VOLUNTARY ASSISTED DYING – OVERVIEW OF THE CURRENT SITUATION – Nov 2020

SUMMARY

1. INTRODUCTION

- Our aim is to support MPs to make well-informed, principled and evidence-based decisions on the next Tasmanian VAD Bill. Voluntary assisted dying laws are now long established, thoroughly scrutinised laws. The number of laws is increasing because of overwhelming evidence they are needed, are working safely and are highly valued wherever they have been passed.
- This paper provides a relatively brief overview of the current situation involving voluntary assisted dying legislation in Australia and overseas and some key issues. It includes links to reliable, trusted sources of relevant information which are independent of DwDTas. All views and claims for and against VAD legislation need to be checked against independent sources of accurate, relevant, reliable information.

2. INCREASING ACCEPTANCE OF THE EVIDENCE - 20 JURISDICTIONS AND COUNTING

- This section includes details of the **21 jurisdictions with a form of legal voluntary assisted dying**; **17 of them with specific legislation.** This **includes New Zealand** after its recent successful referendum.
- The section includes links to the Victorian and WA Voluntary Assisted Dying Acts.

3. VAD LEGISLATION MEETS DEMONSTRATED NEEDS, WISHES AND SUPPORT ACROSS THE COMMUNITY

- Legislation for doctor-provided voluntary assisted dying is a very rare political issue where **support is higher than for any other comparable issue, and the support is very high across the community - across religious and political affiliation, age groups and gender** in Tasmania, elsewhere in Australia and in other comparable countries.
- This section includes links to data on the high level of support for VAD generally, including among Christians, and the likely significant support of doctors for a VAD option. It includes links to policies and views of medical associations (RACGP, RACP and Canadian Medical Association) and to AMA information including a survey report, showing it is likely a majority of its members support a VAD option.

4. VAD LEGISLATION PROVIDES AN ESTABLISHED, SCRUTINISED, SAFE AND RESPONSIBLE OPTION

- **Multiple recent thorough reviews, including parliamentary inquiries**, have gathered a massive amount of evidence and the views of the community and experts. After carefully examining the evidence and views, the reviews and inquiries have reached **consistent conclusions about the need for, and the safety and value of, a legal VAD option**, as well as action on other end of life issues.
- This section includes more details and links to reviews, such as the Victorian, WA and Canadian reviews.

5. DIFFERENCES IN APPROACHES, DETAILS AND OUTCOMES NEED TO BE CONSIDERED

- **All the current VAD laws are working safely, but some have fewer unnecessary barriers and are more effective in meeting people's needs and wishes.**
- This section includes details of similarities and the differences between laws, with the least effective being in the US (Oregon) approach and potentially in Victoria.

6. PALLIATIVE CARE, ADVANCE CARE PLANS AND VAD – ALL ARE NEEDED NOT 'EITHER/OR'

- VAD provides an additional, last resort end of life option, not a replacement for palliative care and other improvements to end of life choice.
- This section includes links to empirical palliative care data and Palliative Care Australia reports.

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1. INTRODUCTION

DwDTas has consistently argued for well-informed, principled and evidence-based decisions on voluntary assisted dying legislation, based on the best available data and evidence, reasonable assumptions and reasoned analysis and conclusions. This paper provides a relatively brief overview of the current situation involving voluntary assisted dying legislation in Australia and overseas and some key issues. It includes links to reliable, trusted sources of relevant information which are independent of DwDTas. Our aim is to support MPs to make well-informed, principled and evidence-based decisions on the next Tasmanian VAD Bill. All views and claims need to be checked against reliable independent sources of accurate, relevant, reliable information. More detailed data is available on request.

Voluntary assisted dying laws are now long established, thoroughly scrutinised laws. The number of laws is increasing because of overwhelming evidence they are needed, are working safely and are highly valued wherever they have been passed. There are **now 21 jurisdictions with a form of legal voluntary assisted dying**; **17 of them with specific legislation.**

Mike Gaffney's End of Life Choices (Voluntary Assisted Dying) Bill 2020 was passed on 10 November 2020 by the Tasmanian Legislative Council, after a thorough, careful and respectful debate. A number of amendments were accepted and others were defeated. The Bill is based on a principled and evidence-based approach and has all the components of a safe, systematic, accountable and transparent legal framework which, as demonstrated by existing legislation, prevents feared risks and abuses. It also contains provisions to ensure that it meets the needs and wishes of Tasmanians, as expressed in the extensive consultation process, and in the Parliamentary debate, eg telehealth, involvement of nurses and no right of health or residential care entities to discriminate against residents who want VAD.

The WA inquiry report, *My Life, My Choice*, identified the **two core reasons for voluntary assisted dying** legislation: *Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.*

A principled response to the issue of VAD requires acknowledgement and a response of empathy, kindness and respect for the people whose needs and wishes are not met by current options, and who are making voluntary, informed end of life choices for medically provided voluntary assisted dying (VAD) to end their intolerable and unrelievable suffering and to achieve the best end of life they can in their very difficult circumstances. These considerations were brought to the fore in the Legislative Council debate.

The major omission from commentaries against VAD is acknowledgement of both these aspects and acknowledgement of the people who will be eligible for medical assistance under the law, with a response of compassion and respect for them. They must all have intolerable suffering resulting from an advanced, incurable and irreversible medical condition expected to cause the death of the person. We have yet to find a single example of this acknowledgement. Many fallacious and misleading claims are also made about risks of VAD which are based on poor quality, inadequate data and a misunderstanding or deliberate misinterpretation of the data. Common fallacies have been refuted repeatedly by every recent, thorough review, including the Australian ones. Those reviews – and others - reached consistent, evidence-based and well-argued conclusions about the effectiveness of safeguards and prevention of risks. For example, the Victorian inquiry found: *The Committee is satisfied, through its research into international jurisdictions, that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.*

2. *INCREASING ACCEPTANCE OF THE EVIDENCE - 20 JURISDICTIONS AND COUNTING*

- There is an **increasing rate of acceptance by parliamentarians** of the evidence of the need for voluntary assisted dying (VAD) legislation and the effectiveness of safeguards to prevent feared risks.

- There are **21 jurisdictions with a form of legal voluntary assisted dying**, all but one in Western liberal democracies similar to ours. Over 200 million people live in the jurisdictions that have legal VAD.
- **Seventeen of those jurisdictions have specific legislation** for VAD, passed by democratically elected parliaments, with detailed requirements for eligibility, the significant roles and responsibilities of doctors and other health practitioners, and for the monitoring, scrutiny and reporting of assisted deaths.
  - Four in 2019 - New Jersey (US) (March 19), Maine (US) (June 19) and **WA** (Dec 19 –operative in mid-2021)**.** In November 2019, the New Zealand Parliament also passed the *End of Life Choice Act 2019*, which received 65% support in the national referendum in Sept 2020 and has now become law.
  - Other laws passed in chronological order: Oregon (1994 and came into operation in 1997), the Netherlands (2002), Belgium (2002), Luxembourg (2008), Washington (US) (2009), Vermont (US) (2013), California (US) (2015), Quebec Province in Canada (2015), Canada (2016), District of Columbia (US) (2016), Colorado (US) (2017), **Victoria (2017)** and Hawaii (US) (2018).
  - In three US States – Oregon, Washington and Colorado - the laws followed majority citizen ballots.
  - In two jurisdictions, Montana State in the US and Colombia in South America, legal VAD relies on court decisions. In Switzerland, the Criminal Code 1942 allows someone to assist a person to suicide as long as it is not for selfish reasons. Commercial services, such as Dignitas, allow access to assisted suicide by people from many countries including Australia. Assisted suicide is legal in Germany as confirmed by a court decision in February 2020 but commercial services are not legal.
- **Over 50% of the laws have been passed in the last 4 years** and this pattern of increasing acceptance is similar to other social law reform for which there is majority support but some strong opposition.
- The first Australian State to pass VAD legislation was Victoria. The *Voluntary Assisted Dying Act 2017* came into operation on 19 June 2019. Comprehensive official information about the law and implementation material is available at https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying.
- In December 2019, WA became the second Australian State with the passing of its *Voluntary Assisted Dying Act 2019*, which will come into operation in June 2021.
- The Queensland Premier made a commitment during the recent election campaign that a VAD Bill will be brought forward to February 2021. The Queensland Parliamentary inquiry recommended a legislative scheme for voluntary assisted dying and the State's law reform body has released a consultation paper on the Bill. A South Australian VAD Bill is to be moved soon.

3. VAD LEGISLATION MEETS DEMONSTRATED NEEDS, WISHES AND SUPPORT ACROSS THE COMMUNITY

- The most common reasons for the laws are shown by Parliamentary and community debates and multiple thorough reviews, reports, articles and commentaries about VAD laws:
  - **to meet the needs of people with intolerable and unrelievable suffering** caused by serious, incurable medical conditions where there is no chance of recovery or improvement; and
  - **to respect people's wishes for the end of their lives and their voluntary, informed choices** made in accordance with their own beliefs, values, what is important to them and their individual circumstances.
- The evidence is very clear that, despite the best skills and efforts of doctors and other health professionals working in palliative and end of life care, s**ome people experience intolerable suffering that cannot be relieved adequately**. There is reliable data and expert opinion (see section 6 below) supporting this and many, many testimonials, as provided to inquiries such as the Victorian, WA and Queensland inquiries into end of life choices and in the media. There have already been many examples in the Tasmanian media and more that will be presented to the Parliament.
- There is **no evidence that doctors are providing VAD to people because they feel a burden**, or have been coerced or manipulated into requesting VAD. Most of the claims about people accessing VAD because they feel a burden are based on an inaccurate and distorted interpretation of Oregon reports.

- The evidence is very clear that **some people are taking desperate action including violent suicides** when they have serious illness and great suffering. Harrowing evidence about such suicides was provided by State Coroners to the Victorian, WA and Queensland Parliamentary inquiries into end of life options, including that they constitute approximately 10% of all suicides.

- Legislation for medically-provided voluntary assisted dying is a very rare political issue because **support is so high, higher than for any other comparable issue and the support is very high across the community - across religious and political affiliation, age groups and gender** in Tasmania and elsewhere in Australia and in other comparable countries. The ABC Vote Compass survey for 2019, with 450,479 respondents, found 90% support, including 77% of Catholics, 76% of Protestants, and 71% "other religion". The Roy Morgan poll in November 2017 found that 85% of national and Tasmanian respondents said 'yes' to the question: "If a ***hopelessly ill*** patient with ***no chance of recovering asks for*** a lethal dose, should a doctor be allowed to ***give*** a lethal dose, or not?". This is consistent with other reputable polls over many years (see our paper *Support for Voluntary Assisted Dying Law Reform*). Recent Tasmanian Bills reflect the wish of the community for this 'last resort' option.

- The report of the 2018 Council on the Ageing (COTA) survey states: *On the topic of assisted dying, **overwhelming support is evident, at 84%** - with results highly consistent across all states and territories. Some differences were found by religion, where support was highest among those with no religion (95%), and lowest among those who identified as Baptist (53%) or Catholic (74%).* The large majority who would investigate VAD for themselves included 57% of Catholic participants and 46% of Baptist participants. (See also Christians Supporting Choice for VAD on why Christian support is high.)

- **The proportion of doctors in Tasmania and across Australia who support and would provide VAD is not known with any certainty.** The data that is available, combined with substantial evidence from overseas experience, indicate that it is reasonable to assume that a significant proportion of our doctors support an option similar to the proposed End of Life Choices (VAD) Bill and the number of doctors prepared to provide VAD will increase over time as awareness and trust in the law increases.

- **Medical associations around the world are reviewing their policies on VAD** and many are adopting a neutral or supportive stance after extensive consultation with their members. This includes the Canadian Medical Association, which also consulted widely with the community as well as its members. The CMA provides equal support for "conscientious participation and conscientious objection" by their members under the law and has consistently advocated for patients as well as doctors.

- Organisations representing nurses generally have neutral policies on VAD eg ACN, ANMWF, NSWNMA.

- The **Royal Australian College of GPs** (80,000 members compared to app. 30,000 AMA members) has a Position Statement on voluntary assisted dying legislation, that is fair, reasonable and patient-centred.

- The **Royal Australasian College of Physicians** is the Australian medical association that has conducted the most extensive consultation process before adopting a more neutral policy on VAD. In November 2018, the College published an updated policy, Statement on Voluntary Assisted Dying, which states: *The RACP respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide, having regard to the will of the community, to research, and to the views of medical and health practitioners.*

- The **AMA** represents about 26% of doctors nationally (2018 figures), and probably a smaller proportion in Tasmania. This should be checked with the AMA. It can only speak for this relatively small membership but the AMA 2016 survey found: "*More than half of respondents (52%) believe euthanasia [doctor-administered drugs] can form a legitimate part of medical care and 45% believe the same for physician assisted suicide [self-administration of drugs]".* A majority agreed VAD should be provided by doctors and this would not negatively affect the trust patients have in doctors. When VAD is to be provided by doctors*, "the vast majority (> 90%) supported it in the case of a person suffering an incurable illness associated with unrelievable and unbearable suffering' while less (<71%) supported it for a terminal illness".* (More details in AMA Review report)

4. *VOLUNTARY ASSISTED DYING LAWS PROVIDE AN ESTABLISHED, SCRUTINISED, SAFE AND RESPONSIBLE OPTION*

- Legal doctor-provided voluntary assisted dying (VAD) is now **long established, with decades of combined experience which has been subjected to rigorous, thorough scrutiny**. The earliest legislation still in operation is the Oregon *Death with Dignity Act* 1994 which began operation in 1997. Voluntary assisted dying has been provided in the Netherlands under legally sanctioned duty of care principles and court judgements for years prior to their 2002 legislation. In 2019, the laws in Victoria and Hawaii came into operation and three more were passed.
- **Multiple recent thorough reviews, including parliamentary inquiries**, have gathered a massive amount of evidence and the views of the community and experts. After carefully examining the evidence and views, the reviews and inquiries have reached **consistent conclusions about the need for, and the safety and value, of a legal VAD option**, as well as action on other end of life issues.
- The extensive 2018 WA report, *My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices*, which resulted from the WA parliamentary inquiry, documents the review and presents arguments, evidence and findings and recommendations about a range of issues including VAD. It followed the Victorian inquiry into end of life choices and passing of the Victorian *Voluntary Assisted Dying Act 2017.* The Queensland Parliamentary inquiry reported on VAD on 31 March 2020 with similar findings and evidence, and made detailed recommendations on a VAD law in that State. A Bill is being prepared by the State's law reform body. Numerous other reviews, chiefly in Canada, supporting VAD include those by the Canadian Supreme Court, the Quebec Superior Court judgement in the Truchon and Gladu case, the Royal Society of Canada and Parliamentary inquiries in the national and Quebec Parliaments. (See for example, the Canadian Parliament Joint Select Committee report, Medical Assistance in Dying: A Patient-centred Approach.)
- Key points made in the WA report are representative of the findings of other inquiries:
  - *Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.*
  - *It is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.*
  - *Overwhelmingly, people want to live. For those left behind, the protracted death of a loved one from a terminal or chronic illness can be devastating.*
  - *How we die has changed over the last 60 years. Medicine and the law have not kept pace with this change, nor with changes in community expectations.*
  - *Having weighed the evidence, the committee concurs with findings by similar parliamentary inquiries in Victoria and Canada that risks can be guarded against and vulnerable people can be protected.*
  - *Those who fundamentally oppose the introduction of Voluntary Assisted Dying lack rigorous evidence to back up their claims. They will inevitably criticise this process.*
- The WA Committee carefully examined overseas practices and claims based on fears about the risks of VAD legislation. It found: "***there is no evidence that vulnerable groups, including people with disabilities, are at heightened risk of assisted dying"*; no evidence to suggest the slippery slope has occurred in the jurisdictions that have legislated for voluntary assisted dying; and *"reports of suicide contagion are not supported in the evidence"***. The Victorian and other reviews reached similar conclusions. None of the reviews have found evidence that VAD laws have reduced trust in doctors or have had negative effects generally on doctor-patient relationships. No evidence has been found of a negative impact on palliative care practices and services or support for ongoing improvements - in fact the opposite. Despite such consistent evidence-based findings, opponents of VAD laws continue to ignore them and to repeat baseless fears about VAD laws.

5. DIFFERENCES IN APPROACHES, DETAILS AND OUTCOMES NEED TO BE CONSIDERED

- All recent, thorough reviews, such as the Victorian, WA and Queensland inquiries, have found that existing voluntary assisted dying systems are working safely, without the feared abuses or risks to certain groups considered vulnerable to manipulation and coercion. However, there are **significant differences, as well as similarities, in their legal requirements and in their effectiveness in meeting the needs and wishes expressed by the community**. The details of these differences have received limited attention in the Australian inquiries but they are relevant and important in determining what is the most effective, as well as a safe, law here. An effective law will meet the needs and wishes of the Tasmanian community and be practical and workable in the Tasmanian situation.

- **All the current VAD laws are working safely, but some have fewer unnecessary barriers and are more effective in meeting people's needs and wishes.** There are two broad models of legislation, the US model and the Canadian/European model. The Victorian law is closer to the restricted US model than the Canadian model. This makes it the "most conservative" VAD legislation, as claimed by the Victorian Premier, but may also make it one of the least effective approaches. There are some differences between the Canadian and European laws.

- **Assisted deaths are a very small proportion of all deaths under all laws**, but particularly low under the least effective laws in US States eg in Oregon reaching 0.52% of all deaths in Year 22 - 2019 report. In Belgium in 2018 they were 2% of all deaths and 4.4% in the Netherlands (2018 report).The Canadian law commenced in June 2016 and the latest report for 2019 shows assisted deaths were 2% of all deaths with a steady growth in cases since 2016 due to greater awareness and acceptance. The report on the first 6 months operation of the Victorian VAD Act showed 52 Victorians had received VAD (0.24% of all deaths in the period).

- Data shows that **there are similarities in who accesses VAD, regardless of the differences between the laws**. The major reason for people accessing VAD is intolerable/unbearable suffering. In over 90% of voluntary assisted dying, the underlying conditions causing the suffering are cancer, neuro-degenerative (such as motor neurone disease), respiratory, cardio-vascular conditions or a combination of conditions. The average or median age is over 70 with only 1 - 2% under 40. Male/female assisted dying is close to 50/50. DwDTas can provide on request detailed, up to date data across a number of jurisdictions including Oregon, Netherlands, Belgium and Canada. The first Victorian report did not include detailed data but it is hoped that future ones will.

- The eligible medical condition is a core aspect of all VAD legislation in determining who will and who will not have access to legal doctor-provided VAD. There is a great deal of misinformation and misunderstanding about the differences:
  - **Terminal illness and a timeframe prognosis have never been requirements in the Netherlands, Belgium and Luxembourg, and they are not requirements in the Canadian or Quebec Province laws**. Eligibility requirements include serious medical conditions and intolerable/unbearable suffering which may result from serious chronic, neuro-degenerative as well as terminal conditions. People access VAD because of the seriousness of their condition and of the suffering that results from their total circumstances, not because they have a particular medical condition or time to live.
  - Amendments are currently being debated In Canada, following a court judgement, to ensure that people who meet all the other criteria (including intolerable suffering) may access VAD (called medical assistance in dying – MaiD) even if their deaths are not "reasonably foreseeable". They will have to meet more requirements than people whose deaths are foreseeable.
  - **Until the Victoria law, US laws were the only ones requiring a prognosis of 6 months or less to live**. **US laws do not have a suffering requirement** and the prognosis requirement is due to restricted US Medicaid funding for people to access affordable 'hospice' treatment available when they have a prognosis of only 6 months or less to live. None of the Australian inquiries recommended prognoses be a requirement, eg WA report: "a prescribed time is too restrictive and cannot be clinically justified". The Victorian and WA VAD laws and the EOLC (VAD) Bill require a prognosis of 6 months or 12 months in the case of neuro-degnerative conditions. The Tasmanian Bill provides for the VAD Commission to allow an exemption from the prognosis requirement.

6. PALLIATIVE CARE, ADVANCE CARE WISHES AND VAD – ALL ARE NEEDED NOT 'EITHER/OR'

- It's a case of both VAD and palliative care, not 'either/or'. The same can be said for improved advance care planning. **VAD provides an option for people who are still competent to express their wishes**. Advance care directives or enduring guardianships come into effect **when people are no longer capable of expressing their wishes**. DwDTas has worked for many years to encourage and assist people to do their end of life planning and make their wishes known. (See our Guide)

- VAD is not a replacement for palliative and other end of life options that work effectively to meet most people's needs and wishes. **DwDTas supports doctor-provided voluntary assisted dying that provides a 'last resort' option for a small proportion of competent adults for whom current options don't work adequately.** That is, it enables them to achieve an end to intolerable suffering, that is otherwise unrelievable, through voluntary assisted dying - when, where and with whom they choose. This meets the needs and wishes of those who will never again be free of intolerable suffering and the devastating effects of their serious, incurable medical condition. **A 'last resort' approach acknowledges the importance of palliative care and other end of life care**, and doctors are required to provide information on palliative care and other options.

- We are very fortunate to have high-quality palliative care in Tasmania, which DwDTas supports very strongly. Many people are assisted by palliative and other end of life care that meets their wishes and circumstances. It is essential that improvements continue in the number and quality of palliative care services in Tasmania, including better home-based care. But, as the respected Tasmanian Professor of Palliative Care, Michael Ashby, commented in his evidence to the 2016 House of Assembly Inquiry into Palliative Care: *There isn't a single area of medicine that has a 100 per cent score, so why would palliative care be any different?* ***Any claims by us that we can relieve all pain are patently nonsense.*** *I think it is very foolish of certain people in our specialty around the world to convey the impression that they can. I don't think anybody these days would make that claim. What I can say is that we can nearly always make a difference for the better.* (p51 of the Inquiry Report). (Our emphasis)

- In Australia reliable data exists in the detailed reports that are provided by over 100 palliative care services to the Palliative Care Outcomes Collaboration. Their reports, including the latest national report (Jan - Jun 20), demonstrate the significant achievements of and improvements in palliative care services across the country. They also confirm Professor Ashby's expert assessment and the evidence that has been provided to multiple inquiries that there are limitations on what palliative care is achieving and can achieve in the foreseeable future. For example, there is a PCOC benchmark that 60% of patients with moderate to severe suffering will have that reduced to mild or absent suffering. This is not being met by most services, despite their best efforts. As the PCOC concludes, "around 5% of people experience severe distress", especially from fatigue and breathlessness. In Professor Ashby's 2016 paper, How we die, provided as evidence to the House of Assembly Inquiry into Palliative Care, he reports that the PCOC data showed that in Tasmania at that time "approximately 50 per cent of patients who have an episode of moderate/severe pain at the beginning of an episode of palliative care will report no pain at the end of the episode of care".

- Palliative Care Australia received two important reports on VAD in relation to palliative care which have informed their new guiding principles that take a neutral position on VAD laws in Australia. The report, Experience internationally of the legalisation of assisted dying on the palliative care sector, October 2018 found: *An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced. Where jurisdictional data is available, there are consistently high levels of patient involvement in palliative care services at the time of the death through assisted dying"* . (p5). Reflections and Learnings: Assisted Dying in Canada and the United States, November 2018 provides valuable first-hand observations from people with experience where VAD is legal and can help to inform the law and its implementation here.