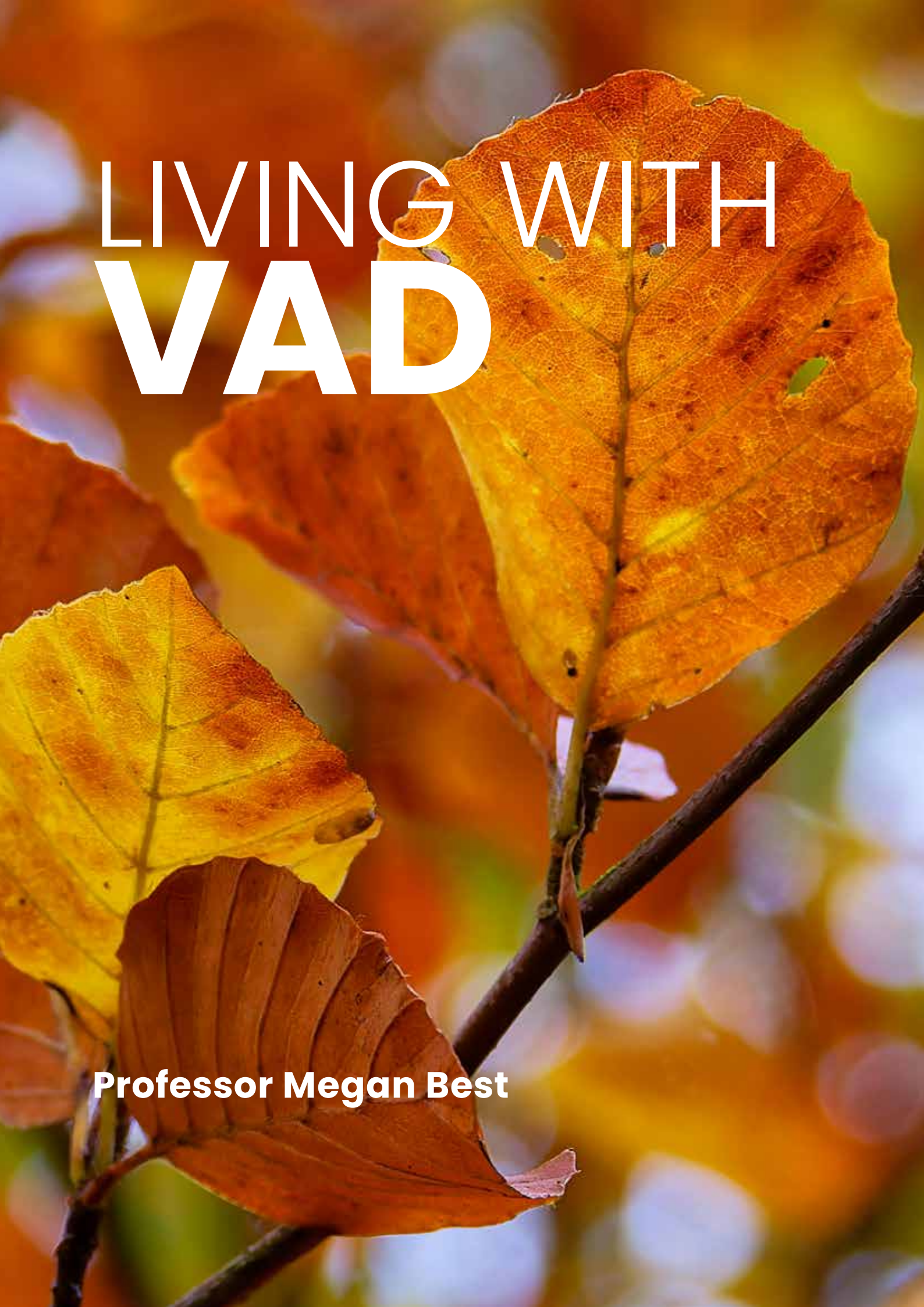




LIVING WITH **VAD**

Professor Megan Best



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Living with VAD

Legalisation of voluntary assisted dying (VAD) in Australia has radically changed the healthcare environment. It has overturned therapeutic norms to the extent that those who are providing what has until now been known as 'best practice' at the end of life are now criticised for being uncompassionate or negligent if they refuse to kill their patients. VAD legislation creates ambiguous care environments which alters the focus of institutions and erodes trust in relationships between healthcare workers and their patients.

For example, a recent article from a Sydney newspaper reported that the NSW state government was proposing to review the impact of all new legislation on suicide rates in light of a growing mental health crisis.¹ The need to consider the influence of policy in housing, health and education was identified, with no mention of the elephant in the room – legal physician assisted suicide, which promotes the idea that death is an acceptable solution for distress and which we know increases non-assisted suicide rates in the jurisdictions where it is legal.²

How can we, as Christians, navigate our way through the new healthcare environment?

In considering this topic, I first want to acknowledge that in order to make a decision that death is preferable to life, one has to experience significant distress. I don't want to minimise the suffering of patients at the end of life. However I firmly believe that it is wrong to 'relieve' suffering by killing the sufferer.

In this paper, the following points will be considered:

- Background to VAD legislation
- Summary of Australian VAD legislation
- Biblical perspectives
- The role of the Christian healthcare worker
- Moral complicity and conscientious objection
- Moral distress
- Going forward

Background to VAD Legislation

For over 2000 years euthanasia - the situation where a doctor kills a patient through administration of a poison - has been a prohibited medical practice. The Hippocratic Oath is an oath of ethics historically taken by physicians. It was originally written in Greece between the fifth and third centuries BC and by the fourth century AD it had become standard for the medical profession. It includes this statement: "Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course".³

I am reminded of a woman who asked me whether a sterile needle was used when euthanasia was performed. The question so perfectly encapsulated how antithetical euthanasia is to the way medicine is traditionally practised. We would normally never dream of not sterilising the needle in medical interventions, but if the patient will soon be dead, it really doesn't matter.

Euthanasia and physician assisted dying are not legitimate healthcare practices according to the World Medical Association (WMA), regardless of what our government legislates. The WMA is firmly opposed to euthanasia and physician-assisted suicide. In its *Declaration on euthanasia and physician-assisted suicide* (2019), it states that "No physician should be forced to participate in euthanasia or assisted suicide, nor should any physician be obliged to make referral decisions to this end."⁴ It recognises euthanasia as a violation of traditional medical ethics.

So how did we get to where we are now, where euthanasia and physician-assisted suicide are listed by our government as standard medical interventions for patients at the end of life? And why are healthcare workers expected to provide it? This is not the case in Switzerland, for example - incorporation of euthanasia into standard medical practice was not inevitable. How has the modern euthanasia practice developed?

After World War II, discussion of euthanasia was, understandably, avoided for some time due to the appalling atrocities of Nazi Germany. Modern discussion of mercy killing began in the Netherlands in 1969 with publication of a book by Dutch psychiatrist JH van den Berg, *Medical Power and Medical Ethics* (*Medische Macht en Medische Ethiek*). His thesis was that doctors caused so much suffering through overtreatment that they had a responsibility to not only forgo treatment but to undo the pain and suffering they had caused by killing the patient. He wrote: "If doctors have caused so much suffering, they must have the courage to kill a patient that would otherwise have died".⁵

The environment of overtreatment and the medicalisation of death that was prominent in western countries at the time led to public criticism of end of life care and calls began for legal euthanasia, to allow individuals to escape the 'living death' of technically-assisted existence. This was accompanied over the next decade by high profile court cases discussing whether comatose patients could ever be allowed to die through cessation of medical care. In the USA, the cases of Karen Ann Quinlan in 1975 and Nancy Cruzan in 1983 raised the issues of the right to remove a ventilator or feeding tube from a patient with no prospect of recovery, and in the UK in 1993, Tony Bland was the focus of a discussion regarding whether withdrawal of life-prolonging treatment including food and water could ever be justified. While these cases were each complex in their own ways, they represent the failure of modern medicine to ask not only, 'How can we prolong life?', but whether we should. And, as concern for death with dignity followed a pattern of neglect of the needs of the dying, it also illustrates how the phrase 'dying with dignity' came to be associated with the push for legalised euthanasia.⁶

Indeed, euphemisms abound in discussions of euthanasia and physician-assisted suicide (EPAS). It is important to be aware that the terms we use impact our moral evaluation of the practices in view. Australian legislation uses the terminology of 'practitioner-administered' VAD and 'self-administered' VAD to distinguish 'euthanasia' and 'physician-assisted suicide'. Canada, and more recently the US, use 'Medical Aid in Dying (MAiD)', while 'dying with dignity' seems to be the preference in the UK. The actual practices they describe are euthanasia and physician-assisted suicide. The terminology of VAD aims to distance the practices involved from the ideas of killing and suicide. However killing and suicide are the most accurate descriptions of what is happening.

However, according to Australian law, a person who dies by VAD does not die by suicide. This definition was created to artificially distinguish VAD from traditional suicide to allow families to access life insurance policies after the death, and to stop police from intervening. Then the idea was taken up literally by the pro-euthanasia lobby to make the process more palatable to the general public. From a logical perspective, however, there is no basis for denying that VAD incorporates suicide. The Australian Federal Court agreed and ruled in November 2023 that "suicide, as used in the criminal code, applied to ending a person's life under state voluntary assisted dying laws... even if those actions had been authorised under state legislation".⁷ VAD is a legal term only. We need to keep using the terms that most accurately describe what is happening. I recently listened to a talk by Dr Theo Boer, a Dutch doctor who has been involved with the administration of euthanasia in The Netherlands, and it was sobering but somehow refreshing to hear him define euthanasia as "doctors killing patients".

Legalisation of EPAS was the result of social change in Australia. With the rise of individual autonomy, there was an increase of the consumer voice and focus on informed consent in healthcare. While this was a positive step in some ways (reducing paternalism), the focus on patient-centred care has also led to elevation of patient autonomy as the most important ethical value in healthcare decision-making, trumping all other values, so that promoting patient choice is seen as the highest ethical good. At the same time, improvements in modern medicine have led to longer lives, which can also mean living longer with disability and degeneration, and possible prolongation of the dying process.

The medicalisation of death has also meant that it is now separated from being a regular part of home life, with most people now dying in hospital. This contributes to the fear of death which has continued to rise in the community. With the fall in religious affiliation, through which one may be able to cope with existential fears at the end of life, it may have been inevitable that high public support for 'right to die' legislation would lead to the passing of laws allowing euthanasia.

No-one talks about it much, but another motivation for passing EPAS laws is that they can save governments a lot of money. Canada has shown that, despite the high costs of implementing VAD, money can still be saved. A 2017 report estimated that the implementation of MAiD would save the Canadian healthcare system up to \$136.8 million per year in 2017, with profits now increased due to expansion of their eligibility criteria to those without terminal illness.⁸ Cancer patients in Canada and America have reported being offered assisted dying instead of (expensive) treatment, or seeking assisted dying when the government failed to provide adequate social support.⁹

Summary of Australian VAD legislation

In Australia legislation concerning end-of-life issues is dealt with on a state basis. The first voluntary euthanasia bill introduced into any Australian parliament was an ACT bill in 1993. It was deemed 'politically inopportune' and didn't pass. Nevertheless, widespread community support for the idea has existed since the 1970s, particularly in Victoria.

The Voluntary Euthanasia Society of Victoria (now Dying with Dignity Victoria) was founded in 1974. In 1985, Victoria was the first parliament to raise the issue, when it appointed a parliamentary committee to look into the 'right to die'. In 1988, Victoria passed the Medical Treatment Act, enshrining a patient's right to refuse medical treatment. In 1991, philosophers Helga Kuhse and Peter Singer surveyed Victorian nurses on their attitudes towards voluntary euthanasia for terminally ill patients. More than 75% of respondents thought it would be good if Australia followed the lead of the Netherlands in effectively decriminalising voluntary euthanasia under certain conditions. And 65% indicated they were willing to be involved in the provision of voluntary euthanasia if it were legal. This study was widely advertised. I remember reading about it on the front page of a newspaper at the time.

In 1995, the world's first euthanasia legislation, the Rights of the Terminally Ill Act, was passed in the Northern Territory, with Dr Philip Nitschke assisting four people to end their lives before it was overturned by the Howard Government's Euthanasia Laws Act in 1997. It took another two decades – and almost 60 failed Bills around the country – before Victoria passed its Voluntary Assisted Dying Act on 29 November 2017.

The failure of so many Australian bills was largely a result of parliamentarians' view that it was impossible to safely legislate for euthanasia. In particular, reports of the abuses in the Netherlands and Belgium led to the rejection of legislation. In the face of the overwhelming evidence of abuse in these low countries, local Australian protagonists announced that rather than focusing on euthanasia legislation, they were modelling Australian legislation on that of Oregon, USA, where physician assisted suicide (PAS), but not euthanasia, had been legalised. The claim was that PAS had been practised safely for decades with no evidence of abuse. Whilst this is technically correct, the reason that there is no government record of abuse, was because the Oregon government doesn't keep any significant records for its physician-assisted suicide program.

Oregon politicians have publicly admitted that they cannot be sure what is happening on the ground, as they rely on doctors self-reporting and no

enforcement provisions exist to see what is actually done. Non-governmental research has found, however, that the seemingly reasonable safeguards for the care and protection of terminally ill patients are being circumvented and suggest that the official data collection is used as a defender of the law rather than a protector of the welfare of terminally ill patients. In fact, evidence suggests that there have been unintended, harmful consequences for patients. These include the death of patients who are not mentally competent and who are not terminally ill.³⁰

When concerns about the adverse consequences of permitting physician-assisted suicide were raised, its advocates tended to dismiss them as unfounded and speculative, since they were not reported. Dangers remain, nonetheless, and we know that there are also problems in Australia. However, as we are modelling our legislation on Oregon's, our government reports are brief and uninformative. Furthermore, our legislation is not completely based on the Oregon model, as we have legal euthanasia as well as physician-assisted suicide. Nonetheless, the parliamentarians were appeased and, in the face of polls suggesting that 85% of the population were in favour, the legislation was passed.

While there are similarities across laws in Australian states, there are also significant differences. When the Victorian legislation was passed, Premier Daniel Andrews described the laws as the most conservative euthanasia regime in the world, with the greatest number of safeguards. However, the 'safeguards' have been viewed by proponents of VAD as barriers to access, so that, over time, as each state considered euthanasia, the laws became less stringent. I think the variations between states also shows how uncertain the legislators are about what is needed to safeguard euthanasia (Table 1).

In all states, to be eligible to access VAD, a person must meet a range of criteria including variations on the following:

- they must be a mentally competent adult, who acts freely and without coercion;
- they must be an Australian resident or permanent resident who has lived in their state for at least 12 months (although some exemptions are possible);
- they must have a disease, illness or medical condition which will cause death within 6-12 months in all states except the Australian Capital Territory (ACT), where no timeline is needed;
- their condition is advanced and is causing intolerable suffering with no treatment *acceptable* to the person. (Note the last condition – it is not that no treatment is *available* to the patient, just that they would *prefer* VAD).

To access VAD, a person must undergo a request and assessment process that includes making (at least) three separate requests for VAD, and eligibility assessments by (at least) two independent medical practitioners. In the table below you can see variation between states, as laws became more liberal over time.

Table 1: VAD law in Australia

VAD Law in Australia				
Jurisdiction	Implemented	Prognosis ¹	Suggest?? ²	IV a choice? ³
Victoria	2019	6-12 months	No	No
WA	2021	6-12 months	Drs and Nurse practitioners	Yes
Tas	2022	6-12 months	All health practitioners	Effectively yes
SA	31/1/2023	6-12 months	No	No
Qld	1/1/2023	12 months	Drs and nurse practitioners	No
NSW	28/11/2023	6-12 months	All healthcare workers and carers	Yes
ACT	3/11/2025	-	All healthcare workers	Yes

¹Time within which death is expected, can vary depending on diagnosis;

² Can healthcare staff raise the subject of VAD with the patient;

³ Can the patient choose between oral and IV administration.

You can see the changes advancing over time:

1. Although the patient's prognosis was initially set as "death expected within the next six months" for patients other than those with neuro-degenerative disease, this was then pushed to twelve months in Queensland. Most recently, the ACT has passed laws where no prognosis is required – the law merely requires that the person is diagnosed with advanced progressive disease that is expected to cause death, but says that a patient may be approaching the end of their life even if death is not expected to result within the next twelve months.
2. Whilst the earlier Victorian legislation does not allow a healthcare practitioner (HCP) to suggest VAD, this changed with Western Australian laws and has persisted in subsequent legislation. In the first year of operation, 124 people died in Victoria under the VAD laws. With HCPs suggesting VAD, 190 people died in the first year in WA – despite a smaller population. In the first 12 months of VAD in NSW, 398 people died using the legislation, with 517 first requests and 373 first assessments in that time. There is increased patient take-up of VAD when it is suggested by a HCP. This is not surprising since most patients consider a doctor's suggestions to be prescriptive.
3. Intravenous (IV) euthanasia was initially only allowed for patients who could not physically take oral medication. Once again, this was seen to be discriminatory, so this also has moved to being a choice for the patient. We know from the experience overseas that, when given a choice, IV administration (euthanasia) is more popular than oral (assisted suicide). The IV choice for NSW patients is approximately 70%, so having an unrestricted intravenous option has also contributed to increased uptake. The reason for this preference has not been well studied, but is probably related to IV medication more reliably causing death than oral, which can fail due to vomiting after ingestion, etc.. It should be noted that intravenous administration gives a false legitimacy to the act in that it makes it seem more like it is a type of medical care. It is also easier to have a doctor inject poison than to kill yourself.

Due to the variations between states, I recommend that all HCPs in Australia download and read the legislation for their own jurisdiction. (Table 2).

Table 2: Australian VAD laws

All healthcare workers are encouraged to download and read the relevant VAD legislation for the jurisdictions in which they work.

Victoria: Voluntary Assisted Dying Act 2017

https://content.legislation.vic.gov.au/sites/default/files/8caaf3b4-28f6-3ad1-acf3-e3c46177594e_17-61aa003%20authorised.pdf

Western Australia: Voluntary Assisted Dying Act 2019

https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc_42491.pdf/%24FILE/Voluntary%20Assisted%20Dying%20Act%202019%20-%20%5B00-00-00%5D.pdf?OpenElement

Tasmania: End-of-Life Choices (Voluntary Assisted Dying) Act 2021

<https://www.legislation.tas.gov.au/view/html/asmade/act-2021-001>

South Australia: Voluntary Assisted Dying Act 2021

https://www.legislation.sa.gov.au/__legislation/lz/c/a/voluntary%20assisted%20dying%20act%202021/current/2021.29.auth.pdf

Queensland: Voluntary Assisted Dying Act 2021

<https://www.legislation.qld.gov.au/view/pdf/asmade/act-2021-017>

NSW: Voluntary Assisted Dying Act 2022

<https://legislation.nsw.gov.au/view/html/inforce/current/act-2022-017>

ACT: Voluntary Assisted Dying Act 2024

<https://www.legislation.act.gov.au/a/2024-24/>

When you read the legislation it can sound like there are a lot of safeguards; however, it is primarily a lot of process. Some of the problems with our laws include the following (note these do not apply to all states):

1. HCPs can suggest that patients should consider accessing VAD.
2. The legislation assumes a VAD patient's decision-making capacity is intact unless otherwise shown, despite the target population for VAD being at high risk of cognitive decline.
3. Doctors who discuss VAD with patients and assess eligibility are not required to have training in areas where they are obliged to give information or make assessments, e.g., prognosis for the patient's disease and palliative care options.

4. No psychiatric assessment is required to determine a VAD patient's mental competency at the time of their decision.
5. There is no requirement for a mandatory palliative care referral to allow patients to fully explore options despite research showing this reduces desire for hastened death.
6. Mental illness is not a disqualifying factor for a person deciding to end their life via VAD. This lack of safeguarding is particularly concerning since research correlates depression with suicidal ideation. Prevalence of depression in cancer patients has been measured as high as 45%.
7. Prognosis is notoriously difficult to predict accurately, and errors in diagnosis have occurred in the past. Most checks and balances occur after the patient's death.
8. Falsification of medical certificates where VAD is not mentioned as cause of death.
9. Removal of conscientious objection in some jurisdictions.

In addition, pressure is rising to persuade the federal government to allow telehealth for VAD patients' eligibility assessments, a medium which is known to reduce the accuracy of clinical assessment.¹⁰ It also reduces the chance that something like coercion will be picked up. Since the federal court has ruled that physician assisted suicide is indeed suicide (see above), this has been delayed for the moment. It seems unimaginable that a decision to end one's life can be made remotely by a doctor you may not know personally.

Another problem is the lack of doctors willing to do the deed. The ACT parliament addressed this by allowing nurses to assess eligibility and administer drugs as well as doctors. Canada has addressed this problem in a different way. In 2019, they passed a ruling that physicians can be forced to facilitate procedures they find morally objectionable, including euthanasia and assisted suicide, by connecting patients with willing providers ("effective referral").

Perhaps the saddest problem of all is that legalisation of euthanasia has moved the focus away from aiming to provide excellent end of life care in Australia, with healthcare funding being moved out of palliative care to finance VAD programs across the country. Premiers of at least two states have publicly stated that they cannot afford to provide palliative care to all patients at the end of life, yet VAD programs continue to be generously supported. For example, the New South Wales Labor Government slashed \$150 million from palliative care funding in the 2023-24 State budget while putting \$97 million into implementation and operation of VAD. Indeed, legalisation of VAD has taken governments off the hook regarding the need to provide good end of life care for all!

Biblical Perspectives

In view of this changing landscape, how should Christians think about VAD?¹¹

The message of the gospel is a message of freedom from the fear of death. All human beings face death, and is something that is fundamentally out of our control (Deut. 32:39). Death reminds us that we are creatures, utterly dependent upon our creator.

Yet for human beings, death is not merely humbling but also threatening and fearful, because we face it not merely as finite creatures, but as sinners. Paul tells us that, "The sting of death is sin" (1 Cor. 15:56). We face death, therefore, as those who have failed to live as we were made to, and so stand condemned and under the wrath of God.

However, as we are told in Hebrews 2:14-15, the Lord Jesus Christ, the Son of God, shared our human nature and condition, "so that by His death he might break the power of him who holds the power of death and free those who all their lives were held in slavery by the fear of death." Christ's conquest of death brings the freedom to face death without fear (Rev 1: 17-18), to submit to it and to face it with confidence and hope as a final trial through which we must pass, beyond which lies glory. It allows us to accept, and even to welcome death when it comes (Phil 1:23) because of where it leads us – to be with Christ - in hope of the day when death will be "swallowed up in victory" through resurrection (1 Cor. 15:54).

Christian thinking about suicide should begin from this understanding of life and death, the fear of death, and the gospel's promise of freedom and life in Christ.

To the despair of suicide, the gospel speaks a word of hope. It says that in Christ there is forgiveness and power, a path to walk in faithfulness through darkness, a community to walk with, and the promise of a future of unimaginable joy and glory where God will wipe every tear away (Rev 21:4). It urges perseverance, even in the face of great dismay and confusion, and assures us that however terrible our sufferings may be now – and they are often very terrible – they are not worth comparing with the glory about to be revealed (Rom 8:18).

In suicide there is also, however, an element of defiance. This defiance can itself be complex. There is something deeply understandable in the desire to refuse to let one's life be defined by mental anguish, deteriorating bodily function, or physical pain. This defiance can reflect a strange affirmation of what is good and of the gift of life. Yet there is also an element of pride in such defiance, for

fundamentally it represents a refusal to accept our condition as creatures and God's right as Creator to give and to take life. It represents a loss of faith in God's grace as Redeemer to sustain perseverance and hope in the face of suffering and despair through the promise of life in Christ Jesus.

For this reason, suicide should be clearly named as a sin. The wrongfulness of suicide is marked out in the law by the sixth commandment, "You shall not murder" (Ex. 20:13). *"This commandment is perhaps best understood as stating that no human being may take a human life without divine approval...By including this prohibition against the taking of human life...YHWH underscores the idea that no human has the authority to destroy the life of another."*¹² It recognises that the deliberate taking of human life is a special boundary that must be carefully safeguarded because human beings are created in God's image (Gen 1:26; 9:6).

Stories of suicides and assisted suicides in the Bible therefore all reflect a clear sense of shame and failure. A biblical example that supports the prohibition of euthanasia is the story of the death of King Saul in Second Samuel chapter 1: David had just become king after the death of Saul. A few days later an Amalekite man came to David and claimed that he had found Saul gravely wounded on the battlefield, and that Saul had begged the man to kill him, so that he would not fall into the hands of his enemies. The man had done so. David's response is to call for the execution of the Amalekite man, on grounds of having killed the Lord's anointed. This story, as well as the sixth commandment, teaches us that it is morally wrong to actively take the life of a terminally ill person who is suffering and asks to be put to death. It is a form of murder.

To insist that suicide is wrong is, of course, much less than what is needed as a pastoral response to a request for VAD. But we need to remember this teaching as it is all too easy to be seduced by the world's arguments for mercy killing in our current work environments.

The Role of the Christian Healthcare Worker

What is the role of a Christian HCP when a patient expresses a desire for hastened death? I am going to use the NSW legislation as my template for this part of the article, but the principles apply to all states.

As shown in Table 2, each state/territory has different laws for EPAS. Implementation of each state's legislation has been overseen by the relevant state/territory health department. A summary of each state's legislation and links to the state implementation guidelines can be found here: <https://end-of-life.qut.edu.au/assisteddying>. Note this website is provided by a pro-VAD organisation.

Is a healthcare worker required to raise the option of legal VAD for their patients? This is obviously not the case in Victoria and South Australia at the time of writing. However, I have been told by practitioners in other states that they have been instructed by administrators to mention VAD as an option whenever they discuss end of life care with their patients. Note that the guidelines offered by health departments are not legal documents, although their instructions need to be interpreted alongside the legislation.

According to the NSW legislation, there is no requirement or duty on a medical practitioner to discuss VAD with patients. However the law provides an exception where a medical practitioner *wants* to initiate such a discussion. If so, they must also provide information listed in the guidelines: essentially these are the patient's treatment options, including palliative care.

What if the patient raises the topic?

First, we need to be clear on what it means to raise the topic. NSW Health has suggested that the following statements constitute a first request for VAD:

"Can you help me end my life?"

"I want you to help me to die"

"How can I get medication to end my life?"

"Can I access euthanasia?"¹³

The medical literature does not support this interpretation.

Desire for hastened death is common in patients at the end of life. Consider a study done by palliative care doctors in Victoria after VAD was introduced.¹⁴ They included 41 patients who expressed a desire to die within palliative care consultations, which was 4% of the local palliative care population at that time. In

this study, a desire to die statement was defined as a request made by the patient for their death to be hastened, a formal VAD request, a verbalised wish for their life to be over, or an expression that it would be preferable to be dead than alive.

The investigators found that desire to die statements were prompted by psychological problems more commonly than physical problems (73% v 46%), yet physical problems were addressed more often by staff. Only 7 of 41 patients commenced the VAD process, and of them, only two died by VAD. These results show very clearly that a desire to die statement is not necessarily synonymous with a request for VAD. The issue is more complex than NSW Health advice suggests.

Research has found that desire to die statements were often interpreted as requests for euthanasia when they were really a cry for help.³¹ It has also shown that desire for hastened death fluctuates over time.³² So the first challenge for us is to understand *what the patient is trying to communicate* when they make a desire to die statement, to explore and understand the triggers and meaning behind it. This includes determining whether such an expression is a true wish to hasten death, an expression of suffering, an acceptance of impending death or a combination of these. It is particularly important to realise that existential distress and spiritual suffering are common in this setting, but often neglected.

In a systematic review examining a total of 255 patients with a desire for hastened death,¹⁵ reasons for wanting a hastened death included: physical factors (e.g. loss of function with resultant loss of dignity and being a burden on others); psychological/emotional factors (e.g. fear of the dying process, and hopelessness associated with inevitability of progressive disease); social factors (e.g. being a burden, being dependent and causing others to suffer); and loss of self (e.g. loss of identity and dignity, loss of control). On further examination of these requests, the underlying meanings were found to be more nuanced - a cry for help, a desire to end suffering, a desire to avoid being a burden on others, a desire to preserve self-determination until the end and a will to live, but not 'like this'.

Importantly, the expression may be a means to communicate needs, feelings and wishes, or a form of control and preservation of personal agency. It may not necessarily represent a desire to die. Studies across cultures have found that existential and psychological concerns tend to be similar.¹⁶

In Australia, with the legalisation of VAD, many patients making desire to die statements are automatically referred to VAD navigators, particularly by junior doctors, without the meaning of the statements being explored. This is a lost opportunity to explore and respond to patient distress and suffering.

Spiritual Suffering

What we are seeing here is the importance of spiritual suffering at the end of life. In my review of over 6,000 papers about suffering in the medical literature, I found many synonyms for spiritual suffering (see Figure 1).¹⁷ You may be aware of others.

Figure 1: Synonyms for spiritual suffering



Diagnosis of a life-limiting illness is known to trigger existential questions, such as 'Why is this happening to me?', 'What do I believe in?', 'Will I be missed?' Such questions require the person to seek meaning in their experiences, to incorporate what they are experiencing into their life story. If the individual does not have the spiritual resources to answer these questions, spiritual suffering may result. Any threat or perceived threat to the self may result in spiritual suffering, often expressed as a disconnection with the person one once was.

Spiritual suffering has been defined as 'an all-encompassing, dynamic, individual phenomenon characterised by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer which is difficult for them to articulate. It is multi-dimensional and usually incorporates an undesirable, negative quality.'¹⁸ This definition is teased out in the cited reference.

Terminally ill patients themselves identify needs related to meaning, spirituality and hope as among the most important aspects of end-of-life care.¹⁹ One cohort of 340 seriously ill patients listed being at peace with God as important as freedom from pain to maintain quality of life at the end of life.²⁰ However, we have plenty of evidence that this kind of care is lacking in our healthcare system.

Spiritual distress develops from an experience of real, perceived or impending loss. Readers of this booklet will know that with terminal illness, the losses can be multiple, and can be experienced in every human dimension, as seen in Table 3 – I'm sure you can think of more.

Table 3: Loss at the end of life



LOSS AT THE END OF LIFE

- **Illness related** – loss of health, body parts, or attractiveness, loss of energy, sexuality, or function
- **Social and financial losses** – financial loss due to inability to maintain one's profession due to sickness or retirement, loss of your home as you move into care, loss of your pets when you can no longer care for them
- **Relational losses** – social isolation due to sickness and hospitalisation, perhaps isolating yourself due to depression, or embarrassment about your appearance
- **Loss of roles and responsibilities** in the family, in the workplace
- **Personal losses** – loss of control over your situation, loss of autonomy, fear of being a burden, loss of dignity
- **Existential losses** – meaning, purpose and hope. Loss of personhood, loss of identity – I am no longer who I was, I don't like what I will be in the future
- **Loss of the future**, with its dreams and aspirations.

Best et al. Conceptual analysis of suffering. 2015.

Many readers may be familiar with Maslow's hierarchy of human needs. According to Maslow, humans always focus on fulfilling their basic needs first. So, in order for a person to fulfil spiritual needs, which are at the top of the pyramid, all needs on the tiers below must be met first (See Figure 2). I use this diagram to reinforce the idea that if someone has significant physical needs, it will be difficult for them to focus on spiritual issues. Therefore, in the most common situations, it is important to ensure that physical care is done well, as a priority. This may require a referral to palliative care.

Figure 2: Maslow's Hierarchy of Needs



But there are limitations to Maslow's depiction of human experience. We know that all dimensions of humans interact with one another, and that sometimes it is not possible to control the problems of the lower tiers, such as pain, without addressing the higher tiers. This is because all dimensions of the human influence each other. Cicely Saunders, founder of the modern hospice movement, coined the term "total pain" to capture the notion that suffering is not only influenced by many factors in the life of the individual, but also that each dimension influences the others, and that all must be addressed for care to be successful.

Figure 3: Whole Person Care



Studies of spiritual well-being have found that subjects with high levels of spiritual well-being will report high life enjoyment even in the presence of high levels of symptoms. This is enormously important to know when you are caring for people at the end of life.²¹

Influence of HCP Perspectives

But it is not only patient factors that are significant in the situation where a patient is experiencing existential need. The importance of the therapeutic relationship cannot be underestimated with regards to how it influences a patient's fear of death and sense of suffering. Professor Brian Kelly, an Australian psychiatrist, conducted a study of 256 terminally ill patients and their doctors to examine how clinician factors influenced a person's desire to die.²² What the study found was that it was not only patients' problems that prompted the desire to die. Importantly, clinician factors also influenced desire to die - namely, the patient's sense of the doctor's perception of them. Lower levels of optimism, and doctors with less training in psychological and palliative care, led to increased desire to die. Conversely, desire to die diminished when patients were in the care of clinicians with psychological and palliative training. In other words, the therapeutic relationship has the power to infer values. Our expertise makes a difference. This is consistent with data that shows that high quality palliative care reduces desire for hastened death.²³

It's obvious that the first step in dealing with desire to die statements is to equip yourself. Personally I think the initial response to a desire to die statement should be, "What's wrong?" Increase your skills and knowledge around how to support and assist those who are truly suffering or feeling their life is a burden through accompaniment, support, symptom management, the fostering of hope, meaning, and a sense of dignity. Be prepared for how to manage requests for hastened death and the factors involved. Seek assistance from colleagues and specialist colleagues. Refer to colleagues if needed.

Canadian psychiatrist Harvey Chochinov's group has developed guidelines to help HCPs respond to desire to die statements,²⁴ but reading the paper in full is recommended. The paper from which these are taken has restricted access, so a summary of recommendations is given here. See Table 4 on the following page.

Table 4: Responding to desire to die statements from patients with advanced disease: recommendations for health professionals²⁴

It is not uncommon for patients with advanced incurable disease to express a desire to hasten their death. Health professionals often have difficulty responding to such statements, and find it challenging to ascertain why these statements are made. Health professionals may struggle to determine whether a 'desire to die' statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally

as a death wish. Recommendations are given here for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature.

Be alert to your own responses

- Be aware that your response can shape the communication; e.g. if you convey impatience or your own feelings of futility, this may have a negative effect on the patient, or it may limit the conversation to follow.
 - Show regard for the person by your verbal and non-verbal behaviour.
-

Be open to hearing concerns

- Ask questions that gently probe emotional concerns.
 - Be alert to verbal and non-verbal signs of psychological distress.
 - Encourage the person, by sensitive prompting where necessary, to express their feelings.
 - Listen actively without interrupting; seek clarification of feelings and concerns.
 - Acknowledge the feeling/s being expressed without needing to actively support the desire to die. Try to match the words you use with the level of emotion the person is experiencing.
 - Use silence appropriately; do not rush to fill gaps in the conversation.
 - Sit quietly through tears.
 - Express empathy, both by your verbal and non-verbal responses.
 - Acknowledge there are individual differences in patients' emotional responses to the impact of life-threatening illness.
-

Assess the potential contributing factors

- For example, check whether the person has appropriate social support; what type and level of assistance may be required?
- Assess for psychological distress (e.g. depression/anxiety) and/or existential distress.
- Assess for delirium, cognitive change and competence.
- Assess the level of understanding regarding goals of care and treatment options.
- Assess for unrelieved physical symptoms – consider referral to palliative care.
- Assess for interpersonal factors (e.g. family conflict, conflict with clinical staff).

Respond to specific issue/s

- Address potentially reversible causes and develop a plan of management.
- Commence planning strategies (e.g. referral, another meeting) for issues that cannot readily be resolved.

Conclude the discussion

- Summarise the main points of discussion; checking your perceptions with the patient's perceptions.
- Ask if there is anything else the patient wants to discuss or if they have any other questions to raise.
- Offer assistance to discuss the patient's situation with others, e.g. in a family meeting
- Indicate your availability for contact to address any questions or concerns and arrange for further appointment to review the situation.
- Explain that it is important for you to let the other members of the treatment team know about this discussion and reassure them that it will be treated in the strictest confidence within the team.

After the discussion

- Document discussion in medical records
- Advise other members of the treatment team, so they can also support the patient.

Full paper is available here:

<https://journals.sagepub.com/doi/10.1177/0269216306071814>

The NSW VAD Guidelines also have information on how to respond to patients and how to determine if a patient is making a genuine request. In particular, it is made clear that in order to be a 'first request', i.e. the question which starts the official process of VAD, the patient must ask the medical practitioner a question that is:

- Clear and unambiguous
- Made during a medical consultation
- Made in person or via telehealth if a face-to-face consultation is not practicable, and
- Made by the person seeking access to voluntary assisted dying.

"A first request can be made using any method of communication the person uses, such as spoken language, sign language or alternative communication, or with the assistance of an interpreter."

Note that in the NSW legislation (as opposed to the guidelines) the person's request for access to voluntary assisted dying must be enduring (16(1)(h)). Therefore, a single enquiry should not be considered to be a formal first request which triggers the VAD process. This is an illustration of the benefit of reading the actual legislation as well as guidelines offered by your state health department.

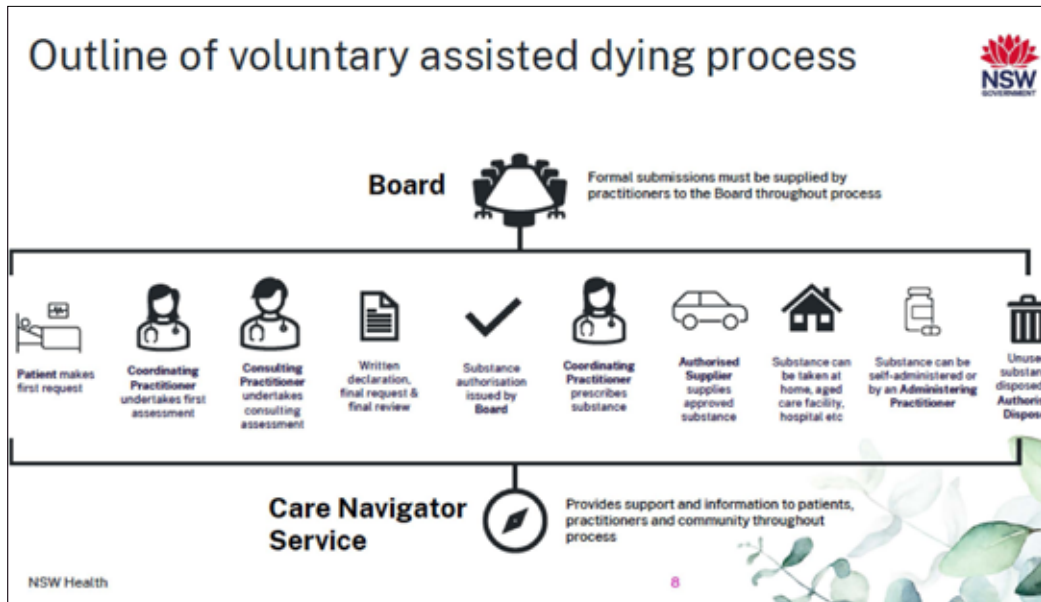
According to the NSW VAD Guidelines, it is NOT a first request if:

- A request is made to someone other than a medical practitioner or outside of a medical consultation.
- A request is made by someone on behalf of someone else (for example family members asking about VAD for their relative).
- A person is asking general questions or expressing interest in VAD or seeking further information but not specifically requesting access to it themselves.
- A request is in an advance care directive.
- The patient is obviously ineligible for VAD.

The guidelines distinguish between someone making a request for access, and simply seeking further information about voluntary assisted dying.

What if the patient's question does constitute a formal first request for information about VAD?

The situation depends on the state, so refer to your state/territory guidelines. This is the process in NSW. There are many steps in the VAD process, but I will be focusing on the first one.



At the time the bill was debated, the government stressed that they protected individual doctors, so they were not required to participate in the VAD process if they had a conscientious objection. Nevertheless, according to the NSW legislation, if you refuse to be involved (whether you term it 'bad medicine' or 'conscientious objection') there are still steps you are legally required to take. You have a duty to inform the patient immediately that you will not accept their request. However, there is no prohibition in the Act to prevent you from continuing a conversation on the topic along the lines suggested above. Disclosing your objection is required before you start a conversation. Whatever your response, it doesn't remove your responsibility to respond appropriately to the clinical situation. Given the need for a persistent request, you may well have had this conversation already.

If you determine that the patient is making a first request to access VAD in NSW, the Act requires you to document the request and the reason for your refusal of the request. Accepting the request makes you the coordinating doctor, which requires training and involves eligibility assessments. If you refuse the request for any reason *other* than conscientious objection, you also have to give the patient information. Whatever your response, you are also required to notify the VAD Board of the request through the NSW Health portal. You could be charged with professional misconduct if you do not comply.

Moral Complicity and Conscientious Objection

These requirements raise the issue of 'complicity', that is, being involved with others in an activity that is unlawful or morally wrong. Would it be somehow compromising or improper for a Christian doctor or nurse to engage in this process? Might that represent a kind of endorsement, or at least insufficient clarity about the wrongness of this course of action? We can imagine Christians disagreeing on such a matter, and each of us needs to decide for themselves what their conscience allows them to do.

We need to think carefully about how and why someone might be implicated in the immoral action of another person. And so, at this point, it is important to distinguish real responsibility and meaningful participation from mere proximity or distaste. The mere fact that a person is near to or in some way involved in an action they disagree with or find objectionable, does not necessarily mean they are implicated in that action.

In ethical terms, whether a doctor or nurse is morally complicit in an action will depend on several factors.

Have you any role in the causation of the act?

Is the patient's desire for VAD influenced by your role? If you have gently counselled the patient regarding alternative paths of action as we have already discussed, this may not be the case.

Are you facilitating the morally wrong act directly?

Are you making the VAD happen? This is an interesting question. By documenting the request and providing information, are you helping the patient achieve their morally wrong aim? By agreeing immediately to the patient's request, you may appear to give the choice some kind of legitimacy that may reinforce their decision – hence the benefit of expressing conscientious objection prior to counselling the patient. You may be the only person who expresses concerns about VAD to the patient. It would be a shame to miss the opportunity.

However, some people think that referral *does* constitute complicity, merely distancing you from the morally wrong act rather than making you a value-neutral service provider. If you are convicted that referral does constitute complicity at this point, you should not go against your conscience (Rom 14:23). However, because it is the law, you may need to consider working in a different area of healthcare. While you do not have control over the legal requirements imposed by the government, you do have control over where you work.

Assisting in patient assessment and practice of VAD *would* constitute facilitation of a morally wrong act.

Does your action perpetuate the moral wrong?

Does your referral increase the likelihood of it happening again? Well, if the patient proceeds with VAD this won't be an issue for that individual. However, it is possible that by expressing your objection to VAD, you may persuade the patient to think differently about it and this may alter their behaviour. Therefore staying in the healthcare system and engaging with patients requesting VAD may seem to you to be the morally preferable route. This course of action would mean continuing to express conscientious objection; by not expressing any objection, you infer that this is a legitimate therapeutic pathway to take.

A doctor who is legally obligated to enter patient details into the NSW Health information portal may find this deeply unpleasant and upsetting, but they are not necessarily complicit in the patient's death through VAD in any meaningful sense. The responsibility for this clearly falls upon the law, the third party, and the patient. However, it may cause moral distress, which we will consider in a moment.

Another issue on which Christians disagree is whether it makes one complicit to continue to care for a patient who has decided to die through VAD, and whether they should agree to be present at the death. This is an issue for a wider range of healthcare providers, including chaplains. One person might feel it is critical to remain with the patient in order to continue to speak the gospel to them till the end. Another might feel that such an act would inevitably only serve to ease the patient's conscience when it ought not be eased. Personally, I think that if you are working in an area where you care for patients at the end of life, you have to consider whether you have a duty of care to continue to care for the patient, regardless of the choices they make.

Many Christians will find this situation confronting and troubling. But we need to distinguish mere proximity to evil from responsibility for evil. When Scripture calls us to 'flee' evil (e.g. 1 Cor. 6:18), it is calling us to flee evil that we might do, that is, be responsible for. It should not be understood as calling for mere distancing from evils we find repellent, as if we might be made unclean by mere proximity to evil. The Christian life is not lived simply according to a logic of clean and unclean, because it is not from outside, but from within, that one is defiled (Mark 7:1-23). Christ does not ask the Father to take his disciples 'out of the world', but to protect them from the evil one and to sanctify them while they journey within it (John 17:15-17). No church, community or hospital is free of evil; and we should beware of assuming that the presence of some particular evil, which has special public prominence, is uniquely corrupting.

That said, we should also beware of overconfidence about this distinction, or about our capacity to make it. It is wise to be cautious and circumspect about such proximity, and to be clear in our determination to 'touch no unclean thing' (2 Cor. 6:17).

Given the complexity of navigating situations and circumstances such as these, it is inevitable that Christians will come to different judgements about what is right to do in each situation. It may be helpful to think about how the apostle Paul navigates the complexities of disagreements over various aspects of obedience in terms of realising that each of us makes a decision "to the Lord", "fully convinced" in their own mind, and so acting "from faith" (Romans 14:5-6). This is one way to understand the idea of 'conscience': it is about one's felt and experienced moral conviction about one's action. In such situations, Paul argues that patience and restraint are called for, in order to protect the brother or sister with whom one disagrees (Rom 14:15).

However, such disagreements have limits. A church seeking to care for people and their families wrestling with VAD would not be able to accept both the view that euthanasia or physician-assisted suicide is an acceptable course of action and the view that it is not; because the attempt to tolerate both positions will itself be corrupting of the community and its witness. In the case of these differences, the effort to understand the opposing position may enable us to care for one another better, rather than corrupting our ability to do so.

Conscientious Objection

Conscientious objection is under attack. Some Australian ethicists have started claiming that conscientious objection has limits and that measures need to be put in place within the healthcare system to minimise any 'harm' to patients resulting from it. Alarming, government research funding to investigate conscientious objection has been given to an academic who has previously written that any doctor that conscientiously objects to legal procedures such as abortion should be deregistered. A document developed by the NSW Health Ethics Advisory Panel Voluntary Assisted Dying Working Group states that 'the mere assertion of a conscientious objection by a health practitioner does not necessarily mean that the ethical threshold for conscientious objection has been reached'.²⁵

Its recommendations go beyond VAD legislation as seen here:

In general, it would only be ethically acceptable for a treating health practitioner to exercise a right of conscientious objection in relation to any aspect of VAD (including those specified in the Act) on the condition that:

- *The patient is advised that the practitioner has a conscientious objection*
- *Where necessary, the patient is reassured that their welfare, care and treatment (according to their own assessment) will not be compromised as a result of the practitioner's objection;*
- *The patient is offered a practical and effective alternative pathway to access VAD, by way of referral or the provision of information;*
- *The requirement for the patient to seek advice and care from another health practitioner does not impose an unreasonable burden or financial cost on the patient or their family or caregivers; and*
- *The patient's access to VAD will not be unreasonably delayed as a result of the health practitioner's conscientious objection.*

**– NSW Health Ethics Advisory Panel
Voluntary Assisted Dying Working Group**

This is a big topic. The state should protect conscience as a human right, but many people are arguing against this. You will need to be able to articulate your reasons for conscientious objection to engage in discussions on this topic in your workplace. For further guidance, there is a document on [Conscientious Objection](#) on the CMDFA website.²⁶

One thing that is clear, is that VAD is now legal in all Australian states and the ACT, and if a patient decides to take this route, after you have offered all alternatives, you will have to accept it. Our health system's prioritisation of patient autonomy means that we may have to accept decisions with which we do not agree. The individual healthcare practitioner will need to consider issues of conscience and decide whether they can continue to work in an area of medicine where VAD is likely to be accessed. I know some Christian doctors who have already made the decision to walk away.

Moral Distress

It is clear that VAD laws in Australia are causing an enormous amount of moral distress in health care workers who are opposed to VAD and whose patients make the choice to access it. Moral distress arises when one knows the right thing to do, but institutional constraints – the hospital, the government, the aged care facility – make it nearly impossible to pursue what one considers to be the right course of action.

Moral distress is what results from repeatedly not having our own values respected. When we are morally distressed, we often feel muzzled, restricted, devalued, unheard or dismissed. We easily become fuelled by anger, disgust, fear, and frustration. Over time, these emotions can fill us with anxiety, depletion or depression. A sense of being fragmented can set in, leaving us to question who we are at our core and what the world is, generally. Research also shows that moral distress has long-term consequences, such as burnout, exhaustion, numbness, disconnection, and '[compassion fatigue](#)'. Therefore, it is a serious problem that needs to be taken seriously.

Powerlessness is at the heart of moral distress. It is the feeling that we have had to, or must, compromise ourselves or something we hold dear, due to external forces seemingly beyond our control. It is also the sense that others don't grasp a moral imperative that is clear to us.

Many possible sources of distress exist in the VAD context. For example, you may not agree with the patient's perception that symptoms cannot be controlled; you may not agree with the VAD navigator's assessments regarding eligibility of a patient (such as their prognosis); you may feel complicit in working close to VAD; patient requests for VAD may leave you feeling that you have failed as a carer; you may be outraged that your government is providing VAD as a legal option for your patients and your taxes are helping to pay for it.

The three classic symptoms of burnout are exhaustion, depersonalisation and a reduced sense of personal accomplishment. They are more common in healthcare workers compared to the general population, and can lead to reduced work performance, and therefore danger to patients.²⁷

One way to combat moral distress is to cultivate moral resilience. Resilience is generally considered to be the ability to recover or adapt well to stress or trauma; it ensures that challenges improve, rather than hurt our lives, and fortifies rather

than weakens our spirit. Resilience helps us to see that difficulties need not leave us permanently damaged; only temporarily challenged. This is another huge area which is beyond the scope of this paper. However, some simple steps to build moral resilience have been developed for nurses. They include the following:

- 1. Practice self-awareness** – that is, focus your attention within situations that are causing moral distress. Being self-aware means continually exploring our feelings, thoughts, and desires. In going into ourselves, we don't try to squash unpleasant emotions or judge them as wrong or weak. We give them space to tell us something new about what's going on. We observe what this says about the distressing situation and us. Doing so allows us to regain a sense of perspective which is needed to remain calmer and in more control, even in situations when we are not in control. In some situations, just recognising that the stress you feel is moral distress, and naming it, can be enough to make it bearable.
- 2. Create a safe space at work** to discuss concerns before they lead to moral distress. Managers have an important role in this.
- 3. Increase self-care** – coping with stress and building resilience improve with good self-care. Take an inventory of your nutrition, sleep, activity and relaxation methods. Everything is easier to cope with when you're healthy. Build a moral community at work to hold each other accountable for self-care. Caring for people with spiritual suffering is taxing work. Take care of yourself.
- 4. In addition, for Christians,** a safe space may be created by meeting with others who share your views so you can debrief regarding your concerns and receive moral support. We also need to protect our spiritual well-being. Research has shown that high levels of spiritual well-being are associated with reduced burnout and compassion fatigue in healthcare workers.²⁸ Make time for God.

Going Forward

I expect that things will get worse.

Throughout the world, all jurisdictions that have legalised and enacted euthanasia or physician-assisted suicide legislation have seen an increase in the number of deaths due to euthanasia over time. Canada has seen a ten-fold increase in MAiD deaths since its legalisation in 2016. This represents an increase of approximately 33% every year.

But it's not just expansion of numbers, it's also an expansion of the criteria for which euthanasia is allowed. In the Netherlands, euthanasia was legalised in 2002 for terminally ill, mentally competent adults who were experiencing intolerable suffering. From there it has expanded to include patients who are not terminally ill, not mentally competent, and not adults, including disabled newborns. A recent journal article described the established practice of euthanasia for 'multiple geriatric syndrome', also known as 'old age', where over a third of the deaths described were primarily motivated by loneliness.

How is this justified? A similar expansion of laws in Canada recently was hailed as a milestone to end discrimination against those who are not terminally ill. Once the principle of state-sanctioned killing is approved, how can it be limited to the suffering, terminally ill? If, as in NSW, euthanasia is promoted as a way for citizens to exercise autonomy, artificial limitations such as a short prognosis cannot stand. State-sanctioned killing becomes a liberty issue. If I decide to end my own life, based on how I personally define quality of life and a meaningful existence, how can the state judge that decision on the basis of general values, societal norms, or consideration of objective rationality? I should not have to justify my decision, rather my decision must, in principle, be respected by the state and society as an act of self-determination. In other words, once state-sanctioned killing is permitted, death on demand will eventually follow.

Experience in the Netherlands suggests that another development that occurs with legal euthanasia is that orchestrated death becomes normalised, and many of the patients in the Netherlands who aren't eligible for euthanasia die through sedation. A story for another day.

Finally, there is evidence overseas that over time there is increasing pressure on doctors to provide assisted dying. VAD is very popular. Patients like it. Families like it. No more waiting around for death to come. This is a challenge for the church. Churches were the first to build hospices to care for the dying in the Middle Ages. There is a role for Christians now to support those who feel abandoned and spiritually lost at the end of life.

One pro-VAD organisation reviewing the practice in Australia and New Zealand has recommended the following reforms:

- Streamline complex bureaucratic processes to be less burdensome for dying people.
- Recognise VAD as an option within high-quality end-of-life care and include it in relevant clinical standards and guidelines.
- Reform the Commonwealth Criminal Code so those living outside Australia's major cities can discuss VAD via electronic communications and telehealth when needed.
- Grow the VAD health workforce to meet growing awareness of and demand for VAD care; and ensure health professionals receive fair compensation for their time and skills.
- Help raise awareness of the VAD option by allowing clinicians to have open and inclusive end-of-life conversations with their patients.
- Produce clear guidance to individual practitioners, hospitals, hospices and aged care facilities so they understand their legal and ethical obligations to the people in their care.²⁹

I urge CMDFA members and other Christian health professionals to try to understand the laws, decide how you want to respond, and upskill so you know how to care for your patients in distress. Although this paper is not written to promote political action, be aware that conscientious objection is under threat. If we are to be "as wise as serpents", we need political awareness. Individually, we can support groups trying to improve the legislation, respond when your professional groups ask for feedback to amend their ethics guidelines, and pray for wisdom and mercy.

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