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PERSONAL VIEWPOINTS

Biggest decision of them all – death and assisted dying: capacity assessments and undue influence screening

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Abstract

Arguably, deciding the timing and manner of one's death is the biggest decision of all. With the Victorian *Voluntary Assisted Dying Act 2017* commencing in 2019, assessing capacity to choose Voluntary Assisted Dying (VAD) becomes a critical issue for clinicians in Victoria, and elsewhere with on-going efforts to change the law across Australia and in New Zealand. We consider how capacity assessment and undue influence screening can be approached for VAD, the role and risks of supported decision-making, and argue for the importance of training to ensure health care professionals are educated about their role.

Introduction

When deciding a case about foregoing life-sustaining treatment, Lord Donaldson of the English Court of Appeal said: 'The more serious the decision, the greater the capacity required'.[1] Arguably, deciding the timing and manner of one's death is the biggest decision of them all. With passage of the Victorian *Voluntary Assisted Dying Act* in November 2017 (hitherto referred to as the Act), for commencement in 2019, assessing capacity to choose Voluntary Assisted Dying (VAD) becomes a critical issue for clinicians in that State. It may also become relevant for clinicians elsewhere with active bills and parliamentary inquiries in New Zealand, the Australian Capital Territory and Western Australia.

Some years ago, one of us proposed an approach to assessing capacity in regards to assisted suicide.[2] We now aim to update and build on that test in light of scientific developments and recent legislative changes. In doing so, we consider three issues: (i) how should capacity assessment, and particularly undue influence screening, be approached in relation to VAD? (ii) what are the role and risks of supported decision-making for VAD? and (iii) the importance of training to ensure health care professionals are educated about their role. We note that the authors of this paper write it with different views about the legalisation of VAD and this diversity brings rigour as positions are collegially tested. Our aim is to raise awareness about these complex and important issues in a changing Australasian context.

Assessing capacity for VAD

The Act requires that an adult must have 'decision-making capacity in relation to voluntary assisted dying' to be eligible to receive assistance to die (section 9 (1)(c) of the *Voluntary Assisted Dying Act 2017* (Vic)). It requires the person to understand, retain and use or weigh relevant information when making their decision and be able to communicate that decision (see Box 1). These are fundamental, internationally accepted capacity principles based on capacity for consent,[3] which formed the basis of the previous proposed approach to capacity assessment.[2]

In addition to assessing capacity, the Act also requires that the two doctors involved in assessing the person are satisfied that they are 'acting voluntarily and without coercion' (sections 20 (1)(c) and 29 (1)(c)). The Act refers to the need to 'protect individuals who may be subject to abuse' (section 5 (1)(i). We agree that testing the voluntary nature of the decision – i.e. freedom from undue influence and abuse – is necessary when undertaking a capacity assessment.[3,4] Although capacity and

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BOX 1 Extracts From Section 4 of the *Voluntary Assisted Dying Act 2017* (Vic)

… Meaning of decision-making capacity
(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;
(b) Retain that information to the extent necessary to make the decision;
(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.
The full text of the *Voluntary Assisted Dying Act 2017* (Vic) is available here:
http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/$FILE/17-061aa%20authorised.pdf

undue influence are distinct legal issues, rigorous screening for undue influence at the time of assessing capacity for VAD has previously been endorsed[2] and we continue to adopt this approach. (Table 1).

What to do when the person requesting VAD has a mental illness

One of the challenges in capacity determination in VAD is the identification of mental illness and consideration of its effect, if any, on decision-making, particularly with regard to judgement or ability to use and weigh information concerning diagnosis, prognosis and risk. Under the Act, a person is not eligible for VAD solely on the grounds of mental illness. However, a person who otherwise meets the eligibility criteria – including because they have an incurable disease, illness or condition that will cause death – may also have mental illness.

Depression and delirium are the most common and relevant disorders to consider in people who make a request for VAD, although chronic psychotic disorders, such as schizophrenia are equally important to exclude. Overseas experience has been that undiagnosed depression remains an issue amongst those who request and are offered VAD in Oregon.[10] Given the prevalence of depression in advanced malignancy, organ failure and diseases, such as motor neuron disease, it is crucial that the doctor assessing the patient is able to identify depression to trigger a referral to a psychiatrist. Importantly, while the presence of depression or any other mental disorder does not preclude capacity for VAD, it does mandate careful assessment.[2] Regimes permitting VAD must ensure diagnosis of well-defined and treatable conditions is not missed and that clinicians can assess the effect of such mental illness on more complex components of decision-making. The Act requires a referral to a health professional with 'appropriate skills and training, such as a psychiatrist in the case of mental illness', when the doctor involved in assessing the person is unsure about their capacity.

What to do when the person requesting VAD has a neurodegenerative disorder

Section 9 (4) of the Act states if the person is diagnosed with a disease, illness or medical condition that is neurodegenerative, that disease, illness or medical condition must be expected to cause death within weeks or months, not exceeding 12 months (i.e. longer than the 6-month time period applied for all other diseases, illnesses or conditions: Section 9 (1)(d)).

Uncertainty of prognostication aside, it is clear that the very criteria for prognosticating death in the next 12 months for people with neurodegenerative diseases such as dementia (e.g. incontinence, loss of weight, mobility and speech) (Gold Standards Framework)[11] imply severe stage of disease. While each individual must be assessed on their own merits, capacity for complex decisions (e.g. driving, complex financial matters) can be lost as early as mild dementia.[3] Therefore, in a general sense, persons who have dementia of a severity that will render their prognosis 12 months or less are highly unlikely to have capacity to request VAD.

Caution is also advised in regards to requests for VAD by persons with motor neuron disease, which is frequently associated with cognitive impairment (especially executive function that affects decision-making and inhibition).[12] These are the very deficits that may affect capacity for VAD and yet may not be obvious to, or detected by, the clinician, unless the person's cognition and capacity are specifically assessed.

Supported decision-making

Principles of supported decision-making are recognised within the Act with a person having capacity if they can make a decision about VAD with 'practicable and appropriate support' (section 4 (4)). This support includes: (i) using information or formats tailored to the particular needs of the person; (ii) communicating or assisting a person to communicate their decision; (iii) giving the person additional time

Table 1 Guideline for clinicians assessing capacity and screening for undue influence for voluntary assisted dying (VAD)†

Capacity criteria	Rationale	Suggested stem questions
1. Can the person understand and retain information relevant to the decision to request VAD		
(a) Does the person understand the nature and extent of their illness and its prognosis?	This is a critical requirement for informed decision-making regarding any healthcare intervention.	What is your illness, and what do you understand about your prognosis and symptom course? What do you expect to happen from here?
(b) Does the person understand available treatments for their illness, and alternatives to VAD including palliative care and advance care planning; and the benefits of such?	Ensuring the person has access to palliative care and can understand the benefits is crucial. Undertaking advance care planning often provides a viable alternative in achieving a sense of autonomy and control to those wanting to end their life.[5] Pursuit of autonomy is a known reason for requests for assisted dying.[6] Appointing a decision-maker is very important to people with terminal illness[7] and it may be a "more achievable capable act" (i.e. requiring less cognitive reserve) than a more complex decision such as request for VAD.	What treatment are you currently receiving? Are you aware of the alternatives to VAD? Have you access to palliative care and are you aware of the benefits of such, particularly in regards to your specific symptoms, fears around dying and team based-supports for yourself and your carers/loved ones? Have you participated in advance care planning, and are you aware of the benefits of such?
(c) Does the person understand the method of VAD, and the consequences of the decision including the risks of adverse events? Has the person given any thought to the potential effect this choice may have on family and friends? Are there any specific cultural considerations relevant to this persons particular circumstances?	Overseas experience shows adverse events can include regained consciousness, and for oral methods, difficulty ingesting or regurgitation.[6] The previous proposed approach to capacity assessment included a consideration of the possible effects of VAD on family and friends.[2]	If you are given VAD, can you explain what you expect will happen? What are the risks of VAD? Are you aware of the possible complications and how likely they are to occur? Have you given any thought to the potential effect this choice may have on your family and friends? Are there any cultural considerations that are important to you that you think may be relevant to consider?
2. Can the person weigh the information and use reasoning to reach a decision?	Note that the decision does not need to be objectively reasonable; the person only has to show evidence of reasoning. Whether the clinician agrees with the decision or not is irrelevant to the assessment of capacity.	Tell me in your own words what you know about your illness and options, the potential consequences of VAD and why you have chosen VAD?
3. Is the decision consistent over time and with past expressed wishes and beliefs?	This is usually reflected in requirements in VAD regimes for the request to be 'enduring'. A person has the right to change their mind, but be wary of change of mind coincident with mental disorder.[3]	How long have you wanted VAD? Have you always supported assisted dying? For example, longstanding proponent of euthanasia, member of Dignitas or other similar organisation?
4. Can the person communicate their choices?	In cases where speech is impaired efforts should be made to support communication. Assessment and discussion should take place in the best possible environment and at the best time to maximise the patient's decision-making powers and to minimise the influence of others (see below).	–
5. In the VAD model as conceived, decisions must be truly autonomous, not obligatory to relieve others of burden. The decision must be free from undue influence, in so far as this can be achieved – such screening, especially for detecting undue influence, will never be infallible. Special care must be taken in relation to those dependent on others for care. Undue influence must be	Person should be assessed on their own, as with any capacity assessment. Older people, who from overseas experience, are likely to be the largest VAD users.[8] One risk for the clinician to be aware of is the vulnerability of older people to the perception of being a burden to family or society, as demonstrated in studies of attempted suicide in older people.[9] Families also suffer	Who first suggested VAD as an idea? Are you requesting VAD for yourself or others around you? If others, who will benefit from your VAD and what makes you think that?

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Table 1 *Continued*

Capacity criteria	Rationale	Suggested stem questions
assessed by having regard to both the person's strength of will and level of pressure being exerted by others.	vicariously from watching their loved one suffer and equally, and understandably, want to see an end to this suffering.[5,9] Clinicians can screen for these and other reasons for potential undue influence.	

†Different authorial expertise and views (e.g. consideration of effects of assisted dying on family and friends) mean that Table 1 reflects the position of authors CP and LS only.

and discussing the matter with them; (iv) using technology that alleviates the effects of the person's disability.

Aligned with contemporary human rights frameworks as articulated in the United Nations Convention on the Rights of Persons with Disabilities,[13] appropriate supports are fundamental to any capacity determination, and no person can be deemed to lack capacity if they have not been given sufficient information to weigh and consider, or practical supports for communication.[3,14] That said, while conceptually endorsing supported decision-making, we consider its application in the context of VAD gives rise to significant risks and should be approached cautiously. Supported decision-making in clinical contexts is in its infancy, with few guidelines available,[14] its many risks elucidated[15] and few doctors familiar with the process. While some aspects of supported decision-making may not be controversial (e.g. giving a person time to consider the decision or allowing them to use technology to communicate a decision), other aspects are. To illustrate, allowing one person to communicate or assist with communicating another's decision raises concerns about potential for undue influence, especially given the gravity of the VAD decision. We anticipate that, given the gravity of a decision about VAD, clinicians would proceed very cautiously, and consider the role and risks of supported decision-making be included in the training provided to health professionals.

The need for education of health care professionals

The Act recognises the need for 'approved assessment training' and there is provision for the Government to approve training including in relation to assessing a person's eligibility for VAD and 'identifying and assessing risk factors for abuse or coercion' (section 114). Both doctors involved in assessments under the Act are required to undertake this training before beginning that role. Furthermore, at least one of the doctors must also have relevant expertise and experience in the disease, illness or medical condition expected to cause the person's death, for example, the specific neurodegenerative disease or cancer. However, that expertise or experience in the specific illness does not equate with training and expertise in the assessment of capacity and undue influence. Furthermore, we note evidence of knowledge gaps in clinicians' understanding of capacity assessments.[16]

The Implementation Taskforce, which is overseeing the introduction of the Victorian VAD regime, will need to ensure that this education is expert-driven, outcome focused and tailored to the clinical and ethical task at hand. There is evidence that suggests clinicians find capacity assessment challenging, yet effective assessments of capacity and screening for undue influence are essential for the VAD regime to operate as intended.

Conclusion

At the centre of VAD legislation is the concept of choice; an ability, albeit within confines of the law, to choose to die and receive assistance with that. That choice presupposes a decision by a person who has capacity and is making their decision freely and voluntarily. For this reason, both capacity assessments and undue influence screening are conceived as integral safeguards for effective functioning of a VAD regime. As we noted at the outset, decisions of life and death are grave ones. We expect clinicians will approach their task to assess capacity in this setting cautiously. Health professionals involved in assessments for the purposes of this Act need to understand the determination of both capacity and undue influence and how risks of abuse might arise in this context. This must be done in a way that enables autonomy, safety and quality care at the end of life.

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