



**SEPTEMBER 2020
END-OF-LIFE CHOICES (VOLUNTARY ASSISTED DYING) BILL 2020**

"KEEP DOING ALL YOU CAN"

Mike Gaffney (MLC for Mersey, architect of the VAD Bill) wrote: "Once the Bill has been tabled and the debate begun, which is currently happening, MLCs will not be overly impacted by the media, but downstairs [House of Assembly] might, especially those who want this to fail. **So, keep doing all you can.**"

This rather large Newsletter has been put together to inspire us all to keep up the momentum in these final critical months, and to provide the factual information on which we must base our responses in the media or to MPs. Rather than general support for Voluntary Assisted Dying, or the reasons that it is much-needed, we need to address the specific concerns of the MPs. These might include, for example, the reasons for a lack of a prognosis (expected time of death); why the Bill doesn't have a "gag" law; why palliative care isn't enough; why nurses should be involved; and the opposition of the AMA.

Some courageous & compassionate nurses, GP's and medical specialists have spoken out in the media about the need for voluntary assisted dying. Yet in a Mercury letter (23/9) Christopher Middleton denigrates them with statements that are factually incorrect. These professionals would have difficulty in standing up for themselves. But we can stand up for them, with letters in support for these brave health professionals by calmly responding to the inaccuracies in such letters with evidence-based answers of our own.

Because of the large size of this special Newsletter, we have included a list of contents so that you can go straight to the items that are of interest to you.

- **FROM THE PRESIDENT - HILDE NILSSON**
- **FROM MIKE GAFFNEY - ARCHITECT OF THE VAD BILL**
- **IT'S OUR TIME TASMANIA - JACQUI AND NAT GRAY**
- **MARGARET SING - VOLUNTARY ASSISTED DYING - OVERVIEW OF THE CURRENT SITUATION**
- **POSITIVE NEWSLETTER FEEDBACK FROM PAMILLE BORG OA**
- **AND A POWERFUL AND MOVING SUBMISSION TO PARLIAMENTARIANS BY PAMILLE BORG OA**
- **ON A LETTER BY DR HELEN MCARDLE, PRESIDENT, AMA TASMANIA - WHIMSICAL COMMENTS BY KEITH ANDERSON, CONCERNED CITIZEN**
- **BILL GODFREY ON WHAT CHANGES HE SEES FROM PRACTICE NOW AND AFTER THIS VAD LAW.**
- **MIKE GAFFNEY'S SECOND READING SPEECH**

STOP PRESS

History was made in Tasmania on Tuesday 22nd September 2020 when Members voted to send Mike Gaffney's End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 to move to the Committee stage for further consideration and refinement. This is the first time in Tasmania that a VAD Bill has progressed this far!

Dying with Dignity Tasmania congratulates Mike Gaffney and thanks him for his tireless efforts to make these gains. However, there is still a long way to go and we must be vigilant and active.

FROM THE PRESIDENT

Mike Gaffney deserves our gratitude and admiration for the enormous amount of time and effort he has devoted to this Bill. He has worked tirelessly over a long period consulting overseas, interstate and all municipalities in Tasmania to bring about a Bill to benefit Tasmanians and one that will suit Tasmanian circumstances. We have had the

opportunity to learn from Victoria and WA and make improvements in our Bill. DwD, and especially Margaret Sing, have contributed much to this process.

Numerous submissions have been made to Mike Gaffney of personal stories by people who have experienced loved ones enduring a terrible dying process, and also many from palliative care and oncology nurses with harrowing descriptions of their daily experiences at work. These stories demonstrate just how common bad deaths are and that palliative care, excellent though it is in Tasmania, cannot always bring relief.

It is disappointing that opponents of VAD have resorted to such underhand tactics with misleading and, at times, deliberate misinformation. This is in stark contrast to the integrity and the measured and factual information from Mike and DwD. Just one example : The AMA and some clergy persist in referring to VAD as “assisted suicide”. It is not suicide (as confirmed by the WA Attorney General last month). People who contemplate suicide can choose either life or death. People requesting VAD are dying. They want to have a choice about the manner of their death. Not the same thing. Opponents also frequently bring up the issue of elder abuse. The Council on the Ageing (COTA) are supporting VAD. In their report they argue that giving elderly people choice is empowering them, and empowered people are not vulnerable people. The knowledge of having a choice toward the end of their lives would be a huge relief and enable them to enjoy and value their life.

Last, but by no means least, I must commend Jacqueline and Natalie Gray, who founded “Your Choice Tas” as a promise to their mother, who suffered terribly towards the end of her life, in an effort to spare such suffering for others. They have been totally committed to the cause of VAD and have launched a most effective campaign, with some support from DwD, in close collaboration with Mike Gaffney.

We've had many courteous and receptive communications and interactions with most MLCs and some MHAs, which we greatly appreciate. I urge everyone to contact your MPs, both in the Upper and the Lower House. This is our opportunity to make our voices heard. Contact me at info@dwtdas.org.au if you would like information or assistance.

Hilde

Solidarity - Back: Keith Anderson, Shirley Haas, Robyn Maggs, Hilde Nilsson, Helen Kershaw, Helen Cutts, Nat Gray and Jacqui Gray. Front: Stefany Wunsch-Stockwin, Mary-Anne Fagan, Noel Woodrow and Helen Brookfield. Absent: Margaret Sing



FROM MLC MIKE GAFFNEY

POINTS FOR DWD MEMBERS TO CONSIDER RAISING WITH MPs:

The importance of the Bill's evolution from its predecessors (that the Victorian legislation was a good starting point, but the WA Bill and now the Tas Bill have made improvements to better serve Tasmanians based on evidence and feedback from those working in the Victorian VAD space). As examples, the Tasmanian Bill:

1. Includes Registered Nurses as AHPs, which will provide greater numbers of health professionals who might be interested in undertaking the training to participate in the VAD process, and will better serve our remote communities, where medical services are often provided by rostered locum doctors but mainly supported by long term permanent community nurses, who live and work in these regional areas. This also provides long overdue recognition of the unique skill sets and professionalism of our nurses, and their capacity to play a role in this space, should they choose to be involved.

2. Removes the 'gag' clause (which is in the Victorian Act). Doctors in WA will be able to initiate conversations around ALL end of life choices, as the 'gag' clause has been identified in Victoria as being a barrier to access for less educated, confident or non-English speaking patients. In Tasmania, we want people to be given ALL of the options so that they are able to make more informed choices about their end of life journey.

3. Contains both a prognosis based pathway (for private self administration) and a non-prognosis based pathway (where an Administering Health Practitioner must be present) - this dual pathway is a first, and it provides greater choice and control for the person. If the latter were to be removed by amendment, the operational flow of the Bill would be reduced to that of the Victorian Bill

The Bill allows for the effective use of Telehealth, which will ease the pathway for PMPs to access specialist information if and when required.

Due to the numbers anticipated to be involved in VAD in Tasmania, we have opted for a Commissioner of Voluntary Assisted Dying rather than a board. Our advice from people working in that space in Victoria is that this will be more efficient and suited to the Tasmanian context.

Members of Parliament are welcome to contact DWD Tas, as the peak body for any advice or evidence-based research which might assist in their deliberations.

DWD Tas Members may like to contact Members to reiterate the importance of ensuring that the Bill is not amended to the point that it is either inaccessible or unworkable.

Kind Regards (In haste)

Mike

MIKE GAFFNEY'S SECOND READING SPEECH

Mike's Second Reading Speech is provided in full at the end of the electronic copy of this Newsletter. If you receive the print copy, and would like to read the speech, contact Helen on 0448 160 751, and a hard copy will be posted to you.

IT'S OUR TIME TASMANIA – JACQUI & NATALIE GRAY

Following the first anniversary of our Mum's death on 18 September 2019, we've taken a few moments to reflect on the past 12 months, marvelling at how rapidly the community awareness and support has progressed and feeling incredibly overwhelmed and honoured to be driving this advocacy campaign for our community. It really is quite extraordinary how profound grief can propel you to pursue the unimaginable. Our campaign, Your Choice TAS, started out as the voice of one heroic lady, our Mum, Diane Gray, who died after an 11-month torturous battle with gastric cancer in September 2019. Our advocacy campaign is a promise we made to our Mum, in her final days, to ensure no one would have to suffer the way she did. 12 months on and our campaign has now evolved into the voice of countless Tasmanians; a voice for loved ones, who bravely faced a terminal illness without the choice of VAD, and for those of us who are yet to travel this path and irrefutably deserve this basic human right - the absolute reassurance they will NEVER have to suffer intolerably. Our Mum's legacy will continue to live on, in our pursuit to give Tasmanians the right to choose a peaceful death through VAD.

And Tasmania, here we are... Making history with the first ever VAD bill introduced in the Tasmanian Legislative Council by Mike Gaffney. We had the absolute privilege of being present in the chamber, during the first set of the second reading speeches in the Upper House, on Tuesday 15 September. The overwhelming emotion, as a result of Mike's remarkable speech, is no doubt captured in the minds of many. We have had a few supporters reach out to us who said they could almost feel the presence of our Mum on that day. A beautiful sentiment indeed.

This week we have had several VAD advocacy billboards positioned around the state. An enormous billboard was positioned on the Midlands Highway (thanks to Helen B), two electronic billboards positioned in Lillico and Somerset, and a mobile billboard is actively roaming Hobart CBD and surrounds on Parliament VAD sitting days. This week we have the arrival of over 100 extra-large corflute signs that will be erected on private property across the State and we have more to come... so stay tuned.



HOW CAN YOU HELP?

It is important to remember; this battle is lost, until it is won. The majority of Tasmanians undoubtedly want the right to access compassionate VAD laws. This is evident in the largest e-petition to ever come before the House of Assembly in August this year. However, access to these laws is now ultimately in the hands of our parliamentarians. Please phone or write to our MP's and urge them to support this bill to end intolerable suffering for our terminally ill. We have created an email template as a guide which you can access here:

<http://www.doingitfordisey.com.au/blog/writing-to-your-mp/>

You can follow our journey and keep up to date on involvement opportunities as the parliamentary process evolves.

Additionally, keep the VAD conversations alive, converse with doctors and health practitioners, engage with friends and family and ensure they've contacted their MP, respond to newspaper articles through a letter to the editor or write an opinion piece for your local or regional newspaper. The opportunities are endless, but, one thing is for sure.... We cannot expect to see change, unless we voice our opinion.

Together we can make Tasmania not just a beautiful place to live, but also a beautiful place to die.

Your Life. Your Right. Your Choice.

Jacqui & Nat Gray

MARGARET SING - VOLUNTARY ASSISTED DYING - OVERVIEW OF THE CURRENT SITUATION

The following paper, *Voluntary Assisted Dying - Overview of the Current Situation*, provides information and links to many independent sources of information, evidence and policies that support the need for voluntary assisted dying legislation and show it has proven to be a compassionate, safe and valued additional end of life option wherever it has been available. We have no doubt that this will be the case in Tasmania. The first page is a summary.

Margaret has also prepared another excellent document - *Table of Data* - which compares features of legislation and statistical data for a number of jurisdictions - Oregon, Netherlands, Belgium, Canada and Victoria - that have successfully implemented VAD. This document may be available on request.

VAD - OVERVIEW OF THE CURRENT SITUATION – JULY 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 **20 jurisdictions with a form of legal voluntary assisted dying; 16 of them with specific legislation**. New Zealand is likely to soon become the 21st.
- 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.

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 20 jurisdictions with a form of legal voluntary assisted dying; 16 of them with specific legislation**. New Zealand is likely to soon become the 21st.

Mike Gaffney, Independent Member in the Legislative Council, has been consulting widely on drafts of his Bill, End of Life Choices (Voluntary Assisted Dying), which he intends to move in the Parliament in August. His Bill is based on a principled and evidence-based approach and has all the components of a safe, systematic, accountable and transparent legal framework. The approach it takes is consistent with more effective laws, because it avoids unnecessary hurdles and barriers to access to VAD in other jurisdictions, including Victoria, such as prognoses of 6 months to live. DwDTas has recommended a number of improvements.

We believe that 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.

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.*

The major omission from commentaries against VAD is acknowledgement of both these aspects and of the people who will be eligible for medical assistance under the law. We have yet to find a single example. What is also missing from claims against VAD laws is acknowledgement of all the components of the systematic legal framework including the accountable system of independent monitoring, scrutiny and public reporting to Parliament. Many fallacious and misleading claims are made about feared risks of VAD are based on poor quality, inadequate data and a misunderstanding or deliberate misinterpretation of the data, even when the claims 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 **20 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.
- **Sixteen of those jurisdictions have specific legislation** for doctor-provided VAD, passed by democratically elected parliaments, with detailed requirements for eligibility, the significant roles and responsibilities of doctors, and the monitoring, scrutiny and reporting of assisted deaths.
 - Three in 2019 - New Jersey (US) (March 19), Maine (US) (June 19) and **WA** (Dec 19 –operative in 2021). (In November 2019, the New Zealand Parliament also passed the [End of Life Choice Act 2019](#), subject to ratification by a national referendum at the same time as Sept 2020 election.)
 - 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 number of laws is likely to increase in coming years** – The [Queensland Parliamentary inquiry](#) recommended a legislative scheme for voluntary assisted dying and a Bill is being prepared by the State’s law reform body; a Bill is likely in SA; Parliaments in Portugal and Spain have had recent votes to support VAD laws; and more laws are expected in other US States.

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, **some 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 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. 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 provided 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*, and numerous other reviews, chiefly in Canada. This includes by the [Canadian Supreme Court](#), 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, supported by all but one member of the Committee, are:
 - *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.
- The [Queensland Inquiry into voluntary assisted dying](#) 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.

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

- All recent, thorough reviews, such as the Victorian and WA 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. We will explain why we believe the Canadian model and not the US/Oregon approach is most suitable for Tasmanians.
- **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.

- 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 Victorian and WA laws, 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. This is not an issue in Australia and neither the Victorian or WA inquiries recommended prognoses be a requirement. The WA report states: “a prescribed time is too restrictive and cannot be clinically justified”.

6. **PALLIATIVE CARE, ADVANCE CARE PLANS 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 plans. **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 \(Jul - Dec 19\)](#), 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.

POSITIVE NEWSLETTER FEEDBACK FROM PAMILLE BORG OA

I appreciated the receipt of the 27 August 2020 Newsletter with its very clear information and its attached list of the contact details for all MLAs. I, like many others, have sent a separately-addressed letter of support for the Bill to each of them. For your records and files, please find attached a copy of one of those letters.

Regards and thanks, *Pamille*

AND A POWERFUL AND MOVING SUBMISSION TO PARLIAMENTARIANS BY PAMILLE BORG OA

To our Tasmanian members of Parliament,

I wish to express my strong support for the end-of-life choices Bill which was tabled on 27 August in the Upper House of the Tasmanian Legislative Council.

I am a 70-year-old permanent resident of Eaglehawk Neck. I was formerly a partner in a large architectural firm for many years and established my own consultancy firm in public art master planning and commissioning. In 2004 I was awarded the Order of Australia for my creation of professional opportunities for emerging Australian artists and craftspeople as well as Indigenous artists in remote communities. I continue to work as a design advice consultant to Parliament House in Canberra.

The provisions of this Bill, if passed, would guarantee for me and for all Tasmanians the essential human right of personal choice for voluntary assisted dying in the face of terminal illness, rather than suffering intolerably at the end of our lives. This provision of choice is consistent with the social contract of our democracy, in which we each have the opportunity to contribute our skills for the good of society while retaining the freedom to live in our lives as we choose, as long as our actions do not infringe on the rights of others or damage the social fabric.

This Bill achieves a clear balance between the right of choice for those with a terminal illness and the safeguards to prevent its provisions from being able to be abused by anyone seeking to harm vulnerable persons. The Bill's degree of provisions of protection is consistent with our form of democracy, which in allowing free choice for its citizens by no means attempts to protect all vulnerable people. If that were so, Australia would not have had 20,933 deaths in 2015 caused by the legal use of tobacco, a known carcinogen (see www.quit.org.au), or the 4186 deaths in Australia in 2017 where alcohol was a contributing factor (see www.abs.gov.au). The potential for mis-use of this Bill's provisions, which will be accessed by only a very small number of people per year, is miniscule by comparison to those numbers of preventable deaths.

I have experienced at close hand the consequences of the absence of voluntary assisted dying provisions. My mother died from breast and bone cancer after eight years of surgery, chemotherapy, and radiation treatments. My father died following two hip fractures and a two-year struggle against a golden staphylococcus infection acquired in hospital, with my sister making the choice to terminate her professional practice as a veterinarian to nurse him alone at home for 18 months before he entered palliative care for his few final weeks of life. I have just spent six years as the power of attorney, executor, and trustee for a former colleague during his period of a sudden debilitating stroke, lingering residential care, and death.

All of these three people were esteemed and vital contributors to their communities, and all three were forthright before their deaths about the fact that they saw no point in having endured very painful, long, debilitating illnesses resulting in death when they could have made the voluntary choice for a dignified assisted end to their lives. The quality of medical and palliative care which they received was high, but it in no way was able to provide an end-of-life process without significant suffering.

The end-of-life health care system in Australia has been under serious strain for a number of years, and its substantial shortcomings have been dramatically revealed during this pandemic crisis. This lack of ongoing adequate funding to public and private institutions and of well-trained, well-paid carers for the aged, whether at home or in residential care, is almost certain to develop into a perfect storm of dysfunction as Australia's aging population grows significantly in coming years. The staggering damage of the ongoing pandemic to the Australian economy will only further inhibit any capacity of future governments to mitigate the aged care system's shortcomings at a time of greater and greater need.

Like many other older Tasmanians, I do not want to add to that burden to the nation by ever entering residential or nursing home care, should I find myself with a terminal illness. I have already familiarised myself with the regulations and opportunities for voluntary assisted dying in Switzerland, and have informed my family members accordingly of my intentions. However, the right of choice which your Bill would instigate in Tasmania, if passed, would remove the sad need for me to go halfway around the world to achieve what should be possible in my home state, near friends and loved ones.

I respectfully urge you and your colleagues in the Upper and Lower Houses to support and pass this Bill. I and other Tasmanians will await the outcome with considerable concern and hope.

Yours sincerely,
M. Pamille Borg AO

**ON A LETTER BY DR HELEN MCARDLE, PRESIDENT, AMA TASMANIA
WHIMSICAL COMMENTS BY KEITH ANDERSON, CONCERNED CITIZEN**

Personal note. I wasn't an addressee of this letter, but it has been circulated widely and it is amazing what can fall off the back of a truck. The letter I received purports to have been written by Dr Helen McArdle, President of AMA Tasmania, and to be a document having the support of the relevant officials and members of AMA Tasmania.

My initial reaction was to assume that it is a spoof, written by mischief makers seeking to discredit Dr McArdle and AMA Tasmania. I have made a few enquiries, but only a few enquiries, and it seems that the letter is genuine. It really was written and authorized by Dr McArdle and really does have the support of officials and members of AMA Tasmania. Wow!

I claim I have reproduced each statement in the letter accurately, and I have used an *italic* font for those statements, to distinguish them from my comments that follow. Read and be amused or alarmed, as is your inclination.

Next week the Voluntary Assisted Dying Bill will be debated in Parliament. This will be the fourth time a bill of this sort has been presented. On each of the previous occasions, the proposed legislation has been defeated.

In my role as President of the Australian Medical Association (AMA) in Tasmania, I want to explain the AMA's position on Voluntary Assisted Dying and our concerns with this legislation. Firstly, the AMA feels that the decision to pass legislation such as this is not a decision for the medical profession but rather one for the community and its elected representatives.

This is a reasonable position. But the concluding paragraphs indicate that the AMA is opposed to VAD and that opposition is inconsistent with the sentiment above, and this inconsistency warns of insincerity.

Doctors have an ethical duty to care for dying patients so that death can occur with comfort and dignity. They have a responsibility to initiate and provide good quality end of life care which strives to ensure that a dying patient is as free from pain and suffering as possible and upholds the patient's values, preferences, and goals of care.

For most patients at the end of life, pain and other causes of suffering can be alleviated through the provision of good quality end of life care, including palliative care that focuses on symptom relief, the prevention of suffering and improvement of quality of life.

As a matter of the highest priority governments should strive to improve end of life care for all Australians through:

- *The adequate resourcing and increased development of both enhanced palliative care services and advance care planning*
- *The development of clear and consistent legislation protecting doctors in providing good end of life care*

“Highest” is an exaggeration. The government has a huge number of high priority tasks and it is unreasonable to expect every task to be allocated highest priority.

Adequate resourcing is, has been and will continue to be contentious and controversial. At least one popular political party favours “user pays” funding. There is also the practical fact of life that unless there is enough funding to buy a reliable magic wand or reliable Tardis, the best palliative care available in 2020 can’t be better than the best palliative care available in 2020, and can’t be as good as the palliative care that might or might not become available in 2220 or 2420.

Advance care planning is very important and should be promoted more enthusiastically, but I suspect that many people put the paperwork in a little bottom drawer when they find that it can be used only for a limited range of options. It is significant that Mike Gaffney’s Bill does not include access to VAD by Advance Care Directive, mostly because of the probably correct anticipation that opponents of VAD would complain about that too.

Mike Gaffney’s Bill is a sincere attempt to introduce clear and consistent legislation. It is weird that the AMA wants to oppose it.

All dying patients have the right to receive relief from pain and suffering, even when this may shorten their life.

A reasonable position.

If a doctor acts in accordance with good medical practice, the following forms of management at the end of life do not constitute euthanasia or physician-assisted suicide:

- *Not initiating nor continuing life-prolonging measures: or*
- *The administration of treatment or other action intended to relieve symptoms which may have a secondary consequence of hastening death*

These are just pragmatic interpretations of the existing legislation allowing pseudo VAD, provided we don’t call it VAD and provided we deny that it looks like VAD.

The AMA acknowledges that laws in relation to euthanasia and physician-assisted suicide are ultimately a matter for society and government and that there are divergent views even amongst doctors. Importantly the AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a person’s life. This does not include the discontinuation of treatments that are of no benefit to a dying patient.

In an important sense, I think society should be grateful for the work palliative care specialists have done persuading the legal community to accept that death by secondary effect can be legal, provided we call it palliative care and emphasise that the effect is “secondary”.

Although this evidently makes sense to many in the medical and legal professions, members of those professions shouldn’t be surprised that the patients receiving this secondary effect treatment think it is just a legal artifice that retains the “Dying” part of VAD, and differs from VAD only because the voluntary part is missing.

Good end of life care includes:

- *Clarity about people's wishes*
- *Good funding of palliative care - facilitating patients to stay at home if they wish*
- *Doctors being clear that they only have to offer treatment which is of medical benefit and being supported to give a dying patient enough medication to relieve any distressing symptoms even if this may hasten death - as long as the intention is the relief of symptoms (palliative care).*

This is mostly just a restatement of the secondary effect principle. Perhaps the word “includes” is significant. Adding VAD as another component of good end of life care would turn the list from a good list into a very good list.

It should be pointed out that Madeleine Ogilvie has attempted on at least two other opportunities to progress legislation of this type – the last occasion being the CARE AND CONSENT TO MEDICAL TREATMENT BILL 2016 which AMA Tasmania and the Federal AMA were asked to assist.

Although some of her supporters value the work Madeline Ogilvy has done, her approach is inconsistent with the objective of developing clear consistent legislation. It seems to be a complicated way of perpetuating the secondary effect convoluted to produce a treatment regime that lawyers might understand; and be the only people who understand. I'm sure that her supporters will complain that my understanding of her strategy is poor, confirming the validity of my complaint.

There is currently legislation of this form in both Victoria and WA. This legislation was developed after extensive consultation through a committee process. In Tasmania, we are continually being told that there are high numbers of patients whose end of life care has not been adequate; however, there is no available data to support or refute these statements. They are anecdotal. An inquiry would be able to quantify the problem and ascertain where things went wrong with an aim to avoid similar incidents.

That there is legislation of the form attractive to the AMA in Victoria and WA and that they also have VAD legislation seems to indicate that the Madeline Ogilvy strategy is inadequate.

The accusation beginning “In Tasmania, we are continually being told ...” seems itself to a statement lacking data able to support or refute it. My observation, admittedly anecdotal, is that hardly anyone claims, “high numbers”, but that official reports, including by at least one Palliative Care body admit that palliative care can't solve all end of life problems. The plea for yet another inquiry seems to be a cynical tactic to delay passing a suitable VAD Bill while we add yet another decimal point to some number quantifying what we already know.

We remain very concerned about several components of the draft Bill. It is long and confusing, seems to have been developed on the run, comprises 160 pages much of which we found difficult to understand and with many points which seemed contradictory.

Some of these complaints might be valid, but most of the complexity arises from the efforts Mike Gaffney made to consult almost everyone and anyone and to accommodate their conflicting concerns as thoroughly as he could. Cynically, I believe that opponents of VAD want a Bill that won't solve problems while supporters want one that will.

The definition of a relevant medical condition is vague and, unlike the legislation in other states, does not include timeframes in which death is likely. It also allows for the relevant condition to be combined with other conditions. Therefore, a patient with diabetes, which if untreated, is likely to cause a person's death combined with arthritis and mild depression would qualify a person to apply for VAD.

“Vague” is a subjective term. Mike Gaffney’s Bill defines what needs to be defined and omits complexities that should be omitted. It omits the prognosis of time to die included in other legislation because this is known to be a fiction. Honest medical people admit that predicting time to die is about as fraught as predicting winning lottery numbers. It is useful and important to ask, “What does including a specific time to die achieve?” Legislation with this restriction is unlikely to serve the needs of any patient, or any doctor, or even any lawyer. About the only benefit I can foresee is the negative benefit of providing interfering busybodies opportunities to make mischief as they indulge their appetites for bush lawyer pedantry.

The convoluted discussion about diabetes and arthritis seems to be an argument for Mike Gaffney’s Bill, not a criticism. What specifically is the AMA seeking? To be a medical profession providing compassionate care for patients? Or to be a bunch of mischief making bush lawyers forcing patients already enduring unwanted and unnecessary suffering and misery to endure even more misery?

In the Victorian legislation, it is an offence for a doctor to raise the issue of VAD with a patient; this is missing from this draft. In addition, in the Victorian legislation, all consultations must occur face to face to be able to assess a patient’s wishes accurately. The WA legislation allows for one of the consultations to be held by videoconference.

At the risk of asking the same question again, what purpose does this gag clause serve? It certainly doesn’t help patients to obtain sensible reliable information from a reliable source. It certainly doesn’t protect doctors from mischievous accusations from interfering busybodies. Contrarily, the gag clause probably makes them more vulnerable to vexatious accusations.

With luck, sense will prevail and squabbles about who asked whom what when will not arise and will not end up in court, but interfering busybodies enjoy interfering so much that this can’t be guaranteed. It is Mike Gaffney’s Bill that is right and the Victorian Bill that needs to be fixed.

And again. What purpose does it serve to insist on a prescribed number of face to face meetings? This seems to be an example of micro management. Mike Gaffney’s Bill correctly anticipates that face to face medicine is the medicine of the past and that telemedicine is the medicine of the future. It is particularly important in Tasmania, where, despite our small geographic size, face to face meeting is often unnecessarily difficult, particularly when the patient is so ill that they are thinking of VAD.

Interstate legislation in effect focuses primarily on self-administration with a health practitioner administration only being allowed where the patient is unable to self-administer. This draft Tasmanian Bill, as it is written, is essentially Physician-Assisted Suicide.

The tone of this paragraph implies that the interstate legislation is superior to Mike Gaffney’s Bill. This depends upon rather warped criteria where the suffering of the patient is unimportant. It is useful to remember that Mike Gaffney’s Bill is for Voluntary Assisted Dying. Actions are voluntary for patients and for medical providers.

We are also concerned about the level of experience of medical and nursing staff involved as this is far less than in either Victoria or WA. In addition, we believe that there should be a Board overseeing the legislation with the ability to form a tribunal to review concerns raised with it.

I think we are getting into territory where the AMA is behaving like a little boy inventing excuses for not doing his homework. VAD might be at the cutting edge of politics, but it is not at the cutting edge of medicine. It wouldn’t be appropriate to allow the local publican to provide VAD, but it is insulting to assert or imply that nursing staff should be excluded. Indeed, it is likely that many patients would feel happier receiving their VAD from a nurse than from a doctor. Probably, Mike Gaffney’s Bill has addressed the issue better than the legislation elsewhere.

And a Board? You must be kidding. Why on earth would anyone in their right mind want to clutter the system with yet more bureaucracy and committees and boards? This is just a “jobs for the boys” proposal, where a few “important” people will be paid heaps of money to keep seats warm.

Our final concern lay with a segment towards the end of the legislation, which allows for a review of the legislation within three years with the ability to extend VAD to children and persons with non-lethal conditions. This is very alarming and should be immediately removed.

And this is a bad idea because...? The Bill proposes a review. If that review reveals that these ideas should be considered further, they might be considered further, if not, then not. Does the AMA really propose that ignorance is preferable to wisdom?

The irony that Dr McArdle urges against emotionalism, but uses the word “children” above is conspicuous. Why did the word, “hypocrisy” pop into my head?

Prior to legislation of this kind being passed in Tasmania, we believe that the following questions should be posed and answered:

- *Has Tasmania genuinely ticked the boxes regarding the four more important foundations of good end of life care which have been outlined above?*
- *Has this legislation followed a reasonable process of consultation and considered all views - because legislation of this importance should not be made on the run.*

This seems to be the invention of a delaying tactic that has no purpose other than to be a delaying tactic. The answer to the first dot point is, “No. Of course it hasn’t, and it never will, and the problem is a combination of our constitution, political ideologies and buck passing deciding who is responsible for what.” Because so many vested interest groups have so many spanners in the works, it is highly unlikely that these problems will be solved in any foreseeable future. Does the AMA really propose that patients having a thoroughly miserable time should just suffer in silence while politicians and lobbyists invent yet more excuses for yet more delay? The AMA seems to have forgotten that the V in VAD is for Voluntary.

And as for considering all views, Yes. The Bill has considered all views. It has tried diligently and thoroughly to accommodate as many of them as can be combined into legislation that will work and that will solve the problems it needs to solve: provide patients control over their plight.

Despite the pressure that the legislature may feel to pass Voluntary Assisted Suicide legislation, bad legislation remains bad legislation. And it is particularly dangerous when it involves life and death.

Voluntary Assisted Suicide? When did Mike Gaffney’s Bill morph into a Bill for suicide? I can’t help remembering a line from a Tony Hancock episode, “I don’t know about you, but I wouldn’t let him operate on me”. In this case, I think a medical person who can’t distinguish VAD from suicide will make mistakes about lots of other important words too, and might even confuse “circumcision” with “castration”.

Probably, the bad legislation is the current legislation which demands that seriously ill patients having such a miserable time that they are contemplating VAD must put up and shut up.

We need to show wisdom in making decisions that are for the genuine betterment of the majority and not allow ourselves to be influenced by emotive arguments and populism based on a lack of understanding about the reality in the community.

Wisdom would be wonderful. It is amazing how many inaccuracies and misconceptions a suitably obsessed author can squash into one tiny paragraph. I identified the following:

Sadly, the AMA position seems to be what we get when a few of its members in senior positions value authority more than the needs of their patients.

Like many people, I tend to think of the AMA as a society of medical practitioners. Maybe Dr McArdle is just reminding me that it is a union, with the moral integrity of a union, and should be given no more respect and credibility than any other union.

It would be interesting to conduct a survey of AMA membership, or preferably of medical practitioners generally, to discover how many agree that this ideological manifesto is consistent with good and ethical medical practice.

We’ll get genuine betterment when the AMA listens more and pontificates less.

And that betterment will benefit the majority too.

“Majority” and “populism” are synonyms, not antonyms.

The lack of understanding is within the upper echelons of the AMA. Most patients know way too well how much suffering is tolerable and intolerable.

The reality is well known by most of the community, despite the efforts of groups stuck in the past to spread fear, uncertainty and doubt, verging on pathological phobia.

It is the AMA that is out of touch with reality. Way out of touch.

Physician: heal thyself.

While the AMA opposes the introduction of this legislation, we will, however, work with the legislatures to make any legislation as safe as possible for doctors and patients if it is adopted.

Thank you for providing wonderful examples illustrating the meaning of words like “patronizing”, “condescending”, and “arrogance”.

BILL GODFREY ON WHAT CHANGES

In considering this Bill, Members need to keep in mind that it is extremely simple. The complexity arises from the fact that it also rouses strong emotions.

The objective of voluntary assisted dying laws is, and always has been, simply this: **"If a person is in his/her right mind, is suffering from a condition which is incurable and will almost certainly lead to a slow and painful death, would prefer to die quickly and easily, and can find a doctor who is prepared to help him/her to do so, he/she may get that help and the doctor may legally provide it."**

Let us assume that the Bill has passed. **What has changed?**

Patient: A person (mature adult) with a specified condition (essentially one that is incurable and cannot be adequately palliated) may request assistance from a participating professional to end their life and the professional may provide that assistance. **CHANGE**

A person may, at any time prior to such a condition arising, prepare a legal document (Enduring Guardian under State Law or Advance Care Directive under Common Law - also known as a Living Will), which sets out the conditions under which they would wish to take such an option if it is legally available, and appoints a person with authority to speak on their behalf within the terms of the document if they are no longer able to speak for themselves.

NO CHANGE

Professional (doctor): A professional who is ethically opposed to providing such assistance has no obligation to take part in it, but must not stand in the way of a patient seeking out one who will. **NO CHANGE**

A professional who does provide such assistance must work within the body of law affecting all their operations.

NO CHANGE

No professional has the right to assume that they know what a client (patient) does or does not want or should or should not want. Their job is to act within their own ethical standards in the best interest of their client in accordance with the client's wishes. **NO CHANGE**

There is very strong evidence that the majority of the population are in favour of such legislation. There is a minority who are very strongly opposed, most on ethical or religious grounds. The tactics of opponents will be twofold with this as has happened historically with all similar socially progressive legislation; to delay it by adding complexity and demanding 'reviews'. They should be treated as being just that - delaying tactics, which will waste a great deal of valuable Members' time.

TUESDAY 15 SEPTEMBER 2020

(with apologies to our newsletter readers for the lack of paragraphs. We simply did not have enough room in the newsletter to include these. It is still well worth reading.)

1 Acknowledgement of the Inaugural Speeches of the Honourable Members for Huon and Rosevears Mr President, I take a short moment to congratulate the Honourable Member for Rosevears on her wonderful inaugural speech and being elected to this place. I would also like to acknowledge the earlier speech by the Honourable Member for Huon, who spoke so eloquently during our last sitting. The first year as a Member brings many challenges and perhaps some quiet reflection along the way. I wish them both the very best on their Parliamentary journey, and offer my genuine support and assistance at any time. End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 - Second Reading Speech - Mr President, I move: That this Bill be now read a second time. Honourable Members, the Bill before you today seeks to provide for, and regulate access to, voluntary assisted dying, to establish the Commissioner of Voluntary Assisted Dying, and for related purposes. I'd like to begin by explaining a little about how this piece of legislation came to be. 2 As Members may be aware, the issue has a long history in this state. Two inquiries have been held, and three Bills pertaining to voluntary assisted dying have been tabled in the other place. I thank former Members the Hon. Lara Giddings and now-Senator Nick McKim, and the current Leader of the Greens, Ms Cassy O'Connor for their hard work and tenacity in constructing and presenting their Bills. Voluntary Assisted Dying, in fact end of life choices in general, is a difficult topic for many people to openly discuss, let alone agree upon, therefore it was not entirely unexpected, in previous political and social climates, that the Bills were not successful despite the best intentions and efforts of their proponents. Greek philosopher, Heraclitus said "the only constant in life is change". And change, things have. Hon. Members, it is not a difficult task for any of us to recall times (which perhaps only seem like yesterday) where the political, familial and community views were very different from those we experience today. I was born in late 1959. Around this time, the societal landscape seems, to younger generations at least, completely removed from current norms - to name but a few issues - the Vietnam War conscription policy, which caused painful divisions between families and friends and ultimately resulted in huge numbers of unsupported and marginalised veterans, the absence of rights for or recognition of indigenous people (still referred to then in the Constitution as 'natives' - it seems almost hard to believe in 2020), and the first wave of feminism since the suffragettes was taking off, with many women foregoing the norm of life at home, keeping house and raising children - women, having been reidentified upon marriage from Miss Jane Jones to Mrs John Smith - women, protesting to 3 demand equality in the workplace, women having control over their own bodies and finances. And, Mr President, there are still changes needed within that space. However, things have changed. Time has marched on. So many of the freedoms, privileges and rights we enjoy today were hard fought, and often just as fiercely resisted. But as I have found frequently on the path to tabling this Bill, the things in life that really matter rarely come easily. Voluntary Assisted Dying (or VAD) became legally accessible in Switzerland with an amendment to the Criminal Code in 1942. Since then, other countries and jurisdictions have adopted the practice for their citizens utilising a range of legislative structures, and interestingly, 50% of all Voluntary Assisted Dying legislation has been passed in the last five years. As VAD has become legal in more jurisdictions, including two of our Australian states, our communities have become more educated and aware... and as Hon. Members may note from their own polling....the average statistics indicated that 85% of people in Australia support the implementation of Voluntary Assisted Dying Legislation, and as Mr Ian Wood of Christians Supporting Choice for VAD stated during his presentation to Hon. Members on the 26th of August, the most recent YouGov Poll of Christians in QLD had 79% Anglican, 68% Catholic and 83% Uniting /Presbyterian in support of VAD. In late 2018, the then-President of Dying with Dignity Tasmania, Margaret Sing advised that after decades of research and lobbying, and having observed the groundswell of support and ultimate success in Victoria, the organisation's executive and members were extremely keen to table a revised Bill which would allow Tasmanians access to voluntary assisted dying. We had lengthy discussions about the best manner in which to introduce the legislation, and it was decided that instead of 'carrying' the Bill if it passed in the other place, that I 4 would, in fact table a Private Member's Bill in this chamber. This anomaly in the Parliamentary process was the subject of much discussion during my Community Forums and communications with many groups and constituents - some optimistically assumed that if I were introducing the Bill,

it must have meant that it had already been passed in the other place. If only that were the case, Mr President. Following on from my meetings with Dying with Dignity Tasmania, I travelled to five jurisdictions where VAD currently occurs (The Netherlands, Belgium, Switzerland, Canada and Oregon, USA), and was introduced (through Dying with Dignity Tas connections) to eleven international experts – all highly regarded in their fields. They included palliative care experts, medical practitioners, university researchers, senior legal counsel, current and former politicians and several health practitioners who are directly involved in the assessment of eligibility for and administration of VAD. Their collective knowledge of constructing and strengthening legislative frameworks, ensuring adequate safeguards and best practices, legal protections for the person and practitioners as well as detailed anecdotal evidence of their own experiences with people utilising VAD, working closely with other end of life services such as palliative care and the families was generously and candidly shared in the interests of trying to help craft a Bill absolutely tailored to suit the Tasmanian environment. The insights gained through these meetings and discussions have been invaluable to the process, and the international experts have all remained but an email or phone call away in the months since my visits - I remain utterly grateful to each of them. Mr President, over the past year, I have had frequent meetings with the Chief Parliamentary Counsel, Ms Robyn Webb. Robyn has been an absolute powerhouse throughout the entire process, and I take a moment here to thank her for her 5 extraordinary contribution in researching, constructing and reviewing this Bill from start to finish. There have been a number of versions (as is common with legislation), as feedback was received, expert advice taken and suggestions for strengthening the Bill were continually raised.... Robyn's professionalism and experience meant that there were never any moments of panic or despair...perhaps the odd raised eyebrow...but the sense of calm resolve was ever present. When the former Premier, the Hon. Will Hodgman gave permission for OPC to assist in the process, I could not have conceived that not only would we have the most senior and experienced drafter on the job, but that over 210 hours of work would go into the drafting, followed by the QA process and preparations for Clause Briefings with Members. I extend my thanks to the Hon Premier and his Government for allowing continued access to OPC - the resultant Bill is a testament to the skill, dedication and tenacity of Robyn Webb and the Office of Parliamentary Counsel. Mr President, in January this year (which seems a very long time ago), I took the Bill on the road, to present a series of Community Forums in every Local Government Area in the State. I found it to be an exciting month with 35 forums. It was a whirlwind of travel, assembling and disassembling IT equipment, projectors and a screen (and for the benefit of my Electorate Officer who received one or two panicked phone calls, I would say that this aspect of the process was one of the more challenging for me). It was often after the forums, talking to people, that I got the very first taste of just how many people had 'a story'....so many of them of distressing and sad experiences...and so many altruistically desperate to support the Bill, as they advocated to me to 'please get this through - we don't want anyone else to go through what our beloved brother, sister, partner, mum, dad, nan, or grandpa did.' Indeed, Mr President, when one person would stand to the side, with tears in their eyes, waiting to tell me about their lost loved one, that was hard enough, but when two people 6 with tears in both of their eyes, I often knew that one would not be here for too much longer. That was very, very hard. Perhaps one of the most beautiful things about Tasmanians is that they are loyal, strong and community-minded. Here these people were, laying bare their most upsetting experiences, knowing that this legislation could not in any way tangibly help their own loved ones, but wanting to help those who may be faced with a similar end of life journey. These face to face meetings, letters, phone calls and emails as well as the hundreds of submissions received, (of which Members received a printed copy two weeks ago) have been a constant reminder to me never to lose sight of just how vital and wanted this legislation is. Even though, in Tasmania, it may involve very small numbers of people and their loved ones, to those individuals (who are contemplating or already experiencing a painful and intolerable decline), the comfort and security that this Bill will provide in assuring that they may find relief from their suffering at a time of their choosing cannot be understated. Throughout the year, Mr President, I have sought and received input into the consultation draft of the Bill by meeting with and contacting a huge number of stakeholder groups and individuals, including the Australian Medical Association - Tasmanian Branch, St Vincents Hospital Victoria, members of the Royal Australian College of General Practitioners - Tasmania, Dying with Dignity Tasmania, the Australian Nursing and Midwifery Federation, the State President and Manager of the Pharmaceutical Society of Australia - Tasmania and a Project Pharmacist from the PSA - Victoria, the Chairperson and Board Members of the Voluntary Assisted Dying Review Board in Victoria, the

Australian Pain Society, Palliative Care Tasmania, The Commissioner for Children, DPAC, TasCOSS, Disability Advocates, Doctors, Nurses, Tasmanian Medical Students and Staff, College Students studying ethics and social issues, and arranged briefings for Members with representatives who are in support of or opposed to the Bill and in some cases for or against the very issue of Voluntary Assisted Dying itself. 7 Mr President, I would at this time like to welcome Jacqui and Nat Gray, who are here for this Parliamentary sitting. I would just like to take a moment to mention the involvement of Nat and Jac. It is fairly likely that most Tasmanians are now familiar with the sisters' story - their mother's heartbreaking and cruel decline - and their decision to fight for Tasmanians to have access to VAD, in memory of their mum and to honour what literally were 'her dying wishes'. From what started as a simple email, explaining their story and sharing a diary entry from their Mum's last days, Nat and Jac were soon openly reliving their family's experience and appealing to Tasmanians to become involved in the debate, through print, radio and social media. The sisters created Your Choice Tasmania – and what a success it has been. The impact that these young women have had on the community in their fight for VAD legislation cannot be underestimated - they have been fearless, selfless and have provided human faces to what may be seen as a complicated and clinical issue. Your Choice Tas created a website, where people could obtain more information, Facebook and Instagram pages, and they produced a brochure urging Tasmanians to take a moment to consider the issue and make their voices heard - 120,000 were distributed - a huge job, involving many generous volunteers. Recently, the Your Choice Tas campaign was extended to include electronic signs and Billboards encouraging Tasmanians to share their opinions and stories with MPs. But Jac and Nat did not restrict their efforts to raising awareness in the community - they encouraged those in support to sign the paper and e-petitions, whose wording was as follows: 8 “The petition of the undersigned residents of Tasmania draws to the attention of the House the urgent need to legalise Voluntary Assisted Dying within Tasmania. Palliative care cannot always relieve the intolerable pain of those with a terminal diagnosis nearing the end of the life, despite the best of intentions and efforts. Many terminally ill patients unnecessarily experience intolerable, prolonged pain. These people should have the right to die a peaceful death in a place and time of their choosing. Tasmanians deserved freedom of choice. Your petitioners therefore request the House to support the forthcoming End-of-Life Choices (Voluntary Assisted Dying) Bill 2020.” Mr President, on Wednesday, the 19th of August, the largest ever e-petition was tabled in the other place. Ms Cassy O'Connor MP sponsored the petition, which was supported by 13,082 Tasmanians. I can remember the excitement, Mr President, that we all felt on reaching 5,000 signatures - it really felt as though Tasmanians were onboard at that point - to have reached 13,082 is nothing short of staggering. I extend my sincere gratitude to Nat and Jac Gray for all of their efforts - I fully appreciate that this fight has taken an immense toll on you and your families, and I know - truly - that your mum, Diane would be so very proud of both of your initiative, resolve and consideration for others. I think she'd be looking down on you right this minute – smiling and glowing at her daughters and grandchild to be. On the subject of “Thank You’s”, Mr President - it really is a process fraught with danger at the Second Reading stage. 9 I would like to acknowledge those Tasmanians who have emailed me their concerns and who will not or cannot support this legislation. I do recognise and respect your opinion, and value your input into this important discussion. However, Mr President, there are so many people who have given this Bill their all - through expert contributions, personal stories (I do not imagine any Honourable Member who has read the submission document, 'Voluntary Assisted Dying - Tasmanian Perspectives' could have done without being affected. So many harrowing accounts of suffering - it would be impossible not to be moved by the pain and distress so many of our fellow Tasmanians have experienced), volunteering with letterbox drops, distributing posters, sharing information on social media, and in so many other ways. Before I discuss the crux of the Bill itself, I would like to place on the record my sincere thanks to everyone, absolutely everyone who has assisted in bringing the End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 to its tabling in this place on 27 August 2020. I hope this Parliament, and the 40 elected representatives will give you the result you were all hoping for. ----- The End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 seeks to provide for, and regulate access to, voluntary assisted dying, to establish the Commissioner of Voluntary Assisted Dying, and for related purposes. For far too long, terminally ill Tasmanians have been unable to legally end their suffering...and I mention the word 'legally' because it is a somewhat disconcerting perhaps uncomfortable fact that a number of families have been devastated by the violent or lonely death of a loved one who made it clear that because they were unable to access a legal, 10

safeguarded, supported and painless process by which they might alleviate their pain....it was simply too much to bear, and they took matters into their own hands. On 7 August 2019, the Western Australian Minister for Health spoke of Coroner's findings that indicated that around 10 percent of suicides are linked to chronic disease or terminal illness. He responded: 'These are the wrongful deaths that we should be concerned about. This is where our compassion is lacking. We can do better than condemn people to suicide. There is also an unknown cost - the cost of unsuccessful suicides. That people are left so desperate is shocking, the distress for their families unimaginable'.ⁱ Mr President, often, the decisions that were made did not just impact upon their person and their loved ones... but our first responders - Police and Ambulance Members, neighbours, those who chanced upon some very traumatic and confronting situations, and in some cases, the emergency department personnel, mental health teams and allied health personnel who supported the person if the attempt was survived. Mr Robert Cooke, in his submission, stated: "I am a serving police officer with over thirty years of operational experience. Too often have I attended incidents of suicide of persons suffering terminal illnesses.... At times the methods employed by people suffering are extremely traumatic and involve the use of firearms, self asphyxia and often drug overdoses. This leaves a terrible legacy for their loved ones, not only grieving for the loss but also dealing with possible lifelong trauma themselves due to the sometimes extreme and violent methodologies employed by the person suffering....¹¹ It is the greatest of certainties that all our lives must end. The right to choose the timing and most humane method of ending one's life is an inalienable human right that none but the person themselves should have the ability to choose, free of fear of prosecution of loved ones and medical staff who may assist them. I firmly believe that this legislation is well overdue, and is capable of being enacted with the strictest of oversight to ensure it is only available to those who meet the required standards. It has been successfully passed in other jurisdictions and I see no reason for the continued denial of choice and dignity to those enduring untold suffering, pain and ultimately death. I hope this issue can be debated maturely and in a timely fashion to expedite its passage through parliament.'ⁱⁱ Honourable Members would recall from reading the submissions I tabled when last we sat, a number of utterly heartbreaking stories of desperate people taking desperate measures, because there was not a kinder, more compassionate option open to them. Mr Bill Godfrey spoke of his family's experience, saying: "I would like members to consider the case of Elizabeth Godfrey, my mother... Over the last ten years of her life she battled intractable pain, which became less and less possible to manage (she was allergic to all opioids) and increasingly destroyed her mobility. In the absence of VAD legislation, she made four attempts at suicide...At the end of 2002 she made the final two attempts. My brother had to tell her to stop the first attempt and she tried again the following night, this time successfully.¹² This led to 2 years of prosecution and ultimate conviction of my brother for an offence against Criminal Code Sec 163 'Any person who instigates or aids another to kill himself is guilty of a crime.' The definition of 'aids' is so loose that any one of the family could have been accused.... The comments made by Justice Underwood on passing sentence make it clear that he was unhappy with both the legislation and the sentence that the law required him to pass. Having been closely involved with this case, I am also aware of other cases where the sufferer and family have gone through a similar agony. It is not humane, it is not necessary and it should be changed"ⁱⁱⁱ Throughout this process, I have had a number of people share with me that their loved one would willingly have adopted this action, but for the fact that they were fearful of implicating a family member. Some people whose pain has been unable to be relieved by palliative care methods or medication have, literally - with no other legal option available - chosen to suffer through the discomfort and agony, because of their care, concern and love for their family members' futures. They simply did not want to take the risk. It is a fact, that without Voluntary Assisted Dying as an option for eligible people, some have contemplated the unbearable choice of two options - ending their life alone so as not to involve family or enduring their pain to the very end....What kind of choice is that? Members would undoubtedly have been moved by some of the harrowing accounts of families' distress at being unable to relieve their loved one's suffering. Some authors recounted feelings of helplessness, guilt, anger and shame, some decades after. Many of them felt that they had let the person down, because they simply weren't able to answer their cries to stop the pain 'just get a gun and shoot me!' or to 'please....just do something to end it...I can't take it anymore'.¹³ What of those people who had an undignified, painful and frightening end to their lives? What of them? Those whose pain, embarrassment, fear and suffering was only relieved after a lingering, painful and intolerably miserable death. Leanda Stone wrote of her father's passing: "We sat by his side, swabbed his dry mouth with moisture, tried to keep his aching body

comfortable while we waited for him to die. I remember watching his malnourished body twitch, seeing him with head injuries from falling after trying to rush to the bathroom in a delirious state. The amount of times I collected and laundered his faecal covered clothes would be enough to shred any man of his right to maintain his dignity, but someone had to do it, while watching, waiting for him to die. He lasted only two days from when he refused nourishment, thank God, because I couldn't possibly watch him suffer any longer." iv Is that what we want for our terminally ill whose pain is unable to be managed or relieved by the most fervent efforts of dedicate palliative care specialist doctors, nurses and support staff? I don't think so. Honourable Members, from the Submissions and anecdotal evidence from medical professionals, we know that there have always been situations in which people were assisted to die. But it remains and always was an unregulated, 'spoken in whispers' practice, whose mere existence speaks volumes about the need for this legislation. Doctors and nurses whose loyalty to and compassion for their patients led them to provide assistance which is essentially illegal and in breach of their codes of ethics, at great 14 risk to themselves, professionally. It happens. We know it happens. As Ms Julia Greenhill wrote in her submission: "The opposition of the AMA to the End-of-Life Choices Voluntary Assisted Dying Bill 2020 should now be considered as resisting a call for reform from the community... Indeed, many doctors already take action to relieve unbearable suffering in their patients, as they are called upon to do, even if this action shortens the lives of their patients. However, at present they are unprotected by law and could face disciplinary and criminal charges."v In the recent paper, titled 'Doctors and the Voluntary Assisted Dying Act 2017 (Vic)vi', from Queensland academic, Jodhi Rutherford, a doctor was quoted as saying: "The slippery slope is much more of a risk where you don't have legislation because that's where, behind the scenes, things are happening and being done without any oversight, without any jurisdiction being in control of it....So, coercion, if it's happening, it could be happening now..." Honourable Members, let us now work together in this Chamber today, to implement a legal framework which can provide a safeguarded and protected process for our medical fraternity, and the admittedly few people who are in genuine and desperate need of access to voluntary assisted dying. 15 It is a fact that palliative care can help the majority of people in achieving a peaceful, comfortable end to their lives....but it cannot and does not work for all patients with all conditions. I received a submission from Ms Madelin Corbin, a Registered Nurse who summed this up more succinctly and genuinely than I possibly could. She wrote: "There is a need for palliative care, very much. But for when things haven't worked. For when pain has escalated beyond the realms of being controlled by medication. When a soul is aching for losing their journey, there needs to be an option. And let me assure you, this is all VAD is. It's an option. Just because it exists does not mean people are obliged to use it.... The passing of this Bill would simply mean that Tasmanians get a choice".vii To expand for a moment on the concept of choice, there is a growing body of evidence from other jurisdictions including Canada and Victoria, that a number of terminally ill patients who were assessed as eligible were so comforted that they had an option to access if the condition became intolerable, that their mental health, capacity to cope and quality of life actually improved - some did not go on to use the VAD substance. But they had the choice. Statistics show that usually about 33% of people who are eligible for VAD do not continue, secure in the knowledge that they have options. Dr Nick Carr of St Kilda, recently wrote: "Overwhelmingly, people have asked for the option of VAD to regain some control and choice; to not have to wait for a possibly unpleasant event to finally kill them; 16 to not have to suffer the indignities of further losses of bodily function but to go quietly and comfortably at a time and with people of their choosing. For many people, just having the option has been an immense relief, even if they never went on to use it."viii Honourable Members may have read the VAD Review Board 'Report of Operations January - June 2020' from Safer Care Victoria, released in late August. Interestingly, in a population of approximately 6.6 million people ix, of 341 applicants in Victoria during the period 19 June 19 - 30 June 20, 124 people self-administered or were administered a VAD substance which ended their suffering. Tasmania has a population of 535,500x people, or approximately 8% of the population of Victoria. On the raw data, this provides a projection of the figures in Tasmania being in the region of 28 applicants, with perhaps 10 people in a calendar year progressing to the actually utilising the VAD substance. Put simply, the End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 will allow a small number of terminally ill Tasmanians who wish to make a choice about the timing and manner of their death, the legal right to access voluntary assisted dying - giving themselves and by extension, their loved ones, surety about their capacity to end their suffering when they so choose. Dr Christiaan Barnard, who is perhaps most famous for performing the world's first successful heart

transplant wrote in his book 'Good Life, Good Death' that a doctor's duty is not only to give the patient a good life but also to give the patient a good death. 17 He acknowledged that his views on patient autonomy had changed from 'preserve life at any cost' during the course of his training and work as a doctor and surgeon. He described the story of a critically ill elderly patient who was found dead in his hospital bed, having disconnected his respirator, leaving a note which stated "The real enemy is not death, the real enemy is inhumanity". xiAnd I think it is humanity, the right to personal autonomy and compassion that are at the centre of this Bill, which seeks to allow eligible people who are suffering intolerably, the option to access VAD. I would like to touch briefly on the research of relatively modern philosophers, Beauchamp and Childress from an article by the Ethics Centre^{xii} The Four Principles that Beauchamp and Childress identified in their book "Principles of Biomedical Ethics as healthcare's 'common morality' are: Firstly, • Respect for Autonomy - They described how 'in a healthcare setting, where patients are often vulnerable and surrounded by experts, it is easy for a patient's autonomous decision to be disrespected.... - The authors stated that 'Respecting autonomy isn't just about waiting for someone to give you the OK. It's about empowering their decision making so you're confident they're as free as possible under the circumstances.' The Next is: • Nonmaleficence: 'First Do No Harm' 18 - Beauchamp and Childress suggested that the Hippocratic Oath, which was used in the past as a moral and ethical framework for doctors be nuanced, in practice; that 'first do no harm' be regarded to mean 'avoiding anything which is unnecessarily or unjustifiably harmful'. The third principle is: • Beneficence: 'Do As Much Good As You Can' - 'Beneficence refers to acts of kindness, charity and altruism....the applications of beneficence in healthcare are wide reaching... beneficence will require doctors to be compassionate, empathetic and sensitive in their 'bedside manner.' And finally, the fourth principle identified by Beauchamp and Childress: • Justice: Distribute Health Resources Fairly - The authors identified that 'healthcare often operates with limited resources...They observe(d) how resources are distributed will depend on which theory of justice a society subscribes to'. Mr President, I have had the privilege of meeting with Palliative Care Tasmania on a number of occasions, as I wanted to really understand what services are currently available, and to discuss the concept that voluntary assisted dying is simply another 'End of Life' choice; unlikely to be required or accessed by many, but for those in need - a great comfort. Whilst I have heard a number of spurious arguments pitting voluntary assisted dying against palliative care, after learning more about the existing options and the amazing support provided by PCT, it was generally accepted that while the numbers of people who will choose VAD are quite small in comparison with those who engage with palliative care, the two are not mutually exclusive nor does a person's engagement with VAD preclude them from receiving support from palliative care providers. 19 CEO Colleen Johnstone, who Honourable Members will recall from briefings gave the assurance that: 'Those people living with a life-limiting illness and exploring VAD will be able to continue to receive palliative care right up until their death'.^{xiii} In other jurisdictions, between 80 and 90% of people accessing voluntary assisted dying are also supported by palliative care services. I believe the figures are likely to be similar in Tasmania. As an aside, the Bill precludes any doctor or nurse from participating in the VAD process, unless said professionals have voluntarily undertaken the requisite training package and have the appropriate qualifications. Furthermore, any health professional who has a conscientious objection to any form of participation in VAD, will not be required to be involved. Of course, these protections apply to professionals working in palliative care services as well. It is a well-known fact that Palliative Care Tasmania's resources are over-subscribed and that the group has repeatedly been required to reapply for funding by constructing a lengthy budget submission - something I appealed to the Government to address in a Special Interest Speech earlier this year, and recently wrote to the Honourable Premier advocating on the organisation's behalf. Pleasingly, the independent Aspex Report - 'Experience Internationally of The Legalisation Of Assisted Dying On The Palliative Care Sector' of 2018 stated that in every other jurisdiction where Voluntary Assisted Dying has been legalised, the resultant focus on the palliative care sector has seen funding increases.^{xiv} 20 I would like to see Palliative Care Tasmania receive more and guaranteed recurrent funding through the Budget Estimates process in any event - they are a wonderful organisation, with providers working incredibly hard in supporting Tasmanian families during what must be very challenging and distressing times - but if the implementation of VAD in Tasmania proves to be a catalyst for expanded investment in this area, this will be a welcome side effect of the legislation. With all of this in mind, I am now inclined to shine a light on the Bill and spend some time examining what its provisions allow and how the process will work in an operational sense. Honourable Members would have perused

the supporting documentation, and perhaps utilised the flow charts provided, and I hope that these documents as well as the Briefing to be provided by The Office of Parliamentary Counsel are and were helpful. I am advised that objectives and principles clauses are not regularly included in legislation, because they can often be no more than a re-statement of what the Act already does. However, I will be tabling the following amendment: A. Objectives and principles (1) The objectives of this Act are – (a) to provide, to persons who are eligible to access voluntary assisted dying, an efficient and effective process to enable them to exercise their choice to reduce their suffering by ending their lives legally; and (b) to ensure that the process provided for the exercise of that choice protects and prevents persons from having their lives ended unwittingly or unwillingly; and 21 (c) to provide legal protection for registered health practitioners who choose to assist, or who choose not to assist, such persons to exercise their choice to end their lives in accordance with that process. (2) A person exercising a power or performing a function under this Act must have regard to the following principles: (a) every human life has equal value; (b) a person’s autonomy, including autonomy in respect of end of life choices, should be respected; (c) a person has the right to be supported in making informed decisions about the person’s medical treatment, and should be given, in a manner the person understands, information about medical treatment options, including comfort and palliative care and treatment; (d) a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person’s suffering and maximise the person’s quality of life; (e) a therapeutic relationship between a person and the person’s registered health practitioner should, wherever possible, be supported and maintained; (f) a person should be encouraged to openly discuss death and dying, and the person’s preferences and values regarding their care, treatment and end of life should be encouraged and promoted; (g) a person should be supported in conversations with the person’s registered health practitioner, family and carers and community about treatment and care preferences; 22 (h) a person is entitled to genuine choices about the person’s care, treatment and end of life, irrespective of where the person lives in Tasmania and having regard to the person’s culture and language; (i) a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in a metropolitan region; (j) there is a need to protect persons who may be subject to abuse or coercion; (k) all persons, including registered health practitioners, have the right to be shown respect for their culture, religion, beliefs, values and personal characteristics. I will now explain the eligibility criteria in this Bill: • Firstly, the person must have attained the age of 18 years. • The person must meet the residency requirements, in that the person: - is an Australian citizen, or is a permanent resident of Australia or has been resident in Australia for at least 3 continuous years immediately before the person makes the first request, and - the person has ordinarily been resident in Tasmania for at least 12 months immediately before the person makes the first request. • The person must be assessed as having decision-making capacity. 23 - Importantly, decision-making capacity is assessed at every stage of the VAD process where the eligibility criteria are determined – at First Request, Second Request, Consulting Medical Practitioner (CMP) Determination, Final Request, and at Final Permission. This is a significantly important safeguard to protect the person and the health professionals involved in the VAD process. - According to Section 11 of the Bill, a person has decision-making capacity when the person has the capacity to: (a) understand the information or advice that is reasonably required in order to be able to make the decision; and (b) remember such information or advice to the extent necessary to make the decision; and (c) use or evaluate the information or advice for the purposes of making the decision; and (d) communicate the decision, and the person’s opinions in relation to the decision, whether by speech, in writing, by gesture or by other means. - Decision-making capacity is something that doctors assess on an everyday basis as part of their practice. The assessment process will reflect current clinical practices in Tasmania. - To quote from a Submission from the WA Joint Select Committee on End of Life Choices in 2018: “ The Victorian Ministerial Advisory Panel felt that given the view of Royal Australian and New Zealand College of Psychiatrists and after feedback from nine months of consultation sessions across the medical community, to add a further consultation to 24 a process that was already rigorous for a person who is dying 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.xv ” - However, it must be reiterated that at any point, if a medical professional is unable to determine decision-making capacity, they must refer the person to a ‘medical practitioner, psychiatrist or psychologist who has the skills and training that are appropriate to make such a determination’ - This Section, S11- 4, was included as another safeguard for the person

and the health professionals involved in the VAD process. • The person must be deemed to be acting voluntarily. - Voluntariness is a core principle of this Bill – in fact the very title of the Bill is a clear and finite expression of what it seeks to provide for those determined eligible: - The End-of-Life “Choices”. (“Voluntary”. Assisted Dying) Bill 2020. - The Bill, in fact, contains protections which ensure that ‘acting voluntarily’ with regard to the VAD process is necessary for the person, for the medical professionals in their various roles, and for the witnesses and contact person (in cases of Private Self-Administration). - However, in this eligibility criteria context, ‘acting voluntarily’ pertains to the person seeking access to VAD. 25 - In drafting this Bill and seeking feedback from stakeholder groups, the issue of coercion was discussed repeatedly at length, and it was acknowledged that many of the safeguards within the Bill (fines, training and mandatory reporting processes) are specifically aimed at deterring and identifying coercion, and if necessary immediately ceasing the VAD process. - It is also worth noting that the Victorian training package for practitioners who wish to participate in the VAD process, contains a module on coercion. I anticipate that the planning for the training package here will draw on the Victorian experience, and that the Commissioner of VAD, and experts involved will make amendments in accordance with this Bill and for the Tasmanian setting. - Two very experienced Victorian doctors (Dr Nick Carr and Dr Cameron McLaren) who provided briefings stated that medical professionals deal with this issue regularly, both within and external to the VAD process, and that doctors are very attuned to (quote) ‘weeding out’ any signs of coercion, and if there is any hint of suspicion, that doctors would (and have in the past) scheduled additional consultations and assessments to ensure the person’s safety and genuine voluntariness. • The person is suffering intolerably in relation to a relevant medical condition. - A relevant medical condition is defined in the Bill as follows: S5-1 ‘a disease, illness, injury or medical condition, of the person that is advanced, incurable and irreversible and is expected to cause the death of the person’ S5-2 ‘a disease, illness, injury or medical condition, of a person is incurable and irreversible and is expected to cause the death of the person if there is no 26 reasonably available treatment that: is acceptable to the person AND can cure or reverse the disease, illness, injury or medical condition and prevent the expected death of the person from the disease, illness, injury or medical condition’. Just as a person who seeks to become involved in the VAD process must be deemed to be acting voluntarily, similarly our medical practitioners and registered nurses may also only be involved if their participation is voluntary. Any health professional may be excluded from involvement at any stage by stating a conscientious objection. In any case, no health professional may BE involved unless they have a minimum of five years of experience following registration as a doctor or registered nurse AND they have voluntarily undertaken the VAD training course, as dictated by the Commissioner of VAD. The health professional who does choose to be involved must update their training every five years. This is also the responsibility of the Commissioner to keep track of individual professionals’ training requirements. Even if a health professional has undertaken the VAD training course, they are not under any obligation to be involved with any or all cases which are presented to them/ I would imagine that the instances of someone undertaking the training and then wishing to not be involved would be rare, but as an example, if a doctor in a small town has been approached by a terminally ill patient whose family are openly opposed to the idea of VAD - and the doctor feels uncomfortable with being involved - the doctor is not obliged to accept a request but may provide the details of the Commissioner and support the person in order to find another doctor who may be comfortable being involved. 27 Similarly, Section 15 of the Bill states that a person may at any time, orally or in writing, inform the person’s Primary Medical Practitioner and Administering Health Practitioner that they no longer wish to access voluntary assisted dying. At the time of this statement, the process ceases, and a note is made in the person’s medical records, and the Commissioner of VAD is informed that they no longer wish to access VAD. It should also be noted that if the person withdraws from the process at any point, there is nothing in the Bill prevents the person from making another first request, at a later stage, and the voluntary assisted dying process from beginning again. In Tasmania, as in Western Australia, doctors will be permitted to discuss the legality and potential availability of VAD as an option with patients. Indeed all options regarding end of life care must be fully explained. This is not the case in Victoria, and it has been reported that this limitation has proven both an oversight and a hindrance to patient care and autonomy. This is not to suggest that the practice is encouraged or advocated, merely that a doctor may advise a person of its availability and in the same manner, a patient may ask their doctor or specialist for more information. Honourable Members have heard Dr McLaren and Dr Carr mention this shortcoming in briefings and provided in articles that they believe it to be an issue that the

Tasmanian Bill has improved. Should a person decide that they wish to make a first request, the Bill dictates that the person must have received the relevant facts in relation to accessing voluntary assisted dying before doing so. The relevant facts are to be contained in a form approved by the Commissioner for Voluntary Assisted Dying, and provide the following: 28 * information as to the operation of the act. * information as to how the person's eligibility is to be determined. * information as to the functions of the Commissioner of VAD and contact details for the Commissioner * information as to what assistance to die the person may receive from a primary medical practitioner or administering health practitioner. * information as to where advice in relation to palliative care, or other treatment, or other pain relief may be obtained. As Honourable members would appreciate from the fifth point, it is a condition of proceeding to the point where a person makes a first request that they have also received detailed information as to what all of their end of life choices may be, and where to seek further help, clarification or support. I felt that this fifth point (section 7e in the bill) was particularly important to include in the relevant facts to ensure that a person contemplating engaging with the VAD process was actively encouraged by their medical practitioner to fully consider and investigate all of the options for managing their condition and potential decline may be, before being permitted to make a first request. If the person has not received the relevant facts, the person is not taken to have made a request, but must be given the relevant facts by the medical practitioner. 29 If a person, who has received the relevant facts wishes to make a first request, the person may 'orally or in writing, in person, request the medical practitioner to determine whether or not the person is eligible to access voluntary assisted dying'. At this point the medical practitioner has 48 hours in which to decide and advise the person whether or not the request is accepted. This is not to say that eligibility is determined - but whether or not the medical practitioner wishes to take the person's request. A medical practitioner who is not an authorised medical practitioner (ie has completed the requisite VAD Course and has the appropriate years of experience) must refuse a first request. A medical practitioner may refuse to accept a request for any reason, including but not limited to a conscientious objection to VAD, and the person must be advised as soon as possible but within 7 days that the request is refused. A medical practitioner who refuses or accepts a request MAY but is not required to, provide reasons for accepting or refusing to accept the request. A medical practitioner who accept a first request becomes known as the person's primary medical practitioner or PMP. I introduce that acronym formally at this point, as it is commonly used within the Bill and the process from this point. The PMP is the Primary Medical Practitioner. It is incumbent on the PMP to advise the person of their decision to accept the request, within 7 days, to note on the person's medical records that the PMP has accept a first request from the person, and to notify the Commissioner for VAD that a first request has been accepted. 30 So you can see, Mr President, that this legislation already has detailed safeguards incorporated. Sections 22 and 23 provide a very detailed list of all of the actions which may or must be taken by the PMP prior to determining the first request. The PMP is obliged to obtain all of the relevant information in relation to the person's medical condition, treatment, any other medical conditions, the prognosis, any complications which have arisen or that may arise, and information relating to reasonably available treatment that may relieve the suffering of the person. The PMP may for the purpose of determining the first request, refer the person to another medical practitioner for examination, request that the person provide more information that they believe is required, request medical records from another medical practitioner, and/or request a psychiatrist, psychologist, or registered health professional to provide information which the PMP believes necessary to make a determination. I was grateful to receive a query from another Honourable Member about the involvement of specialists in the VAD process. As Members would be aware, one of the more complicating and operational road-blocking issues that has been experienced in Victoria (where a specialist opinion is required) is the difficulty of people involved in VAD being able to obtain appointments with VAD trained specialists. Given the difficulty in accessing specialists in Tasmania, and the fact that General Practitioners are indeed specialists in general medicine, Section 23 was introduced to provide assurance that should a PMP require the advice of another specialist in order to prepare for making their determination, they may do so. It should be noted, though - that the PMP is not involved in the process to make a specialist determination about the person's condition, if that is not their specialisation (eg. a GP would not make very specific diagnosis or prognosis of a complicated multiple cancer case 31 - this report would have come from an oncologist) - the PMP's role is to assess the person against the eligibility criteria for VAD. A determination of the first request (whether eligible or not eligible) is to be provided to the person. Copies are to be placed on the person's

medical records and also given to the Commissioner of VAD. If the PMP has determined a person's first request renders them eligible to access VAD, the person may make a second request to the PMP. The process for the second request mirrors that of the first request, but the second request requires the signatures of two witnesses. The person must not make a second request to the PMP within 48 hours of the person having made a first request, unless, in the opinion of the PMP, the person is likely to die within 7 days or the person is likely to cease to have decision-making capacity within 48 hours. Two people must witness a second request, and one of the witnesses must not be any of the following: • a family member, • a person who believes they may benefit financially, • a residential care provider or employee in relation to the person, or • a person who is a resident in the facility in which the person resides. Neither the person's PMP or CMP (Consulting Medical Practitioner) may witness a second request. 32 If the PMP has determined a second request as rendering the person eligible to access VAD, the PMP is to refer the person to another medical practitioner for a second opinion. A medical practitioner to whom the person is referred must advise the PMP within 48 hours whether they accept or refuse to accept the referral. The medical practitioner may refuse the referral for any reason and is not required to but may give reasons as to their decision. A medical practitioner who accepts the referral becomes the CMP or Consulting Medical Practitioner, and receives copies of all medical reports and other information in relation to the person. The CMP may examine or ask questions of the person, and may seek further information from the PMP in relation to the person. The CMP may also refer or request that the PMP refer the person to another medical practitioner for examination, or to a psychiatrist, psychologist, or registered health professional to provide information which the CMP believes necessary to make a determination. A CMP who makes a determination in relation to a person must, as soon as practicable but within 7 days - place a copy on the CMP's medical records in relation to the person, and give to the Commissioner a copy of the determination. The person's PMP is to advise them of the determination, place a copy on the person's records and also send a copy to the Commissioner. In order to prevent undue pressure on doctors and misplaced optimism on the part of the person, if 2 CMPs determine the person is not eligible, the process ends - although this does not preclude the person from commencing the VAD process again by making a new request, the former PMP may not accept a first request for 12 months. (except for certain unique circumstances explained in the Bill) 33 If the person's CMP has determined the person eligible to access VAD, the person may make a final request to the PMP. This request may not be made within 48 hours of the second request unless the person is likely to die within 7 days or to lose decision-making capacity within 48 hours. A final request is an instrument in writing, and once again, it must be determined by the PMP if the person is eligible or not eligible to access voluntary assisted dying. The determination of the final request must be provided in writing and must be made as soon as practicable but within 7 days, the person must be notified of the determination, a record is placed on the person's medical records, and the Commissioner is forwarded a copy. If the person is determined eligible, the PMP must decide whether or not the PMP intends to continue as the AHP - Administering Health Practitioner. AHPs may be medical practitioners or registered nurses who have at least 5 years of relevant experience since registration and have voluntarily completed the VAD training package. The inclusion of VAD-trained, Registered Nurses as potential Administering Health Practitioners acknowledges the unique skillsets, precision and professionalism that our nurses may offer their fellow Tasmanians during the administration stage of the VAD process. If we are to examine the most usual clinical path, we might find that the doctor and/or specialists examine and diagnose the patient, determine the most suitable course of treatment and perhaps prescribe medicines. At this point, a pharmacist makes inquiries of the patient, to ascertain if there are any other medical conditions or existing 34 prescriptions, as a safeguard before supplying the medication. In many circumstances in hospitals, aged care facilities, hospices or in our communities, it is in fact nurses who administer the prescribed substances to a patient, in accordance with the doctor and pharmacist's instructions. In applying this existing clinical structure to the VAD process, the involvement of nurses (especially in a state like Tasmania, where remote and regional communities rely heavily on the support of community nurses if they do not have a permanent doctor or a choice of doctor) seems completely logical. The AHP's role in the VAD process, whether they are a registered nurse or a doctor or a specialist is to once again assess decision-making capacity and voluntariness, before taking the required steps to administer the VAD substance. Unlike the PMP, the CMP or the pharmacist, the AHP does not diagnose a person's relevant medical condition or eligibility, nor do they require qualifications to prescribe a substance. The role is, as the title suggests, to administer under instruction, and in accordance with the process as

the Bill dictates. In a state like Tasmania, which has many regional or remote communities, nurses are often the first 'port of call' for people, they regularly serve for long periods in the one area (which may not have a permanent doctor) providing familiarity and continuity of care. It is a fact that our skilled & experienced nurses are members of one of the most trusted & highly regarded professions in society – community feedback consistently reinforces this concept. Having researched and spoken extensively with the ANMF, doctors and specialists both here and in other jurisdictions, it seemed appropriate to create a legislative framework for Tasmanian Registered Nurses who volunteer to undertake the training, to participate as AHPs. 35 The AHP must sign a statutory declaration declaring that they have completed their training course within five years before their appointment, that they are not a member of the family of the person and that they do not know or believe that he or she is likely to benefit financially as a result of the death of the person. As Honourable Members would have noted from their research and indeed from this summary of the process, there are safeguards at every juncture - for the person, for the family, for the health professionals involved. And I don't believe a Bill dealing with something as important as VAD can really be structured in any other way. Whilst the procedure must be accessible to those eligible - it cannot and should not be rushed, corners must not be cut - every person involved must be both protected and responsible for their role. Sections 64 to 75, provide great detail with respect to the request and issue of a VAD substance authorisation, the issuing of a substance prescription to a pharmacist who is appropriately trained and authorised, the destruction of a substance and the supply of a VAD substance to the AHP by the PMP. I will not go into great detail for this section, as most clauses are reflective of behind the scenes actions taken by the medical professionals involved - the person will likely have little to do with this part of the process, with one exception: Section 69, allows the pharmacist access to the person, either in person or by way of video link, in order that the pharmacist might be satisfied that the prescription relates to a substance which is suitable for use in relation to the person for the purposes for which it has been prescribed. The Pharmaceutical Society suggested that this consultation is vital, as certain types of medical conditions (a malabsorption issue in the stomach, for example) could render the usual substances ineffective. The Bill outlines the 'Final Administrative Requirements' and 'Provision of Assistance to Die' for both the AHP and Private Self-Administration pathways in Parts 13 and 14. 36 If an AHP is satisfied that a person is 'likely on the balance of probabilities, to die within 6 months from a disease, illness or medical condition; or where the person has a disease, illness or medical condition that is neurodegenerative – the person is likely, on the balance of probabilities, to die within 12 months from a disease, illness or medical condition (whether or not it is neurodegenerative)', and the AHP is satisfied that the person will be able to self-administer a VAD substance, the person's AHP must complete and sign a Private Self-Administration Certificate. If the person has met the criteria for and been issued with a Private Self-Administration Certificate, and a contact person has provided written acceptance of their appointment to the AHP and Commissioner for VAD, the person's AHP may supply the VAD substance to the person. In so doing, the AHP is to show the person how to self-administer the VAD substance. Clause 91 details the duties of the contact person – including the requirement to notify the person's AHP that the person has died after privately self-administering the VAD substance, and storing and returning any unused substance to the AHP. A person's AHP must notify the Coroner of the death of a person. If a person has not been issued a Private Self-Administration Certificate, they will proceed with the Administering Health Practitioner (AHP) pathway. The Bill requires that an AHP make a final determination of decision-making capacity and voluntariness within 48 hours before the AHP receives the final permission from the person. Once again, the AHP may refer the person to another practitioner or request more information in order to make the determination. If the person is determined entitled to receive assistance to die, the AHP must advise the person, and confirm the 37 manner in which the VAD substance is to be administered – whether self-administered, with assistance or administered by the AHP. A person who wishes to receive assistance to die may give to the AHP a Final Permission, which is a signed form stating that the person has received advice from the AHP as to the manner in which the substance will be administered, a statement that the person wishes to access voluntary assisted dying and understands that as soon as practicable after permission is given that the person will be provided the substance for self-administration, assisted to administer, or administered the VAD substance according to the wishes of the person as set out in the final permission, and a statement of intent with respect to unexpected complications. As for the Private Self-Administration Pathway, a person's AHP must notify the Coroner of the death of a person. I will now touch briefly on the administrative functions, processes and miscellaneous matters contained within the End-of-Life

Choices (Voluntary Assisted Dying) Bill 2020. The Bill contains provisions in Part 15 for the Review of Decisions. Eligible applicants may apply to the Commissioner of VAD for a review of a decision, by a person's PMP, CMP, or AHP. The Commissioner has the authority to review and make decisions upon applications in this part, but may also 'state in the form of a special case for decision by the Supreme Court any question of law that may arise in the hearing of, or determination of, an application'. Similarly, a party to proceedings who is aggrieved by a determination of the Commissioner may appeal to the Supreme Court against the decision. Part 17 of the Bill outlines information pertaining to the appointment of the Commissioner for VAD, the Deputy Commissioner and Officers of the Commissioner. This section 38 also details the functions and powers of the Commissioner for VAD, delegation, the Commissioner's role in determining VAD substances, and in approving courses of training, which will be constructed in consultation with bodies which represent medical practitioners, registered nurses, the Public Guardian and a person nominated by the Chief Civil Psychiatrist. The Commissioner for VAD is also responsible for keeping records of any notices, requests or other documents provided to the Commissioner by PMPs, CMPs, AHPs, and other persons. The Commissioner must provide an annual report to the Minister, who will then table same within 5 sitting days after receiving the report. Part 17 also contains details of another safeguard, in that a person who suspects any contravention of the Act may notify the Commissioner. The Commissioner may require additional information in order to investigate, and may refer the matter as he/she thinks fit. This is a critical safeguard, as it allows the Commissioner to involve agencies such as Tasmania Police, the Coroner's Court and the Australian Health Practitioner Regulation Agency to assist with the investigation of any suspected breach of the Act. The Bill contains an extensive outline of offences and penalties from parts 122-130. Offences include: • Inducements and dishonest or undue influence • False representation of being authorised to communicate on behalf of a person. • Not communicating faithfully on behalf of the person 39 • Falsification of records • False statements • Dishonest inducement to use a VAD substance • Failing to provide a notice to the Commissioner • Not returning unused or remaining VAD substance to the AHP (Contact Person) • Offences in relation to review. Honourable Members, I spoke earlier of the protections for the persons involved in the VAD process. Part 19 of the Bill provides detail of the safeguards which protect persons who assist in good faith (such as a person who is present at the event), protections for medical practitioners or registered nurses, and for anyone using electronic communications to discuss the person and/or the VAD process. The Bill concludes with a Miscellaneous section, in Part 20. Quite often we may regard a miscellaneous section of a document as perhaps inconsequential or an afterthought....this could not be further from the truth in this Bill One of the most important, and sometimes misrepresented facts regarding VAD is the concept of VAD deaths not being suicide for the purposes of law of State. I would like to read this clause in full. It is an important distinction to make, not only for the purposes of administrative issues such as insurance or wills, but for the peace of mind of any individual and their loved ones who may be struggling with long-held views, perhaps religious on the process of VAD. 40 Clause 137 reads: "For the purposes of the law of this State, a person who dies as the result of the administration to the person, in accordance with this Act, of a VAD substance or a substance under section 87, or the self-administration by the person, in accordance with this Act, of a VAD substance, does not die by suicide." The Miscellaneous section also notes that if there is an inconsistency between a provision in the Bill, and a provision in the Poisons Act 1971 or the Misuse of Drugs Act 2001, the provision of the Bill prevails. This clause with respect to Conflict of Acts is designed to provide clarity to those involved in the VAD process with respect to the usage of VAD substances. The Bill provides authority on a number of reports and reviews which are to follow the implementation of the Act. Firstly, the Commissioner of VAD is to provide, within 10 months a report to the Minister on the operation of the Act. Furthermore, the Governor is to appoint a panel of persons nominated by the Minister to conduct a review of the operation of the Act, matters related to the operation of the Act, the scope of the Act, and the potential scope of the Act as soon as practicable after 3 years. Perhaps one of the more controversial and misreported parts of the Bill pertains to the Review, after 2 years, with respect to young people. I will take a moment to explain why this Review was included and why I have been comfortable in weathering the inevitable sensational media storm which has ensued. 41 "The Governor is to appoint a panel of persons nominated by the Minister to conduct a review to obtain information in relation to whether persons under the age of 18 years in other States or Territories, or other countries, are able to access processes similar to the voluntary assisted dying process under this Act" As Honourable Members would be aware: • Nothing in this clause indicates enthusiasm for or bias towards

extending the Act to include children. • Nothing in this clause means that the Act will instantly mean persons under the age of 18 will be eligible. • Nothing in this clause guarantees an outcome or recommendation to this independent review. • Nothing in this clause compels a Government to act on the information collated in such a review. The review pertaining to young people simply provides a mechanism for an expert panel to review in detail, legislation in other jurisdictions. Whether a panel finds legislation allowing access to VAD processes or similar in other jurisdictions, whether that is deemed acceptable or required is entirely at the panel's discretion. The reality is that any finding or recommendation must still be adopted and actioned by the Government of the day. I am completely aware that this topic makes for an uncomfortable and somewhat confronting discussion, and it may have been easier for me, and for the Bill's debate to simply remove the review before the Bill was tabled. 42 However, Mr President, I was not about to do that. Earlier this year, I was contacted by a Tasmanian constituent and a Victorian family who had experienced similar circumstances. They both relived the horror of their teenage daughters' illness, decline and death. Their beloved daughters were terminally ill and suffering intolerably – each young lady in question and her family wanted for her death to be peaceful, in her home environment and with loved ones by her side. Sadly, that was not to be – it was simply impossible. Those loving parents witnessed their darling girls slip away, after some extremely trying and inconceivably difficult times, in a hospital bed. Those conversations genuinely inspired the inclusion of this clause. I have to be honest, discussing those families' circumstances, and their angst at not being able to take their girl home for the tranquil and gentle death she so wanted, made me feel that we should definitely put structures in place so that this issue can be thoroughly examined and considered in the future. Though I had met with experts in Belgium and the Netherlands, where 'mature minors' may have access to VAD, with parental permission, in exceptional circumstances, I had not planned to address the issue of young people in this Bill. In other jurisdictions, the idea is being explored and reviewed, but of course, it is a difficult thing to understand or contemplate – even if as a parent, you considered what you might do if your terminally ill child begged for your consent as their pain and suffering was unable to be relieved. I would urge Members to compassionately and objectively consider the importance and genuine intent of this clause. It is not designed to predict or assure an outcome – it simply allows for a panel to gather information and gain a deeper understanding of the issue of terminally ill young people who are suffering intolerably, and whether attaining 43 the age of 18 years should be a permanent criterium for accessing VAD in the state of Tasmania. Also, at the 3 year mark, the Governor will appoint a panel to conduct a review as to whether persons suffering from a disease, illness, injury or medical condition, that is not expected to cause the death of the person but that is 'advanced, incurable, and irreversible; and causes the person suffering from pain that is in the opinion of the person, intolerable – ought to have access to the voluntary assisted dying process under this Act'. Again, I reiterate that this review is just that – a review. I will perhaps elaborate further in the Committee stage, or in response to questions raised by Honourable Members if need be. Finally, the Bill requires that a review of the operation of the Act be undertaken at the end of each 5 year period. Honourable Members, I can fully appreciate that the detailed description of the Bill was perhaps a little more formal and certainly more lengthy than my usual contributions in the Chamber. But with a Bill of this magnitude, I felt it was necessary to provide an indepth outline of the Bill's intent, its operation, and the legislative structures which are required to support its implementation and review. I am grateful for your attention today, your attendance at briefings, the research you have conducted to prepare, and indeed your questions and feedback over the past few months. I look forward to your valuable contributions to the debate, which I feel sure will be respectful, learned and informative. On his election, the Honourable Premier expressed to the Tasmanian people his commitment that: 44 "Our government will be a government of conviction, of compassion and importantly, one of opportunity for all." I believe this is a worthy goal for any Government...and perhaps something we should all consider - whether party-affiliated, independent, in opposition or in Government, when we ponder our position on any piece of legislation. Conviction. Compassion. Opportunity For All. Once again quoting from Jodhi Rutherford's paper xvi from the Journal of Law and Medicine, a Victorian doctor was quoted as saying: "We know that a lot of people who access voluntary assisted dying help, never actually use it. But they get enormous relief knowing it's possible. I'm talking to a bloke at the moment who has terminal cancer. And the change in his experience now that he knows this is possible, has been enormous. He is so much less anxious, so much less worried, because he knows that this is going to be a possibility. He might never use it. But there is a huge benefit to him from knowing that it's there." The Bill has been thoroughly

prepared and rigorously consulted, to ensure that its operational functions are safe and logical for those are eligible to choose Voluntary Assisted Dying, and that the person and health professionals are adequately protected. The End-of-Life Choices Bill 2020 provides terminally ill Tasmanians who are suffering intolerably with a humane, safeguarded and compassionate framework which supports their right to access Voluntary Assisted Dying. I genuinely hope that it will provide Tasmanians with the reassurance and comfort that they may choose in their time of need.

45 - Mr President, Honourable Members, I ask you to indulge me for a few moments. Why are we here? No, this is not an existential or even a rhetorical question. It's a very personal and practical one. What I am meaning to ask Members is, more specifically.... Why are you in this Chamber today? What made you put your hand up for the public scrutiny, time away from family and the pressures that come with standing for politics? And if it is not your first term, what made you want to do it again? I suspect that if Members were to provide answers to those questions right now, there would be a range of reasons as to why they entered politics and/or why they continue to work in this space. But I would imagine the one thing we all have in common is this.... We all thought we could make a real difference for those in our communities, and wanted to help by being their voice in the Tasmanian Parliament. Perhaps we had this thought and waded into politics - immediately starting at State level, as our two newest Members (the Members for Huon and Rosevears) have done, or as 46 many Honourable Members here (including myself), by working in, around and with our communities in Local Government before we found ourselves in this esteemed chamber. Perhaps we didn't see it in ourselves, but some encouragement from someone else who felt that we might just be the right person for the job - we just needed a little push. At some point we all made a commitment to try to make this state a better place, to work hard to strengthen and support our communities and above all else, to do our best for those who chose us to advocate for them. It's fairly simple if you think about it. Every time a piece of legislation comes to us, we consider the impact on our communities - both immediate and long term - and we vote accordingly. That is why we are here. That is why we chose to be here. Honourable Members, I know we disagree on many things in this chamber (and sometimes outside). But during this debate, I hope we can all agree to put our communities' wants and needs to the forefront of our thinking. **Every now and again, we find ourselves reviewing a Bill whose impact (whether passed or not) stands to impact literally every person in the state, now and into the future. Today is one of those days. I commend the Bill to the Council.**

This concludes the September DWD Tasmania Inc newsletter.