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Advances and Challenges in the Assessment of Decision-Making Capacity in Older Adults

Heather M. Francis, Combined PhD/ MClinNPsy[a,b,*], Lise Barry, PhD/LLB (Hons), BA Soc Sc[c], Vincent Oxenham, DPsych (Clin Neuro)[a,b], Travis A. Wearne, Combined PhD/ MClinNPsy[a]

[a]School of Psychological Sciences, Lifespan Health and Wellbeing Research Centre, Macquarie University, North Ryde, New South Wales, Australia; [b]Neurology Department, Royal North Shore Hospital, St Leonards, New South Wales, Australia; [c]Macquarie Law School, Lifespan Health and Wellbeing Research Centre, Macquarie University, North Ryde, New South Wales, Australia

KEYWORDS

• Decision-making capacity • Older adults • Voluntary assisted dying • Fitness to stand trial

KEY POINTS

- Assessment of decision-making capacity is a complex and multifaceted process, requiring a thorough understanding of legal principles, medical evaluations, and ethical considerations.
- Assessors must balance the need to protect individuals from harm with the need to respect their autonomy and right to make decisions.
- Older adults are more susceptible to impaired decision-making capacity, due to the impact of aging and neurodegenerative diseases on cognitive processes involved in decision-making.
- Voluntary assisted dying and assessment of fitness to stand trial pose specific challenges in respecting individual autonomy and providing appropriate safeguards.

INTRODUCTION

The assessment of decision-making capacity (DMCA) is a critical aspect of legal and medical practice, particularly when it involves individuals with cognitive impairments who wish to execute a Will, or to appoint someone who can make decisions for them in the future, should they experience serious cognitive impairment. In the United States, this is known as a Durable Power of Attorney, or in Australia as the appointment of an enduring guardian (EG) or enduring power of attorney (EPOA). These legal instruments are essential for ensuring that the personal, financial, and health care decisions of individuals who may experience increased cognitive impairment in the future are made in accordance with their wishes. However, the process of DMCA is complex and requires a nuanced understanding of both legal principles and medical evaluations [1]. This article will provide a background to the legal framework for the assessment of DMCA and will review the 3 most common and complex contexts where DMCA in older adults might be relevant.

Legal Framework and Principles

The legal framework governing DMCA varies across jurisdictions, but there are common principles that underpin the process globally. Capacity is generally defined as

*Corresponding author. School of Psychological Sciences, Macquarie University, 16 University Avenue, North Ryde, NSW 2091. *E-mail address:* heather.francis@mq.edu.au

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ABBREVIATIONS	
AD	Alzheimer's disease
DMCA	decision-making capacity
EG	enduring guardian
EPOA	enduring power of attorney
VAD	voluntary-assisted dying

the ability to understand, retain, and weigh relevant information to make a decision, and to communicate that decision [2]. This definition aligns with the principles outlined in the Convention on the Rights of Persons with Disabilities [3], which emphasizes the importance of autonomy and the right to make decisions. In many jurisdictions, this includes supported decision-making [4], allowing a person to make their own decisions with the support of a trusted adviser.

The law presumes that adults have capacity unless proven otherwise. This presumption is crucial in protecting the autonomy of individuals and ensuring that they are not unjustly deprived of their decision-making rights [5]. However, when there is a concern about an individual's cognition, or fear of a potential legal challenge, a formal assessment is best-practice and can inform a legal determination about whether to impose a substitute decision-maker. This assessment must be decision-specific, meaning that capacity must be evaluated in relation to the particulars of the decision at hand, rather than as a general attribute. A person may have capacity for some decisions, but not others.

Who Can Assess Capacity?

DMCA can be conducted by various professionals, depending on the jurisdiction and the context of the decision. Typically, medical practitioners, such as general practitioners, psychiatrists, and neurologists, are involved in assessing capacity. In some cases, psychologists and neuropsychologists may also play a role, particularly when the assessment involves complex cognitive evaluations.

Case Example

To illustrate the complexities involved in capacity assessment, consider the case of John, an 85 year old gentleman who wanted to revoke his existing EG and EPOA and appoint new ones. John had previously nominated his son as his EG and EPOA, and his son was also a 50% beneficiary in his Will. However, John recognized that his daughter had been his primary carer for several years and wished to acknowledge her contributions by appointing her as his new EG and EPOA. John also wanted to amend his Will to reflect these changes.

John's son, however, indicated that he would dispute any new EG or EPOA and contest the validity of any new Will in court. He argued that John's previous diagnosis of Alzheimer's disease (AD) meant that John lacked the capacity to make these changes. This scenario highlights the potential for conflict and the importance of a thorough and objective capacity assessment.

Ethical Considerations

The ethical considerations in capacity assessment are significant. Assessors must balance the need to protect individuals from harm with the need to respect their autonomy and right to make decisions. This balance is particularly delicate when dealing with individuals with cognitive impairments, as there is a risk of either underestimating or overestimating their capacity.

One of the key ethical principles is the least restrictive alternative, which means that any intervention should be the least restrictive option available to achieve the desired outcome. This principle is enshrined in many legal frameworks and is crucial in ensuring that individuals retain as much autonomy as possible.

International Perspectives

The approach to capacity assessment and the legal instruments of EG and EPOA vary internationally. In the United States, for example, the *Uniform Power of Attorney Act* (2006) [6] provides a comprehensive framework for the creation and use of powers of attorney, including provisions for assessing capacity. In the United Kingdom, the *Mental Capacity Act* [7] sets out the legal framework for assessing capacity and making decisions on behalf of individuals who lack capacity. In Australia, the laws governing EG and EPOA are state-based, with each state having its own legislation and guidelines for capacity assessment [8]. Despite these differences, the underlying principles of autonomy, protection, and the least restrictive alternative are common across jurisdictions.

The assessment of DMCA for individuals with cognitive impairments who wish to appoint an EG or EPOA is a complex and multifaceted process. It requires a thorough understanding of legal principles, medical evaluations, and ethical considerations. By ensuring that capacity assessments are conducted rigorously and fairly, we can protect the rights and autonomy of individuals while providing the necessary safeguards to prevent harm.

This introduction sets the stage for a deeper exploration of the impact of neurodegenerative conditions on DMCA, the specific legal frameworks in different jurisdictions, and the practical challenges in assessing capacity in various contexts. Through case examples and expert insights, this article aims to provide a comprehensive overview of the current state of capacity assessment and its implications for professional practice and interdisciplinary cooperation.

CHALLENGES ASSOCIATED WITH DECISION-MAKING CAPACITY IN OLDER ADULTS WITH NEURODEGENERATIVE CONDITIONS

As described earlier, capacity is generally defined as the ability to understand, retain, and weigh relevant information to make a decision, and to communicate that decision. Impairments in cognition can impact on these abilities in a multitude of ways. For example, deficits in attention can affect an individual's ability to focus on new information, memory difficulties will impact an individual's ability to understand and retain new information related to a decision, executive dysfunction can impair a person's ability to weigh up the options in terms of their consequences, and expressive language may impact on ability to communicate a decision [9]. Thus, older adults can be more susceptible to impaired DMCA in the context of neurodegenerative disease impacts on the aforementioned cognitive domains [10]. DMCA in people with neurodegenerative diseases is often referred specifically to neuropsychologists, due to their specialized expertise in understanding the impact of brain-based disorders on cognitive function and subsequent impacts on decision-making.

Currently, it is estimated that 55 million people worldwide have a diagnosis of a neurodegenerative disease, with nearly 10 million new cases annually [11]. As the incidence of neurodegeneration continues to rise with the aging population, it is anticipated that health care professionals will increasingly be called upon to conduct DMCAs in the years ahead [12]. Health care professionals confront several challenges in assessing DMCA in the context of neurodegenerative diseases, with the subsequent section aiming to address these.

One of the key challenges of assessing DMCA in the context of neurodegenerative disease is that there is a wide spectrum of neurodegenerative diseases, with differing underlying pathologies. And as such, there are differing trajectories of cognitive deterioration. Indeed, in some conditions such as Parkinson's disease, cognitive impairments may develop very late in the disease course or not at all [13]. Thus, having a diagnosis of a neurodegenerative disease is not synonymous with lacking DMCA. Furthermore, due to the slow and gradual progression of cognitive deficits, it is not even the case that having an neurodegenerative disease together with cognitive impairment means that a person lacks DMCA. To add to the complexity, some neurodegenerative diseases such as dementia with Lewy bodies, are characterized by fluctuating cognition [14], which raises the question of when to assess capacity.

Another challenge in conducting DMCA in neurodegenerative diseases is the lack of any standardized assessment tools. While efforts to create such a tool have been made, and a systematic review has shown that the use of a tool does improve consistency among clinicians when conducting DMCA [15], no tool has been developed that is flexible enough to cover the complexities and diverse range of scenarios posed in DMCA. Even if there was a standardized tool, it would require some adaptation to fit the context-specific nature of the decision at hand. For instance, for medical decision-making surrounding leg amputation, nuances such as the patient's specific medical risk factors that could contribute to likelihood of complications following surgery, or level of family support and home modifications required could not be preempted in a standardized tool, yet would all be key considerations in assessing the patient's ability to understand and weigh up the risks and benefits of the potential surgery. Furthermore, while there is a general consensus in the literature regarding the key cognitive domains that should be evaluated during DMCA (particularly, attention, memory, and executive functions) [16], there are no specific cognitive tests that apply across all scenarios. Thus, while cognitive abilities play a pivotal role in the assessment of DMCA, they must not be considered in isolation. Indeed, an individual may demonstrate cognitive impairments, or have a diagnosis of a neurodegenerative condition, and yet retain DMCA [17]. This is particularly the case for less complex decisions. For instance, managing day-to-day finances for groceries is vastly different to being able to manage a stock portfolio. Thus, the evaluation of an individual's capacity to make decisions (despite both of these being financial decisions) necessitates a broader, multidimensional approach that goes beyond cognitive test scores [18]. Given the inherently contextual nature of DMCA, the individual's specific circumstances and situational factors must be integrated into the overall assessment [19].

The considerations in DMCA, of ensuring an individual's rights to autonomy, while simultaneously

protecting vulnerable individuals from making potentially harmful decisions are potentially more salient in individuals with neurodegenerative diseases. They are inherently more vulnerable, meaning informed consent takes on even greater importance, yet is also more difficult. We recommend the early involvement of health care professionals with a deep understanding of both the presentation of neurodegenerative diseases and the assessment of cognition, such as clinical neuropsychologists, to be involved when undertaking DMCA. Early assessment of cognition and behavior can aide in identifying the need to modify the approach and assessment to accommodate for physical, sensory, or cognitive deficits. For example, a patient may have impaired verbal learning and memory, but intact visual learning and memory; thus, accommodations can be made such as the provision of images or flow charts. Or the patient may have expressive aphasia, meaning they are unable to communicate their preferences verbally, in which case, we would recommend supported decision-making using visual multiple-choice response options.

Case Example

Revisiting the case of John, the 85 year old gentleman with a diagnosis of AD whose son argued that his diagnosis meant he lacked the capacity to appoint an EG and EPOA and change his Will. John's solicitor sought the opinion of a clinical neuropsychologist. Neuropsychological testing revealed visuospatial deficits, impaired performance on one test of executive functioning, and low average delayed recall of verbal information. However, he was oriented and performed within normal limits across most cognitive domains. On interview, he demonstrated being able to explain the concept of an EG and EPOA, and his reasoning for appointing his daughter. He provided a good explanation of what a Will is, demonstrated reasonable knowledge of his assets and their worth, and was able to express his reasoning for making changes compared to his previous Will. The neuropsychologist's opinion was that despite his diagnosis of AD *and* demonstrated mild cognitive impairments, he retained capacity to make those decisions.

NEW CHALLENGES: DECISION-MAKING CAPACITY IN THE CONTEXT OF VOLUNTARY ASSISTED DYING

Building upon the existing framework of DMCA in the context of neurodegenerative conditions (NDs), it is crucial to examine the specific complexities associated with capacity assessment for voluntary assisted dying (VAD). The assessment of DMCA in VAD represents one of the most complex and consequential evaluations health care professionals may encounter. Despite variations and nuances in eligibility criteria and assessment procedures of VAD, in countries and jurisdictions where the legislation has been implemented, a thorough capacity assessment serves as a critical safeguard while ensuring eligible individuals can exercise their autonomous rights [20,21].

Key Considerations for the Assessment of Capacity in Voluntary Assisted Dying

The assessment of DMCA for VAD builds upon the general principles of capacity assessment frameworks, examining understanding, retention, weighing, and communication of decisions, but requires enhanced scrutiny due to its irreversible nature [20]. Comprehensive capacity assessment for VAD demands evaluation across 3 key domains. First and foremost, the assessment must be specifically tailored to the decision to pursue VAD and to the gravity and finality of the VAD decision. Clinicians must focus specifically on the patient's ability to understand, retain, and weigh information related to VAD, as well as communicate their decision [20]. While cognitive impairment does not automatically preclude capacity to make decisions about VAD, a thorough cognitive assessment is crucial and should include evaluation of attention, memory, executive function, and language skills.

Second, psychological evaluation must distinguish between appropriate emotional responses to terminal illness and clinical conditions that might impair judgment. Mental illness, including depression, also does not automatically disqualify individuals from making decisions about VAD; rather, the impact of any condition on DMCA requires specific evaluation. The temporal stability of decision-making becomes paramount in these situations, requiring verification that the decision remains consistent rather than fluctuating with circumstantial or mood changes [20].

Third, social and contextual factors require careful consideration to identify any undue influence while respecting cultural approaches to decision-making [20,22]. For example, health care providers must consider power dynamics in relationships, such as when a spouse who is the primary caregiver expresses strong views about VAD that appear to influence the patient's stated preferences or, in some cases, financial pressures that may manifest subtly, such as when family members repeatedly emphasize inheritance concerns or the cost of ongoing care during VAD discussions. Conversely, in multicultural contexts, involvement of

the broader family, religious leaders or community elders may play significant roles in decision-making processes and should not be misconstrued as coercion that, while potentially appearing as external pressure from a Western perspective, represents culturally valid and important support systems for the individual. The key distinction lies in evaluating whether external influences support or undermine the individual's authentic wishes while respecting cultural frameworks for decision-making.

In summary, the key considerations in VAD capacity assessments include cognitive evaluation, understanding and retention of VAD principles, ability to communicate desired wishes, voluntariness, emotional state, cultural considerations and consistency of wishes over time [20,22]. Patients must demonstrate a clear grasp of the VAD process, palliative and treatment alternatives, and consequences, and assessors must be vigilant for any undue influence or coercion affecting the patient's decision [20,23]. Given the significance and irreversible nature of the decision, it is important to assess the consistency of the patient's wishes over multiple sessions [20].

Capacity Assessment of Voluntary Assisted Dying in People with Neurodegenerative Conditions

The application of VAD in neurodegenerative conditions presents unique challenges, particularly regarding capacity assessment and timing of decisions. While most countries exclude conditions such as AD and other form of dementias from their VAD eligibility criteria, international experience, particularly from the Netherlands, Belgium, and Canada, provides valuable insights for future policy considerations [24].

The Netherlands and Belgium have allowed VAD for neurodegenerative conditions since 2002 [24,25] requiring individuals to demonstrate capacity at the time of request and establish clear advance directives. Dutch data indicate that VAD cases involving neurodegenerative conditions come primarily from individuals with amyotrophic lateral sclerosis and Huntington's disease [26,27]. To date, VAD in dementia constitutes a small proportion of all Dutch and Belgian cases [28]. Dutch practice emphasizes the role of advance care planning, allowing individuals to make VAD decisions while capacity remains intact, though implementation must occur while the person can still confirm their wishes [29].

Canada's approach, through Medical Assistance in Dying, initially excluded neurodegenerative conditions but expanded access in 2021 [30]. Their model requires detailed capacity assessment protocols specifically designed for neurodegenerative conditions, with neuropsychological evaluation and continued assessments across various time points. However, controversy remains regarding the timing of decisions, particularly for conditions with fluctuating capacity. Critics argue that allowing VAD in neurodegenerative conditions might create pressure on vulnerable individuals. However, data from jurisdictions with established programs show no evidence of a disproportionate impact on vulnerable populations [31]. The key appears to be robust safeguards and clear assessment protocols. These could include integrating the role of advance care planning in VAD decisions, comprehensive neuropsychological assessment, evaluation of the consistency of the decision at multiple time points, and a "cooling-off period," which gives patients mandatory waiting periods between requests to ensure the decision is well-considered and consistent.

Cultural Considerations in Capacity Assessment for Voluntary Assisted Dying: a Focus on Diverse Australian Populations

The assessment of DMCA for VAD in culturally diverse populations requires careful consideration of cultural, linguistic, and social factors that influence end-of-life decision-making. For illustration of these principles, we will focus on Australia's multicultural composition, including Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities, necessitating a nuanced approach to capacity assessment that extends beyond traditional Western medical frameworks [32].

Traditional capacity assessment tools, developed primarily within Western medical paradigms, may not adequately capture the complexity of decision-making processes in diverse cultural contexts. Research indicates that cultural beliefs, values, and practices significantly influence how individuals understand illness, death, and medical decision-making [32]. For instance, many cultures emphasize collective decision-making processes that involve family members and community leaders, contrasting with Western medicine's focus on individual autonomy [33]. This could be an ambiguous factor to assess in the context of excluding undue influence on patients from culturally and linguistically diverse backgrounds when they make VAD-related decisions.

Aboriginal and Torres Strait Islander peoples' approaches to health care decisions typically involve collective wisdom and cultural protocols. Connection to country, spiritual beliefs about the journey after death,

and the role of elders in decision-making processes are fundamental considerations that impact capacity assessment [34]. The historical context of health care engagement among Aboriginal and Torres Strait Islander peoples profoundly influences current health care interactions. Generations of trauma from colonization, forced removal from country, displacement from traditional healing practices, and institutional discrimination have created deep-seated mistrust in Western health care systems. This history, combined with ongoing experiences of systemic racism and culturally unsafe practices, has contributed to significant health disparities and barriers to health care access. Understanding this context is crucial for health care providers, who must prioritize cultural safety, build genuine trust through respectful engagement with community protocols, and recognize the validity of traditional healing knowledge alongside Western medical practices in the assessment process [35–37].

Similarly, culturally and linguistically diverse communities present distinct considerations in capacity assessment. For instance, key factors affecting capacity assessment in culturally and linguistically diverse populations, can include linguistic barriers, cultural beliefs about death and dying, familial hierarchies in decision-making, and varying levels of health literacy. As such, traditional capacity assessment tools may underestimate decision-making ability when language barriers or cultural differences influence communication styles.

Language and communication emerge as critical factors in capacity assessment across diverse populations. While interpreter services provide essential support, direct translation alone may not capture cultural nuances in understanding and expressing health care decisions [38]. Cultural concepts of illness, death, and end-of-life care often lack direct equivalents across languages, requiring careful consideration in capacity assessment protocols [39].

Religious and spiritual beliefs significantly influence end-of-life decision-making across various cultural groups. Rego and colleagues [40] document how religious beliefs about suffering, death, and the afterlife shape decision-making in a palliative context among different faith communities. These beliefs may affect how individuals understand and weigh information about VAD, requiring assessors to consider religious and spiritual frameworks when evaluating DMCA.

Health care literacy presents another significant consideration in capacity assessment. Varying levels of health care system familiarity, combined with cultural and linguistic differences, can affect individuals' ability to demonstrate DMCA through traditional assessment methods [41]. A modified assessment approach, incorporating cultural knowledge and communication preferences, may more accurately evaluate DMCA in diverse populations.

Future Considerations in Voluntary Assisted Dying Capacity Assessment

As the field of VAD continues to evolve, clinicians should anticipate and prepare for potential developments. For example, with telehealth becoming more prevalent, guidelines for remote capacity assessments for VAD may be necessary. The inclusion of dementias in the VAD eligibility criteria may increase emphasis on integrating VAD discussions into broader advanced care planning processes [42] as more comprehensive frameworks are needed to ensure equitable access and assessment across all cultural groups. As such, there may also be an increased emphasis on developing more nuanced guidelines for cross-cultural capacity assessments as Australia's population diversity grows. Practical implementation of culturally appropriate capacity assessment requires several key elements. First, health care providers need comprehensive cultural safety training specific to end-of-life care and VAD. Second, assessment protocols must incorporate flexibility in timing and communication methods. Third, cultural advisors and interpreters should be integrated into the assessment process from the outset rather than as an afterthought.

Future research priorities include investigating decision-making patterns longitudinally and developing cultural competency in assessments. This includes supporting research led by diverse communities, incorporating traditional knowledge and healing practices, and ensuring assessment processes respect cultural protocols while maintaining clinical rigor. The goal is to create assessment frameworks that recognize and accommodate cultural diversity while ensuring safe and equitable access to VAD for all eligible individuals. The establishment of robust peer support networks will be crucial for maintaining professional standards while supporting clinician well-being.

Case Example

Consider John's case, in the context of VAD: An 85 year old man with early AD requesting VAD due to a concurrent terminal cancer diagnosis. While his family members might challenge his capacity to request VAD based solely on his dementia diagnosis, this scenario illustrates several critical principles in VAD capacity assessment. If John were considering VAD, clinicians would need to ensure that his cognitive deficits do not impair his

understanding of the process, its consequences, and alternatives. Given the complex family dynamics described in his case, they would also need to be vigilant about any potential undue influence from family members. A diagnosis of neurodegenerative disease alone does not automatically preclude VAD DMCA, and cognitive testing may reveal selective deficits (such as John's visuospatial deficits and impaired executive functioning) while preserving key decision-making abilities. The ability to understand, reason about, and communicate health care choices often remains intact despite mild cognitive impairment. Although family dynamics and potential conflicts require careful consideration, they should not override patient autonomy when capacity is present. As demonstrated in John's original assessment, a comprehensive neuropsychological evaluation for VAD would need to establish intact reasoning about medical choices, the ability to articulate an understanding of the VAD process, palliative or treatment alternatives and consequences, consistent decision-making over time, and clear communication of preferences independent of family influence. Reflecting on traditional capacity assessments, such as in the case study of John with AD, VAD requires a more stringent threshold across all domains. While cognitive impairment in some domains might not preclude capacity for particular decisions, VAD demands consistent demonstration of sophisticated understanding and reasoning abilities beyond what other medical decisions typically require.

FITNESS TO STAND TRIAL AND ADJUDICATIVE COMPETENCY

Fitness to stand trial refers to the legal determination of a defendant's capacity to participate meaningfully in their trial process. Also known as "competency to stand trial" or "adjudicative competency," fitness to stand trial is founded on the legal principles that a defendant should only be tried if they can fully understand and engage with legal proceedings [43] and that they have the mental capacity to defend themselves [44]. It is a legal principle that has become a foundation of Western legal systems and is a cornerstone to procedural justice and fairness [2,45]. While fitness to stand trial was originally developed for those with physical and sensory disabilities, the question of fitness to stand trial has broadened to include those with psychological, behavioral, and cognitive impairments [46].

General Standards of Fitness to Stand Trial

The legal standard applied in the determination of fitness varies by jurisdiction. Different countries also uphold distinct standards. For example, Canada's criteria emphasize cognitive understanding, while England and Wales employ the *R v Pritchard (1836)* [47] standard, which focuses on intellectual comprehension and procedural understanding. The United States' *Dusky v United States* (1960) [48] generally promotes rational understanding. However, in clinical practice, a higher threshold for fitness may be applied, such that there is a greater emphasis on rational decision-making [49]. Australia's approach varies between states, with New South Wales applying the criteria set out by the *Mental Health and Cognitive Impairment Forensic Provisions Act* (2020). Despite the slight variations in legal frameworks applied, common benchmarks across jurisdictions include whether a defendant understands the charges they are facing, can engage meaningfully with their legal counsel, and whether they can understand and follow court proceedings.

Fitness to Stand Trial and Cognitive Functioning

The legal standards raised earlier suggest that cognitive abilities are inherently linked to the fitness process. Indeed, research has highlighted that cognitive abilities, such as attention, speed of information processing, memory and higher order executive skills, are fundamental for fitness to stand trial [50,51]. For example, expressive and receptive skills are needed to engage with legal representatives and to understand information as it unfolds by their counsel and the court [52], attention is required to sufficiently engage with information relayed during courtroom dialogs and with legal representatives, memory is needed to learn and retain information relayed by the court, and higher order processes, such as abstract reasoning and consequential thinking (ie, if this, then that), are needed to follow instructions and to understand the impact information provided in court proceedings may have on a defendant's defense strategy. As such, it serves that questions of fitness are largely raised when defendants have conditions associated with cognitive impairments, such as intellectual disabilities [53], psychiatric disorders [51], traumatic brain injuries [54], or other cognitive impairment. The issue of fitness is commonly raised for older adults and for those with neurodegenerative conditions concomitant with cognitive decline [55].

The Assessment of Fitness to Stand Trial

The evaluation of fitness to stand trial relies heavily on the expert opinion of mental health professionals with expertise in forensic matters. Psychiatrists were historically used to provide expert opinion on fitness,

although forensic psychologists, neuropsychologists, and other mental health professionals (eg, general psychologists with forensic experience) are increasingly used to assist the courts in making legal decisions [56]. These evaluations involve structured and/or unstructured interviews, mental state examinations, cognitive assessments, and reviews of medical history in order to determine whether an individual meets the criteria of fitness outlined by the legal standard in the jurisdiction where the court proceedings are to take place. Typically, multiple independent assessments are sought, and experts may be called to provide evidence by the defense and prosecution. While mental health professionals provide expert opinion on the evaluation of fitness to stand trial, the final determination is at the discretion of the court. During a "fitness enquiry," a judge typically determines fitness, though in some regions, a jury may assess it [57]. Notably, there is often a high concordance rate between expert recommendations and court decisions [58–60].

Fitness to Stand Trial and Capacity Are Not Mutually Exclusive

The determination of fitness to stand trial is situation and context specific. It is neither determined from a clinical diagnosis (such as dementia) nor whether an individual has capacity across other areas of their life. For example, a person may lack capacity to make certain lifestyle or medical decisions but may still be deemed fit to stand trial should they be charged with an offense. The reason for these discrepancies is that the cognitive and functional thresholds for fitness to stand trial are considerably lower relative to other areas of competency. Capacity necessitates a higher degree of reasoning, probabilistic thinking, and complex decision-making processes than fitness to stand trial. Legal standards for fitness generally focus on basic foundational cognitive and receptive skills, such as understanding charges, court proceedings and evidence. Indeed, the *Presser* [61] standard (which serves the precedent for the legal criteria for fitness outlined in the *Mental Health and Cognitive Impairment Forensic Provisions Act*) is often noted for its low cognitive demand compared to other jurisdictions [43]. The threshold for fitness is considerably lower in comparison to those outlined in the context of VAD. In other words, these are separate areas of competency, and one does not necessarily inform the other. The determination of fitness may also vary depending on the severity of charges and length of court proceedings. For example, someone who is considered fit to stand trial for a short and straightforward case might struggle with understanding or participating in a prolonged and complicated trial, especially if their mental or cognitive condition deteriorates over time.

Case Example

In the case of John, the 85 year old man with AD, he was also charged with 2 separate sets of historical sex offences that involved underage victims known to him. The events in question occurred during the 1980s. Given John's neurodegenerative condition, and with some suspected cognitive issues in recent meetings, his legal team sought evaluation of his fitness to be tried under section 36 of the *Mental Health and Cognitive Impairment Forensic Provisions Act 2020 (NSW)*.

On interview, John appeared to understand the charges he was facing. He could also verbalize the details of his legal representation, and he had retained information relayed to him by his counsel in recent meetings. He also knew what it meant to enter "guilty" and "not guilty" pleas, and he had an understanding of the consequences that attach to those pleas. He also had an accurate schema (a mental script) of courtroom process in his mind. Cognitively, he demonstrated adequate expressive and receptive language skills, together with sound consequential thinking and reasoning, to communicate with his solicitor and to follow instructions. He also had adequate attention to remain vigilant and engage in a courtroom setting. While he showed difficulty with his retention of information over time, his performance was still within normal limits for his age (low average).

As such, despite the diagnosis of AD, it was determined that the severity of John's cognitive difficulties was not at a level that would preclude his fitness to stand trial. However, given his age and neurodegenerative condition, it would be important to monitor him for signs of further cognitive decline, as it was likely that his cognition would progressively deteriorate in coming years. As such, while he was fit at the time of this assessment, further assessment of his fitness to plea and to stand trial was strongly recommended if his legal matters had not progressed beyond or bypassed the trial phase within the next 6 months.

SUMMARY

In conclusion, capacity assessment demands a sophisticated understanding of legal requirements, cultural differences, and clinical best practices in diverse contexts [20,32,34–37]. Due to increased prevalence of cognitive decline and neurodegenerative conditions in older adults, this population is particularly vulnerable to

impairments in DMCA. No standardized assessment tools are available, which is, in large part, due to the context-dependent nature of each decision. Particular challenges arise in the context of voluntary assisted dying and fitness to stand trial. As the field evolves, clinicians must stay informed about legislative changes, emerging assessment techniques, and ethical and cultural considerations. The complexity of these assessments underscores the need for ongoing research, interdisciplinary collaboration, and continuous professional development in this critical area of health care and law. As clinicians navigate the ethical and practical challenges of capacity assessments, it is crucial for them to maintain a balance between respecting individual autonomy, while also providing necessary protections for vulnerable individuals.

CLINICS CARE POINTS

- Assessment of DMCA is a complex and multifaceted process, requiring a thorough understanding of legal principles, medical evaluations, and ethical considerations in specific contexts and for specific decisions.
- Assessors must balance the need to protect individuals from harm with the need to respect their autonomy and right to make decisions.
- Older adults are more susceptible to impaired DMCA, due to the impact of aging and neurodegenerative diseases on cognitive processes subserving decision-making. However, the presence of neurodegenerative disease does not automatically preclude capacity for decision-making.
- Voluntary assisted dying and assessment of fitness to stand trial pose specific challenges in respecting individual autonomy and providing appropriate safeguards.

DISCLOSURE

The authors have nothing to disclose.

REFERENCES

[1] Edelstein B, Lichtenberg P, Marson D, et al. Assessment of older adults with diminished capacity: a handbook for psychologists. Washington (DC): America Bar Association; 2008.

[2] Grisso T, Appelbaum P. Assessing competence to consent to treatment: a guide for physicians and other health professionals. Oxford, UK: Oxford University Press; 1988.

[3] United nations convention on the rights of persons with disabilities. 2006. Available at: https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx.

[4] Centre for public representation. Available at: https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/.

[5] Moye J, Wood E. Understanding legal and clinical capacities. In: Moye J, editor. Assessing capacities of older adults: a casebook to guide difficult decisions. Washington (DC): American Psychological Association; 2020. p. 9–23.

[6] Uniform Power of Attorney Act of 2006, National Conference of Commissioners on Uniform State Laws. Available at: https://www.uniformlaws.org/committees/community-home?CommunityKey=b1975254-8370-4a7c-947f-e5af0d6cb07c (Accessed 1 April 2025), 2006.

[7] Mental Capacity Act 2005, c.9. Available at: https://www.legislation.gov.uk/ukpga/2005/9/contents (Accessed 1 April 2025).

[8] Australian Law Reform Commision. Elder abuse – a national legal response (Report No 131). Sydney, Australia: Australian Law Reform Commission; 2017.

[9] Hoskin KM, Jackson M, Crowe SF. Money management after acquired brain dysfunction: the validity of neuropsychological assessment. Rehabil Psychol 2005;50(4):355–65.

[10] Purser K, Rosenfeld T. Assessing testamentary and decision-making capacity: approaches and models. J Law Med 2015;23(1):121–36.

[11] World health organisation. Updated 15 march 2023. Available at: https://www.who.int/news-room/fact-sheets/detail/dementia. Accessed October 20, 2024.

[12] Vara A, Young G, Douglass A, et al. General practitioners and decision-making capacity assessment: the experiences and educational needs of New Zealand general practitioners. Fam Pract 2020;37(4):535–40.

[13] Aarsland D, Batzu L, Halliday GM, et al. Parkinson disease-associated cognitive impairment. Nat Rev Dis Primers 2021;7(1):47.

[14] McKeith IG, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies Fourth consensus report of the DLB Consortium. Neurology 2017;89(1):88–100.

[15] Pennington C, Davey K, ter Meulen R, et al. Tools for testing decision-making capacity in dementia. Age Ageing 2018;47(6):778–84.

[16] Sullivan K. Neuropsychological assessment of mental capacity. Neuropsychol Rev 2004;14(3):131–42.

[17] Gregory R, Roked F, Jones L, et al. Is the degree of cognitive impairment in patients with Alzheimer's disease related to their capacity to appoint an enduring power of attorney? Age Ageing 2007;36(5):527–31.

[18] Ganzini L, Volicer L, Nelson WA, et al. Ten myths about decision-making capacity. J Am Med Dir Assoc 2005;6(3 Suppl):S100–4.

[19] Moye J, Marson DC. Assessment of decision-making capacity in older adults: an emerging area of practice and research. J Gerontol B-Psychol 2007;62(1):P3–11.

[20] Waller K, Del Villar K, Willmott L, et al. Voluntary assisted dying in Australia: a comparative and critical analysis of state laws. U Nsw Law J 2023;46(4):1421–70.

[21] White B, Del Villar K, Close E, et al. Does the voluntary assisted dying Act 2017 (vic) reflect its stated policy goals? U Nsw Law J 2020;43(2):417–51.
[22] Peisah C, Sheahan L, White BP. Biggest decision of them all - death and assisted dying: capacity assessments and undue influence screening. Intern Med J 2019;49(6):792–6.
[23] McDougall R, Pratt B. Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation. BMC Med Ethics 2020;21(1):38.
[24] Dierickx S, Deliens L, Cohen J, et al. Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. BMC Psychiatry 2017;17:203.
[25] Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, et al. Trends in end-of-life practices before and after the enactment of the euthanasia law in The Netherlands from 1990 to 2010: a repeated cross-sectional survey. Lancet 2012;380(9845):908–15.
[26] Ekkel MR, Depla MFIA, Verschuur EML, et al. Patient perspectives on advance euthanasia directives in Huntington's disease. A qualitative interview study. BMC Med Ethics 2022;23(1):101.
[27] van Eenennaam RM, Kruithof W, Beelen A, et al. Frequency of euthanasia, factors associated with end-of-life practices, and quality of end-of-life care in patients with amyotrophic lateral sclerosis in The Netherlands: a population-based cohort study. Lancet Neurol 2023; 22(7):591–601.
[28] Marijnissen RM, Chambaere K, Voshaar ROC. Euthanasia in dementia: a narrative review of legislation and practices in The Netherlands and Belgium. Front Psychiatry 2022;13:857131.
[29] Coers DO, Scholten SH, de Boer ME, et al. A qualitative focus group study on legal experts' views regarding euthanasia requests based on an advance euthanasia directive. BMC Med Ethics 2024;25(1):119.
[30] Coelho R, Maher J, Gaind KS, et al. The realities of medical assistance in dying in Canada. Palliat Support Care 2023. https://doi.org/10.1017/S1478951523001025.
[31] van der Heide AVD, Van Delden JJM, Onwuteaka-Philipsen BD. End-of-Life decisions in The Netherlands over 25 years. N Engl J Med 2017;377(5):492–4.
[32] Lambert E, Strickland K, Gibson J. Cultural considerations at end-of-life for people of culturally and linguistically diverse backgrounds: a critical interpretative synthesis. J Clin Nurs 2023. https://doi.org/10.1111/jocn.16710.
[33] Alden DL, Friend J, Lee PY, et al. Who decides: me or we? Family involvement in medical decision making in eastern and western countries. Med Decis Mak 2018; 38(1):14–25.
[34] Neller P, Feeney R, Willmott L, et al. Australian Indigenous people and treatment decision-making at end-of-life. Altern Law J 2024;49(2):104–13.
[35] Curtis E, Jones R, Tipene-Leach D, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. Int J Equity Health 2019;18(1):174.
[36] Nolan-Isles D, Macniven R, Hunter K, et al. Enablers and barriers to accessing healthcare services for aboriginal people in New South Wales, Australia. Int J Env Res Pub He 2021;18(6):3014.
[37] Taylor EV, Lyford M, Parsons L, et al. "We're very much part of the team here": a culture of respect for Indigenous health workforce transforms Indigenous health care. PLoS One 2020;15(9):e0239207.
[38] Dressler G, Cicolello K, Anandarajah G. "Are they saying it how I'm saying it?" A qualitative study of language barriers and disparities in hospice enrollment. J Pain Symptom Manag 2021;61(3):504–12.
[39] Green A, Jerzmanowska N, Green M, et al. Death is difficult in any language': a qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. Palliative Med 2018;32(8):1419–27.
[40] Rego F, Gonçalves F, Moutinho S, et al. The influence of spirituality on decision-making in palliative care outpatients: a cross-sectional study. BMC Palliat Care 2020; 19(1):22.
[41] Stormacq C, Wosinski J, Boillat E, et al. Effects of health literacy interventions on health-related outcomes in socioeconomically disadvantaged adults living in the community: a systematic review. Jbi Evid Synth 2020;18(7): 1389–469.
[42] Mondragón JD, Salame-Khouri L, Kraus-Weisman AS, et al. Bioethical implications of end-of-life decision-making in patients with dementia: a tale of two societies. Monash Bioeth Rev 2020;38(1):49–67.
[43] Mossman D, Noffsinger SG, Ash P, et al. AAPL practice guideline for the forensic psychiatric evaluation of competence to stand trial. J Am Acad Psychiatr Law 2007;35(Supplement 4):S3–72.
[44] *R v Dashwood*, 1 KB 1 at 4. 1943.
[45] Math SB, Murthy P, Parthasarthy R, et al. Fitness to stand trial.
[46] Rogers R, Johansson-Love J. Evaluating competency to stand trial with evidence-based practice. J Am Acad Psychiatr Law 2009;37(4):450–60.
[47] *R v Pritchard*, Court of the King's Bench. 1836.
[48] *Dusky v. US*, 1960.
[49] *Godinez v Moran*, 1993.
[50] White AJ, Meares S, Batchelor J. The role of cognition in fitness to stand trial: a systematic review. J Forensic Psychiatr Psychol 2014;25(1):77–99.
[51] White AJ, Batchelor J, Meares S, et al. Fitness to stand trial in one Australian jurisdiction: the role of cognitive abilities, neurological dysfunction and psychiatric disorders. Psychiatr Psychol Law 2016;23(4):499–511.
[52] Everington C, DeBerge K, Mauer D. The relationship between language skills and competence to stand trial abilities in persons with mental retardation. J Psychiatr Law 2000;28(4):475–92.
[53] Pirelli G, Gottdiener WH, Zapf PA. A meta-analytic review of competency to stand trial research. Psychol Publ Pol Law 2011;17(1):1.

[54] White AJ, Batchelor J, Pulman S, et al. Fitness to stand trial: views of criminal lawyers and forensic mental health experts regarding the role of neuropsychological assessment. Psychiatr Psychol Law 2015;22(6):880–9.

[55] Sawich S, Casiano H. Fitness to stand trial and dementia: considering changes to assessment to meet demographic need. Man LJ 2021;44:177.

[56] Melton GB, Petrila J, Poythress NG, et al. Psychological evaluations for the courts: a handbook for mental health professionals and lawyers. New York: Guilford Publications; 2017.

[57] Rogers T, Blackwood N, Farnham F, et al. Fitness to plead and competence to stand trial: a systematic review of the constructs and their application. J Forensic Psychiatr Psychol 2008;19(4):576–96.

[58] Cox ML, Zapf PA. An investigation of discrepancies between mental health professionals and the courts in decisions about competency. Law Psychol Rev 2004;28:109.

[59] Freckelton I. Rationality and flexibility in assessment of fitness to stand trail. Int J Law Psychiatr 1996;19(1):39–59.

[60] Zapf PA, Hubbard KL, Cooper VG, et al. Have the courts abdicated their responsibility for determination of competency to stand trial to clinicians? J Forensic Psychol Pract 2004;4(1):27–44.

[61] *R v Presser*, 1958.