



# ASSISTED DYING IN AUSTRALIA – A TEMPLATE FOR THE UK?

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## INTRODUCTION

Pressure to legalise assisted dying (AD) is growing in the UK and has been particularly intense since the beginning of 2024. It has been fiercely debated over recent decades, and in the last vote to take place in the Westminster Parliament in September 2015, MPs rejected AD by 330 to 118. However, there are now widespread calls for another vote amidst a concerted media campaign, and advocates of AD appear to feel that a change in the law is within their grasp.

AD covers assisted suicide, where lethal drugs are supplied and the person takes them when they choose; and euthanasia, where a doctor or other health practitioner administers the drugs, either because the person is unable to do so, or prefers this method.

Both forms of AD have been around for many decades in countries like the Netherlands and Belgium, and more recently, Canada. There has been ample time to see what happens when something so radical is implemented. What transpires isn't always what was initially intended, and there is no shortage of evidence to see what would likely happen should the UK choose to go down a similar path.

Legislators who can get themselves past the ethical questions soon focus on what form legislation might take, and inevitably with a procedure as irreversible as AD the matter of appropriate safeguards soon assumes dominance. How can protections be put in place to be certain beyond doubt that someone is making a free and fully informed decision to end their life, and for reasons which some in the community might deem valid, such as unbearable suffering?

Of all the models, some have suggested that the Australian model is the best.<sup>1</sup> The Victorian Government claims it has 'the safest, and most conservative model in the world'.<sup>2</sup> Is that true, and what is it about the regime that seems so appealing? AD in Australia is very new and so the evidence base is nowhere near as advanced as that in other jurisdictions, yet there is enough that a picture is (slowly) emerging.

This paper will describe the current situation in Australia and the evidence that exists about how the system is or is not working as intended. Most of that evidence is very recent and for some states it is simply too early to make any reasonable conclusions, although reference can be made to the international context where similar regimes exist. Also included will be references to safeguards, what they really amount to in practical terms, and challenges to them that have emerged within just a few short years.

## BRIEF HISTORY

Euthanasia was first legalised in Australia's Northern Territory (NT) in 1995 with the *Rights of the Terminally Ill Act 1995*. It was in operation for a short period of time before being overturned by Federal legislation that removed the rights of the Territories to legislate about euthanasia. In 2022, Federal legislation reversed that decision and a law on AD is now being considered in the NT as well as in the Australian Capital Territory (ACT). The characteristics of the NT legislation and how the short-lived Act operated will be addressed briefly later, particularly regarding how its outcomes might be considered with respect to public perception of what a typical euthanasia case might look like, and the eligibility criteria and safeguards.

After many failed attempts to pass AD laws in the six Australian states, finally in 2017 Victoria became the first to do so, followed in rapid succession by all the others. Victoria's Act came into operation in mid-2019, and similar laws in the other states did so from mid-2021 to late 2023. AD laws are broadly consistent from one state to another, although there are some key differences.

## THE PROMISE OF SAFEGUARDS

Much has been made of how 'conservative' Australian AD laws are and how they protect potential participants as well as the public via their numerous safeguards. It has been claimed that there are 68 safeguards in the Victorian system, and 102 in the Western Australian (WA) system,<sup>3</sup> claims that have been used to reassure sceptics that these are laws of the highest rigour and certain to ensure there will be no unwanted side-effects. Reference to extensive safeguarding also comes from the Ministerial Advisory Panels in Victoria<sup>4</sup> and WA,<sup>5</sup> that preceded the passage of the laws.

### Safeguards that are not really safeguards

The way in which the term 'safeguard' is used encompasses eligibility criteria:

There are strict eligibility criteria for accessing voluntary assisted dying. This is one of the safeguards in place to protect vulnerable people.<sup>6</sup>

However, it is arguable whether being over 18 or a permanent resident, for example, are in fact safeguards or merely entry conditions. In any case, permanent residency as a safeguard is meaningless now that all states have AD, and the Territories are likely to follow shortly.

One would be hard-pressed to delineate 68 distinct safeguards as claimed in the Victorian law without stretching credulity about what constitutes a safeguard. Seemingly similar ones count as distinct when in fact they could easily have been combined into one safeguard. For example, safeguards that neither mental illness nor disability alone satisfy the eligibility criteria can be covered in one rather than two separate safeguards.

Other safeguards seem obsolete. For example, one safeguard says all eligibility criteria must be met, but this is really a legal protection to clarify a point rather than a safeguard in itself. There are also safeguards explicitly to protect doctors. They are appropriate – one guarantees conscientious objection – but conscientious objection is already a foundational ethical principle in medicine and naming it as a safeguard might seem to bolster the case for rigour, but it really adds nothing to what already exists.

There are also five safeguards describing offences, which are in fact statements about transgressing other safeguards. And then there are 11 safeguards that describe the functions of the Board, which include 'quality assurance and improvement functions', and 'functions as described in legislation'. Other safeguards require that the Board 'reviews all cases' and 'reviews compliance'. But these are functions of the Board that are not dissimilar to those in any number of bodies described in other legislation on different matters. It is inappropriate to include them as safeguards which claim to make this AD law particularly safe for participants.

Other safeguards similarly amount to not very much at all. For example, the safeguard that anyone can change their mind at any time sounds good, but it is no different to any other medical treatment – if AD were to be so described, which it is, even though it arguably does not fall within the paradigm of medicine. In any case, just about every other medical treatment leaves options open. But with AD the patient is dead. AD is definitively final.

The point is, the sheer number of items listed as safeguards might sound impressive, but the list of those strictly there to protect vulnerable patients could be shortened dramatically, and even those that remain can be so problematic as to confer little actual protection.

‘ ... the Victorian model has established a highly bureaucratic system where many of its “safeguards” are merely checklist items of dubious quality. Indeed ... most of the so-called Victorian safeguards present as merely bureaucratic requirements that will do little to protect a patient in reality.’<sup>7</sup>

### **Safeguard against coercion**

Other eligibility criteria have their own unique problems. For example, the criterion ‘acting voluntarily and without coercion’ relies upon discernment by one or other of the two doctors involved. And while inducing someone to access AD is a criminal offence, detecting such coercion or proving it occurred would be extremely difficult, especially after AD has occurred and it’s too late to ask the patient. In Oregon, two doctors and a psychiatrist were concerned that a woman was being pressured by family members; however, a psychologist was then found who approved her AD, despite concern that her ‘choices may be influenced by her family’s wishes and her daughter ... may be somewhat coercive’.<sup>8</sup> It is unsurprising that medical professionals would disagree with one another, or to find some who are more dismissive of concerns about voluntariness than others. In a parallel context, coercion is well-documented in abortion decisions, and yet medical professionals routinely authorise abortions in such circumstances.<sup>9</sup>

It is quite possible to be under considerable coercion and yet be convincing about a decision being one’s own. Moreover, subtle and ongoing coercion can wear people down and lead them to ‘choose’ something they don’t really want because their choices have become so contracted, and alternatives just seem intolerable. Another form of pressure that can be subtle and internalised is the self-perception of burden, not helped by the knowledge that AD is a much cheaper option than treatment.

Perhaps the most serious risk regarding possible coercion happens when there is a delay between dispensing the lethal drugs and taking them. The Victorian Act permits a patient to keep them for an unspecified time before consumption, and while there is no data published in the official Victorian Reports about the time intervals, it is well known from Oregon that there can be months or even years between dispensing and consuming.<sup>10</sup> What the Victorian Reports do show is that such gaps must be taking place. For the 2022-2023 year, for example, there were 401 cases of drugs dispensed for self-administration and 257 deaths by self-administration. For the 257 there is no data provided about the interval, even though it could have been up to 12 months, and longer for the remaining 144. The point is that since the Act makes no requirement for a witness when self-administration occurs, no one knows the circumstances at the time of death, who was present, or what role they may have played. Someone with an interest may have coerced an undecided patient, assisted with administration, or even actually administered the drugs. Indeed, in the case of more serious malicious intent, administration could have occurred covertly. And of course, the primary witness is dead.

## Ensuring decision-making capacity

The eligibility criterion 'must have decision-making capacity' can also be problematic; its determination relies on a particular set of skills that not all doctors have.<sup>11</sup> This is especially pertinent when there are mental health disorders involved,<sup>12</sup> and yet there is no requirement in the Act for any psychological assessment of capacity. Moreover, determinations about capacity have been found to vary depending on the personal values of physicians, some applying a more stringent assessment when the procedure has more serious consequences, and others not.<sup>13</sup> So rather than this being an objective safeguard, it depends on who the doctor is who is doing the assessing. This was further corroborated by researchers examining oral and written evidence provided to the UK's *Commission on Assisted Dying*; they found that ideas about mental capacity were inconsistent and sometimes at variance with the *Mental Capacity Act 2005*.<sup>14</sup>

But there is another, potentially more serious, risk. Because of the unspecified amount of time between receiving lethal drugs and taking them, there can be no certainty that the patient has retained capacity at the time of death. What happens if someone has lost capacity? Could someone else decide the time has come even though the patient has limited perception about what is happening? Or might a patient fail to follow the instructions and take the drugs in the wrong sequence or dose leading to a traumatic medical crisis? This is a particular risk for those cases specifically mentioned in the Act, namely neurocognitive disorders, and yet the Act makes no provisions for these eventualities. There is a sense in which this risk constitutes the *de facto* provision of assisted suicide by advance directive – the patient with capacity makes a decision, loses decision-making capacity, and dies by lethal drug at a time of compromised or absent capacity.

## Safeguard to restrict what type of suffering counts

In all Australian states the person applying for AD must have a disease, illness or medical condition that is advanced and will cause death within 6 months (or 12 months for a neurodegenerative disease), is incurable, and causes suffering that cannot be relieved in a manner that the person finds tolerable. Suffering can be physical, psychological or existential. Suffering is foundational to the case for AD, and yet psychological and existential suffering are foundational to life for many people at one time or another, and at those times there is often no cure, and things can seem intolerable. This safeguard is problematic because it uses incurable illness with terminality to frame the issue which defines the case for euthanasia, that is, suffering, subjectively perceived. As such, these criteria cannot logically survive, and indeed, elsewhere they haven't, or were never applied in the first place given that logic. For Australia, the wheels have been set in motion, and it is hard to see how the requirements for incurability or terminality will survive.

But there is another problem about the terminality condition. Prognostic accuracy is not particularly good, a recent study finding that when it comes to prognoses of weeks or months left to live (the time frame of AD terminality judgements), only 32% of doctors were accurate.<sup>15</sup> And even though doctors may be overly optimistic in their judgement, there remains a sizeable cohort of 15% who are overly pessimistic.<sup>16</sup> It is these doctors who, if they were to be making judgements about the time left to live for eligibility for AD, could be assisting the deaths of people who have many years left. One might argue that accuracy about the time left to live doesn't really matter that much if someone really wants to die, and that would be precisely the point – the terminality requirement is argued as a safeguard to bolster the appearance of rigour, and yet it can quickly be set aside in the face of suffering deemed intolerable. This is supported not only by calls within Australia for it to be waived, but by the overseas evidence showing it has in fact been waived.

## The 'doctor can't raise AD first' safeguard

One safeguard that seems reasonable at face value only applies in two states and to a limited extent in the others. This is a restriction upon who may initiate a discussion about AD. In Victoria and South Australia,

a doctor may not do so, whereas in the other states, he or she may if palliative care and all other treatment options are raised at the same time. This is a 'safeguard' that really doesn't amount to much, but it sounds good. A patient will very likely be aware of the existence of AD in their State given the huge media attention and public discussion, so the fact that a doctor may not raise it is a moot point, and in any case, anyone else can. Moreover, in those states where a doctor is permitted to raise AD as long as they cover other treatment options, the caveat is meaningless. For informed consent to work at all, doctors are always required to discuss alternative treatment options, so the safeguard in this context simply amounts to permission for the doctor – as a powerful authority figure - to raise AD without the patient even thinking about it.

Even in those states where doctors may not initiate a discussion about AD, such as SA, they are permitted to include information about AD on webpages or in pamphlets and flyers in a waiting room.<sup>17</sup>

### Safeguard by witness

The laws in Australia permit both assisted suicide and euthanasia. With the former, lethal drugs are provided, which, as noted, can then be used at a time of the person's choosing. Family and friends may be present and there need be no other independent witness(es) to verify decision-making capacity, voluntariness, lack of coercion, or the enduring nature of a request at the final moment. However, a witness is required to verify each of these for euthanasia by a doctor, and this can only occur (in Vic but not WA) if the person lacks the ability to self-administer the medication.<sup>18</sup> There appears to be no reasonable justification for the difference. If anything, one would have thought a witness *less necessary* in the case of euthanasia given the presence of a doctor who is independent of the patient and a professional supposedly of the highest probity. The case of a patient who resisted euthanasia in The Netherlands and was physically restrained by family members on the doctor's request should surely ring alarm bells, even though the doctor involved was cleared of any wrongdoing by one of Holland's euthanasia review committees<sup>19</sup> as well as a Dutch court.<sup>20</sup> Under investigation, the doctor involved reported to the euthanasia review committee that 'the patient was not mentally competent, so her utterance at (the moment of euthanasia) was not relevant in the physician's opinion. Even if the patient had said at that moment: "I don't want to die", the physician would have continued with the termination of life.'<sup>21</sup> This is disturbing given that '... *contemporary competence* is regarded as an important safeguard against mistake and abuse ...'.<sup>22</sup>

In Australia, this difference in safeguarding between assisted suicide versus euthanasia suggests an arbitrariness that undermines the argument that the Australian system means patients are protected with the most rigorous of safeguards. What is more likely is that the requirement for a witness for euthanasia cases but not assisted suicide ones is to protect the doctor from possible litigation should anything go wrong. If it were to ensure the doctor acted with probity, then we should all be worried.

### The security of AD drugs

The Australian laws prescribe safeguards designed to ensure AD drugs are kept secure – either kept in a locked container while in the possession of the patient or returned if unused or if a portion remains after the patient's death. This is an obligation of a designated contact person for the patient. These safeguards are to ensure the drugs are only used for their intended purpose, and only by the patient.

There are three problems that could arise.

First, if a patient loses capacity, the security of the locked box could be compromised and its contents at risk of inadvertent use by others, either accidentally or deliberately. The designated contact person may not necessarily be in such regular contact with the patient as to ensure the security of the container

Second, the contact person could claim that the person used the lethal drugs when in fact they died of their condition. There is no legislative requirement for the contact person to provide evidence of drug use,

the Act only requiring return *if the contact person knows* there is an unused drug. In the Victorian Report for 2022/2023, 28% of permit holders died without administration of lethal drugs, a figure presumably derived from the return of unused drugs.<sup>23</sup> However, if drugs were not returned, how can there be any certainty that the cause of death was by lethal drugs? The Act does not require an autopsy of the patient. A contact person could be vulnerable and/or sufficiently distraught about the death as to consider retaining the drugs for their or another's use at another time, even if that were only a portion of the drugs. There is currently before the Queensland coroner a case in which this appears to be precisely what has happened. A man died from ingesting his wife's lethal drugs after she had died without using them.<sup>24</sup>

Third, all of the drugs may not have been consumed by the patient, and the contact person may have failed to return drugs within the required 15 days. The Victorian Act imposes a severe penalty upon the contact person in these circumstances, creating an incentive to hide the fact that drugs remain.

### **Missing safeguard – treatable psychological illness**

None of the AD laws in any of the Australian jurisdictions require a psychological assessment of patients about possible mental illness, which if treated may change a person's perspective sufficiently to not choose AD. Many doctors have limited ability to deal with mental illness and yet they are free to provide AD with no recourse to a specialist.

To not assess a patient's mental health where they are seeking death (due to an illness) runs contrary to the common belief and understanding that a person who wishes to end their life is under severe psychological suffering.<sup>25</sup>

One of the main problems about this particular omission lies in the nature of mental illnesses. They are often multifactorial and episodic. They can also respond to existing treatments and new ones are continually being developed. Much has been written about the social determinants of mental health, and while it is understandable that in the context of a terminal illness diagnosis, depression and anxiety can be precipitated, it is also possible that other aspects of a person's social setting, particularly relationships, can lead to depression and anxiety.

In a study of psychiatric patients seeking euthanasia in Belgium, five domains of suffering were identified – medically related suffering, intrapersonal suffering, suffering related to interpersonal interaction, suffering related to one's place and interaction in society, and existential suffering. A significant burden of suffering for these patients resulted from serious disruptions to important relationships, social isolation and loss, poor socioeconomic circumstances, agonising over questions of meaning, and the perception of being a burden on society.<sup>26</sup> Assistance by, and treatment from, trained psychologists and/or psychiatrists can make all the difference to these forms of suffering.

How many Australian recipients of AD might have had a different outcome had they been able to access quality psychological help at crucial times will remain unknown. But what is known is that in Victoria, for example, the most recent report makes no mention of any referral for psychological assistance to address potentially treatable mental illness.

### **Missing safeguard – avoiding a bad AD death**

One aspect of the AD process that has received limited attention is the nature of an AD death. Central to the case for AD is that it is an expression of mercy, and that such a death is quick, painless, and peaceful. Indeed, one of the more common arguments used to support AD is that it acts as an antidote to suicide that might otherwise occur by degrading and traumatic means.



One might therefore expect there to be a standard agreed protocol for drugs used to terminate life to ensure death is indeed quick, painless, and peaceful. However, that is not the case, and in a recent review, Worthington *et al.* identified numerous different drugs, combinations, and protocols in current use – 17 different drugs for assisted suicide, and 22 for euthanasia.<sup>27</sup> All of these drugs have been developed as medicines in the proper sense, that is, as treatments for a variety of conditions, but when used in combination to cause death, and at much higher doses than for therapy, there is limited if any research.

Writing about Canada's MAiD (Medical Assistance in Dying) protocol for oral use, Harty *et al.* describe the situation as follows:

... the pharmacokinetics and pharmacodynamics listed for the medications below are at typical therapeutic dosing, not MAiD dosing. There has been little to no research into their parameters at such high doses as seen with MAiD.<sup>28</sup>

This is problematic because it is bad science to assume not only that adverse effects observed at lower doses will be similar at higher doses, but also because when used in combinations, drug interactions can change a drug's behaviour considerably. What is known is that the drugs have been known to cause 'burning, nausea, vomiting and regurgitation' as well as seizures, and sometimes patients can regain consciousness.<sup>29</sup>

Concern about what someone might experience during an assisted death has been brought to prominence with the work of Joel Zivot, an anaesthesiologist who has studied capital punishment deaths by lethal injection. His work shows that it is likely prisoners experience severe pain during execution,<sup>30</sup> and given the similarities in drugs used, he says, 'I am quite certain that assisted suicide is not painless or peaceful or dignified. In fact, in the majority of cases, it is a very painful death.'<sup>31</sup> F. Hanna Campbell, researcher in neuropsychiatric AI therapeutics at New York University has similar concerns, noting that 'high doses of pentobarbital can therefore potentially cause, rather than relieve, neuropathic pain during euthanasia. This would mean that pain-blocking during euthanasia is essentially ineffective.'<sup>32</sup> And because paralytic agents are used, the patient cannot move, and hence there would be no outward indication of experiencing pain. Nevertheless, doctors carrying out euthanasia report that they have witnessed no suffering.<sup>33</sup>

In a special report for the journal *Anaesthesia* in 2019, authors from the UK, USA, Switzerland, France and The Netherlands concluded that some AD deaths 'may be inhumane'.<sup>34</sup> Most concern seems to be around assisted suicide where the patient ingests the lethal concoction, even though Zivot's studies with prisoners involved lethal injection. Notably, the proportion of assisted suicides by oral self-administration compared with euthanasia by lethal injection can vary enormously. In Canada for example, nearly all deaths are by lethal injection and hardly any by oral self-administration,<sup>35</sup> whereas in Victoria, the opposite is true – 85% of all AD deaths from the Act's implementation to mid-June 2023 were by oral self-administration,<sup>36</sup> increasing the risk that more deaths could involve complications.

What evidence is there in public records about AD deaths that could shed light on these risks?

Apart from anecdotes<sup>37</sup> and some limited evidence from official reports such as those from Oregon, little is actually known about AD deaths. Details would of course be difficult if not impossible to gather for those who have taken the drugs alone. And even for cases of euthanasia, reporting by doctors, at least in Holland and Belgium is notoriously poor; and there would doubtless be a reluctance for a doctor to report any complications. The most recent report on MAiD from Canada, which is laden with statistics, makes no mention of complications.<sup>38</sup> The complication rate in Oregon was not originally reported for the first few years, but for the year 2022 there were 6 complications for the known 72 cases (8.3%). There were 206 cases with no data gathered, representing 74% of the total number of cases.<sup>39</sup> When considered over the total time period from 1998 to 2022, for the known cases, which represent 40% of all AD deaths, 0.9% of patients regained consciousness.

Time to death can also vary significantly, from 1 minute to 104 hours in Oregon.<sup>40</sup> In Canada, nearly all cases of MAiD involved euthanasia, but for the few that involved oral self-administration, in half of the cases death had not occurred after 60 minutes and so intravenous medications were used.<sup>41</sup> In these cases, a clinician was present, but if there had not been, the time to death could have been much longer, or even required clinical assistance. There was one case (out of 10) where the patient was 'transported to a hospital as a result of adverse effects or a delayed death'.<sup>42</sup>

In summary, the limited evidence that exists suggests that while the majority of *known* AD deaths appear to be peaceful and/or painless, even if sometimes drawn out over many hours and sometimes days, what the patient is actually experiencing during the dying process is largely unknown, even though there are grounds for significant concern. There is clearly a small percentage of cases where something is not going well, and the risk seems to be higher for self-administration. This makes the risk of overall complications significantly higher in the Victorian context versus the Canadian one for example.

The point of raising this issue in the context of safeguards is that this is another area where there appears to be a failure to ensure patient safety – if such 'safety' means a guarantee of a quick, painless, and peaceful death. Perhaps it should not be surprising that the extensive work that typically goes into ensuring drugs are safe for human use does not apply with AD. Unlike therapeutic interventions, with AD one can hardly undertake a clinical trial. This is one more reason why AD can never be good medicine, or indeed medicine at all.

## **IS IT ALREADY TIME TO ROLL BACK THE EXISTING SAFEGUARDS?**

In the few short years that AD has been in operation in Victoria, the first State to legislate, there have already been numerous calls to weaken some of the safeguards. In a paper published less than a year after the Victorian Act came into operation, McDougall and Pratt, writing in the journal *BMC Medical Ethics*, argued for '... caution against engaging in a discourse dominated by safety'.<sup>43</sup> Their concern is primarily about the principle of equal access. This is not surprising, because once a new treatment is construed as healthcare, this principle can be used to great effect. Anything that might limit equality of access to AD can then be scrutinised, debated and removed on the grounds of discrimination. Their primary concerns are with the following safeguards: doctors not being permitted to raise AD; the requirement for one of the doctors to have expertise in the patient's condition; the provision for individual and institutional conscientious objection; the process being long and intricate; and, requiring 3 formal requests.

They are also concerned that equity is not served by there being so few doctors who are prepared to provide AD, and that telehealth cannot be used for AD. The former is unsurprising and will be revisited. The latter restriction comes from federal law that prohibits using a carriage service (telephone, video, etc) 'to publish or distribute material that counsels or incites committing or attempting to commit suicide'.<sup>44</sup> A recent Federal Court case that sought to challenge this on the grounds that AD was not suicide failed, and so AD via telemedicine remains unlawful. However, there is already a move to change the law itself.<sup>45</sup>

Perhaps the most notable complaint made by these authors is that safeguards in general can limit the social acceptability of AD. They rightly recognise that for AD to be fully incorporated into the healthcare system and into the collective psyche as a medically normative practice it will be necessary to convert people wholesale to the ethical probity of the central principles behind AD – that causing death is an appropriate solution to suffering and that individuals have the inherent right to decide when to die according to their own perceptions and theirs alone. If safeguards get in the way, the authors seem to argue, then they must go. The process of normalisation being sought has parallels with abortion, which at least for some circumstances, enjoys a reasonable level of social acceptability. Although, one might argue it will never gain broad acceptability simply because of what it is, and what is transpiring in the US confirms that.<sup>46</sup>



Ethicists writing in academic journals are not the only ones agitating for lifting restrictions.<sup>47</sup> Participating doctors,<sup>48,49</sup> activists,<sup>50</sup> families,<sup>51</sup> and journalists,<sup>52</sup> have also expressed similar wishes. Even members of Victoria's Voluntary Assisted Dying Review Board have advocated for change, recently arguing that patients should be able to use telemedicine to access AD.<sup>53</sup> The Board plans to make a submission to the upcoming five-year review of the Act, and while it is unknown what issues they might wish to address, it is likely, given that several Board members have a history of AD advocacy, that the question of modifying safeguards will be included.

Finally, there have been calls for the removal of the requirement in some states that there be specialists involved who have knowledge of the condition from which the person is suffering.<sup>54</sup> In Victoria for example, at least one of the medical practitioners assessing a patient must have 'relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed'.<sup>55</sup> Removal of this requirement could mean that a patient might miss out on a potentially beneficial treatment that may make a significant difference to whether they seek AD or not.

## ASSISTED DYING EVIDENCE FROM AUSTRALIA

Because AD is relatively new in Australia, the evidence base is very limited, coming primarily from official reports produced by the Boards established under the legislation. Even these reports omit information that would be valuable to understanding the practice of AD in Australia. What follows will be data from the reports followed by research primarily about the experiences and perspectives of medical personnel involved as well as some from families.

However, first there is some information available from the brief experiment with euthanasia in Australia's Northern Territory in the nineties.

### Northern Territory

Euthanasia was briefly available in the Northern Territory under the *Rights of the Terminally Ill Act, 1995*. Seven people applied and four were euthanised.

Details of the cases were published in an article in *The Lancet*. Key findings were that patients experienced social isolation and depression and there was a lack of consensus about whether their illnesses were terminal, a requirement of the Act. The authors also noted,

Pain was not a prominent clinical issue in our study. Fatigue, frailty, depression and other symptoms contributed more to the suffering of patients.<sup>56</sup>

These were vulnerable people. Their decisions were deemed voluntary but given the disagreement among medical professionals about their condition, untreated depression despite psychiatric involvement, lack of social support, and limited palliative care options, whether they made a genuinely informed choice is unlikely. Of particular concern was the perception by patients that psychiatric assessment was a hurdle to be overcome, leading to reticence about providing information that might have enabled assistance from a psychiatrist.

To what extent was the psychiatrist trusted with important data and able to build an appropriate alliance that permitted a genuine understanding of a patient's plight?<sup>57</sup>

It is also noteworthy that Aboriginal opposition to the Act was authoritatively reported to be 'near universal',

... the very fact of the legislation, at least anecdotally, is causing people to be reluctant to present, or to present not as soon as one might, to attend clinics or to go to hospital.<sup>58</sup>

It is possible that other cultural groups may have had a similar response to euthanasia legislation in the context of distrust of authorities.

### Official reports

Official reports on AD are available for Victoria, WA, South Australia (SA), Tasmania, and Queensland, with some only covering part of their first year of operation. These reports are produced by the respective Voluntary Assisted Dying Review Boards, whose role it is to oversee the operation of the respective Acts. Some also have an explicit role to 'recommend safety and quality improvements'.<sup>59</sup> Board members are drawn from a diversity of backgrounds but often have a medicolegal and/or academic background. Some are well-known and vocal advocates for AD, and some have been members of AD implementation task forces. Indeed, it would be surprising to find anyone on these boards who was *not* a supporter of AD. Some Boards are also explicit about their relationships with AD advocacy organisations. For example, the SA Board names Voluntary Assisted Dying South Australia (VADSA) as an 'important and valued stakeholder', which it thanks for its advocacy and hopes to 'share learnings and explore opportunities for collaboration'. VADSA was originally the South Australian Voluntary Euthanasia Society (SAVES) and has been advocating for euthanasia and assisted suicide for over 4 decades. It currently supports AD for dementia patients and mental health sufferers, and views AD as a 'health benefit'.<sup>60</sup>

Reports by the Boards contain some basic statistics and demographics about patients as well as information about the doctors involved and various ancillary bodies. These will be addressed shortly.

Included in all reports are statements that can only be described as glowing accounts of AD by patients and/or family members of their experiences. Whether there were also accounts that were negative in any way is unknown. The accounts are almost promotional in style and their inclusion in publicly available reports takes no account of a possible contagion effect. Such an effect, the Werther effect, is well-documented for in media reports of suicides<sup>61,62</sup> and has resulted in specific guidelines to limit it.<sup>63</sup> Moreover, this effect is not limited to unassisted suicides. Extensive reporting of a double assisted suicide of a well-known Swiss couple resulted in an increase in the rate of assisted suicides, especially of women over 65 years of age, leading to a call for media restraint.<sup>64</sup> There is also evidence of an increase in assisted suicide deaths in Oregon around the time of the heavily publicised death by AD of Brittany Maynard.<sup>65</sup>

In Victoria, the number of unassisted suicides among elderly people has increased by 50% in the years since the implementation of AD.<sup>66</sup> This is unlikely to be because of Covid restrictions since there was no such increase in neighbouring New South Wales (NSW), which also has yet to implement AD. Nor was the increase in suicide across all ages in Victoria, but only amongst the elderly. Advocates for AD had made much of the argument that 50 traumatic suicides a year among the frail elderly would instead be peaceful AD deaths under the new law. But instead of 50 fewer suicides a year among this vulnerable population, there have been about 50 *more* per year. That is, the number of unassisted suicides has increased after introduction of assisted suicide, not decreased as predicted. Is it possible that something akin to the Werther effect is the cause? Promoting assisted suicide legitimises *any* form of suicide for this vulnerable group. Now, many more of the frail elderly die by suicide (in either form) than before the law changed.

The board reports also include supportive statements by the health professionals involved. In the SA Report, this section reads like a drive to recruit more AD doctors – '... Do it, it might seem scary and strange to start with, but it is very rewarding'.<sup>67</sup> 'Scary' perhaps because of the gravity of what is happening, and 'strange' because AD is so foreign to medicine. Recruitment might appear necessary given the reluctance of doctors to be involved and the perceived failure to ensure accessibility. Ambivalent doctors are reassured by statements from their colleagues, reported by the board in Queensland for example, 'The majority of people express that

it has been a very smooth process and they have felt extremely well supported throughout. My involvement is always met with extreme gratitude that voluntary assisted dying is now an option for them.<sup>68</sup>

Promoting AD as healthcare brings it under the umbrella of legitimate treatments which the state ensures must be available to all, even if that is not true for many other medical treatments. Reading the reports is revealing about what happens once an AD law is passed and thereby legitimacy granted. Immediately the machine of bureaucracy swings into action, funds flow from government, structures are put in place, and members of the community take up key roles within the new enterprise. As noted, this often means AD advocates, leaving little room for dissenting or moderating voices. There is much at stake to reassure the public that the new practices are safe and well-managed, and that none of the problems identified by dissenters are happening. This could be damaging to what is seen by some as a new branch of medicine in its infancy.

So the question must be asked - does the information in the reports provide sufficient assurance that AD is indeed safe and well-managed?

### Numbers of cases

Immediately before the Victorian Act came into operation, the then Premier said about 12 people would access AD in the first year and then the numbers would eventually settle to around 100-150 per year.<sup>69</sup> In the first year of operation 346 people applied and were deemed eligible for AD; 239 permits were issued for self-administration (assisted suicide) and 39 for practitioner administration (euthanasia). There were eventually 129 AD deaths. The number of deaths has increased by 56%, 36%, and 11% in subsequent years. The only other state with data for more than 1 year is WA where the numbers went from 191 in the first year to 255 in the second, an increase of 34%. When compared on a per capita basis, there were twice as many AD deaths in WA compared with Victoria. For the remaining states, there is only data for part of 2022/2023, and the numbers per capita are roughly equivalent.

One notable difference is that the proportion of patients euthanised rather than self-administering was much higher in WA than in Victoria – 82% versus 16%. One possible reason may be the more lax requirements for practitioner administration. The question of why in some jurisdictions euthanasia is chosen over assisted suicide may also be because assisted suicide is aligned with suicide in general, along with all the negative connotations that go with it, whereas euthanasia is perceived as a legitimate medical treatment by a health professional. In effect euthanasia becomes autonomy outsourced - the ultimate medical paternalism.<sup>70</sup>

In the lead-up to the passage of the AD Act in Victoria the ministerial advisory body argued in its report that the uptake of AD would be gradual because that is what happens with new medical interventions, so increasing numbers each year should be expected and not indicative of anything particular to AD.<sup>71</sup>

There are several reasons why this is a very weak argument.

First, AD has been widely debated and discussed at length in the community, unlike most new medical interventions. One would be hard-pressed to find someone who was unaware that AD was a legal option, so increasing uptake through increasing awareness is unlikely. It might be argued that accessibility remains a problem because there are limited numbers of doctors prepared to provide AD. However, whilst that is true, they are not overwhelmed with cases by any means. In Victoria, for example, there are currently 347 trained and registered AD practitioners, and there were 306 AD deaths in the 2022/2023 year. Second, AD has been immediately well-resourced by governments whereas many new medical interventions remain out of reach. Some of the review boards are already calling for more funds to ensure AD is accessible to all.<sup>72</sup> In NSW, the latest state to legalise AD, palliative care funding has been seriously cut, some of the savings being used to implement AD, which has been assured government support.<sup>73</sup> Third, many new medical interventions take time to become established because there is uncertainty about efficacy, or ongoing research and

development to refine methodologies. This is not true of AD – it is 100% effective in causing its desired outcome, even if the process, as noted above, can be fraught. It cannot be refined by research and development into a 'more effective' treatment. Fourth, in jurisdictions where AD has been in place for some time, rather than the numbers levelling off after a number of years, they keep increasing. In Belgium for example, numbers have steadily increased from 24 in 2002 to 2966 in 2022, increasing by between 10% and 20% per year.<sup>74</sup> In Oregon, numbers for the past 10 years have been increasing year on year even more rapidly compared with the first 15 years, going from 73 in 2013 to 278 in 2022, an increase of 281%.<sup>75</sup>

These factors point to something different behind the increasing uptake of AD. What is more likely is that the presence of the laws has normalised death by AD through a culture shift in the way end of life is managed. To some, AD becomes a more attractive option with time because the educative impact of the law changes perceptions, people's values shift, and what was once unthinkable increasingly becomes the new paradigm. Part of the shift in values may also come about through self-perceived burdensomeness, with an overtone of increasing pressure from authority figures.

### **The euthanasia doctor**

Doctors who are prepared to participate in AD are relatively few in number; those authorised representing less than 1% of all medical practitioners. Fewer still actually participated. Given AD is in its early stages in Australia, the numbers may rise as recruitment picks up or if attitudes to terminating life by the medical profession keep liberalising.

The reports do not say much about the doctors involved (or where permitted, nurses too), except that for some states what seems to be an emerging phenomenon, consistent with the international experience, is that certain health practitioners soon become prominent in the field – effectively the euthanasia go-to doctors. In Queensland for example, there were 591 first assessments completed and eventually 245 AD deaths in the first 6 months of operation. Other stages were completed but did not result in an AD death for one reason or another, and yet there were only 108 practitioners who participated in at least one stage of the process – doctors can act as a primary assessor, the consulting doctor, or the administering doctor, or all three for different patients. Only a few are doing the bulk of the work – of the 108, 23 practitioners participated in some way with 11 to 20 patients, and 14 dealt with over 20 patients.

The concern with such a small contingent undertaking most AD work is that they are specialists at the fringe of medicine operating from a narrow perspective that becomes self-reinforcing. They undertake what most refuse to do and yet make complex judgements about rubbery things like decision-making capacity, terminality, risk of coercion, mental health, and alternative available treatments for unique conditions. There has rightly been concern about the risk of doctor-shopping, when patients keep going from one doctor to another, eventually finding one who will comply when others have not. But when there are known dedicated euthanasia doctors – known through the AD advocacy organisations or the navigator services provided by health departments – the work is effectively done, and the compliant doctors are known. They might be few in number, but they are quite active.

### **Reasons for accessing AD**

Only one of the official reports (WA) provides data about the reasons patients choose AD. The results are similar to what has been observed in Oregon, with most having to do with loss of dignity, feeling like a burden on others, being unable to enjoy life, and losing autonomy.<sup>76</sup> Unfortunately, each question asked does not distinguish between the actual presence of phenomena or simply concern about them. For example, 45% of patients cited 'inadequate pain control or concern about it' as a reason for accessing AD. There is no way of knowing

who was actually experiencing inadequate pain control – it could have been all the 45% or none, and yet this is surely critical information. Similarly, 71% cited ‘less able to engage in activities making life enjoyable or concern about it’. Framing questions in such a way is an endorsement of preference rather than reality. One can have a concern about something that may not happen, and to act upon a concern rather than an actual phenomenon is at odds with how medicine operates. If someone has no pain but is concerned about it, the response should be ‘let’s treat the pain if it happens’.

## Compliance

All official state reports include a statement of compliance with the respective Acts. The only compliance issues concerned the timeliness of the return of unused AD drugs. Two such cases in Victoria were beyond the legal requirement for return within 15 days, but no action was taken. WA Health was notified of 3 cases related to timeliness of drug disposal, but without any elaboration.

The question of ensuring compliance is complicated by the fact that non-compliance would need to be self-reported. This was a problem recognised by Oregon Health in the early years of AD in that US state:

As best we could determine, all participating physicians complied with the provisions of the Act. ... Underreporting and noncompliance is thus difficult to assess because of possible repercussions for noncompliant physicians reporting to the division.<sup>77</sup>

In his critique of AD and questions of compliance, Keown is more targeted, and blunt:

It is evident that the Victorian law shares a key failing of all other permissive laws: its reliance on the intrinsically ineffective mechanism of self-reporting by physicians. It is incapable of effectively controlling VAD [Voluntary Assisted Dying], either by ensuring that cases are reported or by ensuring that each reported case complies with the requirements of the Act. Far from being designed to detect a mistake or abuse it could not unreasonably be described, rather like the Oregon law, as being designed not to.<sup>78</sup>

States’ boards may readily sign off on compliance, but it may take years for cases of non-compliance to emerge, initially as anecdotes, but perhaps eventually by researchers as they become involved. The Disability Rights Education & Defense Fund has compiled a list of cases from Oregon and Washington State that show clear instances of non-compliance.<sup>79</sup> It is likely that in Australia similar issues of non-compliance will emerge and be reported, but this is unlikely to be via the boards.

## Complications

The report for WA was the only one to describe any complications. Some were related to intravenous line insertion, one involved ‘worsening of pain or discomfort’, and 5 were categorised as ‘other’.

WA’s was also the only report to include data on time to death, and this was only available for administration by a health practitioner; for intravenous drugs, time to death ranged from 1 to 30 minutes; and, for oral administration (via tube), the range was 7 minutes to 6.5 hours. The Victorian report did refer to ‘a number of cases where the time to death following administration of the substance has been prolonged’, but without any detail.<sup>80</sup>

As noted earlier, complications and/or time to death are unknown for cases of self-administration, which so far represent the majority of AD cases in Australia. It is also unknown how many of these deaths may have happened whilst alone, where complications might otherwise have been addressed.

## Other statistics

Each report contains significant data about the process from first assessment to death. Numbers are provided for every stage. There is also a wealth of demographic information about patients. Some of this is useful, but much of it is not, and primarily provides the appearance of scientific rigour rather than valuable information that reassures the public AD is operating in a safe manner.

... the Board seems designed to serve largely as a depository for completed forms, a publisher of statistics and indeed a promoter for VAD.<sup>81</sup>

## What the reports do not include

By definition, AD in Australia only includes euthanasia by lethal injection with specified drugs or assisted suicide by oral ingestion of specified drugs. However, when AD is properly defined as the intentional termination of life, with or without a request from the patient, then other practices come within its remit. For example, non-voluntary euthanasia is nevertheless euthanasia, but it occurs when the patient cannot make a request. Similarly, a deliberate overdose of opiates intended to end life is euthanasia. If it were not, the dose would be titrated to control pain and no more. The difference from formal AD is in the choice of drug.

The reports about end-of-life practices in Holland and Belgium include cases of non-voluntary euthanasia and opiate overdose, even though, as in Australia, they are not specifically called euthanasia. Similarly, when a patient is heavily sedated and food and fluids deliberately removed with the intention of inducing death, a practice that has been called continuous deep sedation (CDS), that is also euthanasia, and has variously been termed passive euthanasia or euthanasia by omission.

The point about raising these types of cases in reference to the Australian context is that what has occurred in Holland and Belgium regarding them tells us much about what a culture of medical life termination looks like. In Australia, the law is strictly about *voluntary* death, but as in Holland and Belgium, it will almost certainly develop a culture that expands beyond voluntarism. When a new medical paradigm is established that is grounded in the belief that inducing death is a legitimate response to suffering, it may start with a condition of voluntarism, but soon the new principle expands to include those perceived to be experiencing similar suffering, but without capacity. In other words, these patients are suffering, and it is presumed that if they could ask for death, they would. And when opiate overdose can act as a substitute to bypass the regulatory hurdles of AD, and a doctor agrees with the patient that their circumstances are in principle so similar as to warrant life termination, then overdose may proceed. In Holland some 40% of deliberate opiate overdoses at the end of life were without consent.<sup>82</sup>

In Holland the category 'non-voluntary euthanasia' is termed 'ending of life without patient's explicit request' and varies from 0.2% to 0.7% of all deaths each year, a figure outstripped by Belgium with 1.7% in 2013. The percentage of deaths by opiate overdose in Holland, termed 'opioids in large doses' or 'intensified alleviation of symptoms', has increased from 20.1% of all deaths in 2001 to 35.8% in 2015.<sup>83</sup> Also increasing in Holland has been the number of CDS cases - from 8.2% of all deaths in 2001 to 12.3% in 2010 and 18.3% in 2015.<sup>84</sup> In Switzerland, a country with an established practice of assisted suicide, CDS cases increased fourfold from 2001 to 2013 (6.7% to 24.5%), an increasing proportion of which involved an intention to hasten death.<sup>85</sup>

The official reports by the AD boards in Australia operate only within the narrow definition of AD under the respective Acts. It is unfortunate that there exists no mechanism to report the complete picture of intentional termination of life and how the different categories may change over time now that the Rubicon has been crossed.



## OTHER RESEARCH

Apart from official reports, the evidence base about the operation of the various AD regimes in Australia is sparse. Much of what does exist is focused on surveys and interviews about perceptions from health professionals involved or family members and other caregivers. Evidence derived from AD patients prior to death is virtually non-existent. Even research more broadly aimed at attitudes and arguments about AD is inadequate. In their 2021 attempt at a systematic review, Kresin and co-workers concluded, ‘... the paucity of academic research and the lack of consistent terminology in this area made such a search untenable.’<sup>86</sup>

The research that is available is derived disproportionately from one source; researchers White and Willmott at *The Australian Centre for Health Law Research* at the *Queensland University of Technology*, who were also authors of an influential report from 2013 that drew the key euthanasia advocates together under the banner of the Australia21 organisation.<sup>87</sup> These researchers have received tens of millions of dollars in State and Federal funding to research AD in Australia, much of which has been used to influence political debate and decision-making in favour of AD. White and Willmott wrote the model AD legislation for Queensland<sup>88</sup> and the training programs for health professionals in Victoria, WA and Queensland.<sup>89</sup> Their recent research largely focuses on what they perceive to be problems with the current system that can be solved by the removal of restrictions and stigma. *The Australian Centre for Health Law Research*, using their research, has produced documents that either seek to assist patients and their families gain access to AD and navigate the process, or agitate for political change.<sup>90</sup> These are not research papers. Those that are aimed at providing information to patients, families and caregivers appear more like publications from a Government authority with titles like ‘Finding support to seek voluntary assisted dying – Information for consumers and caregivers’<sup>91</sup>, or ‘Voluntary assisted dying is legal – but some people are unsure how to access it.’<sup>92</sup>

The Centre has gone beyond providing research to openly acting as a political advocacy organisation. In a document titled ‘Commonwealth telehealth ban is an unfair barrier to seeking voluntary assisted dying’, emotive language derived from qualitative research by White and Willmott is used to denounce the ban – it is ‘crazy’ and ‘cruel’, and a ‘family member was distressed and in hysterics’, it is ‘unreasonable, burdensome and distressing’. The document makes no attempt to even consider why there might be a concern for vulnerable people if widespread ‘counselling or inciting’ about euthanasia and/or assisted suicide using a ‘carriage service’ were permitted. This advocacy document concludes with suggestions as to how the *Commonwealth Criminal Code* might be amended. An amendment would not only enable telehealth discussions between patients, family members, caregivers, and health practitioners, but much broader ‘counselling or inciting to commit suicide’ via AD, in effect opening up the possibility of coercion via a carriage service.<sup>93</sup>

### What do health practitioners say about AD?

Following the passage of the Victorian legislation in 2017, but before implementation in 2019, an exploratory survey study was conducted at one of the major hospitals in Melbourne to investigate the views of clinicians (medical, nursing, allied health, pastoral care, pharmacy; 57% were nursing staff).<sup>94</sup> With the proviso that this is a self-selected sample and may therefore be skewed, the study found that ‘the responses reflected a significant amount of fear and uncertainty’.

The authors identified six main themes of concern.

First, there was fear about the possibility of conflict because of differing staff views about AD and willingness or otherwise to participate. This theme arose from the second theme about strongly held and polarised views. While this was a qualitative study and hence the percentages of one versus another view were not reported, it is not surprising to find a strong diversity of opinion on AD. Third, respondents were concerned about the emotional burden of involvement or witnessing AD deaths. Some also expressed anxiety about guilt

for their possible involvement. Fourth, there was concern about coercion of vulnerable patients. Respondents worried '... that the legislation could be misused by unscrupulous practitioners or families despite the safeguards in place'. Fifth, respondents were apprehensive about organisational challenges involving practical matters like staffing, drug storage and management, the legality of involvement at different stages, workloads, and whether a noisy hospital environment was suitable for a planned death. Finally, the difficulty of determining decision-making capacity was identified by respondents as a problem area, and even when this was not an issue, making an informed decision could be compromised when alternative treatment options were not made available. Despite disagreement about AD itself, a common view was that there should be a 'thorough assessment for depression', which as it turns out, is not happening.<sup>95</sup>

Health practitioners have expressed differing degrees of willingness to be involved in one way or another with AD, with nursing and allied health being more willing.<sup>96</sup> Support for AD legislation has been found to be high in some studies but lower in others – for example, 48% to 76% support.<sup>97,98</sup> When it comes to being involved, the numbers fall away, particularly for acting as an administering practitioner (23%).<sup>99</sup> Moreover, willingness on an anonymous survey can be quite different to actual participation, perhaps explaining why the number of registered practitioners in Victoria for example is so low (<1%), and actual participation is less still. Those who specialise in end-of-life care such as palliative care are the least likely to be willing to participate.<sup>100</sup>

There have been several studies aimed specifically at the views and experiences of doctors who have been involved with AD.<sup>101,102,103,104</sup> These studies mostly utilise 'purposive sampling', a methodology that specifically targets certain doctors, and can be followed up by 'snowball sampling', which uses those doctors to recruit more. The limitations of this approach are obvious as it is open to researcher bias (conscious and unconscious) about who to target, as well as doctor bias about who might be the 'best' additional doctors to include. The outcomes of these studies often focus on perceived barriers to access – mandatory training, poor remuneration for doctors, bureaucratic requirements, lack of willing doctors, prohibition on raising AD, conscientious objection provisions, prohibition on telehealth, ineligibility of junior doctors to participate, and strict eligibility criteria (condition incurable, advanced, and death expected). Participants were 'frustrated by the safeguards',<sup>105</sup> but nevertheless saw ways through the restrictions.

'The legislation is providing an appearance of safety because people have to go through some hoops, but doctors are the experts in manipulating rules for patients.'<sup>106</sup>

As well as identifying perceived barriers to access, doctors also felt the emotional and existential burden of participation. They saw AD as a 'fundamental challenge to medical practice',<sup>107</sup> and were often conflicted about their involvement. Many drew the line at practitioner administration, not wanting to be '... responsible for the ultimate act of causing a person to die'.<sup>108</sup> They were also worried about dealing with families '... if the death did not go as expected',<sup>109</sup> and were also anxious about whether there may be coercion they could not identify.

Despite this complex mix of reactions from doctors dedicated to participating in euthanasia and assisted suicide, White and Willmott conclude that incorporating '... the newly regulated practice of VAD into the profession of medicine should become the immediate goal for government agencies and health services'.<sup>110</sup>

One particular feature of the Victorian AD system is that it operates with prospective oversight rather than retrospective oversight that is far more common internationally. In other words, it seeks to provide some oversight before a patient has died rather than after. White and Willmott question this approach, using the views of doctors selected through purposive sampling, who see prospective oversight as a barrier to access even if it provides some protection to doctors and system safety.<sup>111</sup>

## What do patients and family caregivers say about AD?

Research into the views of patients is virtually non-existent – just one patient was included in the perspectives of patients and 32 caregivers in several papers by White and Willmott using the same dataset.<sup>112,113,114,115</sup> Participants were sourced via purposive sampling from the two major advocacy bodies for AD in Australia – *Dignity in Dying Victoria* and *Go Gentle Australia*. It is almost certain that because of this the participants would be strong advocates of AD and believers in its moral and practical legitimacy. It is therefore unsurprising that the research in all four papers was aimed squarely at perceived barriers to access – the same barriers identified by AD doctors. One paper focussed on how the strategies of caregivers could constitute ‘regulatory action’ to overcome barriers,<sup>116</sup> and while this paper praises their actions and effectively constitutes a ‘call to arms’ for similar action by others, the authors make it clear their target is really the main regulators:

‘Consideration of how these barriers to access can be reduced by other regulatory means is also critical to reduce the ‘regulatory’ burden on patients and family caregivers.’<sup>117</sup>

Besides calling for legal change, these authors also want community awareness initiatives, led by government, but utilising other channels to “... avoid concerns about inducement from the state to consider VAD [voluntary assisted dying]”.<sup>118</sup>

One barrier to access that receives special attention is conscientious objection, both individual and institutional. The authors want individuals to be required to participate in AD by mandated referral to others with no conscientious objection,<sup>119</sup> and institutions (primarily Catholic) to be required to facilitate AD, on the basis that such objections harm patients and constitute a power imbalance.<sup>120,121</sup> Whether AD itself constitutes a harm to individuals, institutions, or societies, is not considered.

Finally, the differences between the first (Victorian) system and the more recent WA one is explored in interviews with 29 stakeholders in WA, recruited using purposive and snowball sampling – health practitioners, regulators and VAD system personnel, health and professional organisation representatives, patients and families. Notably, of the 5 participants in the patients and families category, there was no breakdown to identify the number of patients – there could have been 5 or none. Similarly, of the 7 participants who came from the health and professional organisation representatives, there was no breakdown to identify how many came from advocacy organisations - there could have been 7 or none.

Even though participants cited barriers to access that are similar to those already identified, their overall consensus was that the system is working reasonably well. However, as noted earlier there are approximately twice the number of AD deaths per capita in WA compared with Victoria. This has been interpreted as due to unmet needs in Victoria, rather than vulnerable WA patients slipping through the system.<sup>122</sup> However, the latter could arise from the key differences between the two systems.

Unlike in Victoria, in WA the following are permitted:

- Medical and nurse practitioners can initiate a discussion about AD
- Nurse practitioners can administer lethal drugs
- There is no requirement for involvement of a medical specialist with expertise in a patient’s illness or disease
- Aspects of the AD process are deemed suitable for telehealth (with care to avoid breaching the Commonwealth Criminal Code)
- A patient can have practitioner administration more easily
- Obligations are imposed on conscientious objectors (referral)
- A Regional Access Support Scheme was established for patients, providing financial, travel, accommodation, and personnel support.<sup>123</sup>

Taken together, these differences could have increased uptake and thereby account for the higher rate of AD in WA compared with Victoria.

### **What research is missing?**

The research that has been cited here essentially comes from within the AD system and appears primarily to be focused on expanding it and changing the culture around death. But this is a skewed perspective, and if research is geared to determining the truth about a new medical intervention, as it should be, then there is a desperate need for balanced research that casts the net more widely than asking questions of selected health professionals and family caregivers.

The following is by no means an exhaustive list of some of the research questions in need of answers:

- What are the properly identifiable reasons why patients choose AD?
- What is the impact of AD on the medical and nursing professions and their standards?
- What observations are there about patients' AD experiences by those who do not support AD – or example, from health professionals whose patients left and sought AD from willing providers?
- What are the explanations for the ever-increasing rate of AD?
- What is the emotional impact of an AD death upon family and friends who did not support it, and what is the impact on relationships between family members who disagree about their loved one accessing AD?
- What forms can coercion to choose AD take and what strategies are there to expose it?
- What has been the impact of AD upon palliative care and its resourcing?
- Does treating mental illness change the desire for AD?
- What social and relational factors change the desire for AD?
- Why do people who have been provided with lethal drugs not use them?
- To what extent does AD lead to conflict between health professionals, and what impact does that conflict have on the delivery of healthcare?
- What is the impact of overriding an individual's conscientious objection to AD, and what would be the societal impact of forcing objecting institutions to permit AD?
- Are there different psychological profiles between AD doctors and detractors?
- What are the organisational challenges for institutions implementing AD, are they being resolved, and are there adverse consequences?
- What are the views about determination of decision-making capacity from AD doctors, psychiatrists, objecting health professionals, and family caregivers?
- What are the circumstances of an AD death by self-administration – who was present, what were the complications, was decision-making capacity retained just prior to death, and was there any drug diversion?

At the time of writing, there is minimal if any research that addresses these questions, and yet they remain questions that are central to assessing the impact of a highly controversial, novel, and morally troublesome practice. If foreseen and unforeseen adverse side effects are not properly examined then any perceived benefit, if death can be construed as benefit, may tilt the scales of harm significantly.

## DISCUSSION

It should not be surprising that there were 57 failed Bills attempting to establish AD in Australia before Victoria finally broke through.<sup>124</sup> The reason it is not surprising is because it takes a lot to overturn one of medicine's fundamental guiding principles – doctors should not kill their patients (*primum non nocere*, first do no harm). This goes hand in hand with the long long-held legal position that helping someone kill themselves is contrary to the deeply held respect for life that forms the foundation for human rights. After Victoria, the floodgates opened all too rapidly, leading to a “very recent rush” in all the states that was almost “inexplicable”.<sup>125</sup>

We can argue about what has brought us here, about what kind of society we have become, but here we are, and now comes the task of exploring the impact across a whole range of domains. Unfortunately, despite the confident proclamation that ‘none of the fears that were put forward as reasons not to change the law have been realised’,<sup>126</sup> in reality we do not know nearly enough to back up such an ill-informed claim. But what we do know is so skewed that the truth is almost certainly being obfuscated. As we have seen, the research to date is geared almost entirely towards liberalising law and practice to maximise accessibility via minimising safeguards. In fact, it appears the argument is that AD should receive *preferential* treatment to ensure it thrives, above a host of life-saving measures, including palliative care. Adding to that privileged position, researchers have joined with advocates to force compliance by attacking conscientious objection, a strategy that may have more to do with silencing dissent than increasing access to AD.

Arguments for euthanasia and assisted suicide are generally grounded in utilitarianism – the patient's life can be terminated, all things considered, so that suffering is ended. Using a calculus to weigh up the relevant factors can be made flexible enough to permit something otherwise unthinkable. Alternatively, modern moral philosophers and their followers may be offering ‘a rhetoric which serves to conceal behind the masks of morality what are in fact the preferences of arbitrary will and desire’.<sup>127</sup> True or not, with utilitarianism, various means can be justified if the end is appealing enough. The problem is that the truth itself can be a casualty in public debate and even academic research, skewing or compromising it becoming a justifiable means to achieve the goal of ending suffering via legalising AD. When Belgian doctor Yves de Locht, who lethally injects his patients, states, ‘I don't *feel* like I'm killing the patient [emphasis added]’,<sup>128</sup> we know the truth is being compromised. How can injecting a lethal drug into someone's vein not be killing? Similarly, when euthanasia of those who did not or could not make a voluntary request is not included in euthanasia statistics as in Holland and Belgium, or intentional opioid overdose to terminate life is likewise excluded, or when deep sedation and removal of food and fluids with the express intention to end life (CDS) is also omitted, then the truth has been compromised. The point of good research is finding the truth, but in Australia, there is a paucity of good research, not only into current AD practice and adverse consequences, but especially into the link between AD and other means of intentionally terminating life. Now that permission has been given to health practitioners to kill within certain confines, some will see that as an endorsement for greater liberty to extend practices that similarly terminate life by eliminating suffering and/or serving autonomy. It is crucial that researchers in Australia examine whether AD is having an impact upon these other practices.

Finally, the question of coercion has come to light recently in the UK with comments by prominent journalist Matthew Parris to the effect that it would be a good thing to pressure the terminally ill to accept AD and relieve others of the burden of caring for them.<sup>129</sup> Presumably he meant family members and caregivers, but the community also bears some ‘burden’ through its welfare provisions. A lot of resources could be saved for more worthy causes, so the argument goes. There is a long history of such thinking, and in fact the close alliance between the eugenics movement and the early euthanasia movement is a testament to that. Parris is one of the few to be honest enough to voice this belief – Mary Warnock was another,<sup>130</sup> as was former Australian Governor General Bill Hayden, who said the community should be ‘disencumbered ... of some unproductive

burdens'.<sup>131</sup> In Australia, other than some recipients of AD in WA who cited being a burden as a reason for choosing AD, we have no idea how many felt pressured, either by those who were supposed to be caring for them, or by a society they have a sneaking suspicion is right behind Parris and the like. It is not thought polite to speak of AD in terms of a path that some should be coerced to take, but it seems the secret is coming out. One more thing, Mary Warnock was talking about dementia patients having a duty to die, underscoring how easy it is to slide from voluntary to non-voluntary euthanasia. At least no one need be pressured for the latter.

In conclusion, decision-makers in Britain should be very cautious about claims that Australia has a well-functioning AD system in place that is workable and safe. We really don't know that much about what is happening or about a whole raft of potential adverse consequences, some of which, even within this short time frame may well be happening right under the noses of the review committees, who incidentally have a lot invested in promoting a view that everything's just fine. Holland, Belgium, and Canada are cautionary tales and there is every reason why Australia will follow. At the very least, it would be prudent for the UK to take a precautionary approach and wait. If Australia goes the way of other euthanasia countries as expected, then waiting will have been a wise decision. As for Australia, we are now encumbered with a radical new policy that will be very hard to monitor and equally hard to undo.



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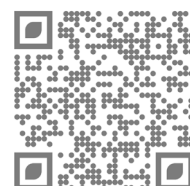
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