Voluntary assisted dying in Victoria: Why knowing the law matters to nurses.

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Abstract

In 2017, Victoria became the first state in Australia to pass legislation permitting voluntary assisted dying. Under this law, only those people who are near the end of their lives may access voluntary assisted dying, and because many of these people require nursing care to manage the progression of their illness or their symptoms, it will invariably have an impact on nursing practice. The Victorian law includes a series of procedural steps as safeguards to ensure that the law operates as intended. To support people who choose voluntary assisted dying and to practice safely within boundaries of the law, nurses must be aware of these requirements and how they operate. However, there are often gaps in nurses' legal knowledge. This was demonstrated in an article that aimed to inform nurses about the operation of Voluntary Assisted Dying Act 2017 (Vic) but contained several errors and misstatements of the law. Our article corrects these errors and discusses how the law is intended to be applied by revisiting the fictional case of Chloe – a woman with a terminal illness who is seeking voluntary assisted dying. As the Voluntary Assisted Dying Act 2017 (Vic) also protects nurses from liability if they act in accordance with its provisions, we conclude that sound knowledge and understanding of its operation support nurses to provide the safe, comprehensive and compassionate care their patients deserve at the end of life.

Keywords

Law, legal knowledge, nurse, nursing practice, Victoria, voluntary assisted dying

Introduction

As one of the 15 nationally regulated health professions in Australia, nurses are required to use the best available evidence to provide safe, person-centred, quality nursing care.[1] Typically, clinical knowledge and technical skills are recognised as central elements in the provision of quality nursing care. However, it is the law that reflects widespread societal ethical considerations, and by mandating or prohibiting certain actions, sets minimum standards of conduct for nurses and other healthcare practitioners.[2] Consequently, laws crafted to govern actions do not passively follow clinical decision-making but rather are a constitutive element of all nursing practice.[2] This sentiment is reiterated in professional practice standards that regulate the conduct of all Australian nurses.[1,3]

The law, however, is not static – just like clinical practice, it evolves over time. A recent example is the law on voluntary assisted dying (VAD). Prior to 2017, no Australian state permitted access to VAD. However, this changed with the passage of the *Voluntary Assisted Dying Act 2017* (Vic) (the Act),[4] which permits a small cohort of people suffering from a disease, illness or medical condition that will result in death to access VAD under strict conditions.[4 s9] People who are at the end of life frequently require nursing care to help manage the progression of their illness or symptoms.[5] With VAD as a legal choice for some dying patients, nurses in Victoria are the first in Australia to experience the operation of this seminal law. Other Australian states have begun to follow Victoria's lead [6,7] so VAD will soon also affect nursing practice in other parts of the country.

Nursing Professor Margaret O'Connor was a member of both the Ministerial Advisory Panel (MAP) that helped draft the VAD law in Victoria and the Implementation Taskforce that advised the Victorian Government on its implementation.[8] During the legislative process she observed that while there was no formal role for nurses set out in the Act, they should 'not shy away from the hard questions that will invariably be asked of them'.[9 p33] This is because, even if not formally involved, nurses may be the first person to receive an inquiry about VAD from a patient at the end of life, and may provide support to a patient or medical practitioner or otherwise be involved in decision-making about VAD.[10] To do this, and ensure they are practising within the law, nurses will need to know how the Act operates in practice.[11]

It is common, however, for there to be gaps in healthcare practitioners' knowledge of the law that regulates their practice.[12,13] Despite substantial interest among nurses in the topic of VAD, [10, 11] their knowledge of the law that underpins it may be limited. A recent article by Gilbert and Boag that sought to 'evaluate the impact of Victorian Assisted Dying Legislation' [14 p1976] is a salient example. While purporting to describe the operation of the Act by applying it to a fictional case study, the article contains errors that could mislead nurses about this law. Many of these errors related to the procedural steps required to access VAD, and it may be argued that for nurses, these are not necessarily problematic. There are three points that we raise to counter this.

First, these steps, although complex, are an important part of the overall framework. Indeed, it was the comfort provided by the careful and rigorous staged process for accessing VAD that enabled lawmakers to reach the view that VAD implemented under these circumstances was safe. Second, research demonstrates that for some nurses, it is detailed attention to making sure the required procedural steps are followed that supports, and enables, the provision of high quality nursing care for patients who choose VAD.[15] Finally, if a nurse undertakes an act in good faith that they believe

on reasonable grounds is in accordance with the Act, they will be protected from liability. [4 s80] For these reasons, this article aims to both correct the errors in the Gilbert and Boag article and assist nurses to understand how the Act operates in practice.

Victoria's voluntary assisted dying law and Chloe's case

Victoria's VAD framework aims to promote the personal autonomy and choice of those people who are suffering at the end of life, while ensuring the safety of the broader community. To achieve this, it combines a 'prescriptive multi-stage assessment process with numerous safeguards and comprehensive oversight'. [16 p1] Although there is widespread community support for legislation permitting people near the end of life to choose the circumstances of their death, the law also needs to protect those who may be vulnerable to abuse. [8] Ensuring the vulnerable are sufficiently protected has resulted in complex legislative procedures, but in order for the law to operate as intended, nurses who care for people who choose VAD will need to be familiar with them. Gilbert and Boag aimed to facilitate nurses' understanding using the fictional case of Chloe as a foundation for their description and analysis. To give context to our discussion and contrast the correct application of the law with Gilbert and Boag's interpretation, the case study that was central to their article is summarised below (Box 1). The discussion that follows sets how the law should be applied in this case.

A summary of Chloe's case study (extracted from Gilbert and Boag, 2019 [14])

Chloe was a 32-year-old resident of Victoria diagnosed with an aggressive brain tumour. Although Chloe was expected to die from the tumour within 3 months, she was offered radiation therapy in the hope that it would extend her life, which she refused. Chloe believed that for her, an early death was preferable to the intractable pain and suffering that a slightly longer life offered.

While Chloe retained decision-making capacity, she approached her General Practitioner (GP), Dr Heslop, to request access to VAD. Chloe was assessed as eligible for VAD by Dr Heslop and her neurologist, and eventually obtained the VAD medication. At the time of her choice, Chloe took this medication and died shortly after.

Box 1 A summary of Chloe's case study

Assessing whether Chloe is eligible for voluntary assisted dying

The Act sets out strict eligibility criteria to govern access to VAD (see Box 2). These criteria are seen as key safeguards to protect those who may be vulnerable to abuse.

The background information about Chloe suggests she would satisfy the eligibility criteria in respect of age and also be very likely to do so in relation to residency. [4 s9(1)(a)-(b)] The next two criteria, however, deserve more detailed consideration. First, although Gilbert and Boag state that Chloe had 'legal capacity to make decisions', [14 p1978] to be eligible Chloe must, in fact, have decision-making capacity *in relation to VAD* (see Box 2). [4 s9(1)(c)] That is, the assessment of whether a person has decision-making capacity is specific to the decision that needs to be made. This distinction is

important: capacity to make one type of decision does not mean that person has capacity to make all types of decisions. A person may, for example, be able to decide on the type of mobility aid they prefer, but this type of decision does not have the same gravity as a decision to access VAD. For this reason, the Act specifically requires a person to have capacity in relation to VAD, and then goes on to clearly define in a later section of the Act what this means (see Box 3).[4 s4(1)] Importantly, for some, capacity to make a decision may depend on the availability of practicable and appropriate support, such as offering information in a form that is tailored to the person's needs, assisting a person to communicate a decision, allowing additional time or using assistive technologies, and the Act provides for this.[4 s4(d)] While Chloe's brain cancer has the potential to affect her decision-making capacity so that extra support may be required, there is no information to indicate whether this is the case. Based on the limited information provided, Chloe is likely to satisfy this criterion.

Voluntary Assisted Dying Act 2017 (Vic)

Criteria for access to voluntary assisted dying (section 9(1))

For a person to be eligible for access to voluntary assisted dying the person must:

- a) Be aged 18 years or more; and
- b) Be an Australian citizen or permanent resident, and ordinarily resident in Victoria, and at the time of making a first request have been ordinarily resident in Victoria for at least 12 months; and
- c) Have decision-making capacity in relation to voluntary assisted dying; and
- d) Be diagnosed with a disease, illness or medical condition that:
 - i) is incurable; and
 - ii) is advanced, progressive and will cause death; and
 - iii) is expected to cause death within weeks or months, not exceeding 6 months [12 months in the case of neurodegenerative conditions: s9(4)]; and
 - iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Box 2 Criteria for access to voluntary assisted dying

Second, we are told that Chloe is expected to die from her brain cancer within 3 months, and this is partly due to her decision to refuse radiation treatment. There are important points to clarify in relation to Chloe's prognosis. Gilbert and Boag state that a person must be 'diagnosed with a terminal illness and likely to die within 12 months' [14 p1978] to be eligible for VAD. However, it is only if a person is diagnosed with a neurodegenerative condition, which brain cancer is not, that this 12-month timeframe applies (see Box 2).[4 s9(4)] Generally, a person must be expected to die within 6 months, [4 s9(1)(d)(iii)] so Chloe's prognosis of 3 months to live will satisfy this eligibility criterion.

The other point is that Gilbert and Boag explicitly link her prognosis (and eligibility) with Chloe's decision to refuse radiation treatment. It is important to be clear, though, that Chloe's refusal of treatment is irrelevant to her eligibility under the Act, given her prognosis of 3 months to live. The

eligibility criteria in the legislation is silent on patients either refusing or having treatment, and we note that refusing treatment is a legal right of all adults with decision-making capacity.[17]

Voluntary Assisted Dying Act 2017

Meaning of decision-making capacity (section 4 (1))

A person has decision-making capacity in relation to voluntary assisted dying if the person is able to:

- a) Understand the information relevant to the decision relating to access to voluntary assisted dying and the effect of the decision; and
- b) Retain that information to the extent necessary to make the decision; and
- c) Use or weigh that information as part of the process of making the decision; and
- d) Communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.

Box 3 The meaning of decision-making capacity

After clarifying how the eligibility criteria should be applied, it appears that Chloe may be able to access VAD. But determining eligibility is only the first step in the process. There are further procedural requirements that act as safeguards and are relevant to nursing practice. Because they were not addressed by Gilbert and Boag, they will be discussed below.

Communicating with Chloe about VAD

A unique feature of the Act is that it specifically regulates how healthcare practitioners communicate with their patients about VAD. We know that Chloe 'discussed assisted dying' with her general practitioner, Dr Heslop.[14 p1978] What is not known, is whether the conversation about VAD was initiated by Chloe or Dr Heslop. This is important because the Act prohibits all registered health practitioners from initiating discussions about VAD with their patients.[4 s8] Recognising that health practitioners, including nurses, are in a position of trust and influence, the prohibition is designed to allay concerns that patients might be unduly influenced to explore VAD.[18] So while medical practitioners and nurses can provide information about VAD if a person they are providing healthcare to raises it, they must not initiate a discussion about VAD. This has significant implications for nurses caring for patients who may be contemplating VAD, because inadvertent breaches can give rise to allegations of unprofessional conduct. [4 s8(3)] If such conduct is proven, this could see them reprimanded or have conditions placed on their professional registration, or even possibly have their registration suspended or cancelled. [19 s4, 20 sch1 s196(2)] Related to the prohibition on raising VAD, registered health practitioners, including nurses, must report instances where they believe that another health practitioner has initiated a discussion that is in substance about VAD. [4 s75(1)(a)(i)] So, for example, if a medical practitioner or another nurse overheard Chloe's nurse initiate a conversation about VAD with her before she had made her first request, they would be obliged to notify the Australian Health Practitioner Regulation Agency (AHPRA). The decision to investigate the notification or take any disciplinary action rests with AHPRA. In Chloe's case, we know that she undertook some independent research about VAD, so it may be that she was the one who raised the

VAD discussion with Dr Heslop. However, the obligation under section 8 of the Act is unique and nurses should be aware of the legal responsibilities it imposes on them.

To begin the process required to access VAD, Chloe must make a 'first request' to a medical practitioner.[4 s11(1)] This is more than a request for information about VAD. Chloe must be quite clear when making her request that she is seeking assistance to die.[4 s11(2)] For example, if Chloe were to ask about the legality of VAD, or what she needs to do to access it, these would be requests for information. In contrast, if Chloe were to say, 'I've had enough. I know it's legal now, and I want you to help me get the drugs so I can die', this would constitute a clear request for VAD. The statement in the case study that Chloe 'discussed assisted dying' with Dr Heslop who 'agreed to her request' [14 p1978] does not provide enough detail to determine whether the legislative requirement of a first request was satisfied. This distinction is critical because without it, the VAD process cannot start. There are further procedural steps that need to be taken after Chloe has made a first request. These are critical to the safe operation of the Act and are described next.

Assessing whether Chloe is eligible for VAD

A person seeking VAD must be assessed independently by two medical practitioners to determine whether the person meets the eligibility criteria. The Act specifies the professional qualifications, expertise and experience required for a medical practitioner to be eligible to undertake VAD eligibility assessments.[4 s10] Gilbert and Boag provide limited detail about Dr Heslop's qualifications and expertise, but even if we assume that Dr Heslop satisfies the requirements, a medical practitioner must not commence a VAD eligibility assessment without first having completed the specific VAD training that has been approved by the public servant who is head of the Department of Health and Human Services.[4 s17] This is another unique safeguard embedded in the Act, and is designed to ensure that all medical practitioners who participate in VAD have the same baseline understanding of their legal obligations.[16] If Dr Heslop satisfies the Act's requirements in terms of qualifications, expertise and experience, and has completed the mandatory training, Chloe's first VAD eligibility assessment could commence after making her first request.[4 ss16,17] If Chloe is assessed as eligible for VAD, Dr Heslop must provide her with information about her illness, prognosis and palliative care options, before the process can continue.[4 s19] Importantly, Dr Heslop must also be satisfied that Chloe's request has been made voluntarily, without coercion and is enduring.[4 s20] At the end of the assessment process, Dr Heslop must notify the Voluntary Assisted Dying Review Board of the outcome of that assessment.[4 s21] The VAD Review Board is responsible for reviewing every instance of VAD, and by overseeing the broad application of the VAD framework, ensures that the Act is operating as designed.[4 s93] If Chloe is assessed as eligible, Dr Heslop will then refer Chloe to another medical practitioner for the second eligibility assessment, known as the consulting assessment.

In Gilbert and Boag's case study, it was Chloe who contacted her neurologist for a second assessment.[14 p1978] However, important information about Chloe's consulting assessment was omitted. First, Chloe cannot contact her neurologist without a referral from Dr Heslop. Second, the medical practitioner that Dr Heslop refers Chloe to must have also completed the mandatory training.[4 s26] Third, the Act requires that one of the medical practitioners assessing Chloe's eligibility for VAD must have relevant expertise and experience in Chloe's disease – brain cancer. Assuming Dr Heslop's only qualification is as a general practitioner, this will not be sufficient to have the required expertise and experience in treating people with brain cancer, so it is imperative that

the medical practitioner undertaking the consulting assessment does.[4 s10] Because the expertise and experience requirements in the Act are narrowly framed, a neurologist may not satisfy this requirement. It is more likely that Chloe would need to be referred to a neuro-oncologist. The legal obligations of the consulting medical practitioner are the same as those that applied to Dr Heslop, including that the outcome of the assessment be notified to the VAD Review Board.

Completing Chloe's request and assessment process

After Chloe has been assessed as eligible by two appropriately qualified medical practitioners, she is required to make a written declaration requesting access to VAD.[4 s34] This is a much more prescriptive process than that described by Gilbert and Boag. Chloe cannot merely present a letter witnessed by her neighbour, to her GP requesting VAD.[14 p1978] The written declaration must certify that Chloe is making the declaration voluntarily and without coercion, and that she understands the nature and effect of the declaration she is making. It must be appropriately witnessed. Importantly, the written declaration must contain the information prescribed by the Act.[4 s34] For this reason, the written declaration form has been included in the schedules to the Act. [4 sch1]

The written declaration must also be witnessed by two people (not one as suggested in the case study).[4 s34(2)(b)] There may be instances when nurses are asked to witness the declaration, so they should be aware of what this involves. A nurse who was directly involved in providing care to Chloe would not be eligible to act as a witness.[4 s35(2)(c)] However, a nurse who did not directly provide care (such as a nurse from another ward or clinic) could be. In contrast to witnessing a person's consent for surgery where a nurse might attest to witnessing a person sign a document, a nurse witnessing Chloe's declaration is required to certify that Chloe made the declaration freely and voluntarily, that she appeared to have decision-making capacity, and understood the nature and effect of her declaration.[4 s36(2)] Chloe's neighbour might be eligible to act as a second witness, but they would be ineligible if they know or believe they are a beneficiary under Chloe's will, or going to otherwise benefit (financially or in any other material way) from Chloe's death.[4 s35(2)(a)] Chloe and the two witnesses must sign the declaration in the presence of Dr Heslop.[4 s36(3)] After completing the written declaration, provided 9 days have elapsed since making her first request, Chloe can make her third and final request for access to VAD.[4 ss37,38]

Obtaining the VAD medication

The case study states that 'Dr Heslop completed the prescription for the lethal medication and Chloes' [sic] mother had it filled by the local pharmacist'. [14 p1978] The Act, however, does not permit Dr Heslop to write the prescription without ensuring that some important procedural requirements are satisfied. First, as the Act contemplates self-administration by the patient as the default method of completing VAD, Chloe needs to appoint a contact person to, among other things, be responsible for returning any unused VAD medication after she dies.[4 s39] Dr Heslop must then certify that the two eligibility assessments, written declaration and contact person appointment form are in order on a final review form. The final review form (with other completed forms) must then be lodged with the VAD Review Board.[4 s41(2)] Dr Heslop can then apply for a self-administration permit.[4 s43] The head public servant of the Department of Health and Human Services may issue a permit if they are satisfied that the VAD request and assessment processes have been completed in compliance with the Act.[4 s49]

It is only after receipt of the permit that Dr Heslop could write the prescription for the VAD medication. The prescription would not be given to Chloe's mother because it could not be filled at the local pharmacy. The Victorian Government established a state-wide pharmacy service (SWPS) as the single pharmacy service in Victoria authorised to dispense VAD medication. Dr Heslop is required to contact the SWPS to discuss the requirements for the prescription, and once written, will send it directly to the SWPS. At Chloe's request, the SWPS will dispense the medication in a locked box. When delivering the medication, the pharmacist will provide Chloe with information about self-administration, storage of the locked box containing the medication, and the process for returning any unused medication by Chloe's contact person.[4 s58] After Chloe receives the VAD medication there is no obligation for her to take it. It is entirely her choice if and when she chooses to self-administer the medication. She can also choose who is with her at the time.

After Chloe has died

It is anticipated that Dr Heslop would be responsible for completing the *Medical Cause of Death Certificate* (MCCD) after Chloe has died. In contrast to the statement that 'Dr Heslop identified her cause of death as a result of medications provided under Assisted Dying Legislation' [14 p1979], acknowledging that those who are accessing VAD are at the end of life, the cause of death will instead be listed as Chloe's underlying disease – brain cancer – rather than the VAD medication. However, as Dr Heslop knows (or believes) that Chloe was the subject of a VAD permit, this must be noted as well.[4 s67(1)] Dr Heslop is also required to notify the Coroner of Chloe's death, but this is not considered a reportable death and will not necessarily trigger a coronial investigation.[4 s67(2)]

Other safeguards and protections

Described as one of the most conservative VAD regimes in the world,[21] the Act contains numerous safeguards to ensure that those seeking access to VAD satisfy the eligibility criteria and have made the decision freely, voluntary and without coercion. Unless a person is physically incapable of ingesting and digesting the VAD medication, they must administer it themselves.[4 s48(3)] This is to ensure that their decision to take the medication is voluntary, and as such, is another safeguard.[16] In the case study when Chloe took the medication, her immediate family were present with her. There may be circumstances where a person requests a nurse to be present as well. Should this occur, the nurse must know that while they are permitted to retrieve the medication from the locked box, and assist to prepare it, they are prohibited from administering it. In jurisdictions where VAD is lawful, there is research demonstrating that nurses are unaware of the scope and legal limits of their practice in relation to VAD, [22] so awareness of this prohibition is important. In Victoria, a nurse who administers the VAD medication, for example by lifting the cup containing the medication to a person's mouth, could potentially face life imprisonment.[4 s84]

While provisions that create statutory offences are designed to protect people from abuse, nurses can be assured that the Act also protects those healthcare practitioners who participate in VAD in compliance with the law. For example, if a nurse was present when Chloe administered the VAD medication, they would not be liable for failing to administer life sustaining treatment when she stopped breathing.[4 s81]

Conclusion

VAD creates new obligations for all healthcare practitioners in Victoria. Extending the case study initially offered by Gilbert and Boag, with appropriate clarification about the requirements of the VAD Act, we have sought to explain what these obligations may require in practice. Much of this will in the first instance fall to medical practitioners. They have a central role in determining eligibility which requires specialised legal training before they participate in VAD.[4 ss17,26] However, while mandatory training on the Act ensures that medical practitioners have a sound understanding of the law, the effective provision of VAD services will inevitably require a multidisciplinary team.[23] Nurses will play an important role in supporting other healthcare practitioners and patients navigate access to VAD.[24] Nurses also have duties to ensure their own conduct falls within the law. They must, therefore, be knowledgeable about this novel and complex legal framework. To enable this, it is incumbent upon healthcare services where VAD is offered to develop clear policies and guidelines that accurately reflect the law. Supporting nurses to implement these policies will benefit not only the healthcare service and individual nurses, but also patients. The healthcare service will benefit by clarifying the role of nurses, reducing role ambiguity and promoting consistent practice.[22] Individual nurses will benefit by having certainty they are acting within their scope of practice, and the prescribed boundaries of the law. Consequently, nurses who are confident in their legal knowledge will be better placed to support patients and provide the comprehensive and compassionate end-of-life care they deserve.

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