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Legal issues for people with young onset dementia

BY PROFESSOR NOLA RIES AND ASSOCIATE PROFESSOR FIONA KUMFOR - FEB 06, 2026 8:35 AM AEDT

SNAPSHOT

- Young onset dementia refers to any type of dementia where symptom onset occurs before the age of 65. Behaviour changes that contribute to legal problems in midlife—criminal offending, relationship breakdown or poor job performance—should prompt consideration of young onset dementia.
- People diagnosed with young onset dementia require timely referral for legal advice. They commonly face legal issues involving employment transitions, disability support, financial protection, appointment of enduring representatives, and wills and estate planning.
- A dementia diagnosis does not automatically mean a lack of decision-making capacity. Capacity must be considered on a decision-specific basis with appropriate supports and effective communication strategies to maximise the person's participation in decision-making.

Michael, aged 57, and his wife Johanna, aged 53, have been married for 17 years and have two children, aged 13 and 15 years. Over the past months, Michael has been experiencing significant difficulties at work, including multiple angry outbursts at colleagues. He has been placed on performance management. Michael has seen his GP who recommended a period of stress leave. At home, Michael has been uncharacteristically cold towards his family. Johanna is considering separation. The situation escalated recently when Michael was charged and had his licence suspended following a road rage incident involving dangerous driving and verbal abuse of a police officer.

What Michael and his family don't yet understand is that these behavioural changes are symptoms of young onset dementia.

Young onset dementia in Australia

Dementia is an umbrella term for conditions that cause decline in a person's cognitive abilities (e.g., judgement, memory or language) that significantly impact their everyday functioning. While over 100 different subtypes of dementia are recognised, the most common forms include Alzheimer's disease, vascular dementia, Lewy body dementia and frontotemporal dementia.

Young onset dementia refers to any type of dementia where symptom onset occurs before the age of 65. It is estimated that at least 30,000 Australians are living with young onset dementia, although comprehensive data is lacking and this number is likely an underestimate.

The presentation of young onset dementia varies considerably depending on the dementia subtype and the location of underlying brain pathology. Alzheimer's disease, the most common subtype, is characterised by memory, navigation and language impairments due to abnormal protein accumulation in the brain's medial temporal lobes and hippocampus, ultimately leading to cell death and brain atrophy.

In people with young onset dementia, frontotemporal dementia is as common as Alzheimer's disease. Unlike Alzheimer's disease, frontotemporal dementia primarily affects behaviour, personality, language and communication. Some individuals show loss of empathy, poor judgement and disinhibited behaviours, while others experience progressive loss of expressive language, including effortful or slurred speech and/or reduced language comprehension.

Disease progression in dementia varies widely. The average time from disease onset to death is seven years. But some people decline rapidly from symptom onset to death within a few years, while others may experience a slower disease course, living with dementia for 15 years or more.

Legal issues and young onset dementia

While legal problems are part of everyday life for Australians, scant attention is given to the legal issues and needs of people with dementia. Our report, *Legal Issues for People Living with Young Onset Dementia in Australia*, examined legal issues across three stages: pre-diagnosis, diagnosis and post-diagnosis. The research was conducted for the Young People in Nursing Homes National Alliance as part of the national Joint Solutions Project. It combined analysis of legal materials and Australian and international research with insights from people living with dementia, their family members, frontline service providers and clinicians.

Pre-diagnosis: criminal legal risks

Returning to Michael's situation, his behavioural and personality changes are red flags that may indicate dementia. Australian research found that one-third to over half of people with frontotemporal dementia exhibit behaviours that may be perceived as criminal offending. The most common behaviours include physical or verbal abuse, theft, hazardous driving and inappropriate sexual conduct. Recent research also explores family members' accounts of potential offending behaviour by their spouse or parent with young onset dementia, and advocates for increased community awareness of young onset dementia and better police training.

First-time or new offending behaviour in clients aged 50 and over should trigger consideration of a referral for neurocognitive assessment. Sections 12-17 of the *Mental Health and Cognitive Impairment Forensic Provisions Act 2020* (NSW) provide mechanisms for diverting defendants with cognitive impairment from the criminal justice system where appropriate.

Beyond criminal matters, young onset dementia might also be a factor in family law matters. Research shows that the onset of dementia is a risk factor for separation and divorce, particularly when symptoms include aggressive behaviour and depressive mood.

Understanding the diagnostic process

The diagnostic process typically includes neurocognitive assessment, neuroimaging (such as MRI, CT or PET scans) and assessment by appropriately trained clinicians including neurologists, psychiatrists or geriatricians. Critically, the process must rule out other potential causes of symptoms, such as substance use or psychiatric conditions.

In a small proportion of people, genetic testing is available to determine whether a person carries a gene linked to elevated dementia risk, but such testing cannot determine whether the individual meets *clinical* diagnostic criteria for onset of dementia. A person may carry the genes but not yet show symptoms. Commonwealth legislation introduced in late 2025 bans the use of adverse predictive genetic test results in life insurance (Treasury Laws Amendment (Genetic Testing Protections in Life Insurance and Other Measures) Bill 2025).

Delayed and incorrect diagnoses are major concerns for people with young onset dementia. On average, diagnosis occurs three years after symptom onset but can be as long as five years. These delays have serious legal implications. They affect people's ability to engage in timely legal and financial planning, access appropriate support services and make informed decisions about employment, family and other matters.

Legal help following diagnosis

Michael and Johanna attended a follow-up appointment after his diagnosis of frontotemporal dementia. A clinician recommended Michael see a solicitor to organise his affairs and gave him an 'end of life planning' checklist from a NSW government website. The checklist included making a will, appointing an enduring guardian and enduring power of attorney, as well as making an advance care directive and a funeral plan. Michael and Johanna left feeling distressed—as though Michael was being told to prepare to die. They face pressing concerns about financial security, accessing care and support, and protecting their children's future but don't know where to begin addressing their legal needs.

Timely legal advice is critical after a diagnosis of young onset dementia. Australian research shows that people with dementia and their family carers are commonly concerned about what will happen in the future. Other research shows they want guidance on legal documents to plan ahead for future decisions. Moreover, Australian best practice guidelines specify that clinicians should refer patients 'to support services with dementia expertise … [including] legal services…' (at 41).

However, our research on young onset dementia described a striking absence of guidance on legal considerations following a diagnosis. The phrase 'get your affairs in order' was frequently repeated, yet families were rarely told what this entailed, how to do it or who could help. A key recommendation was to improve structured legal referrals post-diagnosis, preferably to legal practitioners and services equipped to meet the needs of clients with dementia.

Dementia capability

Australia's National Dementia Action Plan 2024-2034 calls for building 'dementia capable' workforces. For legal practitioners, dementia capability encompasses the knowledge, skills and attitudes to work effectively with clients who seek legal help in the context of dementia. A national initiative in Australia defined core attributes for dementia capable legal practice—spanning five categories: knowledge of dementia; identifying and addressing legal rights and risks for clients; capacity considerations; effective and respectful communication; and systemic advocacy.

A client like Michael might present with multiple legal concerns including:

- criminal charges and driver licence suspension;
- employment issues and potential early retirement;
- access to superannuation and insurance benefits;
- National Disability Insurance Scheme ('**NDIS**') eligibility and access;
- family law issues;
- future planning including wills, estate planning and binding death benefit nominations; and
- enduring power of attorney, enduring guardian and advance care directive arrangements.

Human rights and capacity

While each client has unique legal concerns, our report identified human rights and capacity as core, interrelated considerations for all clients seeking advice after a dementia diagnosis. Australia is a signatory to the *Convention on the Rights of Persons with Disabilities*, which sets out the fundamental human rights of people with disability. Article 12 recognises that people with disability 'enjoy legal capacity on an equal basis with others' and are entitled to 'the support they may require in exercising their legal capacity.' Importantly, a diagnosis of dementia does not equate to a lack of capacity to make decisions or to instruct a lawyer.

Our research revealed a disconnect between these principles and practice. People with dementia are still too often presumed to lack capacity. Practitioners should consult resources such as the Law Council of Australia's best practice guide on capacity and its commentary on rule 8 of the *Legal Profession Uniform Law Australian Solicitors' Conduct Rules*, which requires practitioners to follow a client's competent instructions. Capacity to instruct can be enhanced through appropriate supports, such as providing information in accessible formats, allowing adequate time to consider options and make decisions, ensuring a comfortable consultation environment, and involving trusted support persons appropriately.

Post diagnosis: legal issues in the context of progressive disability

Fragmented services systems

People with young onset dementia and their families—like Michael and Johanna—must navigate multiple systems: disability services, sometimes aged care, as well as health and medical care. While the *National Disability Insurance Scheme Act 2013* (Cth) ('**NDIS**') recognises dementia as a disability, access remains challenging. An Australian study of people with young onset dementia and carers found that fewer than 30 per cent agreed that dementia is understood within the NDIS, and fewer than half considered the processes for accessing NDIS funding easy or fast enough. Another study indicates people with young onset dementia prefer rehabilitation and reablement services to maintain function but these are rarely offered, funded or accessible. Legal advice may be needed for NDIS appeals.

Decision-making arrangements

Our research found that family members appointed as enduring representatives (enduring guardian and enduring power of attorney) were often overwhelmed by the complexity of the role. Many accepted the responsibility without fully understanding the demands of these legal positions (p 26).

In NSW, a typical enduring guardian appointment grants authority to make decisions about accommodation and the provision of healthcare and personal services. Additional functions may be authorised, including decisions about restrictive practices—chemical restraints (e.g., psychotropic medication), physical restraints and other measures still too often used to manage behavioural symptoms in young onset dementia.

The *Aged Care Act 2024* (Cth), which took effect in November 2025, introduced stronger protections around the use of restrictive practices. Consent is now required either from the individual or from a substitute decision maker with legal authority to make decisions about restrictive practices. Consequently, enduring guardian appointments under the *Guardianship Act 1987* (NSW) must now address inclusion of authority to make decisions about restrictive practices.

Planning for medical care

Australian research suggests only around half of people diagnosed with dementia have appointed an enduring guardian, and a minority have made an advance care directive ('**ACD**'). This leaves them at risk of medical decisions being made without input from someone they trust and without evidence of their wishes and preferences.

Lawyers play an important role in strengthening advance care planning ('**ACP**'). Recommended practices include explaining the purpose and value of relevant legal documents to clients, guiding selection of an appropriate enduring guardian who will advocate for the person's will and preferences, providing information about resources such as government-endorsed ACD templates, and encouraging the client to prepare a tailored ACD with a doctor or other health professional involved in their dementia care. Advance Care Planning Australia provides helpful guidance on the law and ACP, with links to relevant forms and templates in each jurisdiction.

Voluntary assisted dying

Voluntary assisted dying ('**VAD**') laws are in effect in all Australian jurisdictions except the Northern Territory. People seeking access to VAD must meet strict eligibility criteria, such as being in the final six to twelve months of a terminal illness and having capacity to consent to the procedure. These criteria generally exclude people with dementia and advance directives cannot be used in Australia to consent to future euthanasia.

Internationally, advance euthanasia directives ('**AED**') are legal in the Netherlands but are rarely acted upon. A recent consensus panel of medical, ethical and legal experts agreed that, if a person with dementia currently expresses a wish to live, this should take priority over a previously expressed wish in an AED, such as 'I request euthanasia if I have to move into a nursing home'. In Canada, a recent national consultation sought views on legalising advance requests for VAD. This reform received broad support, including from people living with dementia.

In Australia, a recent, small-scale survey of 36 people living with dementia found that the vast majority wanted the option to access VAD and supported making VAD requests via advance care directives. While such law reform is unlikely in the near term, people with dementia seeking greater control over the end of their lives are likely to increasingly advocate for change.

The way forward

The prevalence of young onset dementia is set to increase in the coming years. Addressing the legal needs of this population requires action on multiple fronts: better training for legal practitioners in dementia capability, structured post-diagnosis referral pathways to appropriate legal services, and reforms to make support systems like the NDIS more accessible.

A dementia diagnosis should not end a person's autonomy or hope for the future. When people like Michael receive timely, skilled legal guidance, they can protect their rights, maintain control over their lives and plan effectively for the years ahead.

Professor Nola Ries is a professor at the Faculty of Law of University of Technology Sydney and Dr Fiona Kumfor is an associate professor at the School of Psychology and Brain and Mind Centre of University of Sydney.

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