RESTRICTING CONVERSATIONS ABOUT VOLUNTARY ASSISTED DYING:
IMPLICATIONS FOR CLINICAL PRACTICE

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ABSTRACT

Objectives
From 19 June 2019, assisted dying will be lawful in Victoria, the second most populous state in Australia. Section 8 of the Voluntary Assisted Dying Act is a legislative safeguard that is designed to ensure a patient’s request for assistance to die is voluntary. This section prohibits health practitioners from initiating a conversation about assisted dying with the patient. This article explores the potential implications of this prohibition for effective communication between doctors and their patients, and the ability of doctors to provide high quality end-of-life (EOL) care in some cases.

Method
This authors reviewed and analysed literature on the importance of communication at the EOL including the need to understand and appropriately respond to Desire to Die or Desire to Hasten Death statements. A legal critique of section 8 of the Victorian Voluntary Assisted Dying Act was also undertaken to determine the scope of this new duty and how it aligns with existing legal obligations that would otherwise require doctors to provide information about EOL options requested by a patient.

Results
Contemporary literature suggests that open and honest communication between doctor and patient including the provision of information about all EOL options when sought by the patient represents good clinical practice and will lead to optimal EOL care. The provision of such information also reflects professional, ethical and legal norms.

Conclusion
Despite (arguably) promoting an appropriate policy objective, the legislative prohibition on health professionals initiating conversations about voluntary assisted dying may, in cases where patients seek information about all EOL options, lead to less optimal patient outcomes.

INTRODUCTION

Most people, even early on in their lives, have wishes about how they want to die: for example, without pain, with dignity, surrounded by loved ones or in private [1]. While most people also hope that health practitioners will support them in these wishes, many of them feel uncomfortable to speak about death and dying. Yet, good communication is a vital component of providing high quality end-of-life (EOL) care [2, 3]. It allows doctors and patients to develop or deepen a relationship of trust and engage in shared decision-making [4]. Good communication also facilitates discussing important and challenging topics such as the limitations of modern medicine in those with advanced illness, moving from curative or disease modifying treatment to best supportive and palliative care, a patient’s experience and fears associated with their declining health, and death and dying [3].

The Australian State of Victoria has recently joined a small but growing number of jurisdictions internationally to legalise voluntary assisted dying (VAD). This new law permits VAD for competent
adults with an incurable, advanced and progressive condition that is expected to cause death within 6 months (12 months for neurodegenerative diseases) and is causing suffering [5]. Although aspects of the Victorian law align with other VAD regimes internationally, one unique feature is that it prohibits doctors (and other health practitioners) from raising the topic of VAD or suggesting it as a possible treatment option. This article explores the implications of this prohibition on the doctor/patient relationship and its potential to impede high quality EOL care for the dying patient, especially for patients who wish to be informed of all possible treatment options.

**IMPORTANCE OF GOOD COMMUNICATION AT END OF LIFE**

An important component of effective communication is ensuring that patients receive an appropriate amount of information. While patient preferences about the desired level of information varies [4, 6], studies have highlighted that many patients have unmet information needs at the EOL [7, 8, 9], with a substantial proportion wanting detailed information and involvement in EOL decision-making [10].

Provision of relevant medical information is an important component of patient-centred care [11], with doctors ideally tailoring their discussion to match the individual patient’s desired level of detail [12, 13]. For those who want to be more active participants in their medical treatment decisions, conversations ideally include a comprehensive discussion about a patient’s condition including prognosis, recommended as well as alternative treatment options and patient preferences. Omitting any of these elements from the discussion will make it difficult for patients to meaningfully weigh the options and make a fully informed decision regarding their care [14].

Thoughtful discussions as patients approach the EOL are important for a number of reasons. First, open discussions held with a spirit of curiosity provide patients the opportunity to articulate their values, needs and desires. As a patient’s illness advances, this helps inform timing for discussions regarding shifting from curative to other treatment options, including palliative care. Respectful and continuous communication regarding patient wishes is also key to good advance care planning.

Second, extensive knowledge of a patient’s priorities assists clinicians to engage in shared decision-making. This approach recognises that whilst the patient is the expert in their own values and goals, the doctor is the expert in determining which treatment/s will help the patient achieve their desired medical and social outcomes [15]. This framework has gained in popularity in comparison to the more traditional paternalistic approach of doctors making decisions for patients without consultation [16, 17] or, as has occurred in more recent times, doctors mistakenly interpreting respect for patient autonomy to mean patients either dictating their treatment or worse still, left to choose between options without medical guidance.

Third, honest and skilled conversations facilitate the development of trust, creating a safe environment for patients to not only talk about what is important to them as they approach the EOL, but to also articulate their fears and concerns.
When feeling supported and heard, it is not uncommon for patients to express a desire to die at some point during their illness [18], whether that expression is spontaneous or occurs during an exploration of suffering. It is important to distinguish three types of sentiments:

1. The desire that death will come soon (a “desire to die”, DTD) e.g. “I sometimes wish this was all over and I just didn’t wake up one day.”;

2. The desire for someone to hasten or enable them to hasten their death (a “desire for hastened death”, DHD) e.g. “Doctor, I want you to give me something so that I can die” or “Doctor, can you do something to make this happen faster?”; and

3. The desire to end one’s own life immediately to eliminate acute distress (i.e. suicidality). e.g. “I’m going to shoot myself and end it all.”

Studies of DTD, DHD and suicidality are challenging to conduct and interpret but it is important to note that these statements may not represent a true DTD or DHD [19, 20, 21]. These desires may not persist [22], and the motivations behind such requests are often complex and multifactorial [23, 24, 25, 26]. Chochinov et al. followed 200 terminally ill patients for 2 weeks, and reported that 45% expressed a DTD in an initial cross-sectional survey, but only 9% endorsed a “serious and pervasive” DTD two weeks later. Only 1 patient (0.5%) specifically expressed a DHD [27]. Breitbart et al. found that 17% of terminally ill lung cancer patients expressed a DHD, and that DHD was associated with depression, hopelessness and poor social supports [18]. The authors acknowledged that since VAD was illegal in their jurisdiction, it was hard to know whether a DHD statement would have actually led to a VAD request, or whether a DHD was simply a DTD or an “acceptance” of death. More recently, Rodriguez-Prat et al. published a meta-ethnography of 14 qualitative studies of DHD, and found that these statements can be “a reaction to physical, psychological, social and existential suffering, all of which impacts on the patient’s sense of self, of dignity and meaning in life”[24]. In other words, DTD statements should not necessarily be interpreted as clear requests for VAD [28].

RESPONSES TO ‘DESIRE TO DIE’ OR ‘DESIRE TO HASTEN DEATH’ STATEMENTS

People who are diagnosed with incurable and advanced disease are suddenly confronted with the prospect of death and dying. They are challenged to evaluate and explore different paths in order to find the best solution in light of their now limited life expectancy, suffering and lack of quality of life. Given this complexity, it is understandable that different wishes can coexist, including the wish to die [29]. When faced with a statement expressing a DTD, a DHD and/or suicidal ideation, doctors should interpret this as an invitation to explore suffering in a thoughtful and open manner rather than a clear desire to die or request for VAD.

Open-ended questions and commencing the conversation with curiosity rather than any pre-judgment of the meaning of the patient’s DTD/DHD statement may be helpful. Possible responses are included in Box 1.
After a review of the patient’s physical and psychological symptoms, suffering (existential or otherwise), and current supports, the conversation could turn to what medical and non-medical treatment options, interventions or other supports can be utilised to address the patient’s concerns. Although palliative treatments can be very effective for reducing many types of suffering, it may be important not to exaggerate the efficacy of these treatments or create the impression that they will be symptom free [30]. Creating unrealistic expectations can lead to even worse distress in patients and complicated grief in family members when these expectations are not met. Instead, doctors could emphasize the goal of making symptoms manageable, and escalating doses and adding sedation as needed if symptoms exceed what the patient is able to tolerate. In addition, a plan to follow up in a timely manner to continue the conversation might be offered.

RESPONSES TO PATIENT REQUEST FOR INFORMATION ABOUT ALL AVAILABLE TREATMENT OPTIONS

Some patients who have lived with a life-limiting illness for an extended period and are approaching the terminal phase of their illness are likely to want to discuss possible treatment options with their doctor. A patient desiring a high level of information (and possibly control) as they approach their end of life may expressly ask a doctor to provide them with all available treatment options. This request for information may be a well-thought through request, and may be a natural progression of on-going discussions with their doctor over a long period of time as the disease has progressed.

The provision of assistance to die by a doctor to a patient is now lawful, at least in some circumstances, in an increasing number of countries including Canada, some parts of the United States), the Netherlands and Belgium. In Switzerland, providing assistance to a person to die is not regarded as a criminal activity unless there is a ‘selfish motive’. So the question arises whether the doctor should provide information about VAD in response to an inquiry about all treatment options. If the patient expressly asks about VAD, then the doctor would be required to provide that information (or advise the patient of their conscientious objection). But what if the patient asks about all treatment options without expressly referring to VAD?

In such a case, in order to fulfil a doctor’s legal and ethical duties and consistent with well-established professional standards regarding informed consent, a doctor should inform the patient

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Box 1: Possible responses when patient makes a DTD/DHD statement

“It sounds like you are really having a tough time. Can I ask a few questions so that I can better understand what brought you to this point? [Wait for invitation to continue] Can you tell me what is bothering you most right now?”

“You’ve just made a very important statement. I hear you saying that you feel like it would be easier if you just went to sleep and never woke up and/or you want death to come faster. Sometimes when people say that, they are telling me that they are having a rough day and talking about it would be helpful while others have something else on their mind or other plans in place. Is it ok if I ask you more about this?”
of all the available treatment options, including VAD [31, 32].* Informed consent discussions are expected practice for any proposed medical treatments, and are the practical manifestation of a doctor’s duty to respect patient autonomy [33]. During these discussions, doctors should discuss the proposed treatment/s, the benefits, risks, and expected outcomes, and the details of other treatment alternatives, including best supportive care. Faced with the options, and with the guidance of the doctor regarding which treatment option will best assist the patient to realise their goal, the patient then decides which therapeutic option to pursue.

Despite the obligation to discuss VAD in such a case, doctors should take care in phrasing their response. There is a power differential that exists between doctors and patients, and the potential for a patient’s decision to be influenced by the words and tone used. It is preferable to avoid statements such as “You don’t mean that you want me to end your life, do you?”, and to present options in a non-judgmental way. The goal is to create a safe space in which options can be discussed without the patient feeling as though the doctor will view them more negatively or positively based on the option that they select.

| Box 2: Possible response where VAD is lawful, and the patient requests information about all available treatment options |
| “OK, let’s talk about the options. It sounds like the things that are bothering you the most are ... [CONFIRM UNDERSTANDING OF MAIN ISSUE(S)]. For this problem, we can try the following things ... [LIST REASONABLE TREATMENT OPTIONS, IF ANY EXIST].

Often, with time, these treatments can help reduce your symptoms. They usually won’t go away entirely, but the aim is to get you feeling better and that your quality of life is acceptable to you until the day you die. Sometimes, the symptoms do not improve with these treatments, and if you are suffering badly enough, there is another option that we call ‘Voluntary Assisted Dying’. With Voluntary Assisted Dying, a doctor gives a person a medication to end their life. Not everyone agrees with the idea of Voluntary Assisted Dying, and not everyone is eligible for Voluntary Assisted Dying. But I can tell you more about it if this is something you would like to pursue.” |

SECTION 8 RESTRICTIONS ON CONVERSATIONS

The clinical encounter will be more complex in Victoria. Section 8 of the Victorian legislation specifically prohibits a health practitioner from initiating a discussion or in substance suggesting VAD to a person (Box 3). There are two important components to the prohibition: the doctor cannot suggest VAD as a possible treatment option; and cannot initiate a conversation about VAD. The doctor may, however, provide information about VAD if the patient requests it.

* Dr James Downar is not a lawyer and makes no comment regarding a doctor’s legal duty in such a case.
Section 8 is designed to allay concerns that a patient who would not otherwise consider VAD, might do so if it is suggested by a health practitioner [34]. Arguably the potential for influence could be heightened if the suggestion or conversation is initiated by a health practitioner (particularly a doctor), as they are in a position of trust and influence.

When considering the clinical implications of section 8, it is important to distinguish the two scenarios considered earlier. The first involved a patient expressing a DTD or a DHD. For this patient, section 8 is unlikely to affect the doctor’s response. He or she can explore what is underpinning the patient’s statement, and the statements suggested in Box 1 might be helpful.

But the second scenario, where a patient asks to be advised about all possible treatment options without specifically asking about VAD, may present greater challenges for a doctor in Victoria. The first challenge is determining whether the request for all treatment options is a request for information about VAD within the meaning of section 8(2), so that a doctor is permitted to provide it. On balance, the authors believe this would not constitute a request for information about VAD. This interpretation is consistent with the ‘Guidance for Health Practitioners’ recently published by the Victorian Department of Health and Human Services [35]. Therefore, the section 8 prohibition will operate.

The second challenge is more serious, namely achieving an optimal healthcare outcome for the patient who has not been provided with requested information to make an informed treatment choice. The concern is that the section 8 restriction will prevent some patients approaching the EOL from making informed decisions.

The significance of this prohibition should also be placed in context. Research undertaken in countries where assisted dying is legal reveals that it is generally the well-educated who see assistance to die [36, 37, 38, 39]. The reason for this may be multi-factorial, however one factor is likely to be that they are aware of this as an EOL option and seek information to consider it further. A section 8 prohibition would not adversely affect a well-informed person seeking to explore VAD with their doctor. However, it would for a patient who was unaware of VAD as an option. The

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Box 3: Section 8 of the Voluntary Assisted Dying Act 2017 (Victoria)

(1) A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person –
   a) initiate discussion with that person that is in substance about voluntary assisted dying; or
   b) in substance, suggest voluntary assisted dying to that person.

(2) Nothing in subsection (1) prevents a registered health practitioner providing information about voluntary assisted dying to a person at that person’s request.

(3) A contravention of subsection (1) is to be regarded as unprofessional conduct within the meaning and for the purposes of the Health Practitioner Regulation National Law.
prohibition may also discourage others who feel ashamed about or fear their doctor’s reaction to a request for information about VAD.

A final observation is to note the implications on this restriction on the doctor’s clinical practice. To the authors' knowledge, no other law imposes a restriction on a doctor discussing with a patient a lawful treatment option that the doctor, in his or her professional view, believes is an option that the patient may wish to consider. An EOL treatment choice that is not fully informed may not only result in a sub-optimal decision, but also has the potential to cause clinician distress.

**POSSIBLE RESPONSES TO PATIENT REQUEST FOR INFORMATION ABOUT ALL AVAILABLE TREATMENT OPTIONS – FOR VICTORIAN DOCTORS**

The precise ambit of section 8, and when a statement will be regarded as a request for information about VAD is unclear [40] and beyond the scope of this article. Section 8 should not constrain communications between a doctor and patient following a DTD/DHD statement made by the patient. A doctor will still be able to explore the patient’s underlying concerns, and any ways that the suffering might be addressed.

The greater challenge, in the context of a section 8 prohibition, is responding to a patient’s request for information about all treatment options. A clinician will want to support a patient so that he or she can make a decision about treatment that will promote that patient’s values, needs and desires. In rare circumstances, as a result of previous conversations, the doctor may form the view that assisted dying may be something the patient would want to explore [41]. Yet, a doctor in Victoria is prohibited from suggesting VAD as a possible treatment option or initiating a conversation about VAD.

The authors have attempted to craft a possible way forward for a clinician when a patient indicates a desire to know all of the treatments that might be possible in their case (and that patient is likely to be eligible for VAD). The response in Box 4 might provide useful information to the patient, and open the conversation for a further request by the patient to explore VAD should they wish to do so.
**Box 4: Possible response when patient requests information about all available treatment options (without specifically asking about VAD) (Victorian doctors)**

“In order to give you the best advice, I need to know a bit more about you and your values. In general, when someone has an incurable illness and is nearing the end of their life, they want to be comfortable and supported. That is a given, and we will try to do that regardless of any other medical decision that you make, because comfort medications are safe and can be given alongside almost any other treatment.

At the same time, people make other medical decisions based on how they balance quality and quantity of life. For example, people who think it is important to live as long as possible may pursue aggressive treatment, even if that treatment has potential side effects and can reduce quality of life. People who think that quality of life is more important will usually prefer less treatments with fewer side effects. They want to make sure that they are as comfortable as possible for as long as they live, even if they might not live as long as if they had taken the more aggressive treatments.

There are also people who value quality of life so much that if they were suffering very badly, they would rather their life be over so that the suffering would be relieved.

If you can tell me a bit about your preferences and what you want to happen, then I can advise you accordingly.

[Note that even if the patient responds that they fall within the last category, that alone will not be sufficient to enable a doctor to discuss VAD. However, if the patient then expressly asks the doctor for assistance to die, that would be sufficient.]

Until the parameters of the section 8 prohibitions have been judicially tested, we cannot know with certainty what constitutes:

- a doctor ‘suggesting VAD as a possible treatment option’; or
- a doctor ‘initiating a conversation about VAD’.

That said, all five authors (three of whom have legal qualifications) believe that the Box 4 responses do not breach this provision.

**CONCLUDING REMARKS ON IMPLICATIONS FOR GOOD CLINICAL PRACTICE IN VICTORIA**

Section 8 was enacted to ensure VAD is a voluntary choice of a patient, reached without influence of others, particularly doctors (and possibly other health practitioners) who may be in a position of influence for EOL patients. However, the provision has the potential to restrict communication between doctor and patient at a critical time for a patient seeking to make an informed EOL choice.

This prohibition may not present a problem for a well-informed patient who is aware that VAD may be a possible option for them, and specifically asks their doctor about it. However, the prohibition
may result in a less optimal outcome for a patient who genuinely wishes to know their available treatment options, but is not sufficiently appraised to ask about VAD.

In this article, we have suggested some strategies that might be helpful for Victorian doctors caring for patients at the EOL. But the strategies are, at best, workarounds. Indeed, it may even be argued that the Box 4 response contravenes the legislation because the doctor ‘in substance’ initiates a discussion about VAD. Unfortunately, the precise ambit of the prohibition is, at this stage, unknown.

The section 8 restriction on the provision of information for a patient seeking it may present challenges to doctors who feel VAD may be an option that their patient, in a particular case, may want to consider. In this article, we have suggested an approach that may be helpful for a Victorian doctor who is confronted with a request for information about available treatment options. We do however urge health service providers to engage with this issue, including ensuring potential responses that doctors make, do not breach the prohibitions imposed by section 8.

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Lindy Willmott has been engaged by the Victorian Government to design and provide the legislatively-mandated training for doctors involved in voluntary assisted dying. Lindy Willmott is also a member of the board of Palliative Care Australia (but this article only represents her views not those of Palliative Care Australia).

Ben White has been engaged by the Victorian Government to design and provide the legislatively-mandated training for doctors involved in voluntary assisted dying.

Danielle Ko is on the Voluntary Assisted Dying Review Board (but this article represents her views only).

James Downar is a former member of the Physicians’ Advisory Committee for Dying with Dignity Canada, a group that advocated for the legalization of voluntary assisted dying in Canada. He currently works at Bruyere Continuing Care, a Catholic healthcare facility.

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