The Royal
Australian &
New Zealand
College of
Psychiatrists

Inquiry into the NSW Voluntary Assisted Dying Bill 2021 – November 2021

Improving the mental health of the community

Capacity Australia

27th January 2022

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To Members of the Standing Committee on Law and Justice,

During the inquiry I was asked to provide my Opening Statement, which I now enclose as requested but also to demonstrate the significant errors in the recording associated with the "audio-malfunction" in the transcript, which have misrepresented my evidence. I understand the instructions neither to change nor improve the words actually said during the hearing nor the grammar, and instead I rather provide corrections to clarify or amend any evidence which the transcript has incorrectly captured due to audio or other malfunction. Where I have provided whole paragraphs for correction, I do so due to multiple transcription errors, sometimes minor but still changing the meaning of my evidence and therefore requiring correcting. I therefore enclose the following:-

(i) My opening statement;

(ii) Corrections to the transcript where I have highlighted significant errors in the transcript followed by amendments which more accurately capture my evidence;

(iii) Response to the questions put on notice.

1. Opening Statement to the Inquiry by Professor Carmelle Peisah (UNSW Conjoint Professor; USYD Clinical Professor) President Capacity Australia

I am speaking as both a stakeholder representative and expert, on behalf of both the Royal Australian College of Psychiatrists and Australian Human Rights Charity, Capacity Australia of which I am founder and president. I do so because our positions on Voluntary Assisted Dying (may I with the Committee's permission, refer to this as VAD?) are aligned and because Capacity Australia has contributed to numerous such inquiries, including the NSW Legislative Council Inquiry and the ALRC reports on Elder Abuse, as well as being the nominated capacity and decision-making resource for a number of national bodies such as the Australian Aged Care Quality and Safety Commission. I am also co-author of the major AustLii text: Capacity and the Law.[1] I would like to inform the Committee

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[1] O'Neill N., Peisah C. (2021) Capacity and the law. 4th Edition Australasian Legal Information Institute (AustLII) Communities http://austlii.community/wiki/Books/CapacityAndTheLaw/.

that I have submitted several resources[2][3][4] to assist the Inquiry to which I will refer during my Statement and which I request to be Tabled.

My first point in my opening statement is that we applaud the considered and thoughtful manner in which the Committee has dealt with the amendments in the Consideration in Detail, and we support many of the stances, in particular:-

1. Firstly, we support the amendment Part 2 Division 16 conferring ineligibility by virtue of dementia, due to the complexity and seriousness of the VAD decision;
2. Secondly, we support negativisation of amendment Part 1 Division 3, linking lack of capacity with mental illness, while preserving Part 2, Division 16, conferring ineligibility based merely on the presence of mental illness. We, aligned with discussions documented in the Consideration in detail, make a distinction between eligibility for VAD being preserved **for people with mental illness** providing they have capacity, from VAD provided merely **because of mental illness**.
3. Thirdly, we support negativisation of the amendment regarding the actual Voluntary assisted dying substances – discussions of which we feel are clinical matters, not to be legislated. The complication rates discussed are extremely important and part of the role of practitioner and capacity assessor obtaining consent, to ensure that the patient has been provided with relevant information required to make decision, including treatment failures such as prolonged dying and side effects. By necessity this detail must be included in the requisite training for practitioners operating under the Act. We have outlined these obligations in the paper "The biggest decision of them all" .
4. Fourthly, we support the amendments in both Part 12 and Schedule 1 to reinforce abuse safeguarding by elaboration of the meaning of pressure or duress—including elder abuse and by strengthening recommendations for the training in relation to this matter. Again to refer to comments in the Consideration in detail, while not suggesting that all older people are vulnerable, we have a special duty to make sure that the interests of those older or other vulnerable people are protected and that there is no suggestion that they might be acting under any duress or that elder abuse, or other abuse of vulnerable people. We refer the Committee to the papers "*Biggest Decision of them all*" and the "*The nexus between elder abuse, suicide, and assisted dying*".

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[2] Peisah C, Sheahan L, White B. (2019) The biggest decision of them all - death and assisted dying: capacity assessments and undue influence screening. Intern Med Journal 49(6):792-796.

[3] Peisah C, Sampson EL, Rabheru K, Wand A, Lapid M. The human rights of older people with mental health conditions and psychosocial disability to a good death and dying well *The American Journal of Geriatric Psychiatry* 2021 May 30:S1064-7481(21)00342-0.

[4] Wand A., Peisah C. Draper B, Brodaty H (2018) The nexus between elder abuse, suicide, and assisted dying: the importance of relational autonomy and undue influence Macquarie Law Journal 18: 79-92

Our only residual concerns are three-fold

Firstly, we do not think that Part 1, Division 2, Subdivision 4 Principles protects older people and people with disability enough. While we applaud the amendment to Clause 4(1)(i) regarding those living in rural and residential areas, we strongly suggest that an additional clause (j), be added regarding *residents of both aged care and residential disability facilities having entitlements to the same level of access to high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life, as persons not residing in such facilities.*

We note both the recent Royal Commission into Aged Care and Quality and Safety, and the follow up NSW Legislative Council Inquiry into provisions of the Public Health Amendment Bill (Registered Nurses in Nursing Homes, 2020) to investigate understaffing and the need for mandated Registered Nurses in residential care to provide comprehensive care, including management of pain and other forms of distress and suffering. The deficits in palliative care for older Australians in residential care facilities have thus been well-documented and for some constitutes elder abuse by neglect, with violation of the human right to be protected against abuse, torture and cruel, degrading treatment, as stated in the international paper "*The human rights of older people with mental health conditions and psychosocial disability to a good death and dying well*". As noted in this paper, we also cannot forget the human rights to quality end of life care owed to the even more invisible and neglected Australians living with intellectual and physical disabilities in care facilities. From the Consideration in detail. I can see we are all in agreement that we cannot be providing access to VAD as a solution to inadequate care, or be prioritizing access to VAD over the human right to access to highest quality of health care at the end of life and human right to relief of pain and suffering. These issues are even more acute now as highlighted in the Consideration in Detail in the face of the biggest public health crisis that New South Wales has ever faced.

2. Our second concern is our disagreement with the negativisation of the amendment to delete the Part 2, Division 16, reference to the presumption of capacity. We agree with the arguments outlined in the Consideration in Detail, as experts in capacity and the law, that noting the Presumption is contradictory to the starting point used in the Act of this being a rebuttable presumption, appropriately so due the severe and life-threatening illness faced by patients seeking VAD. Further, we agree that this reference to the presumption of capacity is confusing for capacity assessors, given our empirical research internationally regarding the deficits in doctors understanding of law and capacity. I can say with considerable expertise in this area, that the majority of - doctors would never

have even heard of presumption of capacity. As stated in the Consideration, to place reference to this common law concept in a bill where the consequence of the decision being made is death, when we are given a mandate of actively establishing capacity, is both unnecessary and unhelpful.

3. My final point is that we agree with the concerns expressed in the Consideration in detail, as stated, that we ensure that proposals to promote VAD do not undermine efforts to prevent suicide for all, particularly for older people and most so for men over 80 – amongst whom have the highest rates of suicide – often due to untreated depression, pain and medical illness, despite ageist assumptions that advanced age per se renders life not worth living.

Thankyou

2. Corrections to the transcript to correct audio malfunction

1. Page 28, last paragraph, please omit:

are critical matters not to be legislated.

Please replace with

are clinical matters, not to be legislated.

2. Page 29, paragraph 1, Omit

Fourthly, we support the amendment in both part 12 and schedule 1 to reinforce cognitive safeguarding by elaboration of the meaning of pressure or duress

Replace with:

Fourthly, we support the amendments in both Part 12 and Schedule 1 to reinforce abuse safeguarding by elaboration of the meaning of pressure or duress

3. Change page 29, paragraph 4,

From ”I can see we are all in agreement that we cannot be providing access to VAD as a solution to inadequate care or in prioritising access to VAD

To

I can see we are all in agreement that we cannot be providing access to VAD as a solution to inadequate care or be prioritising access to VAD

4. Replace page 29, para 5:

As experts in capacity in the law that [audio malfunction] the presumption is contradictory to the starting point using the act of this being a rebuttable presumption, appropriately so due to the severe and life-threatening illness faced by patients seeking VAD. Further we agree that this requisite to the presumption of capacity is confusing with [disorder].

Replace with

As experts in capacity and the law, that the presumption is contradictory to the starting point used in the Act of this being a rebuttable presumption, appropriately so due the severe and life-threatening illness faced by patients seeking VAD. Further, we agree that this reference to the presumption of capacity is confusing for capacity assessors, given our empirical research internationally regarding the deficits in doctors understanding of law and capacity.

5. Change page 40, paragraph 5 from:

What concerns us at the college and myself as a subject matter expert is that my understanding from the original Victorian legislation is that the neurodegenerative diseases, or may have asked for in the original legislation, was for motor neurone disease. The issue around dementia, which is in fact a neurodegenerative disease, is that the complexity of the VAD decision, as defined in our paper, makes decisions, which is the biggest decision of them all, using the Commonwealth threshold concept of capacity would be the hardest decision to make, but it would be precluded by a diagnosis of dementia. I am speaking as an international expert in this area, but I would have the backing of my colleagues around the world. Because of the complexity that has arisen in the Netherlands and Belgium on issues around dementia around voluntary assisted dying, the nature of the complexity of the decision for voluntary assisted dying renders dementia as a diagnosis and not an appropriate neurodegenerative disorder that would render eligibility for VAD.

To

What concerns us at the College and myself as a subject matter expert is that dementia should be specifically excluded as a neurodegenerative disease conferring eligibility for VAD. My understanding from the original Victorian legislation is that the intent of the original reference to neurodegenerative disease was in regards to motor neurone disease. The issue around dementia, which we would also call a neurodegenerative disease, is that it implicitly involves significant cognitive decline likely to render lack of capacity for VAD due to the complexity of the VAD decision, as defined in our paper, the Biggest Decision Of Them All. This relies on the Common Law threshold concept of capacity, which suggests that the more serious, highest risk decisions require a higher threshold of capacity, VAD being the hardest and biggest decision to make. I am speaking as an international expert in this area but I would have the backing of my colleagues around the world. Because of the complexity that has arisen in the Netherlands and Belgium on issues around dementia around voluntary assisted dying, the nature of the complexity of the decision for voluntary assisted dying, would preclude dementia as a neurodegenerative disorder that would render eligibility for VAD.

Questions on notice:

Question: Page 34 The CHAIR: To aid that, Professor, I will ask you if you could provide a link to the training and the items that you have just identified from the Queensland University of Technology. It sounds like you are happy to take that question on notice

Response: Professors Ben White and Lindy Willmott with colleagues at Queensland University of Technology (QUT) Australian Centre for Health Law Research were contracted by the Victorian, Western Australian and Queensland Governments to design and deliver the training that doctors and nurses involved in VAD must first complete. This training was developed because it is mandated by the legislation in each of these 3 States – the NSW VAD legislation also includes this same training requirement. The team that developed this training have unique skill sets which includes legal experts in VAD and end of life law and regulation; as well as palliative care nursing expertise, medical expertise in VAD and expertise in online training design for health professionals.

The Victorian training has been operational for over two years and the team has published an article on the design process in the Journal of Palliative Care – link available here: Development of voluntary assisted dying training in Victoria, Australia: A model for consideration. (also https://eprints.qut.edu.au/203083/1/Development_of_Voluntary_Assisted_Dying_Training_in_Victoria_Australia_manuscript_.pdf) The WA training has been operational for over 6 months and the Queensland training is being developed.

In addition to the legislatively-mandated VAD training above, they have also developed the online training program End of Life Law for Clinicians. This program, which is funded by the Commonwealth Government, has had over 20,000 modules completed in less than 2 years by a range of health professionals. This program now includes training on VAD, as well as legal issues across the end of life field (e.g. capacity, consent, substitute decision-making, palliative care).

The team are also part of the End-of-Life Directions in Aged Care program (also funded by the Commonwealth Government) and through this program provide online training for those working in aged care about end-of-life legal issues. This also includes training about VAD.

Carmelle Peisah

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Special Issue Article

The Human Rights of Older People With Mental Health Conditions and Psychosocial Disability to a Good Death and Dying Well

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ABSTRACT

The human right to a good death and dying well is as important as the right to life. At stake at the end of life are human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are vulnerable to "bad deaths" due to violations of these rights. In this paper we explore why this is so and examine existing and potential solutions. A human rights-approach to end-of-life care and policy for older persons with mental health conditions and psychosocial disability is one that is needs-based, encompassing physical and mental health, palliative care, social, and spiritual support services provided in the context of inclusive living. Most importantly, end of life care must be self-determined, and not "one size fits all." An important remedy to existing violations is to strengthen human rights frameworks to cater specifically to older persons' needs with a UN convention on the rights of older persons. Finally, as health professionals we have important contributions to make at the coalface by accepting our responsibilities in the area of death and dying. With the concept of the palliative psychiatrist gaining traction and recognition that death is our business, we add that human rights is also our business. (Am J Geriatr Psychiatry 2021; ■■:■■–■■)

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Highlights

- What is the primary question addressed by this study?—We explore why older people with mental health conditions and psychosocial disabilities are vulnerable to human rights violations at the end of life and examine existing and potential solutions.
- What is the main finding of this study?—Key to best practice end of life care are the actualization of human rights to dignity, autonomy, self-determination and respect for will and preferences, equitable access to quality health care that is needs-based, and respect for family and relationships. Older people with dementia, those with serious mental illness, and those with intellectual disability are variably afforded these rights at the end of life.
- What is the meaning of the finding?—An integrated care model that encompasses physical and mental health, palliative care, social and spiritual support must be on offer, while recognizing that good dying is needs-based and self-determined.

The human right to a good death and dying well is as important as the right to life. However, what constitutes a “good death” remains elusive, varies from individual to individual, depending on whose perspective it is viewed from, the person, the family or the health professional.[1−3] In 1997, the Institute of Medicine (now National Academy of Medicine) defined a "decent or good death" as one “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards;" and a "bad death" as characterized by “needless suffering, disregard for patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended."[4]

The divergent perspectives on these concepts mandates a person-centered, self-determined approach[5] at the core of human rights to autonomy, self-determination and respect for will and preferences. However, equally important at end of life are human rights to dignity, equitable access to highest attainable standards of health (including respecting needs arising on account of disability) and respect for family and relationships.[6−8] As articulated in the Convention on Rights of Persons with Disabilities (CRPD),[9] actualization of these rights and the enjoyment of a positive death are equally owed to persons with disability, including older people with mental health conditions and those living in care settings, who are especially vulnerable to human rights violations. In this paper, we outline why this is so and explore potential for enjoyment of human rights to positive dying for older people with mental health conditions and psychosocial disabilities. We conclude with recommendations to drive future care and policy in this area.

Why are older people with mental health disorders vulnerable to experiencing bad deaths? Although just as with good deaths, a bad death for one person is not a bad death for another,[5] usually bad deaths are those that come as a surprise due to lack of communication with health practitioners and lack of advance care planning (ACP), and are associated with unrelieved symptoms and suffering, and unmet needs.[10−12] With regards to surprises, there has been a concerted effort to get conversations started regarding end of life for people with dementia for over 20 years. For example, The Gold Standard Framework, developed the Surprise Question (Would you be surprised if this patient were to die in the next 12 months?) to facilitate discussions between health professionals and persons with dementia and their carers to assess needs, symptoms and preferences to plan care.[13]

A range of initiatives encouraging ACP in care settings including early timely discussions, upskilling of staff and family conferencing have flourished, giving voice to people with dementia at the end of life and challenging paternalistic assumptions that they lack capacity to do so.[10,14,16−18] Aligned with Article 12 of the CRPD, those with impaired capacity have been afforded supported decision making.[19−21] Further hope is inspired by initiatives to increase access to and optimize palliative care in long-term care[12,22−25] and to address suffering and symptom relief, including management of delirium and pain in both care and acute hospital settings.[26−30]

Providing quality death and dying for older persons with mental illness is another matter. If we consider that persons with dementia, particularly those in care settings, are at risk of suboptimal end-of-life care,[31,32] efforts for those with severe and chronic mental illness are almost non-existent.[33] Despite poorer physical health and increased and premature mortality rates compared to the general population,[34,35] people with severe or chronic mental illness have less access to palliative care and mental health services, and parlous rates of ACP.[36,37] These are clear violations of human rights to dignity (Articles 1 and 3, CRPD) autonomy (Article 12) and equitable access to health (Article 25).

Acknowledging rights to autonomy, self-determination and respect for will and preferences, people with severe and chronic mental illness have been “utterly neglected” in efforts to promote ACP[38] and their needs and desires with regards to end of life care ignored.[39] This is often compounded by lack of understanding amongst physicians about capacity and human rights, including the common law presumption of capacity for all adults regardless of disability, and the assessment of capacity for end of life decision making.[40] Yet people with severe mental illness can give voice to end of life preferences[41] and are equally owed rights to self-determination.[42]

Systemic barriers to the enjoyment of human rights fueled by discrimination based on ageism and “mentalism” [7] exist across health and mandate systemic solutions. Such solutions include public mental health initiatives such as the *"Do It Your Way"* project, which integrates service delivery components such as stakeholder coalition, research, education, training and outreach for providers and patients to improve access to ACP and end-of-life care for persons with serious mental illness.[43] Sometimes positive discrimination associated with frailty, often comorbid with serious mental illness,[44] can serve human rights. Frailty agenda in care services can serve as useful levers to ensure equitable access to both quality care and advance planning. For example, in the United Kingdom, frailty pathways, particularly those underpinned by the Comprehensive Geriatric Assessment[45] often include ACP and recognition that someone may be reaching end of life.

These complexities are echoed for older people with intellectual disability (ID) living in community care, often exposed to death and dying yet rarely given opportunity to express end of life will and preferences.[46,47] Assumption of lack of capacity by clinicians[48] based on often partial understanding about the end of life amongst older people with ID[49] compounded by communication difficulties,[50] mean that they are often totally excluded from end of life decision-making.[51] However, burgeoning research supports a more nuanced, supported approach to end of life care and decision-making for people with ID. For example, in care settings, understanding client responses to the death of other clients, which often fuel anticipatory grief reactions regarding their own death, provide opportunities to talk about death and dying.[49,52] Weise et al.[49] identified opportunities to engage in such discussions including 'when family die', 'incidental opportunities', 'when clients live with someone who is dying' and 'when a client is dying'. These are all opportunities for supported decision making. Death with dignity and autonomy in a place of one’s choice is equally owed to people with ID.[52]

CONCLUSIONS

It goes without saying that bad deaths are bad for the dying person, but equally, bad deaths are bad for the mental health of families,[53] and for the moral distress of staff.[54] The experience of death and dying for many older people with mental health conditions has constituted elder abuse by neglect, and violated rights to be protected against abuse or torture and cruel, degrading treatment (Articles 15 and 16 CRPD). Medical assistance in dying (also referred to as Voluntary Assisted Dying, VAD) is not the solution. VAD should not be used as a substitute for humane end of life care, nor should it be a means for relieving family burden.[55] These violations have been worsened by the “tsunami of suffering” associated with the COVID pandemic, where quality dying has gone by the wayside.[56] Access to palliative care has been curtailed by demands on health systems, support from loved ones restricted, and nuanced ACP abandoned in favor of hasty and pragmatic “signing people up” with not for resuscitation orders to assist with triaging.[6]

However, many of the initiatives we have described above suggest hope. None of these challenges to quality dying are insurmountable. We offer the following human rights-based recommendations to guide care and policy for older persons with mental health conditions and psychosocial disability approaching the end of life:

1. An integrated care model that encompasses physical and mental health, palliative care, social and spiritual support must be on offer, while recognizing that good dying is needs-based and self-determined, i.e., based on what the person needs and wants at the end-of-life; [57]
2. The model of care must be provided in a context of inclusive living options and a hierarchy of self-determined care environments, not "one-size fits all"[58];
3. Health care systems must expand their focus of attention from current acute medical and surgical based models for older persons requiring end of life care to holistic chronic care models that optimize quality of life;
4. VAD is a complex and deeply personal issue. Governments must be committed to ensuring that laws governing VAD meet evolving needs, autonomy and freedom of choice, and right to safeguarding of those who are vulnerable. It is equally incumbent upon clinicians involved in capacity assessment for VAD to be mindful of these human rights obligations[59];
5. Develop and implement human rights-based policies and programs in the community and in health care to combat ageism and mentalism. Strengthen human rights frameworks to cater specifically to older persons' needs by supporting a UN convention on the rights of older persons.[7]

Our best contributions as health professionals can be made at the coalface by accepting our responsibilities in the area of death and dying. The concept of the "palliative psychiatrist" (i.e. with palliative care skills) is receiving traction[60,61] as we increasingly recognize that death is our business.[62] We would add that human rights is our business.[7]

AUTHORS' CONTRIBUTION

All authors have made contributions to the conception, drafting, editing, revision for intellectual content and final approval of the manuscript and have agreed to be accountable for all aspects of the work.

DISCLOSURES

None of the authors have any conflicts to declare.

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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?

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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