. As noted in an article by the *Globe and Mail* on 6 February 2015, the Court explained in a ‘*brief, powerful opening paragraph*’ why it was creating a new constitutional right to autonomy over death in some circumstances:

Those who are severely and irremediably suffering, whether physically or psychologically, “may be condemned to a life of severe and intolerable suffering” by an absolute ban on assisted dying. “A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.”

3.21 However, in the alternative, if the Joint Committee considers that special caution needs to be exercised regarding those in this apparently more controversial category (where no likely time of death can be stated), it might

¹⁶ At 127.805 s 2.01

¹⁷ See at <http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do>

recommend a provision that when a doctor, exercising reasonable care and skill in all the circumstances of the case, makes the judgement that the patient's condition is remorselessly progressive and will lead to inevitable death, and that there is no reasonable prospect of preventing this trajectory by medical or surgical means, but the prognosis is greater than (say) twelve months, then the confirmatory opinion of a specialist in the condition from which the patient is suffering would be additionally required. Such an additional screening mechanism (while creating further burdens and intrusion for the patient) might assuage any doubts about the diagnosis and prognosis.

3.22 As far as the number of medical practitioners to be involved is concerned, we accept that it should not be sufficient for one doctor to accept and certify eligibility. However, again, in considering the range of options adopted in various jurisdictions, the less onerous, and the less restrictive, the obligation, the better.

3.23 So, DWDWA suggests that there need be no requirement for a psychiatrist to routinely assess a person to determine that decision-making capacity exists. Such an imposition would be offensive, and would truly add serious insult to desperate injury. Should the primary doctor (often a general practitioner) or the doctor providing the second opinion (perhaps a specialist) think it appropriate, either may in the normal way provide a referral to an appropriate person (psychiatrist or psychologist)¹⁸ before reaching a final conclusion.

3.24 Nor should there be a requirement that routinely one of the doctors must have specialist qualifications relating to the condition in question. Often such a specialist will already be involved in the person's care, and will be called on by the patient (and the treating doctor) to assist in satisfying the requirements of the legislation. However, there may be some cases where that would not be feasible or appropriate. It is to be remembered that in remote areas, access to specialists may be difficult and cause considerable delay; and that some

¹⁸ A possible model is Clause 27 (1) of the Victorian Bill

doctors may choose not to assist, for personal ethical or religious reasons. Difficulties of these kinds beset the operation of the Northern Territory Act.

- 3.25 In the view of DWDWA, there should not be any requirement for a medical practitioner or other person to provide assistance¹⁹, as no doubt some would not wish to do so; however, it is appropriate that such a practitioner refer the patient to another practitioner for assistance.
- 3.26 Any ‘cooling-off’ period that might be thought necessary need not be longer than 48 hours, as proposed in the NSW Bill; alternatively, as found in the Victorian Bill (Clause 38) it might be a period of several days (nine, in Victoria) after the first request, but with an exemption in the case of an imminent death.
- 3.27 Turning to matters of perhaps more mundane detail, we notice that the NSW Bill proposes a minimum age of 25 years, and the Victorian Bill, 18 years. The better course, by far, and consistently with age limits in other areas of life, is to settle on an age of 18 years.
- 3.28 Despite the issue of residence having recently attracted attention in debate on the Victorian Bill, we suggest that this is essentially a red herring, and of no, or, at most, of little consequence. The number of jurisdictions around the world providing assisted dying is growing steadily, and this State (despite, we would hasten to add, its many attractions) is so removed geographically from most populations in the world that any suggestions of ‘death tourism’ are hysterical. Further, other Australians are our countrymen and countrywomen, and should not be excluded.
- 3.29 While in our view it is important that there be mechanisms for reporting assisted deaths (to ensure transparency and, when required, audit or investigation, not however forgetting the role of the Coroner), we consider that the choice of structures and requirements to achieve these goals are

¹⁹ See, for example, Clause 23 of the Victorian Bill

matters of detail and practicality on which the Committee can adequately satisfy itself by comparing legislation passed or proposed in jurisdictions like Victoria, NSW, Oregon and Canada.

4. THIRD TERM OF REFERENCE:

“[To] consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation”

- 4.1 Other than the question of federal laws, our submissions as to this term of reference are to be found in the immediately preceding section of this submission.
- 4.2 It may be necessary for the State to ask the Commonwealth to make appropriate changes to Medicare schedules and the like to ensure that medical practitioners and other health professionals (if any) who provide services in connection with assisted dying are compensated (as they should be, and is appropriate in relation to such difficult and important work). Presumably guidance might be obtained from other state authorities that may have already explored such matters.
- 4.3 Otherwise, and despite the preparation in recent years of relevant draft legislation for consideration by the federal parliament²⁰, it seems likely that matters to be addressed by voluntary assisted dying legislation are matters within the legislative competence of the State, rather than of the federal parliament.
- 4.4 Undoubtedly the Commonwealth of Australia (primarily only by executive action and not by legislative recognition) has adopted many important international instruments regarding human rights, such as the International Covenant on Civil and Political Rights. These may provide assistance in the construction of laws, and certainly are highly important statements of commitment to fundamental human rights. Several such rights, arising from principles such as dignity and autonomy, would be promoted by voluntary assisted dying legislation.

²⁰ Medical Services (Dying with Dignity) Exposure Draft Bill 2014

5. FOURTH TERM OF REFERENCE:

“[To] examine the role of advanced health directives, enduring power of attorney and enduring power of guardianship laws and the implications for individuals covered by these instruments in any proposed legislation”

- 5.1 We note that the content of laws relevant to these topics varies considerably between states, and that Victoria substantially amended its laws while the inquiry and drafting processes for its VAD Bill were being worked through.
- 5.2 Broadly, we believe that the current laws in Western Australia (introduced in fairly recent years) are appropriate, but, importantly, it seems clear that both public awareness of them, and consequently their level of use, are very limited. The result is that they are of little value at the moment, and measures to address this are required.
- 5.3 However, the ability of everyone to appoint a ‘health guardian’, or to state in advance and against the possibility of a future loss of consciousness or capacity, her or his wishes as to treatment in various contingencies, is important and must continue.
- 5.4 This is so despite the fact that any model of VAD legislation likely to be adopted will probably confine its availability to those able to make and communicate their wishes at the time of suffering, rather than in advance.
- 5.5 Any perception of difference in underlying conceptions as between VAD laws and laws permitting advance or proxy expression of treatment wishes is really neither here nor there; it is quite extraneous to the crucial fact of the driving need and demand for legislation to place choice and power to determine the manner and timing of death of those suffering grievously where they must reside in any civilised community – in the hands of the sufferer.