

## An Update on VAD: (Almost) A Year in Review

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The twelve-month anniversary of the implementation of the **Voluntary Assisted Dying Act (2017)** (“the Act”) is this Friday. In this period, I have been involved in 79 cases of application for VAD. More than 30 of these patients have died through the administration of VAD medication, either by self-administration, or through intravenous injection if they were unable to ingest or absorb the liquid medication. I have been present in support of patients and their families at most of these deaths.

Over the last year, we had hoped to establish a baseline, or “normal” year of data and trends against which to compare future years. The COVID-19 pandemic has disrupted every aspect of our lives, and there really is no such thing as “normal” anymore. Terms like “new normal” or “post-COVID-normal” have been touted, but what does this mean when we didn’t really have a “pre-COVID-normal”? Along the way, we have learned much about this new area of medical service. I have been confronted in ways I was not expecting, and I cannot put into words the appreciation I feel for the support and friendship offered by so many along the way. My wife Emma, and daughters Matilda and Ruby deserve mention – “walking the walk” with providing VAD services has proven not to be an office-hours type of role. Many urgent referrals or sudden requests for attendance have spoiled evening or weekend plans for them and has really made me question whether family really does come first when ranked against the suffering of (essentially) a stranger, and whether this is a reflection on my devotion as a husband and father.

Over this time, we as practitioners have grown more comfortable in the service we are providing. Media tag lines of variations of “Death Doctor”(1), and reference to “Suicide Clinics”(2) as if there was some sort of death factory that employed us to do this work have come and gone. I have even been likened to Hitler(3); an experience that helped me learn the rule of staying out of comments sections, although thankfully those comments were deleted by the moderator.

Despite the name calling, my stance remains the same: call me what you like. Patients want this, and I am here to support what they want. Even when I do not want them to go. Most of the people I have helped access VAD haven’t been patients of my own with whom I have had a long-term relationship – most are referred by other practitioners who aren’t interested in providing this service for whatever reason. The patients whom I have looked after for their cancer treatments have been a lot harder to support through this process; it is difficult shifting gears from helping patients stay alive to helping them die. It raises many questions – “Did I do enough?” seems to be the main one that my subconscious likes to poke me with.

I completely support the need to acknowledge and respect conscientious objection and doctors who do not see this as part of our role, but I do feel as though the assessments would be better done by doctors who have known the patients for longer than one or two clinic meetings. Until VAD becomes a standard part of end-of-life care planning alongside Advance Care Directives, Legal Wills, and Medical Treatment Decision Maker appointment, the provision of this service will be shouldered by the few early-adopters. Lest patients go wanting, left with no way to access their legal right to choose the time and mechanism of their death.

One year in, and one might ask: What is working, and what is not? What is working is that people are dying peacefully. They are dying at home, surrounded by family and friends. They are not choking to death, seizing, or taking hours to die, as some opponents of VAD might suggest in their ill-informed accounts of what a VAD-death can be like(4). People are telling those around them that they love them, they are closing their eyes, they are falling asleep, and they are dying gently. I have not had any complications in any of the cases in which I have been involved, nor have I heard of any through discussions with other VAD-accredited doctors. I think it important to remind people that although these have been what I would call “dignified” deaths, they are still deaths. Families and friends are still losing the ones they love; death is still not a “good” thing, nor do I think it can ever be. Equally, dignified deaths

occurred before VAD was available; palliative care services continue to be fantastic supports for terminal patients. I have had many cases die during the application process. This is often mourned as a failure to consider, apply for, or navigate the VAD system in time, but while we frantically search for birth certificates and consulting opinions, and scramble for witnesses for the written declaration form, contact persons, and permit applications, palliative care has remained resolute in controlling symptoms and preserving dignity. For the most part, they should be commended for their maturity in dealing with a practice that they disagreed with, and that many of whom continue to disagree with.

I do hope we are changing (for the better) the grief that those loved ones are experiencing. I hope that we are lessening the trauma associated with the loss of a loved one. I hope that we are changing the way that those people view death, but data needs to be collected to see whether this is happening. Some data has been collected overseas that suggests that this is a potential outcome of VAD introduction – a cross sectional study by Swarte (5) suggested that family and friends of cancer patients who died by euthanasia experienced less-traumatic grief symptoms than the comparative control group. Data needs to be collected locally and contemporaneously. If I am wrong, we can use this data to look at ways to change the way we provide this service to accomplish the goals with which we set out. We need the evidence to inform our practice, and we need the evidence to present to other States, Territories, and even other Nations, to inform them of the lessons we learn along the way. If we are right, and the implementation is having an effect (positive or negative) on the people who remain behind, those States, Territories and Nations can take that into account when considering their own legislation. We are also in a unique position in Australia; Western Australia's legislation is planned to go live mid-2021(6), and we hope that other States may be able to pass similar legislation in the future. If this occurs, we will be able to assess the effect of different legislative restrictions on these outcomes and be able to provide evidence to strengthen recommendations for future legislative change.

What is not working? Where to begin... There is still not enough awareness of VAD in the communities for whom it is important. Terminal patients and their families have more important considerations than remaining self-informed on recent legislative change. Doctors are not allowed to raise VAD as an end-of-life option with patients. Couple this with an implementation period that was focused on how the legislation would be put into use, and not on an awareness campaign directed at the general community, many patients are not aware that VAD even exists as an option. Not only did the implementation period not address community awareness, but the awareness of the Act amongst the medical communities (in both specialist and GP circles) was not addressed. Most doctors do not know what they can and cannot talk about with patients with regards to VAD, so many are avoiding these discussions for fear of saying the wrong thing. No doctors have been educated that a First Request can be made to any registered medical practitioner, and that by law, that practitioner has seven days to accept or reject that request. Too many patients continue to be strung along by doctors who "may" do the training, or who do not want to say no, even though they know that is the answer they have settled on. Doctors continue to break the law through a lack of education that should have been provided as part of implementation.

The requirement of one of the assessors to have "relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person"(7 p. 17) has been problematic. Unfortunately, this has been taken to require one of the assessors to be a specialist in the area of medicine pertaining to the patient's qualifying diagnosis. The effect of this has been multiple. Most importantly, specialist Geriatricians and Palliative Care physicians are not specialists in specific diseases, but they are highly-skilled at managing people in this phase of their life and there are no physicians more qualified to provide prognostic opinion on the person as a whole than these. Equally, highly-skilled and experienced General Practitioners have often been involved in more cases of certain cancers than I have – their knowledge and experience should be respected, regardless of whether it is rubber-stamped by the Royal Australasian College of Physicians or the Royal Australian College of General Practitioners. I am also puzzled by the requirement for one of the assessors to be more than five years post-Fellowship. As a qualified specialist Medical Oncologist, I am looking forward to whatever it is that happens at five years that is so special.

Keeping in mind that many of these patients are in the final stages of their life and are often house- or even bed-bound, specialist physicians who are willing to do home visits have been exceedingly rare. According to the Australian Health Practitioner Regulation Agency (AHPRA)(8), there were 265 Medical Oncologists, 224 Neurologists, and 193 Haematologists registered in Victoria in March 2020. This is compared to 6,637 registered General Practitioners (GPs)(9). We have no breakdown of the number of GPs compared to specialists who have completed

VAD accreditation training, however the VAD Review Board Report (June – December 2019) reported 134 medical practitioners had registered on the portal. The ratio of Medical Oncologists to General Practitioners in Victoria is roughly 1:25. Even if we presume that proportionately-speaking, twice as many Oncologists have registered for the portal as GPs, that will still make the ratio 2:25, meaning that 11 of the 134 registered medical practitioners at the time of the data cutoff for the VAD Review Board Report of Operations, June to December 2019. With a conservative estimate of 70% of cases having a solid organ malignancy (hopefully the actual breakdown of this data will be released soon), and presuming that specialists only provided Consulting Assessments (of which there were 102 in the reporting period), those 11 practitioners were required to see an average of 6.49 cases each in that six-month period, compared to the 123 registered GPs, who each would have seen an average of 1.13 cases in that same six-month period. The number of trained specialists is expected to rise, but the number of VAD applications has been far greater in this second six-month period than the first six-month period on which this report was based. The workload is outstripping the specialist workforce. Many of us have written to the VAD Board asking for more detail in the next report in the hopes that this is closely-examined; my hypothesis is that the few of us actively providing assessments are propping up the system and that it is far from robust. The benefit of a specialist being involved in the process is in ensuring that the patient meets the prognostication requirement of likely having less than six months to live. There seems to be no reason that two of the >6000 Victorian GPs, with a documented prognosis made by a specialist, would not be equally as effective at providing VAD assessments, with a far greater workforce available to provide an equitable service across the state.

The other complicating factor in the specialist requirement is the effect of the Criminal Code Amendment (Suicide Related Material Offences) Act 2005(10), which states that “A person is guilty of an offence if the person uses a carriage service to transmit material that directly or indirectly counsels or incites committing or attempting to commit suicide, and the person intends to use the material to counsel or incite committing or attempting to commit suicide”. What is crucial here is the interpretation of the terms “material” and “suicide”. The term “material” is contentious, but we have been informed that “material” could be construed as verbal information, so that to carry out a Telehealth appointment for the purposes of a VAD assessment could be seen to contravene this Amendment, which carries 1,000 penalty units (currently \$210,000). There are those of us who feel that this could be defended if charges were ever laid, but many are not inclined to accept this level of risk. Further to this, if taken to be applicable to the provision of VAD services, it would in actuality be impossible for the Statewide VAD Patient Navigators to carry out their role; no referrals or cases could be discussed over the phone, and the VAD Review Board would not be able to email forms to us to complete to circumvent some of the technical issues we have had with regards to the portal. This Amendment was and is intended to prevent counsel provided outside of due-process VAD applications, regarding suicide (which is not VAD as discussed next). It is also intended to counter cyber-bullying; to prevent keyboard warriors from telling people on online platforms to go “kill” themselves.

Those of us in favour of VAD take great offense to the synonymisation of VAD and suicide. Suicide is a choice between life and death, whereas VAD is a choice between two deaths. In support of this distinction, we often remind people that those who jumped from the burning and crumbling twin towers of the World Trade Centre on September 11, 2001, were not classified as “jumpers” by the New York City medical examiner’s office(11), and therefore did not commit suicide, even though they took action to cause their own death in an alternate way than they were facing. Our patients are no different; they are facing a death that they do not want, and it is cruel of us to force them to endure when we have a preferred alternative. Preferred *by the patient* – to me, they are the only person who gets a vote in this matter. True patient-centred care occurs when you support a patient’s choice even when you disagree with that choice. I have always been amazed that the only time we ask for competency assessments in hospitals seems to be when the patient does not agree with the recommended treatment plan – if they agree, they apparently must be competent.

The COVID-19 pandemic has affected almost every aspect of all our lives. The impact on VAD assessment provision has been far from the most-significant impact, but it is worthy of note. For Healthcare workers in general, it meant a transition to Telehealth-based consultations essentially overnight. Despite this, the Criminal Code Amendment stood strong. Those of us unwilling to accept 1,000 penalty units of risk continued to see people in our rooms and conduct home visits to make sure these people could still access their legislative right. We gently probed the VAD Review Board, Safer Care Victoria, and our Federal Members of Parliament to address this, but this is a Federal Law; its

interplay with VAD assessments affects so few of us in only one state that it was never going to make it onto the Federal radar in a time where so many other societal changes needed to occur. And gently we did probe, for fear of our work being deemed “non-essential”, and halted. We kept our heads down, begged, borrowed, and admittedly at times, stole surgical masks in order to minimise risks to the patient, their family, ourselves, our family, and those of our own patients whom we had to see face-to-face during the height of the pandemic, and we continued to provide what we feel is essential care. At times, we had to choose between maintaining social distancing, and complying with the Amendment. I violated social distancing many times during my VAD-work over the last few months. If anyone knows how you can possibly sit with a grieving woman as she loses the love of her life and becomes a widow without holding her hand, or how you can refuse a hug to say thank you after spending hours at their home, sitting with the patient and their family as they farewelled their mother, I am all ears. Call me old-fashioned, but an elbow-bump or foot tap in place just does not send the same message.

The legislation is not perfect. To expect perfection in an area where there is so little experience in the Australian setting as we have would be unfair and unrealistic. A quote from Voltaire seems apt: “*Il meglio è l'inimico del bene*” (Perfection (or “the best”) is the enemy of the good). The Victorian Legislative Council, implementation committee, and VAD Review Board have done, and continue to do marvellous work, and we have been able to do good through this legislation. Recommendations for legislative review and modification will undoubtedly be attacked with slippery slope arguments; I learned at University that slippery slope arguments were one of the cornerstones of a fallacious argument and I’m still not sure why they’re not dismissed on sight.

My recommendations are not centred on broadening eligibility criteria as some would expect. What is demanded to substantiate the eligibility criteria, however, can often be an illogical barrier – a person living in Melbourne for 50 years who never took out citizenship or permanent residency is not eligible, for example. A person who was born in Victoria, who doesn’t have a passport, who hasn’t needed a birth certificate for many years will need to apply to the Department of Births, Deaths, and Marriages for a new birth certificate, which will take two weeks. By then, the first assessment will be more than seven days old and will be invalid and need to be repeated. Another example is how there can be inadvertent discrimination against female patients; on top of the other documents they often need to also supply a marriage certificate if their birth certificate and drivers’ license bear different surnames.

These are not reasonable delays for ensuring compliance with legislation; these are needless obstructions. For water to find its level, it must be permitted to move. The legislation must be permitted to review and adapt around unintended outcomes, such as the seven-day limit to upload an assessment – this was intended to prevent doctors from dragging their feet and delaying the process by not uploading their report. There have been times were IT issues, or sourcing substantiating documentation has taken longer than seven days, such as in the example above, and this rule then introduces delays by stipulating that the assessment needs to be repeated. It is infinitely unlikely that their eligibility status will have changed from eligible to ineligible in that seven days.

Not all recommendations I have are to improve access. There is one area I feel an extra safeguard would be worthwhile considering. Currently, the Coordinating Medical Practitioner refers directly to the Consulting Medical Practitioner. Presumably, these two have a prior relationship. Perhaps they feel the same way about more liberal access to VAD for the general population. Perhaps the Consulting Medical Practitioner relies on referrals from the Coordinating Practitioner and feels pressure if they disagree with the patient’s eligibility. This does not feel as robust as it should for such an important process. There should be centralised, blinded allocation of consulting medical practitioners so that these assessments are truly independent and inscrutable. Such a mechanism already exists in The Netherlands – SCEN (Support and Consultation in Euthanasia in the Netherlands)(12), and a corollary must be considered in Victoria.

In summary, providing VAD assessments has been a truly rewarding experience, peppered with bureaucratic frustrations and the occasional difference of opinion. There are aspects that are working, aspects to improve, and aspects for other states to learn from. But learning relies on the interpretation of data. The scientific method requires us to measure our outcomes and modify our approach to problems to improve systems. We need to collect data, the VAD Review Board needs to release their data, and we need to analyse all data with transparency. To end this article in the style of many great researchers would, “more data is needed”.

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