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Submission to the NSW Parliamentary Inquiry into supported decision-making for adults with disability and older people in NSW.

13 March 2026

Submitted by Associate Professor Fiona Kumfor, School of Psychology, University of Sydney and the Dementia Law Network; Professor Nola Ries, Faculty of Law, University of Technology Sydney (UTS) and the Dementia Law Network; Mr Steven Davison, Young People in Nursing Homes National Alliance.

Terms of Reference:

That, pursuant to section 28B(1)(e) of the Ageing and Disability Commissioner Act 2019 (the Act), the Committee conduct an inquiry into and report on supported decision-making for adults with disability and older people in NSW, with particular reference to:

a) the lived experience of people seeking to access appropriate support to make decisions for themselves
b) barriers to implementing models for supported decision-making across legal, financial, health, education, employment and care systems in NSW
c) the distinct experiences of and challenges faced by Aboriginal people and people from culturally and linguistically diverse backgrounds
d) the role and functions of the Ageing and Disability Commission (the Commission) in relation to supported decision-making
e) possible changes to the functions of the Commission, including legislative amendments to the Act, to enhance supported decision-making
f) measures to ensure that substitute decision-making is an alternative approach that is employed in appropriate and limited circumstances
g) other related matters

Executive summary

This submission is jointly provided by the Dementia Law Network and the Young People in Nursing Homes National Alliance. It focuses on people living with dementia, with special attention to young onset dementia. It draws on research, including the recent report *Legal Issues for People Living with Young Onset Dementia in Australia* (UTS, 2025), which forms part of our submission.

Young onset dementia is a terminal condition with symptom onset before age 65 that affects an estimated 30,000 Australians and is characterised by long diagnostic delays, diverse symptom profiles, and substantial life impacts, including disrupted employment, financial instability, and parenting responsibilities. People with young onset dementia, as with late onset dementia, are often assumed to lack decision-making capacity at, or soon after, diagnosis.

Our research identifies significant barriers to implementing supported decision-making across health, legal, disability and aged care systems. These include: inconsistent and medically-driven approaches to capacity assessment; limited professional training on dementia-specific presentations and supports; fragmented service systems; and the absence of clear legal duties to provide decision-making support. Families commonly report receiving little guidance following diagnosis and face ethically challenging decisions without adequate information, training or systemic support.

To address these gaps, our submission recommends: legislative reform to embed supported decision-making as the preferred and enforceable framework in NSW; dementia-specific training for health and legal practitioners; integrated access to legal and advocacy services for people with dementia and their families; targeted support for individuals with dementia who do not have trusted family or social networks and who face heightened vulnerability to public guardianship; and consideration of innovative volunteer, navigator and/or professional roles to support and, if necessary, make decisions, to ensure that public guardianship is truly a last resort for people with impaired decision-making capacity.

Introduction

People with dementia in NSW, including young onset dementia, experience significant barriers to supported decision-making, leading to premature and avoidable use of substitute decision-making arrangements.

This is a **joint submission** from the **Dementia Law Network** and the **Young People in Nursing Homes National Alliance**. The Dementia Law Network (www.dementialawnetwork.org/) brings together researchers, clinicians, legal practitioners, people living with dementia, their families and the broader community to advance knowledge on issues at the intersection of law and dementia. The Young People in Nursing Homes National Alliance (https://ypinh.org.au/) is the national peak body for younger people living in or at risk of being placed in residential aged care.

Our submission relates to the Terms of Reference:

> *b) barriers to implementing models for supported decision-making across legal, financial, health, education, employment and care systems in NSW; and*
>
> *f) measures to ensure that substitute decision-making is an alternative approach that is employed in appropriate and limited circumstances.*

Background on Young Onset Dementia

Our submission has a particular focus on supported and substitute decision-making in the context of young onset dementia. While dementia is typically associated with older age, it is estimated that ~30,000 Australians have young onset dementia.

People with young onset dementia experience substantial delays in diagnosis (on average ~3.5 years from onset of symptoms to diagnosis).[1] The delay in diagnosis means a delay in individuals accessing health, legal and other support services. This impacts on outcomes including effective legal, financial and care planning, and taking proactive steps to build support networks. In addition, people with young onset dementia are at different life stages to those with late onset dementia (symptoms after age 65), are typically still in the workforce and often still have children or other dependents living at home. The impact of a dementia diagnosis is, therefore, different for young vs late onset dementia. This includes a range of critical employment, financial, legal and health decisions that have significant implications for the current and future security of the individual and families.

People living with young onset dementia often present with symptoms that differ from the memory problems most commonly associated by the general public with dementia. Many individuals experience early changes in executive functioning, social cognition, communication or behaviour, depending on the dementia subtype. These symptoms can significantly affect judgement, organisation, impulse control, language or the ability to interpret social cues – yet these symptoms are often not recognised or accounted for in capacity assessments. Because supported decision-making relies on identifying and adapting to a person's specific cognitive profile, a lack of understanding of 'non-memory' presentations leads to premature assumptions of incapacity and inconsistent provision of support.

Our submission is informed by our recent report commissioned as part of the *Joint Solutions – Young Onset Dementia Project*[2] which is included as an Appendix to our submission:

> Nola Ries, Sascha Callaghan, Kristina Chelberg, Evelyn Rose & Fiona Kumfor, **Legal Issues for People Living with Young Onset Dementia in Australia** (University of Technology Sydney, 2025). DOI: 10.71741/4pyxmbnjaq.30021721.

This report highlights the following key issues:

1. **Incorrect assumptions about capacity**

Many people with young onset dementia are assumed to lack decision-making capacity simply because of their diagnosis. This can lead to early guardianship or substitute decision-making arrangements, without first exploring how the person might be supported to participate meaningfully in decisions affecting their life.

2. **Shortcomings in capacity assessments**

Current capacity assessment practices often fail to recognise the diverse cognitive profiles and support needs of people living with young onset dementia. Capacity assessments are often rushed or conducted in unfamiliar environments and do not include adequate supports that could help the person with dementia to engage meaningfully.

In the context of supported decision-making, accommodations tend to focus on supporting someone with language or communication difficulties, memory loss or sensory changes (i.e., vision and hearing). Typical accommodations which are recognised include: communication and information accessibility (e.g., easy-read formats); time and environment adaptations; and including support structures (e.g., friends and family) to help the individual understand options and consequences. People without support networks are at higher risk of premature substitute decision-making through public guardianship and administration processes.

There are also challenges for legal practitioners in making capacity assessments. This may result in deferral by lawyers to either medical diagnoses as a proxy for capacity, or medical assessments of capacity that are not always aligned to legal capacity assessments. In the main, this is an artefact of inadequate training of legal practitioners.

Understandably, legal practitioners may be concerned about exposure to criticism that the involvement of a support person in a client's legal consultation has facilitated undue influence, or even abuse.

There is a clear need for specific training for legal practitioners in administering capacity assessments, understanding different legal tests of capacity, how to appropriately support client decision-making, and the agency of the client to take risk.

Initiatives that connect legal and medical/health professionals, including joint continuing education on capacity assessment and supported decision-making, would enhance consistent practices and improve experiences and outcomes for people living with dementia.

3. Lack of awareness and accommodations for diverse cognitive profiles

Young onset dementia can often present with non-memory symptoms, including executive dysfunction and social cognition. In posterior cortical atrophy, the initial symptoms include impaired visual and spatial processing. It can be difficult, even for health professionals, to identify potential areas where the person may need support, as some cognitive difficulties (e.g., executive dysfunction, social cognition) may be subtle or misinterpreted, unless specifically identified for assessment.

A person with executive dysfunction can have difficulty in planning and organising information, sequencing decisions, cognitive flexibility (i.e., considering alternative options or becoming stuck on one idea), self-regulation and impulsivity.

For people with social cognition impairment, difficulties include understanding the intentions of others, being able to take into account the perspective of another person, and judging trustworthiness (e.g., can be readily swayed and vulnerable to scams).

It can also be difficult to determine the extent the person with social cognition impairment understands the consequences of decisions involving other people (e.g., financial arrangements or care relationships). This means that people with social cognition impairment may make poor financial decisions[3], trust individuals who are manipulating them, or misunderstand conflicts of interest.

Combining accommodations to structure decision-making (e.g., presenting one option at a time, making decisions over multiple conversations, providing decision-making scaffolds) together with safeguards to prevent abuse, undue influence and exploitation, are essential to appropriately supporting decision-making in people with executive dysfunction and social cognition impairment.

4. Lack of awareness and reluctance to engage in future planning

Younger people are generally less aware of the need for, and less likely to have, legal planning documents in place, or when an issue requires a legally framed response (e.g., conflict in employment cessation or access to superannuation/insurance). Research (yet to be published) has found a tendency to avoid thinking about the future in people with young onset dementia and their families [4]. This approach ultimately leads to reactive decision-making when a crisis arises - for example when the person with dementia declines and decisions about care need to be made. This avoidance of decision-making may also mean there is inconsistent recognition of 'will and preferences' during crises.

5. Fragmented legal and service systems

People with young onset dementia are systematically disadvantaged by current age-based services and systems. There is poor coordination between disability (NDIS), aged care, health and legal services, making it hard for people to access consistent supported decision-making mechanisms and legal advice when needed. This is compounded when people are under public guardianship and/or public trusteeship.

For example, the arbitrary age delineation between accessing NDIS and Aged Care is challenging for people with dementia and their families to navigate. The NDIS system is also poorly designed and equipped to support people with progressive conditions such as dementia. When time-dependent decisions need to be made, public guardians are often unable to facilitate supported decision-making and so substitute decision-making becomes inevitable.

Public guardians often do not have sufficient time or resources to facilitate supported decision-making or even elicit the views of those under guardianship, especially those with complex presentations such as young onset dementia. Frequent changes in personnel mean that relationships between the public guardian and those who know the person best can be frayed or severed. When individuals are unable to engage in supported decision-making, the preferences that the person recorded before they lost capacity, may be lost or deprioritised, especially if they are 'solos' (see below).

This means that public guardians are often both first and last resort substitute decision-makers, effectively bypassing consideration of the rights or views of the person under guardianship or their trusted family members.

6. Dominance of substitute over supported decision-making

The legal and policy frameworks in NSW still rely heavily on substitute decision-making models. Supported decision-making continues to be under-implemented in law and practice. While some policy frameworks invoke supported decision-making, there is little legal clarity regarding enforceable obligations to provide support that helps the person make decisions. This issue is amplified by the current NSW *Guardianship Act 1987* defaulting to substitute decision-making models.

Legislative reform is overdue to respond to the 2018 NSW Law Reform Commission report on the *Guardianship Act 1987*, which recommended a new *Assisted Decision-Making Act*. New legislation would have the benefit of formally enacting supported decision-making, including ensuring that roles with substitute decision-making powers (e.g., enduring power of attorney, enduring guardian) must support decision-making where possible.

It is also essential to address the particular disadvantages and risks faced by 'solos'—people who, by choice or circumstance, lack trusted family members or close friends to support decision-making or act as substitute decision-makers when needed. These risks are especially acute in the context of young onset dementia, where relationships may deteriorate in the years preceding diagnosis. In conditions such as frontotemporal dementia, changes in social cognition, behaviour and personality frequently dominate early clinical symptoms and may be misinterpreted as rudeness, thoughtlessness or a lack of empathy. Before a diagnosis is made, these misunderstandings can erode relationships, leaving an ex-partner as the individual's only remaining connection – someone who may be unwilling to provide support or unsuitable to do so due to conflicts of interest.

'Solos' face heightened risks that their needs and views will be ignored, and that decisions will automatically default to a public substitute decision-maker. System-level strategies are needed, such as renewed investments in well-trained and vetted volunteer supporters as well as new navigator or professional roles that people could proactively appoint and prepare as supporters and enduring representatives. Supported by the Australian Research Council, the University of Technology Sydney is leading a new program of research on these innovative models, led by Professor Nola Ries, co-founder of the Dementia Law Network. Training is also needed to ensure that service providers who interact with solos can provide effective decision-making support to minimise public guardianship as a first, rather than last, resort.

7. Training gaps for professionals

Both legal and health professionals lack dementia-specific training in how to implement supported decision-making. This leaves them ill-equipped to assist people to participate in decisions. Our interviews with family members found that people are often told by their health care provider to *"get their affairs in order"* but carers of people with young onset dementia report that there are limited, if any, resources about what this process entails. Access to qualified legal advice – and effective support to engage in legal planning and decision-making – is a critical component of holistic dementia care. However, "getting affairs in order" is too often framed as an imminent total loss of capacity and the end of life. Legal planning should instead be reframed in an empowering way – preparing for 'the rest of life', not the 'end of life'[5] – that emphasises a right to supports for decision-making.

Evidence suggests that there is a prevailing 'medicalised' approach to determining whether a person has decision-making capacity. This results in capacity being a binary assessment universally linked to a particular diagnosis, rather than looking closely at a person's situation and areas where they can make decisions and where they need assistance. This is partly caused by the limited understanding across health professions that a diagnosis of dementia does not preclude a person from participating in decision-making. This lack of knowledge stems from inconsistent training regarding capacity across institutions, states, disciplines and specialities. Even recently trained clinicians may lack sufficient understanding of the legal definition of capacity.

8. Ethical challenges

Our interviews with carers and service providers highlighted the real-world challenges in implementing supported decision-making. Families and professionals face difficult ethical judgements about how to weigh a person's apparent present preferences, against broader life goals, practicality and safety.

As an example, one of our interviews with carers revealed:

> *"There's a huge disconnect between what the law says about capacity and what happens in real life. I'm meant to let him [husband] make his own decisions - but I'm also responsible if things go wrong. No one helps you walk that line."*
>
> - Carer of a person with young onset dementia

Our research also uncovered an over-use of capacity assessments to challenge decisions that may be perceived as risky, with inadequate understanding of the 'dignity of risk', or resources about how to support a person whose decision involves a degree of risk, regardless of how small. Possible conflict between duty of care of health care providers and the person's ability to make decisions that are not risk-free is an additional complexity which warrants consideration.

To promote decision-making in young onset dementia we recommend the following actions:

Recommendations

1. **A public campaign** to improve awareness of the heterogeneity of dementia presentations and subtypes (e.g., frontotemporal dementia, dementia with Lewy bodies, posterior cortical atrophy, young onset Alzheimer's dementia).
2. **Training for health professionals** on capacity, the decision-specific nature of capacity, how and when assessments of capacity should be undertaken, as well as training on effective adaptations and measures to ensure people with dementia can engage in decision-making with support. This training can be modelled on material available for people with intellectual disability.
3. **Training for legal practitioners** to promote the attributes of a dementia-capable practitioner[6], based on models that have been positively evaluated in pilot testing[7], and involving people living with dementia.
4. **Expanded legal and advocacy services** integrated within healthcare systems.
5. **Focused research on supported decision-making in young onset dementia**, non-Alzheimer's dementia syndromes (e.g., frontotemporal dementia) and consumer experiences of assessments of decision-making ability and supported decision-making.
6. **Update to the Guardianship Act** 1987 to:
    - Require evidence that reasonable decision-making supports are offered before guardianship is considered.
    - Prioritise the person's will and preferences over a 'best interests' approach and require that those preferences be followed unless doing so creates serious risk of harm.
    - Clearer emphasis on capacity being decision-specific.
    - A specific provision that confirms that a person should not be considered as lacking capacity solely because they have a disability.
7. **Consideration of innovative volunteer, navigator and/or professional roles** to support and, if necessary, make decisions, to ensure that public guardianship is truly a last resort for people with impaired decision-making capacity.

These reforms would help ensure that people with young onset dementia in NSW can exercise their rights, maintain autonomy for as long as possible, and avoid unnecessary or premature guardianship.

References

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[1] Loi SM, Goh AMY, Mocellin R, et al. Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. *Int Psychogeriatr* 2022; **34**(4): 367-75.

[2] Blackwood A, Davison S, Morkham B. (2025) Time won't wait… The Joint Solutions Young Onset Dementia Project Final Report. Young People In Nursing Homes National Alliance. https://ypinh.org.au/wp-content/uploads/2025/08/The-Joint-Solutions-Young-Onset-Dementia-Project-Final-Report.pdf

[3] Kumfor F, Wei G, Ries N, et al. Examining the propensity and nature of criminal risk behaviours in frontotemporal dementia syndromes and Alzheimer's disease. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring* 2024; **16**(2): e12577.

[4] Lai M. How people with young-onset dementia living in the community in Australia, and their families, make decisions and plan for the future: University of Sydney; 2020.

[5] Yapp, G., Sinclair, C., Kelly, A., Williams, K., Amgarth-Duff, I., & Agar, M. (2018). Planning for the rest-of-life, not end-of-life: Reframing advance care planning for people with dementia. In *Dementia as social experience* (pp. 134-156). Routledge.

[6] Ries, N., & Donner, K. (2024). Dementia Capability for the Legal Profession (UTS), https://opus.lib.uts.edu.au/handle/10453/176021.

[7] Ries, N., & Johnston, B. (2025). Dementia training for lawyers: results from a pilot evaluation study and implications for building dementia capability in the legal profession. *Psychiatry, Psychology and Law*, *32*(2), 153-174.

ISSUES PAPER

Legal Issues for People Living with Young Onset Dementia in Australia

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01 Executive Summary

This report examines legal issues and their implications specific to young onset dementia. The circumstances and needs of people with young onset dementia, and those who support them, are often different from those of older people.

The report addresses several key questions:

1. What are the key **legal issues** relevant to young onset dementia, considering a **continuum** that spans prevention, receiving a diagnosis, living with dementia, and the end of life?
2. What are the **legal problems and needs** of people with young onset dementia, their families and the service systems with which they interact, with attention to the **differences** between onset of dementia at younger and older ages?
3. What are the **key legal gaps** associated with young onset dementia in: the law; government policy; access to legal services; and policing and court processes?
4. What are the **specific legal issues** associated with the National Disability Insurance Scheme (NDIS) and My Aged Care (MAC) system in relation to young onset dementia, especially in light of the recent legislative changes?
5. What **services/advice streams** currently exist to assist individuals and organisations deal with legal issues arising from young onset dementia?
6. What **reforms are needed** and what are priority areas for research to provide evidence to guide reform recommendations?

Note on Language Use

This report follows Dementia Australia’s guidelines and research-based recommendations to ensure that language used in relation to dementia is respectful, accurate and inclusive. Terms such as 'dementia sufferer' and 'carer burden' are intentionally avoided, as they can reinforce negative stereotypes and diminish the dignity of individuals living with dementia. We recognise that language evolves and that the perspectives of those with living experience are essential in shaping how we communicate about young onset dementia.

02 Introduction

An estimated 30,000 people in Australia live with young onset dementia, which refers to any type of dementia where symptom onset occurs before the age 65 years.[1] Current estimates, however, rely on data that are out of date, out of context, or self-reported and may therefore under-estimate the actual number of people affected.[1] The prevalence of young onset dementia is increasing for a range of reasons, including improved awareness and diagnosis, lifestyle and environmental factors.[1, 2, 3]

The Australian Institute of Health and Welfare (AIHW) notes:

> The needs and care requirements of people with younger onset dementia, their families and informal carers are often different from those of older people. A diagnosis may occur at an age when the demands of family and work are at a peak, placing a severe strain on family and carer dynamics and finances. People with younger onset dementia often retain good physical health, which can affect the appropriateness of dementia services that are targeted at older people.[1]

It is a policy priority to avoid placement in care environments that do not meet the needs of people with young onset dementia, including diversion from aged care facilities. The AIHW reports that 41% of people with young onset dementia are from culturally and linguistically diverse backgrounds, around half of whom were born in a non-English speaking country. This highlights the need for culturally appropriate services in the community, in supported accommodation, and for family and carers.

International studies have noted the significant differences in the profiles and needs of those with young onset dementia compared to late onset dementia.[4, 5]

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03 Research Approach

In preparing this report, we conducted:

1. **Detailed literature review**
   A national and international review of the academic and grey literature on legal issues arising in the context of young onset dementia. This review included academic publications, government reports, and practice-based resources relevant to legal needs, capacity and rights protections. The findings from this review formed the basis of our initial identification and analysis of legal issues.
2. **Qualitative interviews**
   To supplement and ground this review in living experience, we also undertook qualitative research to better understand how legal issues manifest and impact in practice, including seven in-depth interviews with people who have living experience of young onset dementia, family members, and clinical and service professionals.
3. **National roundtable**
   We also conducted a multi-participant roundtable with frontline support coordinators, service providers and clinicians. Insights from stakeholders are highlighted in the report.

A full thematic summary of the interviews and roundtable discussion is attached at Appendix A.

De-identified quotations from interviews and the stakeholder roundtable are included throughout this report to illustrate key issues and living experiences. Where necessary, minor edits have been made to improve clarity of spoken English quotations, preserving the speaker's original meaning, language and tone. This research was approved by the UTS Human Research Ethics Committee (ETH24-10212).

The consultations highlighted the complexity of navigating fragmented systems, the relational nature of decision-making, and the ways in which legal rights may be misunderstood, ignored, or overridden in practice.

Several participants expressed that their experiences did not reflect the formal legal protections theoretically available to them, especially in areas such as capacity assessments, access to the National Disability Insurance Scheme (NDIS), and the exercise of legal authority by appointed representatives or public institutions.

Insights from both the literature and qualitative data have informed this report, helping to identify formal legal gaps and deficiencies in implementation.

In particular, they underscore that legal supports must be responsive not just to statutory frameworks or legal rules, but to the real-world contexts in which people with young onset dementia live, seek support and guidance, and make decisions.

04 Legal Issues — An Overview

Legal issues, needs and barriers are under-researched in the context of dementia, including for people with younger age of onset.[6]

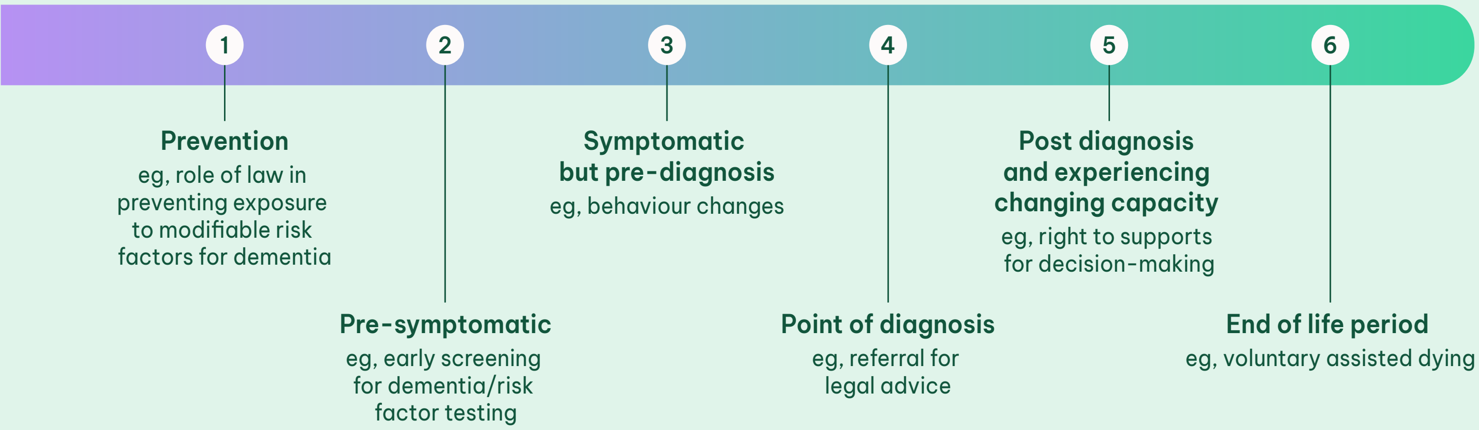
Age-appropriate services for younger people living with dementia should include specific support for their legal issues, however 'such services appear scarce and highly under-researched.'[7]

When considering reforms, it is important to differentiate between the written law ('law on the books') and its practical application. For instance, the written law, such as a particular Act, might clearly outline rules designed to promote and protect the rights of individuals with dementia or other cognitive disabilities. However, actual knowledge, attitudes, behaviours, and practices in the real world may not align with these legal requirements. In other situations, laws themselves might be outdated or otherwise fail to address the circumstances of people with dementia and their support networks. For example, the New South Wales *Guardianship Act 1987* is over 30 years old and calls for substitute decisions based on potentially paternalistic judgements of a person's 'best interests' rather than on the 'will and preferences' of a person living with a capacity-affecting condition.

Legislative reform by governments must always be accompanied by appropriate implementation strategies to ensure that people and organisations affected by and subject to the written laws are aware of their rights and duties and act accordingly.

Legal issues along a continuum

The key legal issues and fields of law relevant to young onset dementia can be considered along a continuum, spanning prevention of dementia through to the end of life. Understanding when and how legal issues arise is vital for providing appropriate support for people living with young onset dementia, their carers and families.



1 Prevention

Dementia prevention engages the field of **public health law**. All levels of government enact and enforce laws that aim to prevent exposure to risk factors for illness and injury and create conditions that promote health.[8] In the context of dementia, legal rules and standards can address modifiable risk factors for dementia and create conditions that enable healthy lifestyles and behaviours. The field of **sports law** is relevant. Concussion and chronic traumatic encephalopathy (CTE) in sports raise concerns about repeated head injuries as a risk factor for dementia.

2 Pre-symptomatic

In the pre-symptomatic phase, legal issues primarily revolve around early screening for dementia and risk factor testing. Ethical and legal concerns arise regarding the **consent and privacy** of individuals undergoing such tests. **Discrimination in insurance and access to services** is another critical issue, where individuals may face unfair treatment based on their risk factors.

3 Symptomatic but pre-diagnosis

During this phase, symptoms of young onset dementia may involve cognitive impairment, changes in behaviour and personality. Aggressive or disinhibited behaviours may be perceived as criminal offences, leading to contact with law enforcement personnel and the **criminal legal system**. Police and other first responders need training and resources to identify and respond appropriately to ensure people with potential dementia receive appropriate care and support. Behaviours that are symptoms of illness should not be criminalised.

4 Point of diagnosis

At the point of diagnosis, **advance legal planning** is an important need. Practice guidelines recommend referring individuals for legal advice on matters such as appointing enduring representatives and making or updating a will. **Disclosure of the** diagnosis and accessing entitlements and supports may raise legal issues in the context of **employment, insurance** and **superannuation**. **Driving** is another significant legal issue. Health conditions that affect fitness to drive are subject to reporting to licensing authorities. Loss of a driver's license can significantly impact an individual's independence and mobility.

5 Post-diagnosis

Post-diagnosis, **health law issues** are paramount, including **consent to treatment** and **decision-making** for care. **Employment law issues** may arise for individuals who need to adjust their work arrangements or cease employment. **Family law** issues may arise due to relationship breakdown. **Legal entitlements** to a range of services and supports must be navigated. Changing capacity necessitates **supported** and **substitute decision-making arrangements**. As symptoms progress, entry into a permanent residential service may be needed. Individuals have rights to safe and quality care; particular legal concerns may arise in relation to use of **restrictive practices** in institutional care settings.

6 End-of-life

Advance legal planning enables people to exercise some degree of choice and control over their end of life care, such as through making **advance care directives**. Legal questions may arise in regard to eligibility to access voluntary assisted dying.

05

Core Legal Concepts — Human Rights and Capacity

Human rights and capacity: two core and interrelated concepts in law and dementia.

Human Rights

Australia is a signatory to the Convention on the Rights of Persons with Disabilities (CRPD). This international legal instrument sets out the fundamental human rights of people with disability. Of particular relevance to people living with dementia, the CRPD sets out rights in relation to:

- participation in decision-making
- equal recognition before the law
- non-discrimination
- living independently and being included in the community
- health and care
- liberty and security
- respect for privacy, and
- freedom from exploitation, violence and abuse.[9]

Laws, legal frameworks and their implementation, and policy of governments and their agencies, in Australia should promote and protect these fundamental human rights.

Capacity

Capacity refers to the ability to understand and make decisions (decision-making capacity). In legal contexts, capacity is relevant to an individual's ability to understand and engage in legal matters, such as making decisions about their rights and obligations, making legal documents and participating in legal processes. Capacity is important for any legally binding decision a person makes — such as consenting to medical treatment, making a will, entering into contracts (for example, signing a residential lease or buying a car), and consenting to sex, and impacts many of the issues dealt with elsewhere in this paper.

Legal presumption of capacity

It is presumed in law that an adult has capacity to make decisions and manage their affairs, unless there is evidence to the contrary.[10] A diagnosis of dementia, on its own, should not lead to a presumption of lack of capacity.

Cognitive disability, human rights and decision making

The CRPD recognises that individuals with cognitive disability should not be deprived unnecessarily of their decision-making rights. They should be supported to retain their capacity to make decisions, or to retain a level of involvement with the decisions that affect their lives, to the greatest extent possible. These principles have been incorporated into Australian law and practice in many contexts including in mental health acts and guardianship acts where supported decision making is now a recognised principle.[11, 12, 13, 14]

Supported decision making assists individuals with cognitive impairment to exercise their rights to autonomy, dignity and inclusion in decision-making processes, and aims to ensure that decisions affecting the person align with their "will and preferences" even when the person is no longer able to make legally binding decisions for him or herself.[15]

Determining capacity to make decisions

In Australian law, determining decision-making capacity is based on legal principles set out in various statutes and authoritative court decisions.[16]

Capacity is decision-specific, which means that capacity must be considered in relation to a specific decision. Decisions vary in complexity and the seriousness of the implications for the person. Other factors can influence capacity. For example, a person may be better able to make decisions at certain times of the day, or under certain conditions, such as in a calm and quiet environment, and with appropriate supports.

Capacity is functional, which means that determining whether a person has capacity is based on what the person can do, not whether they have a particular diagnosis. A person with dementia is still presumed to have decision-making capacity unless there is evidence of impaired functional skills. Functional skills include:

1. **Understanding**—The person must be able to comprehend the information relevant to the specific decision. This includes understanding the nature, purpose and consequences of the decision, as well as available alternatives and their implications.
2. **Ability to use and weigh information**—The person must be able to use and weigh the information as part of the reasoning process. This involves evaluating the benefits and risks of various options and making a reasoned choice.
3. **Retention**—The person must be able to retain information long enough to weigh it up and make a decision. While perfect recall is not necessary, the person must be able to retain the information sufficiently well to participate meaningfully in the decision-making process.
4. **Communication**—The person must be able to communicate their wishes by some means, with support if necessary.

When a person's capacity to make a decision is in doubt, an assessment by a suitably qualified health practitioner can be helpful. If there is a dispute about a person's capacity, a formal determination may be required by application to a relevant court or tribunal.

Issues

The legal principles regarding capacity are generally well-defined. However, there are variations in statutory language across jurisdictions, and older laws still reference 'best interests' decisions rather than those based on the 'will and preferences' of a person. Additionally, supported decision-making has not yet been consistently integrated into all relevant legislation.

Numerous practical issues arise in relation to capacity and dementia, which can lead to discrimination and the denial of rights for people with dementia:

- **Assumptions about Dementia and Capacity:** There is a common misconception that a diagnosis of dementia automatically implies a lack of capacity. Conversely, people with young onset dementia may experience negative impacts from assumptions by others that they have capacity simply because they are considered 'too young' to have dementia.[86]
- **Binary Perception of Capacity:** Capacity is often viewed as an 'all or nothing' concept.[17]
- **Deficiencies in Capacity Assessments:** There are significant shortcomings in how capacity assessments are conducted by both health and legal professionals. Referrals for capacity assessments can be overused or misused, such as using them to challenge decisions made by individuals with dementia that are perceived as unwise or risky. For instance, a study in a hospital setting found that over half of the referrals for capacity assessments were unnecessary, as the patient either clearly had or did not have capacity.[18]
- **Inadequate Support and Resources:** There is insufficient awareness about the issues around capacity. There are inadequate resources, including time and practical guidance, to support decision-making of people living with dementia, especially for decisions with legal implications, or that hold a degree of risk. This includes recognition and time for supported decision making and understanding the will and preference of people who require decision support.[19]

There is limited research that specifically examines capacity issues (eg, assessment of capacity, supporting capacity) for people with young onset dementia.[20] Available research has mainly involved people with dementia aged over 65, and there is a general lack of research on consumer experiences with capacity assessments.[21]

Insights from Stakeholders — Capacity and decision-making

A consistent theme was that people, including workers in health, disability and other service systems, too often **underestimate or ignore the decision-making abilities of individuals with dementia.** The negative consequence is a premature defaulting to substitute decision-makers.

Participants described scenarios where individuals were excluded from conversations, not because they lacked capacity, but because they were not given the time, support or respect needed to participate meaningfully. Formal assessments were sometimes conducted in rushed or unfamiliar settings, without accommodations or preparation.

> It just feels quite unfair to expect a person with a cognitive condition to just rock up to a capacity assessment without any opportunity to prepare. These are high-stakes evaluations, and they're often done cold.
>
> — Allied health practitioner

> Health professionals quickly revert to 'call the EPOA' enduring power of attorney - even when people can still participate. There's not even a conversation about whether support might help.
>
> — Service provider

Stakeholders also reflected on the real-world challenges of supporting decision-making for people with young onset dementia. Participants described capacity as being relational, dynamic and highly context-dependent. Families and professionals often face difficult ethical judgments about when to step in and how to weigh a person's apparent present preferences, against broader life goals, practicality and safety.

> You want to respect their choices - but what do you do when the decision is clearly unsafe, and they don't understand why it's risky?
>
> — Carer

> There's a huge disconnect between what the law says about capacity and what happens in real life. I'm meant to let him [husband] make his own decisions - but I'm also responsible if things go wrong. No one helps you walk that line.
>
> — Service provider

> I know you keep talking about me or people with younger onset dementia, but you've got to push the support towards sometimes the care partner. Because they need the help to help me, does that make sense?
>
> — Person living with dementia

These insights reinforce that supported decision-making requires more attention and adequate time in health care and other settings, and benefits from a relational understanding between the person with dementia and their supporter. Supporters also require assistance with the challenges that come with these roles, including tensions between promoting autonomy as far as possible, while ensuring safety and family harmony.

06 Legal Issues

Advance personal planning

The law enables adults to plan for future periods of impaired capacity and the end of life. The process of advance planning may include:

- Estate planning, including **making a will** to distribute assets upon death.
- The appointment of **enduring representatives** who have legal power to make decisions for a person during periods of incapacity. This includes a financial enduring power of attorney for money and property decisions and an enduring decision-maker for health-related matters (known by different legal terms, such as an enduring guardian or a medical treatment decision-maker).
- Making advance directives to express values and instructions, including **advance care directives** to guide future decisions about health-related matters and medical care.

Clinical practice guidelines emphasise the need for individuals diagnosed with dementia to receive information and advice on legal planning as well as other issues such as applying for formal supports (eg, NDIS) and eligibility to maintain a driver's licence.[22]

Effective planning helps to protect people's rights and interests in anticipation of future changes in decision-making capacity.

Issues

Younger Australians are less likely than older people to be aware of and have legal planning documents. Following a dementia diagnosis, younger people report they are encouraged to make a will and appoint enduring representatives, especially before capacity may be called into question.[23] However, such guidance has been criticised as unduly focused on preparing for the end of life, rather than preparing for life with dementia.[24, 25, 26]

There are gaps in data on the uptake and quality of advance legal planning by people with young onset dementia. Australian research indicates that a majority of older people with dementia have made a will and enduring appointments, but less than half report having an advance care directive (ACD).[27]

Research shows flaws in public understanding of legal planning documents, insufficient professional advice in preparing legal documents, deficiencies in drafting of legal documents, and inadequate selection and preparation of people appointed into enduring roles.[28]

All of these factors put people with dementia at risk of future decisions that go against their wishes and interests. For example, research into the abuse of older people indicates that financial enduring power of attorney appointments are implicated in an estimated 50 to 85 percent of cases of financial abuse.[6] People appointed as enduring medical decision-makers for a person with dementia can experience distress in the role and inconsistent preferences for end of life care may exist between people with dementia and their family members.[29]

There are gaps in practical resources that aim to educate enduring representatives about their legal role and responsibilities.[28] Website resources on advance planning topics should include plain-language information on legal frameworks.[30]

Advance personal planning

Some people with young onset dementia are at risk of being 'unrepresented.' This refers to a person who does not have an appropriate substitute decision-maker, nor a relevant advance directive to guide decisions, during periods of incapacity.[31, 32] Representation for dealings with government agencies is also a concern for people who lack nominees for Centrelink and the NDIS. More attention is needed to address the needs of people with dementia who do not have the support of close and trusted family and friends, especially as the proportion of people ageing solo increases.[33]

Insights from Stakeholders – Advance legal planning

Stakeholders described advance legal planning as both essential and often poorly supported. While clinical guidelines recommend early legal advice post-diagnosis, participants reported that advice was frequently vague, delayed, or narrowly focused on preparing for death (rather than planning for continued autonomy and life with dementia) or simply not provided. This is despite evidence that life expectancy after diagnosis of young onset dementia averages around 10 years.[34]

Health practitioners may be reluctant to raise the topic of advance planning for a range of reasons including a lack of knowledge of the law and processes. Families report being unaware of the importance of appointing enduring representatives (e.g. financial enduring power of attorney, enduring guardian) until an urgent problem occurs. There may be confusion about who has authority to make decisions, especially when legal documents are not in place. Families also raised concerns about enduring legal documents not being recognised across jurisdictions.

> People suddenly discover they've got to get their affairs in order and don't really know how to do that.
> – Carer

> It would have been helpful if we were told about enduring guardianship early on, before things started to unravel.
> By the time we were in crisis, it was already too late.
> – Carer

> A woman in my support group moved her husband to WA, and they wouldn't accept her POA. She had to go through guardianship and lost financial control. I asked the lawyer [if our NSW documents would be enforceable in Queensland]—he had to look it up.
> The geriatrician didn't know either.
> – Carer

These insights highlight the need for clear, well-supported, and a nationally consistent approach to legal planning—not just as a technical step, but as a safeguard for the rights and autonomy of people with dementia and those supporting them. Stakeholders called for plain-language resources, professional education, and national consistency in the recognition of enduring legal documents.[28, 35]

Disability and aged care systems

People with young onset dementia, their carers and families must navigate the disability system, and sometimes the aged care system, as well as the health and medical care system. Services are often fragmented, with a lack of clarity about responsibilities and assumptions about care being provided through another service.[36] Needs are not identified and addressed in a holistic manner.[37] For example, people with young onset dementia express preferences for rehabilitation/reablement services to maintain function, however this is rarely offered, funded or accessible.[38]

There are several barriers to accessing best practice care under the NDIS for people with young onset dementia.[39] These include:

- difficulties in meeting access eligibility criteria due to assessors' lack of knowledge or insufficient recognition of disability
- difficulties getting adequate funding because plans do not allow for changing disability needs over the disease course

These barriers are often incompatible with the progressive nature of young onset dementia and contribute to younger people with dementia being subject to avoidable admission to hospital and remaining there for long periods.

The Royal Commission into Aged Care Quality and Safety called for no younger people in residential aged care (Recommendation 74). Implementation of this recommendation has involved multiple agencies, including the Department of Health and Aged Care, the Department of Social Services, National Disability Insurance Agency (NDIA) and the Australian Institute of Health and Welfare (AIHW).[40] The NDIA now has a dedicated team specifically responsible for ensuring that participants under 65 do not become homeless and ensure access to permanent residential aged care in such circumstances.

Issues

Legal issues arise in relation to eligibility for, access to and problems with services, including home supports, respite residential care and permanent residential care. Proposed changes to the NDIS must consider eligibility criteria, objectives and management plans tailored to the unique requirements of people with progressive conditions such as young onset dementia.

Those younger people still living in residential aged care facilities report needs for increased independent advocacy and supported decision-making to navigate complex service systems and exercise a right to choice of housing.[41] Service gaps contribute to people with young onset dementia 'bouncing' between supported independent living settings, hospitals and psychiatry services.[36]

People sometimes are faced with recommendations from providers or other advisers to move into aged care after the age of 65. This can be for a range of reasons, the main one being a need for ongoing nursing services, The NDIS legislation has a section (s29(1)(b)) that provides that if an NDIS participant enters permanent residential aged care after the age of 65 for the first time, they automatically lose their NDIS eligibility. This carries risks for care and support as the NDIS funds a greater range and quantity of support than aged care. Because aged care is a means tested system, a move into residential aged care means the person is subject to assets testing and a fee regime. Specialist advice is required regarding the legal and financial implications of moving into aged care.

Insights from Stakeholders — Navigating the NDIS and fragmented systems

Stakeholders described the NDIS as a structurally misaligned system for people with young onset dementia.

Although dementia is recognised under the NDIS Act as a disability, the system is designed around fixed impairments and static planning frameworks—not the progressive, at times unpredictable, nature of neurodegenerative disease.

Families frequently had to self-fund functional assessments by allied health professionals in order to demonstrate eligibility. Once accepted, the 12-month planning cycle failed to accommodate symptom progression. Outcomes were inconsistent, often depending more on the planner assigned than on assessed need.

> It so much comes down to which planner you get. There's no consistent outcome or understanding.
>
> — Allied health practitioner

Several participants described the need for a system "quarterback"—a knowledgeable advocate to help families understand their options, coordinate services, and make timely decisions.

> Once you've had that initial diagnosis, you really need a quarterback—someone who can sit down with you and say: Here's what happens next. Otherwise, people just get lost in the system.
>
> — Carer

People with dementia and carers also described the burden of repeatedly proving impairment to different planners who did not understand how dementia presents.

> The planner was shocked by how articulate I was and said I didn't sound like I had dementia.
>
> — Person living with dementia

> By the time they reach NDIS, families are already exhausted. And then they have to fight to get in.
>
> — Service provider

Some described a deeper conceptual mismatch: while the NDIS philosophy is built around "choice and control," many people with dementia are navigating progressive changes in insight and capacity, and families were often asked to step back in ways that felt legally and ethically unsafe, and without any guidance or support.

> Families are put in impossible positions—they have to both prove how impaired the person is, and then step back and let them make the decisions.
>
> — Service provider

Participants called for a dedicated young onset dementia pathway within the NDIS, along with more flexible planning models, specialist navigation hubs, and better training for planners and health professionals.

Human rights issues

RESTRICTIVE PRACTICES

Human rights issues arise for younger people with dementia in a range of settings including their own homes and residential care facilities. **Restrictive practices** are a persistent concern, including:

- **Chemical Restraint:** This involves using medication to control a person's behaviour or restrict their movement, where the primary purpose is not to treat a medical condition. Examples include using sedatives or antipsychotics to manage agitation or wandering.
- **Environmental Restraint:** This restricts a person's access to their surroundings, including items and activities, to influence their behaviour. Examples can include locking doors (including doors requiring codes), removing access to mobility aids, or limiting access to certain rooms or outdoor areas.
- **Mechanical Restraint:** This involves using devices to restrict a person's movement. Examples include bed rails (when used to prevent getting out of bed rather than for positioning), lap belts on wheelchairs, or restrictive clothing.
- **Physical Restraint:** This involves using physical force to prevent, restrict, or subdue a person's movement. Examples include holding someone down, physically blocking their path, or forcibly guiding them.
- **Seclusion:** This involves the confinement of a person in a room or physical space from which they are prevented from leaving voluntarily, especially when they are in the room alone.

Australian research shows chemical restraint is common in both residential NDIS[42, 43] and aged care facilities to manage behavioural expressions of need, which may be labelled as 'wandering' or 'non-compliance'.[44, 45] Use of antipsychotic medication increases substantially for people in the six months after entry into residential aged care. These drugs can be a form of unlawful chemical restraint, a key issue raised in the Aged Care Royal Commission.

Recommendations from the Royal Commission instigated increased regulatory requirements for aged care providers to obtain informed consent to administer restraints.[46] The *Aged Care Act 2024* provides restrictive practices may only be used as a 'last resort to prevent harm' after attempting alternative strategies and obtaining informed consent (with further regulation to be prescribed under rules).[47]

More research is needed on prescribing practices around psychotropics specific to those with young onset dementia, although international rates of prescription are very high.[48, 49]

Legal and clinical pathways must be strengthened to avoid the use of restraints as a 'first resort' for responding to the behavioural and emotional expressions of need among younger people with dementia in residential care. An additional concern is that prescribed psychotropics[50] may be classed as 'treatment' (eg, for depression, pain or management of psychotic symptoms) rather than identified as chemical restraint, which have different requirements for consent. It also raises ambiguity about the extent and reporting of chemical restraint in residential care settings.

SURVEILLANCE

Surveillance technology in care settings may help to deter and detect occurrences of violence, abuse and neglect. For example, South Australia piloted a trial of CCTV in residential aged care facilities, which involved 'trade-offs between privacy/dignity and functionality'.[51] An evaluation of this trial also found in-principle agreement to the use of AI surveillance systems.

However, practical and ethical tensions arise in relation to surveillance technology, such as the extent to which it empowers or disempowers people with dementia and carers, its practical effects in improving safety, and its potential to displace in-person contact and care.[52]

There are no dementia representative organisations in Australia that endorse blanket use of surveillance, as it raises issues of consent, privacy, as well as restrictive practice.[53],[54],[55] Literature suggests public support for CCTV in public spaces in residential care facilities (aligned to the public perception that surveillance reduces crime, which may not be accurate). However, automated systems should not be a substitute for sufficient staffing and should only be used consistent with a social licence to improve care and must be monitored in real time.[56]

Use of unobtrusive monitoring technology in home settings can support independence to live at home with real-time information about sleeping, eating and other activities. Such data collection may enable prevention and early intervention for health risks. However, such monitoring could easily overreach and become intrusive 'big brother' style surveillance.[57] A wide range of social, ethical and regulatory implications are raised by intelligent assistive technology for dementia — including ethics, informed consent, identity, privacy and security, and appropriate regulation.[58]

Emerging concerns have also been raised about technologies that enable remote tracking, data collection, and environmental control in the homes of people with young onset dementia. These may include GPS-enabled wearables, apps that share live location or behavioural data, and smart-home systems that allow a third party to remotely lock doors or control appliances.[59] While often marketed as assistive or protective[60], these systems raise complex legal and ethical issues—particularly where the person's capacity is declining or previously given consent is no longer valid. In such cases, what begins as voluntary support may drift into de facto detention or surveillance without review or safeguards.

Current regulatory frameworks have not yet clarified when and how these technologies constitute restrictive practices under disability or aged care law, or how substitute consent should be governed over time.

This is a particularly urgent issue for people with young onset dementia who may be highly independent at the outset of their condition but become vulnerable to coercion, overreach or loss of autonomy as their condition progresses. Specific legal guidance is needed to ensure such technologies are used transparently, with meaningful safeguards, and in a way that preserves dignity and rights.

More work is needed to understand the particular views and preferences of people with young onset dementia in relation to surveillance and other technology.

Principles on human-computer interaction (HCI) and design acknowledge that it is essential to be sensitive to the differences in needs and experiences of younger and older persons with dementia:

> These younger individuals living with dementia are independent, often still working, engaged with life, live with less severe cognitive decline and are very capable of providing informed consent on their own behalf. They are actively involved with their health decisions, reflective about their situation, and tech savvy.[61]

SEXUAL EXPRESSION

Sexuality needs are often neglected in people with young onset dementia, especially when they are in residential care, despite people's wishes to maintain a spousal sexual relationship or otherwise engage in sexual activity.[62]

A range of issues relating to sex and sexual intimacy have been identified for people with young onset dementia and their partners including shifts in roles and responsibilities, declines in relationship quality, changes in identity, and self-esteem, increasing social isolation and loneliness, shifts in intimacy, and changes in sexual activity.[63]

A national survey of residential aged care facilities in Australia found that 'most residential aged care staff do not have access to policies on sexuality or sexual health to guide them in their practice.[64] Sexual assault and other sexually abusive behaviours are also serious problems in residential aged care settings.[65] Legally mandated reports are required in accordance with the Serious Incident Response Scheme.[66]

People with dementia face restrictions on their rights to sexual expression and intimacy, particularly due to uncertainties about affirmative consent laws and how to support decision-making in relation to sexual activity.[67] Some guidance exists on how to assess capacity for sexual consent by a person with dementia.[68]

The only reference by the NDIA or the NDIS Quality and Safeguards Commission to NDIS participants and sexuality is in the Commission's NDIS Practice Standard for providers:

- *Each participant's autonomy is respected, including their right to intimacy and sexual expression.*[69]

Advance sexual directives have been proposed as a way for people to document preferences in relation to sexual expression and activity during future periods of reduced capacity.[70] The legal effect and implications of such directives requires further attention.

Individuals with young onset dementia who are living at home, physically active and socially engaged, may use dating apps or online platforms to initiate new relationships. Families and carers may express concern that the person's interest in romance or sex is impulsive, out-of-character, or places them at risk of exploitation. This can lead to informal restrictions on digital access or movement, without clear legal authority or frameworks for assessing capacity, consent and risks.

Disinhibition as a symptom of dementia may intensify emotional vulnerability or reduce sexual judgement. At the same time, many individuals retain awareness of their needs and the desire for companionship. The absence of clear protocols for supporting safe, consensual intimacy - both inside and outside of long-term partnerships - places pressure on families and may lead to overreach, coercion or unjustified restrictions. However, these issues need to be balanced with considerations of risk, and consent should be central to all interactions with others.

Legal guidance is urgently needed to clarify how capacity to consent should be evaluated in all contexts - established relationships, informal situations and digital contexts - and how families and support workers can uphold dignity and autonomy while managing real risks. This includes clearer education on supported decision-making, appropriate privacy boundaries, access to individual advocacy, protocols for support workers and other paid staff on how to report suspected abuse or exploitation, and legal remedies for coercion, abuse or exploitation.

Insights from Stakeholders — Human rights in care

Stakeholders reflected on the legal and ethical tensions surrounding restrictive practices and surveillance in both residential and community-based care for people with young onset dementia. While legislative reforms have sought to limit the use of restrictive practices (including restraint), participants described unintended consequences—such as delays in necessary treatment or confusion over whether or not a proposed intervention supports autonomy, or is 'restrictive'.

> When someone is terrified—hiding under their bed, unable to eat and drink because of their high levels of anxiety… in these extreme states it's difficult to say, let's distract with doing some painting and going for a walk. Sometimes these strategies don't work... To leave someone in that level of distress without medical support is not just cruel—it's inhumane... The protective barriers that are now in place for chemical restraint are so strong that none of these decisions are taken lightly. But they must be made with the health professionals who understand the context. But the public guardian will absolutely say no on all accounts even if it's to support improved quality of life, so they're able to live their life. I think we've just probably gone too far one way.
>
> — Service provider

In community-based settings, stakeholders described problems in how basic safety technology—such as sensor mats or overnight alerts—are classified. Restrictions on funding for active overnight care placed some individuals at risk, or meant that because of night-time activity, they might be forced to leave supported independent living (SIL) and move to aged care once they turn 65. One service provider suggested that sensor mats could help overcome this problem so the person could stay living in their SIL home.

> There's a real minefield around surveillance in community settings. Something as basic as a sensor mat beside a bed—used to alert a carer if someone's getting up at night—might be classed as a restrictive practice. I've had different answers from the NDIS: sometimes yes, sometimes no. That makes it really hard to recommend what people need. Families want to keep their loved ones safe and out of aged care, but SIL providers worry about being seen to monitor people inappropriately We're trying to minimise restrictive practices, but the system won't fund the support people need to live independently. It's a real challenge.
>
> — Allied health practitioner

Younger people with dementia may be highly independent and aware—and can experience surveillance and restriction not just as safety measures, but as unwanted infringements on their dignity and autonomy. But these insights highlight the need for restrictions that are ostensibly designed to safeguard autonomy, to take into account person-centred planning and informed clinical judgement, so that autonomy and quality of life are preserved in reality, and not paradoxically restricted.

Medical and health law

The law plays an important role in structuring and regulating the relationship between health professionals and their patients:

- the legal **duty of care** of professionals to provide reasonably competent care in accordance with current standards of practice
- the rights associated with **consent to treatment**, and
- **privacy** and **confidentiality** in relation to collection, use and sharing of personal information.

Legal issues arise along the trajectory from seeking a diagnosis, to post-diagnosis care and support, and to palliative and end-of-life care.

Issues

BARRIERS TO DIAGNOSIS

People with young onset dementia experience barriers to timely and accurate diagnosis. These barriers are accentuated for some groups of people[71]:

- living in regional/remote areas[72]
- initially diagnosed with a psychiatric condition[73]
- from marginalised socio-economic and cultural backgrounds[71]
- First Nations people.[74]

This is despite evidence of increased risk of young onset dementia in these groups[75, 76, 77, 78].

Pathways to diagnosis for young onset dementias often involve higher economic costs and emotional consequences due to unnecessary service contacts, waiting times and distress.[79] These factors may contribute to some people not obtaining a formal diagnosis, with negative legal repercussions, such as delayed legal planning, discriminatory responses to misunderstood symptoms, and barriers to legally available supports.

DIAGNOSIS DISCLOSURE

The legal duty of care generally requires disclosure of the diagnosis directly to the patient. Some people may express a preference not to know a dementia diagnosis, either for themselves or a relative, for reasons including fear of negative mental health consequences and religious and cultural values.[80] Such issues can be addressed through pre-diagnosis counselling and integrating family members, where appropriate, in preparation for a diagnosis. Studies on the disclosure of a dementia diagnosis show that correct terminology is not always used based on uncertainty of diagnosis as well attempts to minimise distress, avoid negative connotations and use culturally appropriate language.[77, 81, 82] Health practitioners and family/carers can dominate conversations, even in early stages of dementia, which undermines the individual's rights to participate in their own care and decision-making.

INFORMATION PROVISION

Diagnosis consultations should balance the amount of information provided, pacing it over several appointments to avoid overwhelming patients.[83] An Australian study with carers of people with dementia found that, at the time of diagnosis, carers prefer information about dementia-specific services and supports; information about legal and financial matters was preferred later.[84] Essential first topics to cover include: information about the diagnosis, treatment, some key first steps, and a nominated point of contact. People with a diagnosis who are in the workforce will need information around their employment rights, and may need to be signposted to government or financial advisory services for advice on income support options.[83, 85, 86, 87]

RECORDING CONSULTATIONS

People may wish to record their consultations with health practitioners to assist with their recall of information and to share with family and care partners.[88] Studies suggest that there are specific benefits of recording information at the point of diagnosis for cancer patients[89] and patients from CALD backgrounds.[90]

While recordings may be helpful in the context of receiving a diagnosis of young onset dementia and follow-up care, there are important privacy issues to consider. Legal rules governing consent to recording vary by jurisdiction.[91]

SUPPORTED AND SUBSTITUTE DECISION-MAKING AND ONGOING CARE

Health practitioners have identified challenges in adequately supporting people with young onset dementia. Concerns include:

- greater complexity of young onset dementia compared to older persons with dementia (e.g., impacts on driving, employment, parenting)
- concerns by staff of older adult dementia services about their competency/lack of specialist training in young onset dementia, and
- systemic inadequacies in healthcare that are specific to people with young onset dementia.[92]

Health professionals also need training and resources to support people with dementia to make their own care and treatment decisions.[93] In circumstances where the individual is unable to make specific medical decisions, in all but emergency situations, professionals will need to engage with an appropriate, legally authorised, decision-maker, such as an enduring representative previously appointed by the person.

GUARDIANSHIP

In the absence of a personal representative for the patient, an application to a tribunal may be required. A high volume of guardianship applications across Australia are dementia-related. Staff and members of guardianship tribunals need more training on dementia and proceedings need to be inclusive and accessible for people living with dementia.[94, 95]

Available data on guardianship decisions do not differentiate by age to compare applications and outcomes for people with dementia at younger versus older ages. A review of a sample of tribunal decisions from NSW and QLD regarding guardianship of people with young onset dementia reveal key tensions and concerns:

- disagreement between family members/care partners
- people with no family or care partners
- safeguarding concerns about care services
- consent and management of restrictive practices, and
- complexities of dementia alongside another disability or condition, such as Down Syndrome or substance abuse.

These decisions also show that hospital discharge planning is a critical point in the pathway for care of people with young onset dementia. Research in the geriatric care context shows extended hospital stays for older people awaiting guardianship hearings, gaps in clinicians' understanding of capacity assessments and guardianship, a need for more attention to supported decision-making, and disparities between patient preferences and guardianship outcomes.[96, 97] More research is needed to understand these issues for people with young onset dementia.

State guardianship is a common outcome for people who do not have close family or friends available or willing to be appointed as a decision-maker. State guardians have large caseloads and, without the time and resources to get to know their clients, face challenges in making decisions that align with individuals' unique values, interests and preferences.[98]

Community guardian programs — such as in Western Australia (WA) and Victoria — have sought to address this challenge. These programs involve committed volunteers who are recruited and trained by the Office of the Public Advocate, and then matched with adults who are subjects of a guardianship order to serve as advocates and decision-makers.[99] Although Victoria's program is no longer operational[100], WA's program continues with a small number of volunteers. Such programs deserve further attention and invigoration.

Insights from Stakeholders — Guardianship and decision-making

Stakeholders raised serious concerns about the failures of guardianship systems to deliver relational, responsive and rights-based decision-making for people with young onset dementia. Participants described the system as unresponsive, impersonal, and fundamentally disconnected from the people it is meant to serve.

> I feel very sad for people with younger onset dementia [who don't have support] because our communication and dealings with the public guardian and trustee would be no less than appalling and dissatisfactory on every single level... They don't know the residents at all. They never visit them. They have no contact with them.
>
> – Service provider

Participants also described how family members appointed as enduring representatives (e.g. EPOA, enduring guardian) were often overwhelmed by the complexity of the role. Many accepted the responsibility without understanding what it would require, or struggled with the ethical implications of intervening when the person's wishes seemed out of step with their current needs.

> We have so many people say, 'Oh no, I'd never go against her wishes… I'm not actually going to take over, you know, like, if that was ever to become necessary.' You get people accepting to become an attorney, but having it in their own mind that they wouldn't actually want to have to make any decisions on behalf of that person—even if that became required.
>
> – Allied health practitioner

> People have this all-or-nothing view… like, 'I'm not willing to do all, so instead I'm going to do nothing.' Whereas… providing a bit of scaffolding around the situation would actually be preferable. But how is somebody who's never dealt with dementia, or managing somebody else's finances, or a complicated financial set-up—and feels uncomfortable about this role they've taken on without understanding it—how are they ever going to do that?
>
> – Allied health practitioner

> You want to respect their choices, of course you do. But when you see them doing something that's clearly going to cause harm, what do you do? It's just up to you to guess.
>
> – Carer

> Family members can also disagree among themselves about care, which puts clinicians in a difficult position. These decisions involve interdependent relationships between the person and their family, which makes disagreements hard to navigate.
>
> – Medical specialist

These insights reflect that substitute decision-making is not just a legal role, but a deeply relational and often personally challenging one. Participants called for better education, clearer legal frameworks and sensitive, personalised support to help appointed decision-makers navigate the grey areas between protection, respect and shared responsibility.

PARTICIPATION IN RESEARCH

People living with dementia may be interested in taking part in research studies. They value the opportunity to help advance knowledge on care and supports, and may seek out clinical trials to access experimental treatments. Some people may also wish to make arrangements to donate their brain or other bodily tissues for research following their death. There are a number of organisations who are keen to secure brain donations from those with and without a diagnosis of young onset dementia.[101, 102, 103, 104, 105, 106, 107] however, according to a 2019 government review "...dementia brain banks in Australia face significant operational challenges and a unique funding challenge".[108]

Research has identified ethico-legal issues and barriers to research participation for people with dementia[109], but with greater focus on those aged 65 and older.[110]

Legal concerns centre on:

- consent, including the capacity of individuals with dementia to make decisions in relation to research participation
- substitute decision-making by appropriate legally authorised representatives, and
- legal oversight of research with participants who may be at greater risk of exploitation or harm due to impaired capacity.

In Australia, participation in research by people with cognitive impairment is governed by state and territorial laws that have varying definitions, rules and processes[111], as well as the *National Statement on Ethical Conduct in Human Research (National Statement)*[112]. The most recent amendments to the *National Statement* acknowledge historical barriers to research participation and highlight the importance of inclusive research practices:

> In the past, the design, review and conduct of research have directly or indirectly caused people experiencing physical or mental ill-health or disability to be disempowered or excluded from research due to assumptions about their ability to make decisions or provide consent... There is an ethical imperative to include people with physical or mental ill-health or disability in research and to facilitate their independent decision-making. (p.83)[112]

More attention is needed in regard to effective supports that enhance the capacity of people living with dementia to make decisions about taking part in research and continuing in studies over time as their condition progresses. As part of future planning, people with dementia may document their wishes and preferences for research participation in an advance research directive.[113] Advance research directives are discussed in in the *National Statement* at Guideline 4.5.6 (p. 84).[112]

Australian researchers have developed a dementia-focused advance research directive document, with input from people with experience of dementia and interests in dementia research.[114] The directive and accompanying guidance are available on the StepUp for Dementia Research website.[115]

END-OF-LIFE CARE

A recent review found similarities in end-of-life care needs for younger and older people with dementia in relation to palliation of physical and psychological symptoms.[116] Improving early initiation of advance care planning was cited as ‘crucial’ for people with young onset dementia ‘given the more rapid progression of disease affecting cognition and decision-making capacity’.[116] See also *Advance Personal Planning* section above.

Medical and health law

Voluntary assisted dying (VAD) laws are in effect in all Australian states and will take effect in ACT in late 2025. Ironically, the Northern Territory - the first Australian jurisdiction to pass VAD laws but which were subsequently disallowed by the Commonwealth - will be the only jurisdiction without legal access to VAD.[117] People seeking access to VAD must meet strict eligibility criteria. Most importantly for people with dementia, laws across Australia require that people seeking access to VAD have current capacity to consent to the procedure.

Advance directives cannot be used in Australia to give consent to future euthanasia. Advance euthanasia directives (AED) are lawful in the Netherlands, however are rarely acted upon due to doctors' ethical concerns. A recent consensus study in the Netherlands determined that:

> expressions of a person with dementia should be considered throughout the progression of decision-making disabilities. In such cases, a wish to live should be prioritised over an AED. Although substitute decision-making is not an option in case of euthanasia requests, both people around the person with dementia as well as their AED can be supportive in the decision-making process. Advance directives with formulations such as 'if I have to admitted to a nursing home, then I want euthanasia' are found to be infeasible.[118]

Research on voluntary assisted dying has predominantly focused on health practitioners, including their knowledge of legal aspects.[119, 120] The voices of people with dementia must be a priority for future research.[121]

Insights from Stakeholders — — End-of-life care and early planning

While views on VAD were not widely discussed in interviews, participants strongly endorsed the importance of early planning for health decisions, including end-of-life care.

Some people living with dementia felt that their appointed guardians should be able to make decisions right up to VAD, while others noted the vulnerability of people with dementia and felt that safeguards were important. Interviewees generally emphasised the need to plan as much as possible while the person retains capacity, and highlighted the emotional challenges for carers trying to honour previously expressed wishes.

> We had it [legal planning] in place quite early. And we probably thought about it when I had more capacity. Yeah. The more capacity you have, the better decisions you make.
>
> — Person living with dementia

> You want to do the right thing, but no one tells you what that looks like. And it's so hard to know if you're doing what they would have wanted.
>
> — Carer

These accounts reinforce the value of supported advance care planning—not only for legal clarity, but to preserve dignity, reduce uncertainty, and strengthen relational trust at the end of life.

Criminal law

Symptoms of young onset dementia may include changes in behaviour and personality, such as disinhibition, socially inappropriate behaviour, aggression, and changes in judgement and reasoning.[122] These behaviours can lead to contact with police and the criminal legal system.[123]

A developing body of research in Australia[124] and other countries - such as the United States[125], Sweden[126, 127] and Japan[128] - investigates criminal offending in dementia, linking executive dysfunction to the commission of impulsive violent or anti-social acts. These behaviours are of particular concern in frontotemporal dementia (FTD)[129], especially behavioural variant FTD (bvFTD). At least one-third to over one-half of people with FTD exhibit behaviours that may raise allegations of physical and verbal abuse, theft, hazardous driving and inappropriate sexual conduct.[130],[131] People with FTD may also experience impairments in understanding and using language and in expressing sympathy and empathy[132, 129], which may compromise effective communication when questioned about alleged offending.

It is increasingly recognised that the criminalisation of behavioural symptoms of dementia is unjust. Accused persons with dementia who cannot be held legally culpable due to brain pathology[133] should be diverted from criminal punishment and receive appropriate care and behavioural support.[131]

Domestic violence

Domestic violence concerns may arise both as the person with young onset dementia as a victim or as an alleged perpetrator. Dementia-related behaviours have also been investigated in the context of spousal and family caregiving and risks of violence.[134, 135] An Australian study that involved 71 families of people diagnosed with young onset dementia found that over 90% of family carers reported "difficult-to-manage" behaviours, including aggression, disinhibition and inappropriate social behaviour.[122] A UK study of over 200 family carers found that nearly half (47%) reported experiencing recent abusive behaviour from the person with dementia.[136]

Other studies of family carers have reported that at least one-quarter experience physical violence in providing care for their relative with dementia.[137] Aggressive and disinhibited behaviours contribute to increased carer stress[138, 139] and can escalate to police involvement.[140, 141, 142, 143]

Spousal carers of a person with dementia have reported sexual aggression and assault.[134] Hypersexuality was described in one study as "the most stressful dementia symptom to manage".[135]

In Australian homicide cases against an accused person with dementia, court documents indicated frontotemporal dementia is the most common diagnosis, nearly all offenders are male and victims are frequently a current or former intimate partner.[144, 145] These gendered patterns were also found in an international review of homicide cases and dementia.[146]

Violence towards people with disability

The Disability Royal Commission reported that rates of violence are higher for people with disability than those who do not have a disability. This includes assault, sexual assault and intimate partner violence, financial and emotional abuse. Residential aged care facilities are high-risk settings for physical assaults, as demonstrated by a NSW analysis of 700 police-recorded events in these facilities.[147] A majority of people involved in resident-to-resident violence have a dementia diagnosis and a history of behavioural symptoms.[148, 149] In addition to reporting serious incidents to aged care regulators, facilities must also make timely reports to police when warranted, including for incidents involving residents with dementia.[66]

Legal proceedings

People with cognitive impairments experience particular vulnerabilities in criminal proceedings that are based on rational thought and action frameworks.[131] Research from Queensland highlights that individuals with cognitive and psychosocial disabilities find interactions with the criminal legal system extremely stressful, feeling alienated due to authorities' lack of understanding of their impairments.[150] Studies from England, Wales and the US reveal similar concerns, noting that cognitive impairments like dementia hinder equitable participation in legal processes.[151] These conditions affect individuals' ability to access legal representation, participate in their defence, comply with court orders, and maximise their safety if detained. Professionals working in criminal legal systems have gaps in knowledge about how dementia might affect a person's behaviour, abilities and needs.[152] Legal and social work professionals report difficulties in advocating for clients with dementia due to the complexity of legal processes and insufficient accommodations.[153]

Detention

Most literature on dementia and the 'correctional' arm of the criminal legal system focuses on older adults. However, insights are relevant to people with young onset dementia who are detained in settings that include police watch houses, remand centres, prisons and secure psychiatric (forensic) facilities. Studies from Australia, the US, UK, France, and Sweden show that prisoners with dementia are exceptionally vulnerable to the conditions of detention.[154, 155] They struggle with understanding and adhering to rules, leading to unfair disciplinary actions, and are more susceptible to victimisation by other detainees. Extended detention is a significant issue. In California, a 13-year analysis found that people with dementia were less likely to be restored to competency for trial and were detained twice as long as others in psychiatric institutions.[156] A UK study found that conditions in forensic institutions often did not meet the clinical or risk needs of people with dementia.[157]

Insights from Stakeholders — Criminalisation of behavioural symptoms of dementia

Stakeholders described a range of experiences where behavioural symptoms in the context of young onset dementia—such as aggression, disinhibition, paranoia and confusion—brought individuals into contact with police or mental health crisis teams. In some cases, the response was traumatising and inappropriate, leading to arrest, hospitalisation or court involvement. In other cases, outcomes were more positive when responders had prior awareness of dementia and took a care-focused approach.

> He rang the police one night and reported me for taking his money. He was verbally abusive at the time and through the phone, and they [the call taker] heard and said, 'No, I have to send somebody for a welfare check.'… I was very fortunate that it was an older Sergeant that came… He looked at me and said, 'Have you got an official diagnosis?' I said, 'Yes, I have.'
>
> — Carer

> They arrested [my husband] and took him to hospital. Didn’t wait for the ambulance. And then… put in [a domestic violence report]. I went to court four times in the next five months, which I couldn’t tell him I was doing… He was already traumatised, not understanding what he was doing in a psych ward.
>
> — Carer

> “The police agitated him. Everything… Like young onset dementia, we’ve got to learn how to actually approach these people without escalating a situation.
>
> — Carer

> People with young onset dementia are more likely to be seen as difficult or noncompliant rather than unwell.
>
> — Service provider

Carers also described being misjudged by authorities—sometimes treated as victims when they were seeking help for a medical issue, or drawn into complex court proceedings that failed to understand the nature of the illness. On occasion, carers report being subject to apprehended violence orders, where police inaccurately suspect the person with young onset dementia is at risk. While protecting the person with dementia is critical, police should be encouraged to work with families and carers to ensure best outcomes for all affected.

These experiences illustrate the need for consistent, dementia-literate responses from frontline services. Stakeholders called for:

- Better recognition of behavioural symptoms of neurodegenerative illness
- Diversion from the criminal legal system wherever possible
- Training for police, emergency departments, and courts in recognising and responding to behaviours in the context of dementia
- Support for carers navigating behavioural crises, especially where safety is at stake.

Issues

Numerous issues arise in the context of dementia and contact with police and the criminal legal system:

- Lack of awareness of behavioural symptoms of young onset dementia, leading to risks of inappropriate policing responses and prosecutions
- Even when symptoms are recognised, some accused people are unable to access timely neurocognitive assessments. Costs and waitlists are barriers to obtaining medical evidence to support diversion from the criminal legal system
- In legal proceedings, issues include determining an accused person’s mental capacity, including their mental state at the time of the alleged offence, the impact of memory impairment on a purported confession, fitness to plead and fitness to stand trial
- The unique needs of people with dementia, regardless of age, are not adequately recognised in custodial settings, leading to violations of basic human rights.

Criminal law

More research is needed to understand how behavioural symptoms of dementia manifest and lead to contact with the police, as well as strategies to reduce the risks of harm for people living with dementia, carers and community members.

The intersection between domestic violence and dementia warrants more investigation.[158, 159] Few studies on dementia and criminal offending have sought the perspectives of people with dementia; one reason for this gap is that insight into wrongdoing and awareness of harm to others may be limited, especially in FTD.[160]

Discrimination

PROBLEMS AND ISSUES WITH GENETIC TESTING

Certain genetic variations can increase the risk of developing young onset dementia. For example, mutations in genes such as APP, PSEN1, and PSEN2 are known to be associated with early-onset Alzheimer's disease.[161] Autosomal dominant pattern genetic inheritance accounts for less than 15% of cases of young onset dementia.[162]

Genetic testing for young onset dementia carries several potential risks, including psychological, ethical, and societal implications, with particular concerns related to discrimination in insurance, employment and other areas.

INSURANCE RISKS AND GENETIC DISCRIMINATION

As a general rule, applicants for insurance are required to disclose any information relevant to the insurer's assessment of risk, including genetic information. This duty of disclosure is part of the mutual obligations of insurers and the insured to act in 'utmost good faith' under the *Insurance Contracts Act 1984* (Cth). This may include results from genetic tests and family medical history if it indicates a predisposition to conditions such as young onset dementia. The obligation to disclose does not apply to health insurance, as community-rated health insurance in Australia prevents risk-based underwriting.

Up until recently, relevant results of genetic tests were required to be disclosed in life insurance applications, and the potential for this to increase the costs and/or limit the availability of life insurance was a matter of great concern, alongside fears that such impacts might discourage people from having potentially useful genetic testing.[163, 164] However over the past five years, significant legal safeguards have been introduced to protect individuals from the need to disclose genetic information in these circumstances. After a partial moratorium was introduced in 2019, the Australian government embarked on a period of extensive community consultation and, on 11 September 2024, it announced it would introduce a total ban on the use of adverse predictive genetic testing results in life insurance. Individuals will still be required to inform insurers or prospective insurers of results which are diagnostic in nature.[165]

It was recognised that genetic testing is important to help people manage or avoid hereditary conditions, and there are significant benefits to its use in medical research. These reforms were designed to encourage genetic testing wherever appropriate without fear of insurance penalty.

The proposed ban on the use of predictive genetic test results in life insurance does not extend to the use of biomarker or other predictive test results. For example, individuals will still be required to provide the results of testing for tau and beta amyloid levels that may be used to predict risk of the development of Alzheimer's disease. There is the potential for requirements to disclose dementia biomarker information to result in inappropriate discrimination against people who will never go on to develop dementia.[166]

GENETIC DISCRIMINATION EMPLOYMENT

There are few reports of employment-related genetic discrimination in Australia. In 2010, the Australian Law Reform Commission noted “only a small number of cases” — although this included one case where an individual with a family history of a degenerative neurological condition was initially rejected for a position with the public service. The man was informed that he would only be employed if he could provide evidence that he did not have the genetic mutation that causes Huntington’s disease.[167] Even so, the ALRC described the use of genetic information in employment as "still largely only of theoretical concern" at that time.

Nevertheless, employers may have an interest in obtaining genetic information about employees for a number of reasons, including economic incentives, occupational health and safety factors, and selecting the best person for the job. For example, in some industries, employers are required to conduct pre-placement health assessments and genetic information may be relevant on these occasions.

It is possible that genetic test results could lead to bias in hiring or promotions, particularly if an employer perceives an individual as at risk of diminished productivity due to future illness.[167] This risk is heightened in industries with demanding roles where employers might view a genetic predisposition to dementia as a liability.

While the *Disability Discrimination Act 1992* (Cth) prevents discrimination based on genetic status, and any actions would need to demonstrate that they were not unfairly discriminatory within the terms of the Act, there appears to be a gap in the Australian Government's support for people with progressive diseases to stay in employment. While Australia's Disability Strategy 2021-2031[168] (ADS) identifies employment as a priority area, there is no specific reference in either the ADS, the Australian Disability Employment Strategy[169] or the ADS Employment Targeted Action Plan[170] to supporting people who either (a) acquire disability during their employment or (b) have a progressive condition (like young onset dementia) to remain in work.

Driving and Travel

DRIVING

A diagnosis of dementia raises issues about medical fitness to drive. Driving licencing laws across Australia have rules about reporting health conditions to licensing authorities. The laws vary across jurisdictions, however, all states and territories have legislation that requires a driver to advise their driver licensing authority of any long-term or permanent injury or illness, disability or medical treatment that may affect their safe driving ability.[171]

In addition, all Australian governments have endorsed requirements for the assessment by clinicians of fitness to drive.[172] These standards guide how health practitioners assess and manage patients with conditions that may affect their fitness to drive. Professional assessments inform the decisions of driver licensing authorities.

In Australia, there is no legal obligation on any individual other than the person with dementia or medical practitioners to report concerns about driver safety to licensing authorities. although some jurisdictions provide avenues for people to report concerns about another person's ability to drive safely.173

Driving and travel

For people with dementia, restricting or cancelling their driver's licence can significantly impact their independence, lifestyle and identity, and contribute to social isolation.[174] Losing a licence can also affect employment and lead to early workforce departure. This is especially important for people with young onset dementia as the diagnosis comes when they are likely to have significant financial and family responsibilities.[175]

People living with young onset dementia desire to be treated individually and not be subject to automatic loss of licence.[174] A review of literature on driving capacity and assessments for people with dementia recommended against blanket prohibition of driving and advocated for periodic assessments (for example, on a six-month basis).[176, 177]

Impaired driving ability and loss of a licence is a whole-of-family problem that can cause stress and conflict.[178] Family members report a range of strategies to reduce risks, such as by hiding keys or preventing access to a vehicle.[179] Family carers may face additional responsibilities for providing transport.

TRAVEL

People living with dementia and their carers may face adverse treatment when undertaking travel. Research on the perspectives of people with young onset dementia on the right to travel and freedom of movement describes a lack of understanding and accommodation of non-physical/cognitive disability by airports. Ad hoc support generally depends on the kindness of individuals rather than supports embedded at a structural level, including by airlines and airports.

People living with dementia and carers have recommended practices to reduce the stress and anxiety of travel[180], including:

- designated security assistance
- staff training, especially on cognitive disability and appropriate accommodations[181]
- not separating travel companions
- hidden disability identifiers (eg, sunflower).[182]

Legal claims test the balance between the rights of travellers with disabilities and the duties of transport providers. The case of *Sheila King v Jetstar Airways (*2012) involved a refusal of boarding to a woman in a wheelchair on the basis that two passengers requiring wheelchair assistance were already on the flight. The judge found Jetstar's discrimination was justified on the basis of that providing assistance to a third passenger in wheelchair would cause unjustifiable hardship/expense to Jetstar.[183] This decision has implications for people with cognitive or other hidden disability.[184]

Insights from Stakeholders – Driving, travel and the tension between safety and freedom

Driving is not just a transport issue—it is a marker of independence and adult identity. Losing a driver's licence can have wide-reaching effects on work, autonomy, mobility and social participation. Stakeholders expressed concerns about inconsistent and premature licence cancellations, especially when based on generalised assumptions rather than individual capacity assessments.

Driving and travel

> The neurologist used rules that he had developed… he says two years after you get your diagnosis, you stop driving. But he doesn't take into account how many years into dementia that diagnosis is… I knew I'd eventually have to stop, but the way it happened was just a complete shock.
>
> – Person living with dementia

Some carers felt powerless to raise concerns or intervene, even when they believed their loved one's driving was unsafe:

> "There's no way a spouse can go to Roads and say, 'My husband's not safe.' They just say: 'He has a licence. It's up to him.'"
>
> – Carer

Stakeholders emphasised that decisions about driving should be based on evidence, not blanket policies. They also raised the need for legal and emotional support during the transition to non-driving life.

> "It should be a tested thing—not a blanket rule. Losing my licence changed everything."
>
> – Person living with dementia

Beyond driving, participants described challenges with other forms of transport, including air travel. People with cognitive disability often have unrecognised or misunderstood needs in transit environments. However, positive stories also emerged–particularly when airport and airline staff had relevant training and recognised visible cues to identify hidden disability.

> "One good thing that has happened is the sunflower lanyard. That's been really useful for me… we've been treated so well. They get a wheelchair, help with the luggage, talk through what I need. It's been a really positive experience."
>
> – Person living with dementia

Participants highlighted the **tension between preserving dignity and ensuring safety**–and the need for policy, services and law to help balance these considerations sensitively.

Stakeholders called for:

- Individualised and periodic capacity-based assessments for driving
- Improved coordination between general practitioners (GPs), occupational therapists (OTs) and licensing authorities
- Support for carers managing safety concerns and transport transitions
- Broader adoption of inclusive transport practices (for example, hidden disability identifiers)
- Public education about non-visible disability and rights of travellers with dementia.

Driving and travel

Issues

- People with a diagnosis of young onset dementia and families need clear information about the legal responsibilities of driving. They seek more support and guidance to navigate challenges, including help to transition to public/alternative transport options.[178]
- There are inconsistent practices among health practitioners in reporting to authorities and assessing and monitoring fitness to drive. Some health practitioners ignore statutory reporting duties in order to preserve a therapeutic relationship with a patient with dementia (or other reportable condition).
- A person who discloses a dementia diagnosis may be presumed unable to travel alone and require a doctor's certificate based on a capacity assessment. Aviation practices place discriminatory burdens on persons with dementia to 'plan, negotiate, explain, arrange, submit to assessment and complain' in order to travel. These burdens are inconsistent with rights protected under the Convention on the Rights of Persons with Disability.[185]

Employment and income supports

For younger people with symptoms of dementia, delayed and missed diagnoses contribute to workplace tensions, declining work performance and dismissal without benefits causing permanent financial consequences.

Post-diagnosis, many people wish to continue working. In theory, open communication facilitates workplace adjustments and support. In practice, individuals who are aware of their diagnosis may be reluctant to identify their condition for fear of being misunderstood, of being discriminated against, or being subject to increased monitoring. Some are concerned that disclosure of diagnosis will affect their workers compensation coverage.

Dementia should be reframed as not 'alien' to the workplace and as a disability that can be consistent with continuing safely at work, as for other forms of disability.[186, 187]

Income supports are key for people who leave the workforce. A high proportion of people with younger onset dementia receive governmental income support, as noted by the Australian Institute of Health and Welfare:

> *People who develop dementia while still working may face a sudden or early retirement, resulting in significant social, emotional and financial impacts on the person and their family. In the 2016 Census (4 to 5 years after the first dispensed dementia-specific medication), 21% of the study cohort who were still aged under 65 reported that they were employed, and 72% were unemployed or not in the labour force. When only people aged 60–64 were analysed, people with younger onset dementia were less likely to be employed (7.4%) than all Australians of the same age (46%).*
>
> *People aged 60–64 with younger onset dementia were also more likely (53%) to report lower income categories (personal annual income between $1 and $25,999) than all Australians of the same age (30%). This may partly reflect the high proportion of the study cohort receiving income support through Centrelink. Four years after their first dispensed dementia-specific medication, 71% of those in the 30–64 age group who were still alive received a Centrelink payment: 36% received the Disability Support Pension and 29% received the Age Pension.*[1]

Issues

- For people in the workforce, receiving a diagnosis of young onset dementia raises legal issues around disclosure of diagnosis[188], entitlement to reasonable adjustments, discrimination and ceasing employment[189].
- Legal issues for carers who are working include access to flexible working arrangements and leave.
- For employers, clear and up-to-date policies and procedures are essential to ensure legal obligations are met in relation to human resources and work health and safety. Better awareness, understanding and upholding legal rights of their workers with young onset dementia can extend their time in employment, help to preserve functional abilities and enhance feelings of being valued.[189]

Consumer law

People living with dementia may experience changes in financial capacity and socio-emotional behaviour that increase their vulnerability to scams.[190, 191, 192] Capacity to enter into contracts may be questioned[193] and appointment of a trusted enduring power of attorney is an important strategy for managing future legal and financial affairs.

Resources developed for people with other conditions may be useful models for adaptation[194], such as the co-designed scam awareness online training tool for people with acquired brain injury (ABI)[195] and Monash University's ABI scam research publications[196]. The prevalence of romance and dating scams in ABI, often mediated by social media, highlights the need for support and education for online competencies post-diagnosis.[197]

Disability and aged care services increasingly focus on consumer choices in market-based systems.[198] Regulatory frameworks must provide appropriate rights and protections for consumers, including access to information to enable informed consumer choices and standards that ensure safety and quality of services.

Issues

- **Financial vulnerability –** Changes in cognitive function may increase susceptibility to financial scams, including online fraud, romance scams and deceptive sales practices.[191, 192, 199]
- **Contractual capacity –** Individuals with dementia may face challenges in demonstrating legal capacity when entering into contracts, leading to disputes or exploitation.[193]
- **Financial enduring power of attorney (FEPOA) –** It may be necessary to appoint a trusted decision-maker for financial and legal affairs before capacity declines. Risks of financial abuse must be considered in FEPOA appointments.
- **Consumer protection –** Proactive enforcement of consumer protection rules may deter exploitative practices. Individuals with dementia may need support to enable them to exercise their rights as consumers when accessing disability, health and other services.

Family law

Young onset dementia has profound and complex effects on families. Unlike late onset dementia (onset of symptoms after age 65), symptoms often disrupt significant mid-life responsibilities, when individuals may be managing careers, raising children, in the midst of long-term relationships and supporting ageing parents. They may be homeowners with a mortgage, renters, busy professionals and family breadwinners.

Under such circumstances, a diagnosis of young onset dementia affects many domains including intimate relationships, household finances, and parenting.[200] These impacts give rise to unique challenges that are not typical in family law, and remain largely unexamined.[201]

For many couples, the personality and behavioural changes associated with young onset dementia can erode relationships.[132, 202, 203] In interview studies from the US[132] and UK[203] participants described how changes in their partner's capacity to communicate led to an effective "loss of relationship."[203]

Financial pressures are an additional challenge.[129] In addition to reduced earnings, families face increased financial burdens related to medical expenses, home modifications and formal care and support services.[200] In the event of separation and divorce, these pressures can lead to disputes over spousal maintenance, asset division, and financial settlements, particularly where capacity issues are involved.

Children are also uniquely affected by young onset dementia. Symptoms of young onset dementia often emerge when individuals have dependent children. Families may require legal guidance regarding parental responsibilities and custody arrangements in the event of relationship breakdown.

Further research is required to examine how family law processes can be strengthened to accommodate the complexities of young onset dementia.

Issues

- **Decision-making capacity** — Cognitive impairment may affect an individual's ability to participate in legal proceedings, raising questions about the validity of decisions in divorce, property settlements, and custody matters where an individual has not had access to appropriate support. This may be exacerbated by delayed diagnosis in young onset dementia.
- **Impact on parenting and caregiving** — Families require legal guidance on parental responsibilities, child custody, and the appointment of guardians or decision-makers for dependent children.
- **Family conflict and crisis** — Changes in a person's capacities and needs, combined with financial pressures, can cause disputes over arrangements for personal legal decision making, access to children, control of family finances and use of care services.
- **Need for legal awareness and research** — Family lawyers require training in how to manage dementia-related legal challenges, and further research is needed to explore the intersection of young onset dementia and family law, particularly regarding custody, financial settlements, and dispute resolution processes.

Privacy and data rights

Artificial intelligence (AI) is increasingly being used in the diagnosis and management of young onset dementia, with promising applications in speech analysis, cognitive assessment, and predictive modelling – and likely more to come.[204] However, these tools raise significant legal and ethical concerns, particularly around privacy, consent, and bias.[205]

In November 2024, the Australian Senate Select Committee on Artificial Intelligence released its report on adopting AI in Australia.[206] The Committee examined Australia's readiness for AI. It highlighted the need for robust legal and regulatory frameworks to manage the risks posed by AI technologies, including concerns about algorithmic bias and data privacy in high-risk sectors such as healthcare. These recommendations are particularly relevant in the diagnosis and management of young onset dementia.

Issues

- **Privacy risks and data security –** AI-driven diagnostic tools require access to personal health data, raising concerns about unauthorised use, data breaches, and lack of control over sensitive information. The **Privacy Act 1988 (Cth)** should be updated to address the unique risks posed by AI in processing sensitive health data.
- **Informed consent challenges –** Individuals with cognitive impairment may experience difficulties in comprehending and consenting to AI data collection, particularly in complex systems involving multiple data sources. Simplified consent procedures and involvement of a supported (or substitute) decision-maker may be necessary.
- **Algorithmic bias and discrimination –** AI models trained on non-representative datasets have shown lower diagnostic accuracy for racial minorities, leading to misdiagnoses or delays in treatment. Without systematic auditing and inclusive data collection, these disparities will persist.
- **Use of secondary data –** AI developers often incorporate publicly available recordings and social media data without explicit individual consent, raising concerns about the exploitation of vulnerable populations.
- **Transparency and accountability –** AI-generated healthcare decisions must be explainable and subject to challenge by patients and clinicians. Without clear regulatory oversight, individuals may have no recourse if an AI model produces incorrect or harmful outcomes.

Public health law

The field of public health law is concerned with the role of law in creating socio-economic conditions that promote population health and in preventing exposure to risk factors for illness and injury.[207] Laws play an important role in:

(a) reducing the risk factors for dementia that are largely outside individual control; and
(b) creating conditions that enable healthy lifestyles.

For example, robust laws and standards are necessary to reduce community risks of exposure to air pollution, an identified risk factor for dementia.

Modifiable risk factors for dementia – and other chronic conditions – include unhealthy body weight, physical inactivity, smoking, high blood pressure and diabetes.[208] Nutritious diets and regular physical activity are enabled through laws that govern the foods and beverages we consume and the environments in which we live, work and play.

Issues

- **A 'Health In all Policies/Health for all Policies' approach**[209] calls for various sectors and different levels of government to work together to assess the health implications of policy and program proposals, avoid unintended health-harming impacts, and coordinate activities that will reduce the modifiable risk factors for dementia.
- **Challenges:** Governments may face criticism of running a ‘nanny state’ if they implement regulations that restrict consumer choices. Public support for regulation may be low, given low awareness of the risk factors for dementia that are preventable.[210] Food, beverage and other industries may oppose government policy and seek to avert it by adopting voluntary codes that lack enforceability.[211]

Sports Law

Head injuries, particularly concussions and repeated brain trauma, are a specific risk factor for dementia, including young onset dementia.[212] The health and social benefits of sport are well recognised by Government, and are actively encouraged under policies such as Australia’s national sport plan, *Sports 2030*.[213]

However, legal issues arise due to the increasing recognition of the link between sports-related head injuries and long-term neurological consequences including chronic traumatic encephalopathy (CTE) and young onset dementia.[214, 215, 216]

In response to these issues, Australian sporting bodies have introduced concussion management protocols. Critics argue, however, that these measures are inconsistently enforced, especially at the community level. The Senate Committee’s 2023 report highlighted regulatory deficiencies, such as the lack of a national injury insurance scheme, insufficient longitudinal studies, and inconsistent diagnostic definitions. Some jurisdictions have implemented no-fault accident insurance schemes to support athletes without needing to prove liability[217], a measure suggested for Australian sports.

Concerns about a link between sports-related head trauma and conditions like young onset dementia and CTE raises questions about informed consent and duty of care, especially for children. Economic and social pressures may also lead players to downplay symptoms, undermining welfare policies. Neuroprotective rule changes, like limiting full-contact training and banning high-risk tackles in junior sports, are being explored as a preventive strategy. Such measures often face resistance from traditionalists within sporting cultures.[214]

Issues

- **Liability and Compensation Challenges** – Athletes have filed class actions against major sporting organisations (eg, AFL[218]) for failing to protect players from head trauma risks. Civil lawsuits for brain injuries are costly, time-consuming, and uncertain, making legal redress difficult for affected players. For example, establishing the legal requirement of causation is difficult as not all athletes with repeated concussions develop CTE or young onset dementia.
- **Voluntary Assumption of Risk Defence** – Sports organisations argue that players accept the risks associated with contact sports, complicating legal claims for compensation. However, the consent to the risk of harm may not be sufficiently informed and special issues arise for the obligations owed to children and youth participants.

- **Insurance and Compensation Gaps —** Current workers' compensation schemes exclude professional athletes, limiting their access to financial support for long-term neurological conditions. Insurers are reducing or denying coverage for concussion-related claims, leaving athletes without financial protection. The lack of a national injury insurance scheme, insufficient longitudinal studies, and inconsistent diagnostic definitions weaken legal protections for athletes.
- **Inconsistent Concussion Management —** While concussion protocols exist, they are poorly enforced, especially at the community level, leading to ongoing risks for players.
- **Diagnostic Uncertainty and Medico-legal Issues -** Because a definitive diagnosis of CTE can only be made post-mortem, uncertainty exists for clinicians in how to clinically diagnose and treat those with CTE symptoms.[219]

07

Improving Access to Legal Services

People diagnosed with young onset dementia require timely access to legal information, advice, and support to navigate issues such as advance personal planning, employment rights, income supports and financial entitlements, and access to a range of disability, health and social support services.[220, 221] Despite the increasing recognition of dementia-related legal needs, many legal services remain geared toward older populations, creating accessibility barriers for younger individuals.

One promising approach to improving legal access is the health-justice partnership model, which integrates legal assistance within healthcare settings. These partnerships have proven effective in supporting individuals with chronic and life-limiting conditions by ensuring they receive coordinated medical and legal care.[222] Expanding these partnerships to neurocognitive assessment and memory clinics, neurological and neuropsychiatry outpatient units, and dementia care services where individuals with young onset dementia undergo assessment and diagnosis, may help them and their families with early legal intervention, helping them make informed decisions about their future.[223]

Additionally, there is a growing need for dementia capability in the legal profession, with specific requirement for better understanding of the challenges associated with young onset dementia.[224]

The Law Society of NSW is developing a new specialist accreditation in elder law, which is a welcome development for people seeking help with dementia-related legal issues. However, the 'elder law' branding highlights the importance of developing legal expertise that specifically addresses the specific challenges and issues faced by younger people with dementia.[225]

Innovative models from other life-limiting conditions, such as cancer and HIV services, provide referral-based legal assistance for patients and caregivers.[226] Similar models could be adapted to offer *pro bono* legal support for people living with young onset dementia, particularly in areas such as NDIS access and supports, employment support, discrimination assistance, advance personal planning and income support.

International models

Several international models provide valuable insights into improving legal access for people with young onset dementia.

Germany’s National Dementia Strategy (2020) is particularly notable, as it is the only national framework that explicitly addresses legal issues for people with dementia, including young onset dementia.[227]

The Strategy includes recommendations for free legal advisory services, integration of legal and long-term care supports, and training for general practitioners and legal professionals to improve dementia-related legal awareness.

Similarly, the National Plan to Address Alzheimer's Disease (2023) in the United States has introduced grants for dementia-capable legal services, funding pilot programs to train lawyers and provide legal resource websites for individuals with cognitive impairment.[228]

In the United Kingdom, community-based supportive care models, such as the ACE Club Program in Wales and England, provide peer support and social inclusion services that promote autonomy and access to general advice, though they do not yet include structured legal assistance.[229]

These initiatives highlight the importance of embedding legal support within broader dementia care networks, ensuring early intervention, improved legal literacy, and greater accessibility of legal services for people with young onset dementia.[222, 224] Adopting elements of these international approaches—such as free legal advisory services, cross-sector collaboration between healthcare and legal professionals, and specialised dementia training for lawyers—could significantly improve the legal landscape for people living with young onset dementia in Australia.

Insights from Stakeholders – Legal and service navigation

Stakeholders consistently described the system navigation experience as **fragmented, confusing and emotionally draining.** People with young onset dementia and their families must coordinate across multiple systems—NDIS, health, aged care, guardianship, legal—without clear guidance or reliable information.

> Improving access to legal services and advice would probably have the greatest amount of change in the shortest period of time. Just speaking from experience, most of the referrals that I get… I'm on the phone with them sometimes over an hour just clearing the misinformation and the misguidance… They've been given conflicting information or providers trying to take advantage of them… The hospital and social workers will tell someone one thing, then a support coordinator and an NDIS provider will tell them another. Then the NDIS enquiries will tell them something else, and then an residential aged care facility will tell them something different again.
>
> – Service provider

Many families were unaware of their legal rights or overwhelmed by bureaucratic complexity. The need for clear, trusted guidance—early and ongoing—was a dominant theme.

> The people that have the quarterback to help them navigate—that makes all the difference.
>
> – Person living with dementia

> You actually need a coordinator… someone to be the centre point to help with all the other things that are going along… There's a lot of care support out there, but that's not the same as actually having someone who can say: here's what you need to do next.
>
> – Carer

Carers also reported confusion and conflicting guidance, even when they had good health literacy and established networks.

> I was working in health—and I still found it difficult…
>
> – Carer

Participants called for:

- Multidisciplinary legal-health navigation hubs for newly diagnosed individuals and their families
- Pro bono or subsidised legal support embedded in dementia care pathways
- Written resources to explain legal responsibilities, rights and decision-making options
- Better coordination between health, disability and legal systems
- Navigation roles or "quarterbacks" trained in dementia-specific issues to walk alongside families

08 Recommendations

Drawing from the issues identified in this report, the following key recommendations are proposed to improve legal protections, access to services, and policy responses for people living with young onset dementia.

1. Strengthening Legal Protections and Rights
    - Ensure that all laws and policies related to young onset dementia are underpinned by human rights frameworks, particularly in areas of decision-making capacity, discrimination, and access to services.
    - Implement consistent standards for capacity assessments, ensuring they are decision-specific, and based on supported decision-making principles.
    - Review and strengthen anti-discrimination protections, particularly in employment, insurance, and access to services, to prevent unfair treatment of individuals with young onset dementia.
    - Strengthen dementia capability in the legal profession to ensure practitioners have the knowledge and skills to work with and advocate for people living with dementia.
2. Improving Access to Legal Services and Advice
    - Expand health-justice partnerships to integrate legal assistance within healthcare settings such as neuropsychological assessment and memory clinics, neurology and neuropsychiatry outpatients units, and dementia care services.
    - Develop specialist legal services that address the unique legal challenges of young onset dementia, including disability rights, legal and financial planning, family law, and criminal justice interactions.
    - Increase access to disability advocacy for people with young onset dementia and their families.
    - Increase the availability of *pro bono* and community legal services for people living with young onset dementia and their families, particularly in regional and rural areas.
    - Improve legal literacy and public awareness through accessible resources and targeted information campaigns on key legal rights and obligations.

- Improve practical resources for people living with young onset dementia and their families - for example via the creation of a young onset dementia legal toolkit and an online legal support service.
- Ensure legal practitioners receive training on supported decision-making frameworks, capacity assessment, and the impact of dementia on legal autonomy. Consider credentialling of practitioners who have specialist training.

3. Reforming Legal and Policy Frameworks

- Ensure eligibility criteria, assessment processes, and decisions on funding for the National Disability Insurance Scheme (NDIS) and aged care services adequately account for the needs of people with young onset dementia.
- Modernise laws that deal with enduring representative roles and guardianship to prioritise support for decision-making and reduce reliance on public guardianship and administration. Where the latter are required as a last resort, strengthen arrangements to protect the will and preferences of people living with cognitive disability.
- Ensure roles under federal legislation, such as nominees for NDIS and Services Australia, do not duplicate or clash with roles in place under state and territory laws.
- Strengthen consumer protections to safeguard individuals with young onset dementia from financial abuse, scams, and exploitative contracts.
- Reform sports law and workplace compensation policies to provide long-term protections for individuals at risk of neurodegenerative conditions due to head trauma or other causes of neurological injury.
- Introduce alternative dispute resolution into the NDIS review system to reduce the legal complexity of internal reviews. This would reduce delays in resolving matters and increase the participation of participants with young onset dementia and their families.

4. Enhancing Criminal Justice and Law Enforcement Responses

- Improve training for police, courts, correctional facilities and first responders to recognise and respond appropriately to individuals with young onset dementia who come into contact with the criminal justice system or are at risk of doing so.
- Develop diversion programs to ensure that individuals with young onset dementia are redirected to appropriate care pathways rather than being exposed to police and justice system responses and are at risk of having their behaviour criminalised.

- Address issues of violence and coercion in caregiving settings including:
    - domestic violence - including person with young onset dementia -to-others and others-to-person with young onset dementia
    - aggression in supported accommodation (for example, NDIS and aged care) - including resident-to-resident, staff-to-resident, and resident-to-staff, and
    - avoidable use of restraints and restrictive practices.

5. Addressing Emerging Legal and Ethical Challenges

- Update privacy and data rights laws to protect sensitive health data of people with young onset dementia, including data used in AI-driven diagnostic and care management systems.
- Ensure algorithmic transparency and fairness in AI models used for dementia diagnosis, risk assessment and access to treatment options.
- Improve access to advance planning tools for individuals with young onset dementia, ensuring that legal and medical professionals, as well as disability personnel, provide guidance on appointment of enduring representatives, wills, and advance care directives.
- Establish a standing monitor of the intersection of young onset dementia and legal issues, particularly in areas such as capacity, criminal justice involvement, and discrimination in financial services, and conduct further research into issues of current and future importance.
- Targeted research is needed to better understand the legal issues for people from minoritised groups - including First Nations people - who develop young onset dementia and are at heightened risk of discrimination, stigmatisation and worse outcomes.
- Address the challenges associated with delayed diagnosis of young onset dementia, which can result in capacity issues affecting legal decision-making at critical life stages, including financial and medical decisions, including the role of a provisional diagnosis of young onset dementia.

09 Conclusion

Young onset dementia presents unique and complex legal issues and implications that span human rights, disability law, disability care, aged care, employment, criminal justice, and other areas of law.

Despite growing awareness, legal and policy frameworks in Australia often remain geared toward older populations, failing to address the distinct needs of younger individuals facing dementia-related challenges.

This report highlights critical gaps in legal protections, service accessibility, and policy responses, emphasising the urgent need for reform. Strengthening legal safeguards, expanding access to legal services, improving cross-sector collaboration, and reforming outdated policies will be essential to ensuring dignity, autonomy, and justice for people living with young onset dementia.

Lessons from international models, particularly Germany's National Dementia Strategy, which makes specific provision for legal services for those with young onset dementia, provide valuable insights into how legal frameworks and frontline services can be strengthened to enhance protections and support for individuals with young onset dementia.

Ongoing consultation and research with stakeholders, including individuals with living experience, carers, healthcare professionals, and legal experts, will be essential to shaping effective reforms and best-practice legal interventions.

10 References

[1] Australian Institute of Health and Welfare. (2024). *Australia's health 2024: data insights: Improving Australia's dementia data for national action.* <https://www.aihw.gov.au/reports/australias-health/dementia-data>

[2] Hendriks S, Ranson JM, Peetoom K, Lourida I, Tai XY, de Vugt M, Llewellyn DJ, Köhler S. Risk Factors for Young-Onset Dementia in the UK Biobank. JAMA Neurol. 2024 Feb 1;81(2):134-142. <https://jamanetwork.com/journals/jamaneurology/fullarticle/2813439>

[3] Cations M, Withall A & Draper B. Modifiable risk factors for young onset dementia. Current Opinion in Psychiatry 32(2), p 138-143, March 2019. <https://journals.lww.com/co-psychiatry/abstract/2019/03000/modifiable_risk_factors_for_young_onset_dementia.15.aspx>

[4] Wong JFW, Kirk A, Perlett L, Karunanayake C, Morgan D, O'Connell ME. Characteristics of Young-Onset and Late-Onset Dementia Patients at a Remote Memory Clinic. Can J Neurol Sci. 2020 May;47(3):320-327. <https://www.cambridge.org/core/journals/canadian-journal-of-neurological-sciences/article/characteristics-of-youngonset-and-lateonset-dementia-patients-at-a-remote-memory-clinic/3540B81EFAB18492E0C098E65B6BBFCC>

[5] Wong D, Pike K, Stolwyk R, Allott K, Ponsford J, McKay A, Longley W, Bosboom P, Hodge A, Kinsella G, Mowszowski L. Delivery of Neuropsychological Interventions for Adult and Older Adult Clinical Populations: An Australian Expert Working Group Clinical Guidance Paper. Neuropsychol Rev. 2024 Dec;34(4):985-1047. <https://link.springer.com/article/10.1007/s11065-023-09624-0>

[6] Mayrhofer A, Mathie E, McKeown J, Bunn F, Goodman C. Age-appropriate services for people diagnosed with young onset dementia (YOD): a systematic review. Aging Ment Health. 2018 Aug;22(8):927-935. <https://www.tandfonline.com/doi/full/10.1080/13607863.2017.1334038>

[7] Bakker C, Verboom M, Koopmans R. Reimagining Postdiagnostic Care and Support in Young-Onset Dementia. J Am Med Dir Assoc. 2022 Feb;23(2):261-265. <https://www.jamda.com/article/S1525-8610(21)01059-8/fulltext>

[8] Ries N, Shelley J. 'Public Health Law' *in* White BP, McDonald FJ, Willmott L, Then SN. Health Law in Australia. Thomson Reuters Australia, Limited; 2023, pp xxx-xxx.

[9] Kingston D, Batsch N, Mittler P. (2017). Access to the United Nations Convention on the Rights of Persons with Disabilities by people living with dementia: Brief for Alzheimer associations. Alzheimer's Disease International. <https://www.alzint.org/resource/access-to-united-nations-convention-on-the-rights-of-persons-with-disabilities-by-people-living-with-dementia-crpd>

[10] See eg, *Murphy v Doman* [2003] *NSWCA 249*.

[11] Legislation Victoria. Mental Health and Wellbeing Act 2022 (Vic). State Government of Victoria. Sections 19, 25. <https://www.legislation.vic.gov.au/in-force/acts/mental-health-and-wellbeing-act-2022/002>

[12] ACT Legislation Register. Mental Health Act 2015 (ACT). ACT Government. Sections 6,25. <https://www.legislation.act.gov.au/View/a/2015-38/current/html/2015-38.html>

[13] NSW Legislation. Guardianship Act 1987 (NSW). NSW Government. Section 4. <https://legislation.nsw.gov.au/view/html/inforce/current/act-1987-257>

[14] Legislation Victoria. Guardianship and Administration Act 2019 (Vic). State Government of Victoria. Section 9. <https://www.legislation.vic.gov.au/in-force/acts/guardianship-and-administration-act-2019/009>

[15] Australian Law Reform Commission. Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124). ALRC. 24 November 2014. Chapter 3. <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124>

[16] O'Neill N, Peisah C. CapacityAndTheLaw. AustLII Communities. 14 December 2021. <https://austlii.community/foswiki/Books/CapacityAndTheLaw/WebHome>

[17] Hegde S, Ellajosyula R. Capacity issues and decision-making in dementia. Ann Indian Acad Neurol. 2016 Oct;19(Suppl 1):S34-S39. <https://journals.lww.com/annalsofian/fulltext/2016/19001/capacity_issues_and_decision_making_in_dementia.8.aspx>

18 Pesanti S, Hamm B, Esplin B, Karafa M, Jimenez XF. Capacity Evaluation Requests in the Medical Setting: A Retrospective Analysis of Underlying Psychosocial and Ethical Factors. Psychosomatics. 2017 Sep-Oct;58(5):483-489. <https://www.sciencedirect.com/science/article/pii/S0033318217300907?via%3Dihub>

19 Sinclair C, Gersbach K, Hogan M, Blake M, Bucks R, Auret K, Clayton J, Stewart C, Field S, Radoslovich H, Agar M, Martini A, Gresham M, Williams K, Kurrle S. "A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making. J Bioeth Inq. 2019 Dec;16(4):587-608. <https://link.springer.com/article/10.1007/s11673-019-09945-x>

20 Brown S. *Social Work Perspectives on Mental Capacity Act Decision Making in the Context of Practice with People with Young Onset Dementia.;* 2023. (PhD Thesis, Royal Holloway, University of London). <https://pure.royalholloway.ac.uk/ws/portalfiles/portal/59995690/Final_approved_Phd_Thesis_Stefan_Brown_April_2024_FINAL_.pdf>

21 Sullivan K, Purser K. Developing and piloting the Consumer Experience of Capacity Assessment Tool (CECAT). Psychiatr Psychol Law. 2021 Nov 7;29(5):752-764. <https://www.tandfonline.com/doi/full/10.1080/13218719.2021.1976300>

22 Foxe D, D'Mello M, Cheung SC, Bowen J, Piguet O, Hwang YT. Dementia in Australia: Clinical Recommendations Post-Diagnosis. Australasian Journal on Ageing. 2024 Jun;43(2):394-402.

23 Loi SM, Cations M, Beard C, Tjokrowijoto P, Stange D, Withall A, Moylan N, Cartwright J, d'Cunha N. The Joint Solutions Young-Onset Dementia Report. Royal Melbourne Hospital, University of Melbourne, Department of Psychiatry. Melbourne. October 2024, p. 61. Data primarily reflects people who are Caucasian and well-educated.<https://ypinh.org.au/wp-content/uploads/2024/11/FINAL-Joint-Solutions-young onset dementia-SIG-Research-Report.pdf>

24 Yapp G, Sinclair C, Kelly A, Williams K, Amgarth-Duff I, Agar M. *8 Planning for the Rest-of-Life, Not End-of-Life Reframing Advance Care Planning for People with Dementia*. 2018, pp. 134-156. <https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/Planning-for-the-rest-of-life-not-end-of-life.pdf>

25 Van Rickstal R, Vleminck A, Engelborghs S, Versijpt J, Van den Block L. A qualitative study with people with young-onset dementia and their family caregivers on advance care planning: A holistic, flexible, and relational approach is recommended. Palliat Med. 2022 Jun;36(6):964-975. <https://journals.sagepub.com/doi/10.1177/02692163221090385>

26 Van Rickstal R, De Vleminck A, Aldridge MD, Morrison SR, Koopmans RT, van der Steen JT, Engelborghs S, Van den Block L. Limited engagement in, yet clear preferences for advance care planning in young-onset dementia: An exploratory interview-study with family caregivers. Palliat Med. 2019 Oct;33(9):1166-1175. <https://journals.sagepub.com/doi/10.1177/0269216319864777>

27 Bryant J, Mansfield E, Cameron E, Sanson-Fisher R. Experiences and preferences for advance care planning following a diagnosis of dementia: Findings from a cross-sectional survey of carers. PLoS One. 2023 Jun 12;18(6):e0286261. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0286261>

28 Australian Human Rights Commission (AHRC). Empowering futures: a report on enduring powers of attorney (2024). AHRC. 10 September 2024. <https://humanrights.gov.au/our-work/age-discrimination/publications/empowering-futures-report-enduring-powers-attorney-2024>

29 Fetherstonhaugh D, McAuliffe L, Shanley C, et al. "Did I make the right decision?": the difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia. Dementia 2019; 18(5): 1601–1614.

30 Dupont C, Smets T, Monnet F, Pivodic L, De Vleminck A, Van Audenhove C, Van den Block L. Defining the content of a website on advance care planning in dementia: a focus group study with family and health professionals. BMC Med Inform Decis Mak. 2023 Nov 8;23(1):254. <https://bmcmedinformdecismak.biomedcentral.com/articles/10.1186/s12911-023-02359-1>

31 Kim H, Perkins M, Pope TM, Comer P, Song MK. Medical Decision-Making Practices for Unrepresented Residents in Nursing Homes. J Am Med Dir Assoc. 2022 Mar;23(3):488-492. <https://www.jamda.com/article/S1525-8610(21)00639-3/abstract>

32 Dixon JD, Josyula AV, Javier NM, Zweig Y, Singh M, Kim L, Thothala N, Farrell TW. American Geriatrics Society position statement: Making medical treatment decisions for unrepresented older adults. J Am Geriatr Soc. 2024 Nov 30. <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.19288>

33 Lowers J, Brus K, Smith C, Kavalieratos D, Hepburn K, Perkins MM. "How do You Take that Much Time for One Person's Life?" Experiences of Dementia Caregivers Who are Not Immediate Family. J Appl Gerontol. 2025 Jan;44(1):166-175. <https://journals.sagepub.com/doi/10.1177/07334648241265197>

[34] Gerritsen AAJ, Bakker C, Verhey FRJ, Pijnenburg YAL, Millenaar JK, de Vugt ME, Koopmans RTCM. Survival and life-expectancy in a young-onset dementia cohort with six years of follow-up: the NeedYD-study. Int Psychogeriatr. 2019 Dec;31(12):1781-1789. <https://www.intpsychogeriatrics.org/article/S1041-6102(24)02415-3/fulltext>.

[35] Australian Human Rights Commission (AHRC). Achieving Greater Consistency in Laws for Financial Enduring Powers of Attorney - Submission to the Attorney-General's Department. 13 December 2023. <https://humanrights.gov.au/sites/default/files/ahrc_submission_to_consultation_on_epoa_reform__1.pdf>

[36] Cations M, Loi SM, Draper B, Swaffer K, Velakoulis D, Goh AM; Australian Young Onset Dementia Special Interest Group. A call to action for the improved identification, diagnosis, treatment and care of people with young onset dementia. Aust N Z J Psychiatry. 2021 Sep;55(9):837-840. <https://journals.sagepub.com/doi/10.1177/00048674211037542>

[37] Dementia Australia. Submission to the Royal Commission into Aged Care Quality and Safety - People with Younger Onset Dementia in the Aged Care System. 2020. <https://www.dementia.org.au/sites/default/files/2024-02/Dementia-Australia-submission-on-younger-onset-dementia.pdf?slug=sites&slug=default&slug=files&slug=2024-02&slug=Dementia-Australia-submission-on-younger-onset-dementia.pdf>

[38] Laver KE, Crotty M, Low LF, Clemson L, Whitehead C, McLoughlin J, Swaffer K, Cations M. Rehabilitation for people with dementia: a multi-method study examining knowledge and attitudes. BMC Geriatr. 2020 Dec 9;20(1):531. <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01940-x>

[39] Cations M, Day S, Laver K, Withall A, Draper B. Post-diagnosis young-onset dementia care in the National Disability Insurance Scheme. Aust N Z J Psychiatry. 2022 Mar;56(3):270-280. <https://journals.sagepub.com/doi/10.1177/00048674211011699>

[40] Department of Social Services. Younger people in residential aged care (YPIRAC) toolkit. Department of Social Services. 2025. <https://www.dss.gov.au/supporting-younger-people-residential-aged-care>

[41] Oliver S, Gosden-Kaye EZ, Jarman H, Winkler D, Douglas JM. A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities. Brain Inj. 2020 Sep 18;34(11):1446-1460. <https://www.tandfonline.com/doi/full/10.1080/02699052.2020.1805124>

[42] Victorian Department of Families, Fairness and Housing. Information for Authorised Program Officers. Department of Families Fairness and Housing Victoria. (2021). <https://www.dffh.vic.gov.au/information-authorised-program-officers>

[43] Leif ES, Fox RA, Subban P, Sharma U. 'Stakeholders are almost always resistant': Australian behaviour support practitioners' perceptions of the barriers and enablers to reducing restrictive practices. Int J Dev Disabil. 2023 Feb 1;69(1):66-82. <https://www.tandfonline.com/doi/full/10.1080/20473869.2022.2116908>

[44] Cain P, Chejor P, Porock D. Chemical restraint as behavioural euthanasia: case studies from the Royal Commission into Aged Care Quality and Safety. BMC Geriatr. 2023 Jul 19;23(1):444. <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-023-04116-5>

[45] Chelberg K. "Vulnerable Monsters": Constructions of Dementia in the Australian Royal Commission into Aged Care. International Journal for the Semiotics of Law - Revue internationale de Sémiotique juridique. 2023;36. <https://link.springer.com/article/10.1007/s11196-023-09979-w>.

[46] Federal Register of Legislation. Aged Care and Other Legislation Amendment (Royal Commission Response) Act 2022. Australian Government. (2022). <https://www.legislation.gov.au/C2022A00034/asmade/text>

[47] Federal Register of Legislation. Aged Care Act 2024. Australian Government. (2024). Sections 18, 163. <https://www.legislation.gov.au/C2024A00104/asmade/text>

[48] Mulders AJ, Fick IW, Bor H, Verhey FR, Zuidema SU, Koopmans RT. Prevalence and Correlates of Neuropsychiatric Symptoms in Nursing Home Patients With Young-Onset Dementia: The BEYOnD Study. J Am Med Dir Assoc. 2016 Jun 1;17(6):495-500. <https://www.jamda.com/article/S1525-8610(16)00032-3/fulltext>

[49] Riedl L, Kiesel E, Hartmann J, Fischer J, Roßmeier C, Haller B, Kehl V, Priller J, Trojan M, Diehl-Schmid J. A bitter pill to swallow - Polypharmacy and psychotropic treatment in people with advanced dementia. BMC Geriatr. 2022 Mar 16;22(1):214. <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-022-02914-x>

[50] Aged Care Quality and Safety Commission. Psychotropic medications used in Australia - information for aged car. Aged Care Quality and Safety Commission. 13 February 2020. <https://www.agedcarequality.gov.au/resource-library/psychotropic-medications-used-australia-information-aged-care>

[51] PricewaterhouseCoopers Consulting. Evaluation of the CCTV Pilot Project Final evaluation report June 2022. <https://yoursay.sa.gov.au/76876/widgets/369614/documents/241882>

[52] Vermeer Y, Higgs P, Charlesworth G. 'Surveillance Technology in Dementia Care: Implicit Assumptions and Unresolved Tensions' *in* Brankaert R, IJsselsteijn W. *Dementia Lab 2019*, pp.101-109. *Making Design Work: Engaging with Dementia in Context*. Springer Nature; 2019.

[53] Dementia Australia. *Review into Technology and Closed-Circuit Television in Aged Care*. (2022). <https://www.dementia.org.au/sites/default/files/2024-02/Review-into-Technology-and-CCTV-in-aged-care-South-Australia-Oct-2022.pdf>

[54] Neeland J. Renewed Push for CCTV Cameras in Aged Care, NDIS & Home Care Settings - Hellocare. Hellocare. 16 October 2024. <https://hellocare.com.au/renewed-push-for-cctv-cameras-in-aged-care-ndis-home-care-settings>

[55] Hansard Daily. Hansard Daily: Legislative Council - Wednesday, 30 October 2024. South Australian Government. <https://hansardsearch.parliament.sa.gov.au/daily/uh/2024-10-30/41>

[56] Porock D, Vafeas C, Towell-Barnard M, Emery L, Doleman G, Alan J. Cross-sectional survey of staff and family perspectives on the use of CCTV in Australian residential aged care. Australas J Ageing. 2024 Sep;43(3):570-580. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.13304>

[57] Wrede C, Braakman-Jansen A, van Gemert-Pijnen L. How to create value with unobtrusive monitoring technology in home-based dementia care: a multimethod study among key stakeholders. BMC Geriatr. 2022 Nov 30;22(1):921. <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-022-03550-1>

[58] Jotterand F, Ienca M, Wangmo T, Elger B (eds). *In*telligent Assistive Technologies for Dementia: Clinical, Ethical, Social, and Regulatory Implications. Oxford University Press; 2019. <https://academic.oup.com/book/31779?login=true>

[59] Behera CK, Condell J, Dora S, Gibson DS, Leavey G. State-of-the-Art Sensors for Remote Care of People with Dementia during a Pandemic: A Systematic Review. Sensors (Basel). 2021 Jul 8;21(14):4688. <https://pmc.ncbi.nlm.nih.gov/articles/PMC8309480/#sensors-21-04688-t001>

[60] Turner, B. Assistive Technology solutions for those with Dementia. Smarter Homes Australia. 3 October 2024. <https://smarterhomesaustralia.com/ndis-dementia-assistive-technology-solutions>. See an example of such marketing for NDIS assistive technology for Individuals with dementia

[61] Frost D, Dillon S, Grady S, Thurlow J, Leong TW, Bell J. (2020). Approaches for Authentic Engagement: Younger Onset Dementia. *in* Brankaert R, Kenning G. (eds). HCI and Design in the Context of Dementia. Human–Computer Interaction Series. Springer, Cham. <https://link.springer.com/chapter/10.1007/978-3-030-32835-1_6>

[62] Horne M, Youell J, Brown L, Brown-Wilson C, Dickinson T, Simpson P. Feasibility and acceptability of an education and training e-resource to support the sexuality, intimacy and relationship needs of older care home residents: a mixed methods study. *Age and Ageing*. 2022;51(10). <https://academic.oup.com/ageing/article/51/10/afac221/6776176>

[63] Holdsworth K, McCabe M. The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: a systematic review. Int Psychogeriatr. 2018 Jan;30(1):15-29. <https://www.intpsychogeriatrics.org/article/S1041-6102(24)01551-5/fulltext>

[64] McAuliffe L, Fetherstonhaugh D, Bauer M. Sexuality and sexual health: Policy in Australian residential aged care. Australas J Ageing. 2020 Jun;39 Suppl 1:59-64. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.12602>

[65] Smith DE, Wright MT, Ibrahim JE. Aged care nurses' perception of unwanted sexual behaviour in Australian residential aged care services. Australas J Ageing. 2022 Mar;41(1):153-159. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.13014>

[66] Aged Care Quality and Safety Commission. (2023). The Serious Incident Response Scheme | Aged Care Quality and Safety Commission. <https://www.agedcarequality.gov.au/providers/serious-incident-response-scheme>

[67] Barry L, Parsons R. Striking the Balance: A Human Rights Approach to Consent for People with Dementia in Residential Aged Care. Griffith Law Journal. (2023) 11(1), 39-69. <https://griffithlawjournal.org/index.php/gjlhd/article/view/1240/1123>

[68] Healy E. Intimacy and Dementia: An Ethical Approach to Risk-Based Decision-Making. *Caring for the ages*. 2023;24(6):13-14. <https://www.caringfortheages.com/article/S1526-4114(23)00291-3/fulltext>

[69] NDIS Quality and Safeguards Commission. Core module: Rights and responsibilities. NDIS Quality and Safeguards Commission. (2024). <https://www.ndiscommission.gov.au/rules-and-standards/ndis-practice-standards/core-module-rights-and-responsibilities>

[70] Astle SM, McAllister P, Stanfield MH, Yelland E, Gimarc C. Assessing Public Opinions of Sexual Advance Directives Among Older Adults With Dementia. J Appl Gerontol. 2022 Nov;41(11):2272-2281. <https://journals.sagepub.com/doi/10.1177/07334648221114632>

[71] Burkinshaw K, Tsourtos G, Cations M. System and policy-level barriers and facilitators for timely and accurate diagnosis of young onset dementia. Intl J Geriatr Psychiatry. 2023; 38(1). <https://onlinelibrary.wiley.com/doi/10.1002/gps.5859>

[72] Gulline H, Carmody S, Yates M, Bevins A, Brodtmann A, Loi SM, Lim YY, Macklin H, Glennen K, Woodward M, Ayton S, Ayton D. Equity of access in rural and metropolitan dementia diagnosis, management, and care experiences: an exploratory qualitative study. Int J Equity Health. 2025 Mar 17;24(1):74. <https://equityhealthj.biomedcentral.com/articles/10.1186/s12939-025-02434-1>

[73] Sharma S, Ryan B. Diagnosis of dementia in under 65-year-olds often faces frustrating delay. The University of Auckland. 15 January 2025. <https://www.auckland.ac.nz/en/news/2025/01/15/dementia-diagnosis-under-65-year-olds-often-delayed.html>

[74] Bradley K, Hughson JA, Hyde Z, Atkinson D, Russell S, Quigley R, Bessarab D, Flicker L, Radford K, Smith K, Strivens E, Thompson S, Blackberry I, Belfrage M, Smith R, Malay R, Ducker B, Sullivan K, Allan W, Giles B, Humphry T, Lavrencic LM, Pond D, LoGiudice D. Detection of cognitive impairment, dementia and associated risk factors among Aboriginal and Torres Strait Islander peoples: Retrospective baseline audit results from a stepped-wedge cluster-randomised controlled trial. Australas J Ageing. 2025 Mar;44(1):e70007. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.70007>

[75] Wang AY, Hu HY, Ou YN, Wang ZT, Ma YH, Tan L, Yu JT. Socioeconomic Status and Risks of Cognitive Impairment and Dementia: A Systematic Review and Meta-Analysis of 39 Prospective Studies. J Prev Alzheimers Dis. 2023;10(1):83-94. <https://pubmed.ncbi.nlm.nih.gov/36641612/>

[76] Cations M, Withall A, Draper B. Modifiable risk factors for young onset dementia. Current Opinion in Psychiatry 32(2), p 138-143, March 2019. <https://journals.lww.com/co-psychiatry/abstract/2019/03000/modifiable_risk_factors_for_young_onset_dementia.15.aspx>

[77] Lai M, Jeon YH, McKenzie H, Withall A. Journey to Diagnosis of Young-Onset Dementia: A Qualitative Study of People with Young-Onset Dementia and their Family Caregivers in Australia. Dementia (London). 2023 Jul;22(5):1097-1114. <https://pmc.ncbi.nlm.nih.gov/articles/PMC10262327/>

[78] Bryant J, Noble N, Freund M, Rumbel J, Eades S, Sanson-Fisher R, Lowe M, Walsh J, Piterman L, Koch S, Meyer C, Todd E. How can dementia diagnosis and care for Aboriginal and Torres Strait Islander people be improved? Perspectives of healthcare providers providing care in Aboriginal community controlled health services. BMC Health Serv Res. 2021 Jul 16;21(1):699. <https://pmc.ncbi.nlm.nih.gov/articles/PMC8283853/>

[79] Davies-Abbott I, Anthony BF, Jackson K, Windle G, Edwards RT on behalf of the Rare Dementia Support (RDS) Research Team. The Diagnostic Pathway Experiences of People Living with Rare Dementia and Their Family Caregivers: A Cross-Sectional Mixed Methods Study Using Qualitative and Economic Analyses. International Journal of Environmental Research and Public Health. 2024; 21(2):231. <https://www.mdpi.com/1660-4601/21/2/231>

[80] Karen A, Sullivan, Karen Graham and Lauren Parkinson, 'Ratings of the Reasons for and against the Disclosure of an Alzheimer's Disease Diagnosis: Has Anything Changed in the Past 20 Years?'. 2023; Aging & Mental Health, 27(6):1135. <https://www.tandfonline.com/doi/full/10.1080/13607863.2022.2107174>

[81] Yates J, Stanyon M, Samra R, Clare L. Challenges in disclosing and receiving a diagnosis of dementia: a systematic review of practice from the perspectives of people with dementia, carers, and healthcare professionals. International Psychogeriatrics, 33(11), 1161 - 1192. <https://www.intpsychogeriatrics.org/article/S1041-6102(24)03459-8/fulltext>

[82] Merl H, Veronica Doherty K, Alty J, Salmon K. Truth, hope and the disclosure of a dementia diagnosis: A scoping review of the ethical considerations from the perspective of the person, carer and clinician. Dementia (London). 2022 Apr;21(3):1050-1068. <https://journals.sagepub.com/doi/10.1177/14713012211067882>

[83] Fox S, Foley T, Cahill S, Kilty C. "Give me the knowledge, and I can do what I want with it, it's my right and my choice": Triangulated perspectives on the disclosure of young onset dementia. Dementia (London). 2023 Nov;22(8):1757-1775. <https://journals.sagepub.com/doi/10.1177/14713012231191958>

84 Berghout M, Waller A, Lachapelle N, Noble N, Nair BK, Sanson-Fisher R. Preferred type, timing and format of dementia information: A cross-sectional survey of carers of people living with dementia. Australas J Ageing. 2024 Mar;43(1):131-139. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.13251>

85 O'Malley M, Carter J, Stamou V, LaFontaine J, Oyebode J, Parkes J. Receiving a diagnosis of young onset dementia: a scoping review of lived experiences. Aging Ment Health. 2021 Jan;25(1):1-12. <https://www.tandfonline.com/doi/full/10.1080/13607863.2019.1673699>

86 Kilty C, Cahill S, Foley T, Fox S. Young onset dementia: implications for employment and finances. Dementia (London). 2023 Jan;22(1):68-84. <https://journals.sagepub.com/doi/10.1177/14713012221132374>

87 Stamou V, Fontaine J, O'Malley M, Jones B, Gage H, Parkes J, Carter J, Oyebode J. The nature of positive post-diagnostic support as experienced by people with young onset dementia. Aging Ment Health. 2021 Jun;25(6):1125-1133. <https://www.tandfonline.com/doi/full/10.1080/13607863.2020.1727854>

88 Hyatt A, Prictor M. Many Australians are recording their visits to the doctor – some without permission. The Conversation. Published December 11, 2024. <https://theconversation.com/many-australians-are-recording-their-visits-to-the-doctor-some-without-permission-244637>

89 Hyatt A, Lipson-Smith R, Gough K, Butow P, Jefford M, Hack TF, Hale S, Zucchi E, White S, Ozolins U, Schofield P. Culturally and linguistically diverse oncology patients' perspectives of consultation audio-recordings and question prompt lists. Psychooncology. 2018 Sep;27(9):2180-2188. <https://onlinelibrary.wiley.com/doi/10.1002/pon.4789>

90 Prictor M, Elwyn G, Hyatt A. How often are patients recording their healthcare consultations in Australia and why? An online survey. PEC Innov. 2024 Nov 8;5:100355. <https://www.sciencedirect.com/science/article/pii/S2772628224001031?via%3Dihub>

91 Prictor M, Johnston C, Hyatt A. Overt and covert recordings of health care consultations in Australia: some legal considerations. Med J Aust. 2021 Feb;214(3):119-123.e1. <https://onlinelibrary.wiley.com/doi/10.5694/mja2.50838>

92 Faulkner T, Dickinson J, Limbert S, Giebel C. The experiences and perspectives of older adult mental health professional staff teams when supporting people with young-onset dementia. Dementia (London). 2024 May;23(4):567-583. <https://journals.sagepub.com/doi/10.1177/14713012241236106>

93 Sinclair C, Bajic-Smith J, Gresham M, Blake M, Bucks RS, Field S, Clayton JM, Radoslovich H, Agar M, Kurrle S. Professionals' views and experiences in supporting decision-making involvement for people living with dementia. Dementia (London). 2021 Jan;20(1):84-105. <https://journals.sagepub.com/doi/10.1177/1471301219864849>

94 NSW Department of Communities and Justice. (2021). Statutory Review Report of the Statutory Review of the Civil and Administrative Tribunal Act 2013. <https://www.parliament.nsw.gov.au/tp/files/81453/Report%20of%20the%20Statutory%20review%20of%20the%20Civil%20and%20Administrative%20Tribunal%20Act%202013.pdf>

95 Dementia Australia. (2019). Review of the NSW Civil and Administrative Tribunal Guardianship Division: A Response from Dementia Australia. <https://www.dementia.org.au/sites/default/files/2024-02/Dementia-Australia-response-to-NCAT-reveiw.pdf>

96 Connolly J, Peisah C. Waiting for guardianship in a public hospital geriatric inpatient unit: a mixed methods observational case series. Intern Med J. 2023 Aug;53(8):1339-1346. <https://onlinelibrary.wiley.com/doi/10.1111/imj.15916>

97 Jackman M, McDermott F, Sadler J, El Hage N, Lee H. Guardianship patient characteristics and outcomes in geriatric social work practice: Australian context. Soc Work Health Care. 2021;60(8-9):614-630. <https://www.tandfonline.com/doi/full/10.1080/00981389.2021.1990189#abstract>

98 Schultz A. Should guardianship orders be abolished? Crikey. Published September 21, 2021. Accessed May 4, 2025. <https://www.crikey.com.au/2021/09/22/should-guardianship-orders-be-abolished/>

99 Office of the Public Advocate, Western Australia. (April 2024). Community Guardianship: OPA information. Western Australian Government. <https://www.wa.gov.au/organisation/department-of-justice/office-of-the-public-advocate/community-guardianship-opa-information>

100 Office of the Public Advocate, Victorian Government. (2021). OPA Annual Report 2020-2021 - Office of the Public Advocate. <https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/annual-reports/opa-annual-reports/359-opa-annual-report-2020-2021>

101 NeuRA. (2025). Sydney Brain Bank. <https://sbb.neura.edu.au>

102 Faculty of Medicine and Health, University of Sydney. (2025). NSW Brain Tissue Resource Centre. The University of Sydney. <https://www.sydney.edu.au/medicine-health/industry-and-community/support-us/nsw-brain-tissue-resource-centre.html>

103 Australian Sports Brain Bank. Home. Australian Sports Brain Bank. <https://www.brainbank.org.au>

104 The Florey. (2024). Victorian Brain Bank | Scientific facilities and research services. The Florey. <https://florey.edu.au/our-research/scientific-facilities-and-research-services/victorian-brain-bank>

105 Wesley Research Institute. (2023). Biobank. Wesley Medical Research. <https://www.wesleyresearch.org.au/biobank>

106 MS Australia. (2016). Home - MS Brain Bank. MS Australia. <https://msbrainbank.org.au>

107 Dementia Australia. Brain tissue donation. Dementia Australia. (2024). <https://www.dementia.org.au/living-dementia/later-stages-and-end-life/brain-tissue-donation>

108 Nous Group. (2019). *Dementia Brain Banking in Australia*. (2019). National Institute for Dementia Research (NNIDR) and Dementia Australia. <https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Dementia-brain-banking-in-Australia.pdf>

109 Götzelmann TG, Strech D & Kahrass H. The full spectrum of ethical issues in dementia research: findings of a systematic qualitative review. *BMC Med Ethics*. 2021;22(32). <https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-020-00572-5>

110 Hosie A, Kochovska S, Ries N, Gilmore I, Parker D, Sinclair C, Sheehan C, Collier A, Caplan GA, Visser M, Xu X, Lobb E, Sheahan L, Brown L, Lee W, Sanderson CR, Amgarth-Duff I, Green A, Edwards L, Agar MR. Older Persons' and Their Caregivers' Perspectives and Experiences of Research Participation With Impaired Decision-Making Capacity: A Scoping Review. Gerontologist. 2022 Feb 9;62(2):e112-e122. <https://academic.oup.com/gerontologist/article/62/2/e112/5899769?login=true>

111 Ries NM, Thompson KA, Lowe M. Including People with Dementia in Research: An Analysis of Australian Ethical and Legal Rules and Recommendations for Reform. J Bioeth Inq. 2017 Sep;14(3):359-374. <https://link.springer.com/article/10.1007/s11673-017-9794-9>

112 National Health and Medical Research Council (NHMRC). (2025). National Statement on Ethical Conduct in Human Research 2025 | NHMRC. <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2025> (in effect from 1 October 2025).

113 Ries N, Johnston B, Jeon YH, Mansfield E, Nay R, Parker D, Schnitker L, Sinclair C. Advance planning for research participation: Time to translate this innovation into practice. Australas J Ageing. 2023 Mar;42(1):225-233. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.13161>

114 Ries NM, Johnston B. Making an Advance Research Directive: An Interview Study with Adults Aged 55 and Older with Interests in Dementia Research. Ethics Hum Res. 2023 May-Jun;45(3):2-17. <https://onlinelibrary.wiley.com/doi/10.1002/eahr.500171>

115 Step Up for Research, University of Sydney. (2024). Advance Research Directive - StepUp for Dementia Research. StepUp for Dementia Research. <https://www.stepupfordementiaresearch.org.au/useful-resources-2>

116 Dang J, Yong ACW, Fong ZH, Ang K, Ng ASL. A Systematic Review of Palliative Care Needs in Young-Onset Dementia. J Am Med Dir Assoc. 2024 Oct;25(10):105219. <https://www.jamda.com/article/S1525-8610(24)00641-8/abstract>

117 Go Gentle Australia. Voluntary assisted dying in the Northern Territory. Go Gentle Australia. <https://www.gogentleaustralia.org.au/nt>

118 de Boer ME, Coers DO, Sizoo EM, Ten Bokkel Huinink DMJ, Leget CJW, Hertogh CMPM; DALT project group. Seeking consensus on dilemmas related to euthanasia in dementia based on an advance directive: a Delphi study from a medical, ethical and legal perspective. J Med Ethics. 2025 Jan 28:jme-2024-110276. <https://jme.bmj.com/content/early/2025/01/27/jme-2024-110276>

119 Sellars M, White BP, Yates P, Willmott L. Medical practitioners' views and experiences of being involved in assisted dying in Victoria, Australia: A qualitative interview study among participating doctors. Soc Sci Med. 2022 Jan;292:114568. <https://www.sciencedirect.com/science/article/abs/pii/S027795362100900X?via%3Dihu>

[120] O'Connor M, Martin C, Willmott L, Haywood D, Lawrence BJ, Breen LJ. Australian Health Professionals' Attitudes toward Voluntary Assisted Dying: A Cross-Sectional Survey. *Social Sciences*. 2021; 10(11):429. <https://www.mdpi.com/2076-0760/10/11/429>

[121] Matthys A, Cash B, Moorhead B. The representation of Australians living with dementia in voluntary assisted dying research: A scoping review. Australas J Ageing. 2024 Dec;43(4):664-674. <https://onlinelibrary.wiley.com/doi/10.1111/ajag.13371>

[122] O'Connor CMC, Fisher A, Cheung SC, Caga J, Piguet O. Supporting behaviour change in younger-onset dementia: mapping the needs of family carers in the community. Aging Ment Health. 2022 Nov;26(11): 2252-2261. <https://www.tandfonline.com/doi/full/10.1080/13607863.2021.1966744>

[123] Goel R. Grandma got arrested: Police, excessive force, and people with dementia. *U Richmond Law Rev*. 2023;*57(2)*:335. <https://lawreview.richmond.edu/files/2023/03/Goel-57URichLRev335.pdf>

[124] Kumfor F, Wei G, Ries N, Bennett H, D'Mello M, Kaizik C, Piguet O, Hodges JR. Examining the propensity and nature of criminal risk behaviours in frontotemporal dementia syndromes and Alzheimer's disease. Alzheimers Dement (Amst). 2024 Apr 11;16(2):e12577. <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/dad2.12577>

[125] Liljegren M, Naasan G, Temlett J, Perry DC, Rankin KP, Merrilees J, Grinberg LT, Seeley WW, Englund E, Miller BL. Criminal behavior in frontotemporal dementia and Alzheimer disease. JAMA Neurol. 2015 Mar;72(3):295-300. <https://jamanetwork.com/journals/jamaneurology/fullarticle/2088872>

[126] Liljegren M, Landqvist Waldö M, Rydbeck R, Englund E. Police Interactions Among Neuropathologically Confirmed Dementia Patients: Prevalence and Cause. Alzheimer Dis Assoc Disord. 2018 Oct-Dec;32(4):346-350. <https://journals.lww.com/alzheimerjournal/abstract/2018/10000/police_interactions_among_neuropathologically.14.aspx>

[127] Ekström A, Kristiansson M, Björkstén KS. Dementia and cognitive disorder identified at a forensic psychiatric examination - a study from Sweden. BMC Geriatr. 2017 Sep 18;17(1):219. <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0614-1>

[128] Shinagawa S, Shigenobu K, Tagai K, Fukuhara R, Kamimura N, Mori T, Yoshiyama K, Kazui H, Nakayama K, Ikeda M. Violation of Laws in Frontotemporal Dementia: A Multicenter Study in Japan. J Alzheimers Dis. 2017;57(4):1221-1227. <https://journals.sagepub.com/doi/abs/10.3233/JAD-170028>

[129] Tan YL, Lo YKJ, Ho CSH. Psychological and social impacts of frontotemporal dementia on caregivers and family members - A systematic review. Gen Hosp Psychiatry. 2024 Jan-Feb;86:33-49. <https://www.sciencedirect.com/science/article/abs/pii/S0163834323001871?via%3Dihub>

[130] Liljegren M, Landqvist Waldö M, Frizell Santillo A, Ullén S, Rydbeck R, Miller B, Englund E. Association of Neuropathologically Confirmed Frontotemporal Dementia and Alzheimer Disease With Criminal and Socially Inappropriate Behavior in a Swedish Cohort. JAMA Netw Open. 2019 Mar 1;2(3):e190261. <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2729467>

[131] Anderson J, Baird A. Sentencing and placement of offenders with dementia: a significant contemporary challenge for the criminal justice system. *Psychiatry, Psychology and Law*. 2024:1-21. <https://www.tandfonline.com/doi/full/10.1080/13218719.2024.2377583>

[132] Rasmussen H, Hellzen O, Stordal E, Enmarker I. Family caregivers experiences of the pre-diagnostic stage in frontotemporal dementia. Geriatr Nurs. 2019 May-Jun;40(3):246-251. <https://www.sciencedirect.com/science/article/pii/S0197457218304361?via%3Dihub>

[133] Mendez MF. Culpability for offenses in frontotemporal dementia and other brain disorders. Int J Law Psychiatry. 2023 Jul-Aug;89:101909. <https://www.sciencedirect.com/science/article/abs/pii/S0160252723000523?via%3Dihub>

[134] Band-Winterstein T, Avieli H. Women Coping With a Partner's Dementia-Related Violence: A Qualitative Study. J Nurs Scholarsh. 2019 Jul;51(4):368-379. <https://sigmapubs.onlinelibrary.wiley.com/doi/10.1111/jnu.12485>

[135] Harel D, Band-Winterstein T, Goldblatt H. Between sexual assault and compassion: The experience of living with a spouse's dementia-related hypersexuality-A narrative case-study. Dementia (London). 2022 Jan;21(1):181-195. <https://journals.sagepub.com/doi/10.1177/14713012211032068>

[136] Cooper C, Selwood A, Blanchard M, Livingston G. Abusive behaviour experienced by family carers from people with dementia: the CARD (caring for relatives with dementia) study. J Neurol Neurosurg Psychiatry. 2010 Jun;81(6):592-6. <https://jnnp.bmj.com/content/81/6/592>

[137] Rosen T, Makaroun LK, Conwell Y, Betz M. Violence In Older Adults: Scope, Impact, Challenges, And Strategies For Prevention. Health Aff (Millwood). 2019 Oct;38(10):1630-1637. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2019.00577>

[138] Kang M, Farrand S, Walterfang M, Velakoulis D, Loi SM, Evans A. Carer burden and psychological distress in young-onset dementia: An Australian perspective. Int J Geriatr Psychiatry. 2022 Jul;37(7):10.1002/gps.5765. <https://pmc.ncbi.nlm.nih.gov/articles/PMC9328388/>

[139] Tookey SA, Greaves CV, Rohrer JD, Stott J. Specific support needs and experiences of carers of people with frontotemporal dementia: A systematic review. Dementia (London). 2021 Nov;20(8):3032-3054. <https://journals.sagepub.com/doi/10.1177/14713012211022982>

[140] Hochgraeber I, Köhler K, Stöcker H, Holle B. The dyadic relationship of family carers and people living with dementia - an umbrella review. Aging Ment Health. 2023 Sep-Oct;27(10):1965-1974. <https://www.tandfonline.com/doi/full/10.1080/13607863.2023.2215191>

[141] Benbow SM, Kingston P. Spontaneous concerns about risk and abuse reported by people with dementia and their carers. *The Journal of Adult Protection*. 2017;19(2):92-99. <https://chesterrep.openrepository.com/bitstream/handle/10034/620482/Benbow%20and%20Kingston%20Dementia%202017%20concerns%20about%20risk%20-prepublication%20version.pdf>

[142] Fieldhouse JLP, van Dijk G, Gillissen F, van Engelen ME, de Boer SCM, Dols A, van der Waal HJ, Regeer BJ, Vijverberg EGB, Pijnenburg YAL. A caregiver's perspective on clinically relevant symptoms in behavioural variant frontotemporal dementia: tools for disease management and trial design. Psychogeriatrics. 2023 Jan;23(1):11-22. <https://pmc.ncbi.nlm.nih.gov/articles/PMC10092374/>

[143] Ries N, Kumfor F. Behaviour Changes and Perceived Criminal Offending: An Exploratory Study of Accounts from Carers of People living with Dementia. (Submitted manuscript)

[144] Baird A, Kennett J, Schier E. Homicide and dementia: An investigation of legal, ethical, and clinical factors of Australian legal cases. Int J Law Psychiatry. 2020 Jul-Aug;71:101578. <https://www.sciencedirect.com/science/article/pii/S0160252720300376?via%3Dihub>

[145] Reutens S, Butler T, Hwang YIJ, Withall A. An examination of criminal offenders with dementia in Australian courts. Psychiatr Psychol Law. 2024 Jan 16;32(1):92-105. <https://www.tandfonline.com/doi/full/10.1080/13218719.2023.2280518#d1e162>

[146] Sundakov-Krumins TE, Lubbe S, Wand APF. Homicide and Dementia: A Systematic Review. Dement Geriatr Cogn Disord. 2022;51(1):1-17. <https://karger.com/dem/article/51/1/1/827993/Homicide-and-Dementia-A-Systematic-Review>. Although this analysis does not explicitly address young onset dementia, it does include data on offenders over the age of 55, so addresses a cohort likely to be impacted by young onset dementia.

[147] Withall A, Karystianis G, Duncan D, Hwang YI, Kidane AH, Butler T. Domestic Violence in Residential Care Facilities in New South Wales, Australia: A Text Mining Study. Gerontologist. 2022 Feb 9;62(2):223-231. <https://academic.oup.com/gerontologist/article/62/2/223/6282452?login=true>

[148] Woolford MH, Stacpoole SJ, Clinnick L. Resident-to-Resident Elder Mistreatment in Residential Aged Care Services: A Systematic Review of Event Frequency, Type, Resident Characteristics, and History. J Am Med Dir Assoc. 2021 Aug;22(8):1678-1691.e6. <https://www.jamda.com/article/S1525-8610(21)00221-8/abstract>

[149] Murphy B, Bugeja L, Pilgrim J, Ibrahim JE. Deaths from Resident-to-Resident Aggression in Australian Nursing Homes. J Am Geriatr Soc. 2017 Dec;65(12):2603-2609. <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.15051>

[150] Ellem K, Dowse L, Rowe S, Holland L, Cullin J, Parker M, Henderson C. (2023). Final Report Insights from People with Lived Experience of Disability and the Justice System. <https://qai.org.au/wp-content/uploads/2024/07/UQ-Final-Report-Insights-from-people-with-lived-experience-of-disability-in-the-justice-system.pdf>

[151] O'Neill A, Heathcote L, Archer-Power L, Ware S, Shaw J, Senior J, Forsyth K. Providing appropriate health and social care for people with dementia or mild cognitive impairment in the criminal justice system of England and Wales: a thematic analysis of prisoner and staff interview data. Health Justice. 2025 Jan 20;13(1):5. <https://healthandjusticejournal.biomedcentral.com/articles/10.1186/s40352-024-00313-5>

[152] Soones T, Ahalt C, Garrigues S, Faigman D, Williams BA. "My older clients fall through every crack in the system": geriatrics knowledge of legal professionals. J Am Geriatr Soc. 2014 Apr;62(4):734-9. <https://agsjournals.onlinelibrary.wiley.com/doi/abs/10.1111/jgs.12751>

[153] Werner P, Doron I. The Legal System and Alzheimer's Disease: Social Workers and Lawyers' Perceptions and Experiences. J Gerontol Soc Work. 2016 Aug-Sep;59(6):478-491. <https://www.tandfonline.com/doi/full/10.1080/01634372.2016.1239235>

[154] Brooke J, Diaz-Gil A, Jackson D. The impact of dementia in the prison setting: A systematic review. Dementia (London). 2020 Jul;19(5):1509-1531. <https://journals.sagepub.com/doi/10.1177/1471301218801715>

[155] O'Neill A, Heathcote L, Archer-Power L, Ware S, Shaw J, Senior J, Forsyth K. Providing appropriate health and social care for people with dementia or mild cognitive impairment in the criminal justice system of England and Wales: a thematic analysis of prisoner and staff interview data. Health Justice. 2025 Jan 20;13(1):5. <https://healthandjusticejournal.biomedcentral.com/articles/10.1186/s40352-024-00313-5>

[156] Bartos BJ, Renner M, Newark C, McCleary R, Scurich N. Characteristics of Forensic Patients in California With Dementia/Alzheimer's Disease. J Forensic Nurs. 2017 Apr/Jun;13(2):77-80. <https://journals.lww.com/forensicnursing/abstract/2017/06000/characteristics_of_forensic_patients_in_california.6.aspx>

[157] O'Sullivan PCJ, Chesterman LP. Older adult patients subject to restriction orders in England and Wales: A cross-sectional survey. *Journal of Forensic Psychiatry & Psychology*. 2007;18(2):204-220. <https://www.tandfonline.com/doi/abs/10.1080/14789940601110906>

[158] McKenzie M, Kirkwood D, Tyson D, Naylor B. (2016). Out of Character? Legal Responses to Intimate Partner Homicides by Men in Victoria 2005–2014: Discussion Paper No. 10. Domestic Violence Resource Centre Victoria. <https://www.academia.edu/28562629/Out_of_Character_Legal_Responses_to_Intimate_Partner_Homicides_by_Men_in_Victoria_2005_2014>

[159] Rose E. *Domestic Violence as State Crime*. Routledge; 2021.

[160] Griffin J, Oyebode JR, Allen J. Living with a diagnosis of behavioural-variant frontotemporal dementia: The person's experience. Dementia (London). 2016;15(6):1622-1642. <https://journals.sagepub.com/doi/10.1177/1471301214568164>

[161] Marsh JA et al. Evaluating pathogenicity of variants of unknown significance in APP, PSEN1, and PSEN2. Neurotherapeutics 2025;22(3): e00527.

[162] Jarmolowicz AI, Chen H-Y, Panegyres PK. The Patterns of Inheritance in Early-Onset Dementia: Alzheimer's Disease and Frontotemporal Dementia. *American Journal of Alzheimer's Disease & Other Dementias*. 2014;30(3):299-306. <https://journals.sagepub.com/doi/10.1177/1533317514545825>

[163] Australian Law Reform Commission. Essentially Yours: The Protection of Human Genetic Information in Australia (ALRC Report 96). ALRC. Published May 30, 2003. <https://www.alrc.gov.au/publication/essentially-yours-the-protection-of-human-genetic-information-in-australia-alrc-report-96>

[164] Newson AJ, Ayres S, Boyle J, Gabbett MT, Nisselle A. Human Genetics Society of Australasia Position Statement: Genetic Testing and Personal Insurance Products in Australia. Twin Res Hum Genet. 2018 Dec;21(6):533-537. <Human Genetics Society of Australasia Position Statement: Genetic Testing and Personal Insurance Products in Australia | Twin Research and Human Genetics | Cambridge Core>

[165] Treasury Ministers. (11 September 2024). Total ban on the use of adverse genetic testing results in life insurance | Treasury Ministers. <https://ministers.treasury.gov.au/ministers/stephen-jones-2022/media-releases/total-ban-use-adverse-genetic-testing-results-life>

[166] Emily A Largent, Shana D Stites, Kristin Harkins, Jason Karlawish, 'That would be dreadful': The ethical, legal, and social challenges of sharing your Alzheimer's disease biomarker and genetic testing results with others, *Journal of Law and the Biosciences*, Volume 8, Issue 1, January-June 2021, lsab004. <https://academic.oup.com/jlb/article/8/1/lsab004/6124576?login=false>

[167] Australian Law Reform Commission (ALRC). (28 July 2010). Evidence of genetic discrimination in Australia. ALRC. <https://www.alrc.gov.au/publication/essentially-yours-the-protection-of-human-genetic-information-in-australia-alrc-report-96/30-genetic-discrimination-in-employment/evidence-of-genetic-discrimination-in-australia>

[168] Australian Government. (2021). Australia's Disability Strategy 2021–2031. Disability Gateway. <https://www.disabilitygateway.gov.au/document/3106>

[169] Department of Social Services. (2021). Employ My Ability - Disability Employment Strategy. Department of Social Services. <https://www.dss.gov.au/disability-employment-strategy/resource/employ-my-ability-disability-employment-strategy>

[170] Australian Government. Australian Disability Strategy - Employment Targeted Action Plan. Disability Gateway. <https://www.disabilitygateway.gov.au/document/3151>

[171] Austroads. (2017). Assessing Fitness to Drive - Appendix 3 Legislation relating to reporting. Austroads. <https://austroads.gov.au/publications/assessing-fitness-to-drive/ap-g56/legislation-relating-to-reporting>

[172] Austroads. (2017). Assessing fitness to drive for commercial and private vehicle drivers (2022 Edition): Medical standards for licensing and clinical management guidelines. <https://austroads.gov.au/publications/assessing-fitness-to-drive/ap-g56>

[173] Transport for NSW. (2021). Worried about someone's ability to drive? NSW Government. <https://www.nsw.gov.au/driving-boating-and-transport/driver-and-rider-licences/health-conditions-and-disability/fitness-to-drive/concerns-for-a-driver>

[174] Scott TL, Rooney D, Liddle J, Mitchell G, Gustafsson L, Pachana NA. A qualitative study exploring the experiences and needs of people living with young onset dementia related to driving cessation: 'It's like you get your legs cut off'. Age Ageing. 2023 Jul 1;52(7):afad109. <https://academic.oup.com/ageing/article/52/7/afad109/7227151?login=true>

[175] Svanberg E, Spector A, Stott J. The impact of young onset dementia on the family: a literature review. Int Psychogeriatr. 2011 Apr;23(3):356-71. <https://www.intpsychogeriatrics.org/article/S1041-6102(24)02888-6/fulltext>

[176] Camilleri L, Whitehead D. Driving Assessment for Persons with Dementia: How and when? Aging Dis. 2023 Jun 1;14(3):621-651. <https://www.aginganddisease.org/EN/10.14336/AD.2022.1126>

[177] Kim YJ, An H, Kim B, Park YS, Kim KW. An International Comparative Study on Driving Regulations on People with Dementia. J Alzheimers Dis. 2017;56(3):1007-1014. <https://journals.sagepub.com/doi/abs/10.3233/JAD-160762>

[178] Cations M. A devastating loss: driving cessation due to young onset dementia. Age Ageing. 2023 Sep 1;52(9):afad174. <https://academic.oup.com/ageing/article/52/9/afad174/7275523?login=true>

[179] Ries N, Kumfor F. (Manuscript under review).

[180] Peterson CM, Birkeland RW, Barsel S, Statz TL, Gaugler JE, Finlay JM. "Sick with stress": perspectives on airport travel from persons living with dementia and their travel companions. *Disability & Society*. 2022;39(1):234–254. <https://www.tandfonline.com/doi/full/10.1080/09687599.2022.2070060?scroll=top&needAccess=true#abstract>

[181] Tata A, Ebbatson DM, Fluke PC. Exploring the Implementations of Hidden Disability Assistance Program in Australian Airports. *International Journal of Aviation, Aeronautics, and Aerospace*. 2024;11(2). <https://commons.erau.edu/ijaaa/vol11/iss2/8/>

[182] Hidden Disabilities Sunflower. (2021). Airports and airlines around the world. Hidden Disabilities Sunflower Scheme. <https://hdsunflower.com/au/insights/post/airports-around-the-world>

[183] *King v Jetstar Airways Pty Ltd (No 2)* [2012] FCA 8.

[184] Chris Edwards et al, 'Exploring Autism-Friendly Initiatives in Australian Airports: "A Lot Better than a Lot of Airports That I've Experienced"' 0(0) *Current Issues in Tourism 1* ('Exploring Autism-Friendly Initiatives in Australian Airports').

[185] Rochford-Brennan H, Jenkins M. 'Travel and Dementia: One Story, Many Rights' *in* Flynn E, Arstein-Kerslake A, Clíona de Bhailís, Maria Laura Serra (eds). *Global Perspectives on Legal Capacity Reform*. Routledge; 2018.81-88

[186] Smeets B, Janssen N, Peetoom K, Boots L, Bakker C, de Vugt M. 'Too young to sit at home': a qualitative study conducted among employees with young-onset dementia and their relatives. Aging Ment Health. 2024 Aug;28(8):1119-1128. <https://www.tandfonline.com/doi/full/10.1080/13607863.2024.2345132>

[187] Nygard L, Nedlund AC, Mäki Petäjä Leinonen A, Astell A, Boger J, Issakainen M, Engvall AL, Heuchemer B, Rosenberg L, Ryd C. What happens when people develop dementia whilst working? An exploratory multiple case study. Int J Qual Stud Health Well-being. 2023 Dec;18(1):2176278. <https://www.tandfonline.com/doi/full/10.1080/17482631.2023.2176278>

[188] Kohl G, Koh WQ, Scior K, Charlesworth G. "It's just getting the word out there": Self-disclosure by people with young-onset dementia. PLoS One. 2024 Sep 30;19(9):e0310983. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0310983>

[189] Page L, Meredith P, O'Reilly M, Donohue G, Stanley M. Understanding employee experiences of developing younger onset dementia within the workplace: A scoping review. Work. 2025 Jan;80(1):24-60. <https://journals.sagepub.com/doi/10.3233/WOR-230469>

[190] Chokesuwattanaskul A, Penn D, Albero C, Johnson JCS, Benhamou E, Russell LL, Hardy CJD, Marshall CR, Rohrer JD, Warren JD. Inappropriate trusting behaviour in dementia. Front Neurol. 2024 Sep 3;15:1433135. <https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2024.1433135/full>

[191] Boyle PA, Yu L, Schneider JA, Wilson RS, Bennett DA. Scam Awareness Related to Incident Alzheimer Dementia and Mild Cognitive Impairment: A Prospective Cohort Study. Ann Intern Med. 2019 May 21;170(10):702-709. <https://www.acpjournals.org/doi/10.7326/M18-2711>

[192] Gibson J. "Absolutely astonished": Victor's dad lost his life savings to scammers, but the bank paid it all back. *ABC News*. https://www.abc.net.au/news/2023-09-11/anz-reimburses-460k-to-customer-targeted-by-scammers/102816204. Published September 10, 2023

[193] Barton TM. *On Being a Consumer Living with Dementia, a Socio-Legal Study of the Contractual Consequences*. 2021. (PhD Thesis, University of Exeter)

[194] Carminati JJ, Ponsford JL, Gould KR. Co-developing 'The CyberABIlity Scale' to assess vulnerability to cyberscams for people with acquired brain injury: Delphi and cognitive interviews with clinicians and people with acquired brain injury. Brain Impair. 2024 Jan;25:IB23065. <https://www.publish.csiro.au/ib/Fulltext/IB23065>

[195] Cyberability. (2025). The Cyberability Project. Monash University. <https://www.cyberability.org.au/>

[196] Cyberability. (2024). Research. Monash University. <https://www.cyberability.org.au/research>

[197] Gould KR, Carolan M, Ponsford JL. Do we need to know about cyberscams in neurorehabilitation? A cross-sectional scoping survey of Australasian clinicians and service providers. Brain Impair. 2023 Sep;24(2):229-244. <https://www.cambridge.org/core/journals/brain-impairment/article/do-we-need-to-know-about-cyberscams-in-neurorehabilitation-a-crosssectional-scoping-survey-of-australasian-clinicians-and-service-providers/D2572ABFB991DC974FB7E489B8CA11D1#>

[198] House of Representatives Standing Committee on Health, Aged Care and Sport. (2017). Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia - Chapter 4. Consumer Protection. Australian Parliament. <https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/AgedCareFacilities/Report/section?id=committees%2Freportrep%2F024167%2F26040>

[199] Chokesuwattanaskul A, Penn D, Albero C, Johnson JCS, Benhamou E, Russell LL, Hardy CJD, Marshall CR, Rohrer JD, Warren JD. Inappropriate trusting behaviour in dementia. Front Neurol. 2024 Sep 3;15:1433135. <https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2024.1433135/full>

[200] Knight J, Pepper A. Supporting a family living with young-onset dementia: a case study. *British Journal of Neuroscience Nursing*. 2024;20(1):13-19. <https://www.magonlinelibrary.com/doi/full/10.12968/bjnn.2024.20.1.13>

[201] Loi SM, Cations M, Velakoulis D. Young-onset dementia diagnosis, management and care: a narrative review. Med J Aust. 2023 Mar 6;218(4):182-189. <https://onlinelibrary.wiley.com/doi/10.5694/mja2.51849>

[202] Massimo L, Evans LK, Benner P. Caring for loved ones with frontotemporal degeneration: the lived experiences of spouses. Geriatr Nurs. 2013 Jul-Aug;34(4):302-6. <https://www.sciencedirect.com/science/article/abs/pii/S0197457213001808?via%3Dihub>

[203] Oyebode JR, Bradley P, Allen JL. Relatives' experiences of frontal-variant frontotemporal dementia. Qual Health Res. 2013 Feb;23(2):156-66. <https://journals.sagepub.com/doi/10.1177/1049732312466294>

[204] Schor NF. Equipping AI for Unbiased and Inclusive Neurology. JAMA Neurol. 2025 Mar 1;82(3):211-212. <https://jamanetwork.com/journals/jamaneurology/article-abstract/2827122>

[205] Petti U, Nyrup R, Skopek J M, Korhonen A. Ethical considerations in the early detection of Alzheimer's disease using speech and AI. *2023 ACM Conference on Fairness Accountability and Transparency*, 1062–1075. <https://dl.acm.org/doi/pdf/10.1145/3593013.3594063>

[206] Senate Select Committee on Adopting Artificial Intelligence. (November 2024). *Select Committee on Adopting Artificial Intelligence (AI): Report*. Commonwealth of Australia. <https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/RB000470/toc_pdf/SelectCommitteeonAdoptingArtificialIntelligence(AI).pdf>

[207] Ries N, Shelley J. 'Public Health Law' *in* White BP, McDonald FJ, Willmott L, Then SN. Health Law in Australia. Thomson Reuters Australia, Limited; 2023, pp 697-727.

[208] Livingston G, Huntley J, Liu KY, Costafreda SG, Selbæk G, Alladi S, Ames D, Banerjee S, Burns A, Brayne C, Fox NC, Ferri CP, Gitlin LN, Howard R, Kales HC, Kivimäki M, Larson EB, Nakasujja N, Rockwood K, Samus Q, Shirai K, Singh-Manoux A, Schneider LS, Walsh S, Yao Y, Sommerlad A, Mukadam N. Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. Lancet. 2024 Aug 10;404(10452):572-628. <https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(24)01296-0/abstract>

[209] Greer SL, Falkenbach M, Siciliani L, McKee M, Wismar M, Figueras J. From Health in All Policies to Health for All Policies. Lancet Public Health. 2022 Aug;7(8):e718-e720. <https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(22)00155-4/fulltext>

[210] Australian Institute of Health and Welfare (AIHW). (April 2024). Dementia Awareness Survey. AIHW. <https://www.aihw.gov.au/reports/dementia/dementia-awareness-survey/contents/about>

[211] Dry T, Baker P. Generating Political Commitment for Regulatory Interventions Targeting Dietary Harms and Poor Nutrition: A Case Study on Sugar-Sweetened Beverage Taxation in Australia. Int J Health Policy Manag. 2022 Dec 6;11(11):2489-2501. <https://www.ijhpm.com/article_4182.html>

[212] Li Y, Li Y, Li X, Zhang S, Zhao J, Zhu X, Tian G. Head Injury as a Risk Factor for Dementia and Alzheimer's Disease: A Systematic Review and Meta-Analysis of 32 Observational Studies. PLoS One. 2017 Jan 9;12(1):e0169650. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0169650>

[213] Commonwealth Department of Health and Aged Care. Sport 2030. Australian Government. <https://www.sportaus.gov.au/__data/assets/pdf_file/0005/677894/Sport_2030_-_National_Sport_Plan_-_2018.pdf>

[214] Senate Standing Committees on Community Affairs. (2023). Concussions and repeated head trauma in contact sports - Report. September 2023. <https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Headtraumainsport/Report>

[215] Qi B, Tan J, Feng D, Guan L, Li J, Cao M, Zou Y. Prevalence of Chronic Traumatic Encephalopathy in Athletes With Repetitive Head Impacts: A Systematic Review and Meta-Analysis. Scand J Med Sci Sports. 2025 Apr;35(4):e70047. <https://onlinelibrary.wiley.com/doi/10.1111/sms.70047>

[216] Priemer DS, Perl DP. Neurotrauma: 2023 Update. Free Neuropathol. 2023 Sep 20;4:14. <https://www.uni-muenster.de/Ejournals/index.php/fnp/article/view/5076/5218>

[217] icare. (2023). Sporting injuries. NSW Government. <https://www.icare.nsw.gov.au/injured-or-ill-people/sporting-injuries>

[218] Supreme Court of Victoria. (2025). Rooke v AFL Group Proceeding (Class Action). The Supreme Court of Victoria. <https://www.supremecourt.vic.gov.au/areas/group-proceedings/Rooke>

[219] Kim PS, Beran RG. Legal medicine implications of a multidisciplinary approach to managing Traumatic Encephalopathy Syndrome in Australia. Front Neurol. 2023 Jun 30;14:1179319. <https://www.frontiersin.org/journals/neurology/articles/10.3389/fneur.2023.1179319/full>

[220] Oyebode JR, La Fontaine J, Stamou V, O'Malley M, Parkes J, Carter J. Establishing and sustaining high-quality services for people with young onset dementia: the perspective of senior service providers and commissioners. Int Psychogeriatr. 2024 Jun;36(6):492-501. <https://www.intpsychogeriatrics.org/article/S1041-6102(24)04895-6/fulltext>

[221] Issakainen M, Mäki-Petäjä-Leinonen A, Heimonen S, Nedlund A, Astell A, Boger J, Rissanen S, Nygård L. Experiences of influencing one's own life when living with working-age dementia. *Ageing and Society*. 2023;43(8):1934-1953. <https://www.cambridge.org/core/journals/ageing-and-society/article/experiences-of-influencing-ones-own-life-when-living-with-workingage-dementia/600D3D9E7B29F660F1EA86A980AE9D3F>

[222] Tobin-Tyler E, Boyd-Caine T, Genn H, Ries NM. Health Justice Partnerships: An International Comparison of Approaches to Employing Law to Promote Prevention and Health Equity. J Law Med Ethics. 2023;51(2):332-343. <https://www.cambridge.org/core/journals/journal-of-law-medicine-and-ethics/article/health-justice-partnerships-an-international-comparison-of-approaches-to-employing-law-to-promote-prevention-and-health-equity/B28E7BEF680AEBCDD9E48C1718E91962>

[223] Justice Connect. (2016). Seniors Law. Justice Connect. <https://justiceconnect.org.au/our-services/seniors-law/>

[224] Ries N, Donner K. (2024). Dementia Capability for the Legal Profession. University of Technology Sydney. <https://airdrive.eventsair.com/eventsairaueprod/production-qlsevents-public/6095c7b61b484336a5a036917ced37a6>

[225] Law Society of NSW. (2025). Specialist Elder Law Program to benefit older Australians. The Law Society of NSW. <https://www.lawsociety.com.au/specialist-elder-law-program-benefit-older-australians>

[226] Cancer Council Australia. Support Services - Legal, Workplace and Financial Planning Referral Services. Cancer Council Australia. <https://www.cancer.org.au/support-and-services/practical-and-financial-assistance/pro-bono-program>

[227] German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and German Federal Ministry of Health. National Dementia Strategy. <https://www.nationale-demenzstrategie.de/fileadmin/nds/pdf/2021-01-05_Nationale_Demenzstrategie_EN.pdf>

[228] US Department of Health and Human Services (US HHS). (2024). National Plan to Address Alzheimer's Disease: 2024 Update. US HHS. <https://aspe.hhs.gov/sites/default/files/documents/dc2ff0be0e08df15971fce57cb8e5c7a/napa-national-plan-2024-update.pdf>

[229] Davies-Quarrell V, et al. The ACE approach: promoting well-being and peer support for younger people with dementia. *Journal of Mental Health Training, Education and Practice*. 2010;5(3):41-50.

Appendix:
Stakeholder Consultations

Executive Summary

This appendix presents an in-depth thematic analysis of legal and related issues affecting people with young onset dementia in Australia, drawing on data from individual interviews and a multidisciplinary service provider roundtable. Eleven key themes are explored, ranging from diagnosis and legal planning to systemic issues in aged care, disability services and guardianship.

Each theme integrates first-hand accounts from people with young onset dementia, family carers and professionals, highlighting gaps in current services and pointing to urgent areas for reform. The findings underscore the need for relational, rights-based and coordinated approaches to care, and call for structural changes across the National Disability Insurance Scheme (NDIS), aged care, legal and health systems.

Key recommendations include:

- Early and accurate diagnosis through coordinated, multidisciplinary services
- Streamlined access to the NDIS with specialist support pathways for young onset dementia
- A national framework for supported decision-making and legal planning
- Carer recognition and coordinated, whole-of-life support
- Integrated funding models based on need, not age
- Balanced approaches to risk that respect both autonomy and safety

Methods

This thematic analysis draws on two primary data sources:

- In-depth Interviews (February–March 2025): Semi-structured online interviews were conducted with two people living with dementia, three family carers, an allied health practitioner and a medical specialist, both with expertise in dementia.
- Service Provider Roundtable (13 March 2025): A semi-structured online group discussion involved ten experienced professionals who work in key services and sectors, including aged care, disability support coordination, advocacy and neuropsychiatry.

The interviews and roundtable sought participants' perspectives on:

- the legal issues faced by individuals with young onset dementia in Australia;
- the impacts of these issues on quality of life and access to services; and
- the changes in policy or law that could better support people with young onset dementia and their support networks.

Transcripts were analysed using a qualitative descriptive method in order to synthesise key themes. Themes were developed iteratively through review, comparison and synthesis across both datasets. Illustrative, de-identified quotations share participants' views and experiences. This research was approved by the UTS Human Research Ethics Committee (ETH24-10212).

Thematic Analysis

Eleven key themes emerged across the interviews and the roundtable:

- Diagnosis and access to care
- Navigating NDIS and fragmented services
- Decision-making capacity and autonomy
- Legal advice and planning support
- Guardianship failures
- Discrimination and stigma
- Driving and licensing
- Criminalised behaviours and public safety
- Aged care vs. NDIS system tensions
- Restrictive practices and risk aversion
- Carer responsibilities and lack of coordinated support

Theme 1: Diagnosis and Access to Care

People with young onset dementia often face prolonged delays in receiving a correct diagnosis. The diagnostic process is frequently complicated by the non-typical presentation of symptoms—such as changes in personality, language, or executive function—which may not be immediately recognised as dementia. As a result, individuals are often misdiagnosed with psychiatric conditions such as depression, anxiety, or even relationship dysfunction. This delay can cause profound distress and disorientation for individuals and their families.

The lack of access to dementia-specialist clinicians—particularly outside urban centres—further exacerbates this problem. Several participants in interviews and the roundtable noted the systemic failure to provide a single point of access or guidance during the diagnostic process. The fragmentation between aged care, mental health, and disability systems results in confusion, inappropriate referrals, and inconsistent care pathways.

"People with young onset dementia find themselves caught between multiple systems like aged care, NDIS, mental health." (person with young onset dementia)

"Because I could talk like this [very articulately], the doctor just thought well, I obviously don't have any problems." (person with young onset dementia)

"Most of the neurologists who work in dementia have expertise in Alzheimer's, but they know very little about frontotemporal dementia." (person with young onset dementia)

"Often they were rare presentation... a behavioural onset Alzheimer's or a language onset condition... which is poorly understood even within the medical field. It can take a long time for younger people to be diagnosed." (allied health practitioner)

"We received the reports [directly] and were sitting in our lounge room here with no doctor support, nothing. We read the diagnosis ourselves." (carer)

In addition to emotional turmoil, delayed diagnosis significantly impacts legal and financial planning, access to services (such as NDIS or My Aged Care), and employment protections. In some cases, families received the diagnostic report without any medical debrief, leaving them to interpret the findings on their own. Others described situations where the person with young onset dementia was sent to a psychiatric facility instead of a dementia service, resulting in further distress and trauma.

This theme highlights the urgent need for:

- **Early and accessible diagnostic services** with expertise in young onset presentations
- **Integrated assessment pathways** spanning aged care, mental health and disability systems
- Clear follow-up processes for explaining diagnosis and supporting next steps for individuals and families, including **referrals for legal advice**
- **Improved awareness among GPs and allied health professionals** to detect and refer atypical dementia cases early

Addressing the diagnostic challenge is not only a clinical issue. It also affects access to justice and social participation. Diagnosis is a crucial first step in a complex legal, relational and personal journey that will require consistent, compassionate and competent support.

Theme 2: Navigating NDIS and Fragmented Services

The National Disability Insurance Scheme (NDIS) was designed to provide person-centred, tailored support for Australians living with disability. However, people with young onset dementia and their carers described significant barriers to accessing and navigating this system. From initial application to plan implementation and review, the NDIS often fails to align with the progressive nature of dementia.

Participants described practical challenges in gathering evidence for NDIS applications. Cursory reports from a GP that simply stated "dementia" led to rejections. It is important to fully describe functional impairment and potential for deterioration, rather than focusing solely on the dementia label. Support coordinators had to spend time educating GPs about how to provide reports with descriptive details, in a way that aligned appropriately with NDIS and other support eligibility criteria. Families had to self-fund private occupational therapy assessments to justify eligibility—often while already in crisis.

Once accepted into the NDIS, participants found the planning process lacked the flexibility to accommodate unpredictable cognitive and physical changes. The 12-month planning cycle, with its fixed goals and support categories, did not reflect the day-to-day variability of the condition.

"It so much comes down to which planner you get... there's no consistent outcome or understanding of options." (allied health practitioner)

This inconsistency led to significant inequities. Some participants reported receiving generous plans with dedicated support coordination; others were left to navigate the system alone, often without the cognitive or emotional reserves to do so. The metaphor of a "quarterback" emerged in one interview as a powerful image of the missing system navigator—someone who could coordinate services, explain options, and guide the person and their family through the complexity of aged care, disability, and health systems.

"Once you've had that diagnosis, you can go to a quarterback... it's fairly important to do it fairly soon, because there are changes... if you haven't got what people think is a capability to sign up, then you've got a problem. You missed the opportunity." (carer)

"The people that have the quarterback to help them navigate—that makes all the difference." (person with young onset dementia)

Others described the emotional exhaustion of advocating repeatedly for services and confronting bureaucratic inflexibility. The burden of "proving" impairment to planners—who often misunderstood the nature of dementia—compounded family distress.

"I had to try and do something myself to help Mum because she was looking after me and my dad at the same time." (person with young onset dementia)

"By the time they get to the NDIS, they're two or three years into their battle... then they get to the front of the NDIS, they have to bang down the door." (support coordinator)

In some cases, the system's own logic—emphasising "choice and control"—created ethical dilemmas as the person's capacity changed. Carers described being required to step back and allow decisions to be made autonomously, even when this contradicted the person's previously expressed preferences or involved risks to their safety or wellbeing.

"Families are put in impossible positions—they have to both prove how impaired the person is, and then step back and let them make the decisions." (service provider)

This theme reveals not only a service gap but a conceptual mismatch between the NDIS framework and the reality of neurodegenerative conditions. While dementia is recognised as a disability under law, the systems intended to support people with young onset dementia often require them to perform levels of insight, documentation and planning without adequate supports.

To address these challenges, participants called for:

- A dedicated **young onset dementia stream within the NDIS**, modelled on the fast-tracked pathway available to people with motor neurone disease
- More flexible **planning frameworks that recognise the progressive trajectory** and allow plans to evolve responsively
- Specialist **navigation hubs** that integrate legal, health and disability advice and walk alongside families post-diagnosis
- **Consistent training** for planners, GPs and allied health professionals in understanding and documenting dementia-related functional impairments

Theme 3: Decision-making capacity and autonomy

The concept of decision-making capacity is foundational to ethical and legal frameworks in health, disability and aged care. Yet for people with young onset dementia, the application of these principles is far from straightforward. Both interviewees and roundtable participants described a system that struggles to support meaningful participation—one that frequently defaults to risk-averse, binary thinking.

While the law recognises that capacity is decision-specific and a presumption of capacity should be the starting point, in practice, clinicians and service providers often make assumptions about incapacity based on diagnosis alone. Substitute decision-making mechanisms, such as Enduring Power of Attorney (EPOA) or guardianship appointments, were frequently invoked without first exploring ways to support the person to make or participate in decisions.

"Health professionals quickly revert to, 'Have you called the EPOA?' when in fact, particularly for the younger onset, even with word-finding issues, they very much can be involved in all of their decisions." (service provider)

Carers described the ethical and emotional difficulty of navigating these situations —particularly when the person's expressed wishes conflicted with concerns about safety or previous values.

"When I know it's not a good day, he doesn't need access to much money. Two drinks and he's horrible... to keep him safe and to keep me safe, [restricting access to money] needs to happen." (carer)

"The bank will only accept our power of attorney if [spouse] has absolutely no contact with money.

but he still needs some money for himself for his independence." (carer)

Some carers tried to maintain a supported decision-making approach even after legal powers had been activated, grounding their decisions in prior shared understanding.

"We would always consult each other… we've always treated it as supportive decision making." (carer)

"If I'm making a decision like that, I'm making a decision that I know he wanted before he had a cognitive impairment." (carer)

Others described the grief and moral strain of overriding a person's wishes in situations where judgement and insight had clearly diminished.

"There's too much risk of you hurting somebody else [if he drives]… but he still wants the freedom to go." (carer)

NDIS planners and disability support workers were described as equally uncertain about how to implement supported decision-making. Some found disagreements within families difficult to navigate in a supported decision-making context, while others disengaged from the person altogether once legal authority was assigned to someone else.

Participants called for a more relational and context-sensitive approach—one that recognises the knowledge and care that families bring, while also upholding the rights and dignity of the person with dementia. They recommended:

- A **national framework** for assessing and supporting capacity in neurocognitive conditions
- **Training for health professionals, support coordinators, and carers** on supported decision-making and how to balance rights with risk
- **Resources for families** to help navigate ethical tensions and act consistently with the person's values over time
- **Practical tools** to facilitate shared and supported decision-making—such as communication aids, decision support plans, and flexible consent frameworks that could respond to changing capacity over time and allow for different levels of participation depending on the type of decision.

This theme acknowledges that autonomy, in the context of dementia, is not necessarily the same as individual independence. Rather, autonomy often takes a relational form—and is preserved and promoted within relationships of trust, shared personal history, and often familial and spousal love. Supporting decision-making at best is able to accommodate this complex reality. This also indicates that those without close family support may struggle to fully realise their will and preferences as cognitive capacity declines.

Theme 4: Legal Advice and Planning Support

Early access to legal information and planning support is critical after a diagnosis of young onset dementia. However, interview and roundtable participants described a striking absence of guidance during this period. 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.

Many families encountered professionals—doctors, social workers, discharge planners—who assumed that legal planning was someone else's responsibility. In the absence of structured referrals, families were left to initiate processes such as enduring powers of attorney (EPOA), advance care directives, and guardianship applications on their own, often during periods of emotional distress and cognitive decline.

"That period immediately post-diagnosis can involve a bit of: 'Well, you better get your affairs in order.' But people don't quite know what that involves." (service provider)

The lack of proactive support also created inequality. Families with prior legal knowledge or strong social networks were able to act early. Others delayed key decisions, only realising the importance of having legal plans in place when a crisis arose—such as hospital admission, financial mismanagement or behavioural escalation.

"Improving access to legal services and advice would probably have the greatest amount of change in the shortest period of time" (NDIS team leader)

"We were lucky. The accountant that we had at the time [our insurances were] set up was a good bloke. His wife was a nurse and he understood dementia. We had good policies. He helped us claim when my husband had to retire early because of his condition" (carer)

Without clear support, families may be left navigating emotionally charged, legally complex decisions with little guidance, during a critical window for planning and participation.

Participants also noted a gap in legal literacy among health professionals. GPs, specialists and allied health workers often lacked confidence or knowledge about when and how to initiate legal planning conversations, or how to refer to appropriate support. As a result, families were sometimes misinformed, or legal planning was left too late.

This theme underscores the need for legal planning to be seen as a time-sensitive holistic care issue, not merely a legal one. Planning early not only preserves autonomy for the person with dementia, but also helps carers feel prepared for the future and reduces reactive, crisis-driven reliance on systems such as Guardianship Tribunals.

Participants recommended:

- **Structured legal referrals** post-diagnosis, preferably to professionals and services equipped to meet the needs of clients with dementia (e.g., through health-justice partnerships or other services where professionals have additional training and collaborative networks that support comprehensive legal help)
- **Written guides and decision-making tools tailored** to the young onset dementia context
- **Legal literacy training for health and service providers**, especially around EPOAs, capacity and consent
- **Community legal services** with **dedicated dementia streams, co-located** in memory clinics or hospitals

Above all, this theme reflects the high stakes of missed timing. Without early legal planning, people with young onset dementia and their families can find themselves in crises with no clear authority to make critical care, financial and other decisions, no access to funds, and the loss of the chance to make legally enforceable decisions about future care and other matters.

Theme 5: Guardianship Failures

Stakeholders raised serious concerns about the failures of guardianship systems to deliver relational, responsive and rights-based decision-making for people with young onset dementia. Participants described the system as unresponsive, impersonal and fundamentally disconnected from the people it is meant to serve.

"I feel very sad for people with younger onset dementia [who don't have support] because our communication and dealings with the public guardian and trustee would be no less than appalling and dissatisfactory on every single level…They don't know the residents at all. They never visit them. They have no contact with them." (service provider)

Participants also described how family members who had taken on enduring appointments (enduring guardian or EPOA) were often overwhelmed by the complexity of the roles. Many accepted the responsibility without understanding what it would require, or struggled with the ethical implications of intervening when the person's wishes seemed out of step with their current needs. They lacked training and clear guidance on how to exercise their decision-making authority.

"We have so many people say, 'Oh no, I'd never go against her wishes… I'm not actually going to take over, you know, like, if that was ever to become necessary.' You get people accepting to become an attorney, but having it in their own mind that they wouldn't actually want to have to make any decisions on behalf of that person—even if that became required." (allied health practitioner)

"People have this all-or-nothing view… like, 'I'm not willing to do all, so instead I'm going to do nothing.' Whereas… providing a bit of scaffolding around the situation would actually be preferable. But how is somebody who's never dealt with dementia, or managing somebody else's finances, or a complicated financial set-up—and feels uncomfortable about this role they've taken on without understanding it—how are they ever going to do that?" (allied health practitioner)

Carers described the ethical uncertainty of acting in a person's best interests when they lacked insight, especially in situations where there was no formal legal authority to guide decisions.

"You want to respect their choices, of course you do. But when you see them doing something that's clearly going to cause harm, what do you do? It's just up to you to guess." (carer)

Clinicians highlighted how complex family dynamics in the context of dementia can further complicate substitute decision-making.

"Family members can also disagree among themselves about care, which puts clinicians in a difficult position. These decisions involve interdependent relationships between the person and their family, which makes disagreements hard to navigate." (specialist medical practitioner)

Participants advocated for more relational and context-sensitive approaches to guardianship—ones that centre the individual's history, preferences and evolving needs. They also stressed the need for better training for family who take on legal decision-making roles (enduring guardian/EPOA) but lack training to manage the complex legal and emotional terrain.

This theme highlights the need for:

- **Person-centred guardianship models** that prioritise relationships, continuity and wellbeing
- Regular and meaningful **engagement between public guardians and the individuals** they represent
- Training, legal advice and **structured support for family members acting in decision-making roles**
- **Simplified pathways** to establish supported decision-making arrangements before crises occur

Theme 6: Discrimination and Stigma

Discrimination and stigma were recurring themes across the interviews and the roundtable, shaping how people with young onset dementia were perceived, treated and supported. Unlike presentations of dementia in older adults, young onset dementia often affects people in midlife—raising children, working and managing households. Its relative invisibility and age-defying profile frequently led to disbelief, dismissal or inadequate responses from services.

One participant described how her neurologist treated her as if she had no awareness of her condition, despite being articulate and knowledgeable. *"He would be treating me as if I had no concept or understanding what was happening to me... and talk about me in the same room with somebody else... would never listen to me when I said something, even though I knew what I was talking about."* (person with young onset dementia)

Other participants echoed this frustration, noting that service providers often failed to understand the complexity and variability of young onset dementia. An allied health professional observed that many people with dementia do not fit the stereotypical presentation. *"Often they were rare presentation... a behavioural onset, Alzheimer's or a language onset condition... which is poorly understood even within the medical field."* (allied health practitioner)

In aged care and residential settings, stigma was tied not only to the diagnosis but to environmental and social exclusion. Roundtable participants voiced concern that people with young onset dementia were often placed in older adult care facilities without meaningful engagement. One provider described how younger residents were at risk of being *"left in front of the TV all day"* with no age-appropriate stimulation or activity, a reflection of low expectations rather than the person's actual capacity.

Across contexts, participants highlighted how the stigma of dementia intersects with broader assumptions about capacity. When formal guardianship or support coordination was introduced, people were sometimes excluded from conversations—even when they still had the ability to contribute meaningfully. This tendency to *"talk over"* or ignore people with dementia, rather than assessing their individual needs and preferences, contributed to a deeper sense of marginalisation.

Participants suggested improved training and cultural change across services—especially in health, disability and aged care—so that assumptions about age, capacity and appearance do not override the voices and autonomy of those living with young onset dementia.

Participants recommended:

- **Public education** campaigns to challenge age-based stereotypes of dementia
- **Age-inclusive dementia services**, including appropriate housing and day programs
- **Provider training** on recognising **invisible disability** and neurodiversity
- **Strength-based approaches** that recognise retained abilities and lived expertise

Theme 7: Driving and Licensing

For many people with young onset dementia, the loss of a driver's licence is more than a safety issue—it marks a profound shift in independence, identity and autonomy. Driving connects people to employment, appointments, community participation and daily structure. Losing a licence can be experienced as a symbolic and practical loss of adult agency. At the same time, concerns about fluctuating abilities, lack of insight and road safety create difficult ethical terrain for families, clinicians and regulators.

One participant described the distress of having her licence revoked based on a rigid timeline that ignored her individual presentation and early diagnosis. *"I think it should be tested—not just a blanket rule that doesn't look at your ability... It made a huge difference to my life to lose that ability" (person with young onset dementia).* She reported that her neurologist refused to refer her for an occupational therapy assessment, stating, *"OTs won't know about this type of dementia... I'm the expert. I'm the only one that can make the decision."* (person with young onset dementia)

By contrast, one carer spoke of trying to prevent her husband from driving once it became unsafe, and the relief when a clinician intervened. *"The psychiatrist wrote to Roads and said that [my husband] would never have spatial awareness to be a safe driver again, and so his licence was revoked.*

So we were lucky." However, she noted how difficult it is for families to act without professional support: *"There's no way a spouse can go to Roads and say, 'My husband's not safe.' He's got a licence. Until they actually take it off him, he's got a licence"* (carer).

Another carer described how her husband passed a formal driving assessment on two *"good days,"* but this did not reflect his overall risk profile. *"He pulled himself together, and he did it on two consecutive days and they were good days… then he fell in a heap for a week."* She recalled warning the occupational therapist, *"She wouldn't listen to the fact that I'd said there are good days and bad days… I will still be taking your keys when I don't think you're able to drive."* (carer)

Without formal authority or coordinated support, carers were often left to manage risk alone. *"I had him actually blow in a breathalyser 'cause I wasn't sure. He was blowing 0, but there's no way I would have let him drive."* (carer)

The loss of a licence also introduced secondary harms. Without photo ID, individuals struggled to access basic services and participate in social life. *"We had a 40th birthday to go to… they would not let him in 'cause he did not have photo ID… Even with me holding a [notice] saying he had dementia, they were so rude about it."* (carer)

These experiences reflect the deep tensions between autonomy and safety, between respecting a person's identity and protecting them from harm.

Participants recommended:

- A **nationally consistent approach to driving assessments** that incorporates condition-specific guidelines and multidisciplinary input
- Development of **safe, supported alternatives to driving**, particularly for younger people with families and community roles
- Proactive **counselling and support during the transition away from driving**, including transport planning and general psychological support
- Mechanisms for carers to raise safety concerns without immediately triggering licence cancellation

This theme illustrates how systems built around protection and safety must also account for emotional and social identity. Losing a licence is not simply losing a mode of transport – it is often symbolic of decline and has a significant impact on real and perceived independence.

Theme 8: Criminalised Behaviours and Public Safety

Behavioural symptoms that may occur in young onset dementia—such as impulsivity, aggression, paranoia or disinhibition—can sometimes trigger emergency responses from police, paramedics or mental health services. These behaviours are not wilful, but reflect underlying neurological changes. Nevertheless, participants described scenarios in which people with dementia were treated as dangerous, criminal or psychotic, rather than as people living with a medical condition.

Several carers shared distressing stories of their loved ones being arrested, hospitalised, or subjected to legal processes without recognition of their dementia. One carer recounted:

"They arrested [my husband] and took him to hospital. Didn't wait for the ambulance… put in [a domestic violence report]. I went to court four times in the next five months, which I couldn't tell him I was doing… He was already traumatised, not understanding what he was doing in a psych ward." (carer)

Another carer described how her partner, confused and suspicious, accused her of theft and called the police. In this case, an experienced police officer responded with care and insight:

"He rang the police one night and reported me for taking his money. He was verbally abusive at the time and through the phone, and they [the call taker] heard and said, 'No, I have to send somebody for a welfare check.'… I was very fortunate that it was an older Sergeant that came… He looked at me and said, 'Have you got an official diagnosis?' I said, 'Yes, I have.'" (carer)

People living with dementia were also vulnerable to exploitation—yet not always recognised as such. One participant described how her father, who had dementia, was suspected of criminal behaviour when he was actually being manipulated by others:

"My dad himself actually got caught up with people who were managing to steal things and use him as a repository of… the stolen goods… He didn't understand what was happening… They treated them as if they were the criminals, not the… unwitting receiver[s] of… stolen goods." (person with young onset dementia)

These experiences were emotionally devastating for carers, who found themselves navigating court systems, police interventions, and hospitalisations while attempting to protect and advocate for a person with declining cognitive abilities. Participants noted that once someone had been criminalised or scheduled under mental health legislation, it became harder to access support through health channels, because the label of "offender" or "psychiatric case" followed them through the system.

Complexities also arise where the person with dementia has difficulty communicating with police, leading to confusion about the situation at hand (eg, whether the person with dementia is at risk or not). Participants called for urgent cross-sector reform to ensure health-first, trauma-informed responses to risk and behavioural crises. They recommended:

- Embedding **neurocognitive expertise** in police and mental health crisis teams, with rapid access to clinical consultation
- Developing **non-carceral**, multidisciplinary responses to behavioural distress—including community mental health, outreach teams, and dementia-informed safe spaces
- Ensuring that carers have access to legal advocacy and emotional support when systems respond with force
- Reviewing mental health legislation to take account of young onset dementia and provide appropriate pathways to care

This theme underscores a critical systems failure: people with young onset dementia are not criminals—they are unwell. But without targeted training, service coordination, and compassionate legal frameworks, they are too often treated otherwise.

Theme 9: Aged Care vs. NDIS System Tensions

A key structural injustice faced by people with young onset dementia lies in the division between Australia's aged care and disability systems. Eligibility for support is split based on age: those under 65 may access the National Disability Insurance Scheme (NDIS), while those over 65 must rely on the aged care system. This policy division creates deeply inequitable outcomes for people with similar needs, based solely on which side of the age threshold they fall.

Service providers in the roundtable highlighted this as one of the most glaring systemic failures. The funding gap is substantial: people with young onset dementia on the NDIS can access tens or even hundreds of thousands of dollars in flexible, tailored supports. Those who develop dementia after 65—or who 'age out' of the NDIS—are instead placed on aged care packages that are often insufficient to meet their complex needs.

"We have one resident who's on a $500,000 [NDIS] package… yet every other resident with dementia is not entitled and not afforded that kind of support. They're on a $20,000-a-year aged care package." (service provider)

Participants stressed that the inequity is not driven by clinical judgement but by structural eligibility. *"There is an enormous disparity… it's not based on diagnosis. It's not based on symptoms. It's based on whether you're in the disability system or the aged care system."* (service provider)

They also raised concerns about people who had been receiving appropriate supports through the NDIS but lost access after turning 65. The process of being transferred to aged care was often automatic, poorly communicated and against the person's preferences. *"The NDIA… have made a decision that they are not going to fund… [and] instead… feel that the best place for him… is residential aged care. Completely against his wishes…"* (support coordinator)

This forced transition brought emotional distress, loss of services and disruption in care coordination. The right to choose the most appropriate form of care was often lost—despite the fact that many people with young onset dementia may not want, need, or belong in residential aged care. Even when aged care is appropriate, services often lack the flexibility, rights orientation and younger-person inclusion that NDIS structures are designed to support.

Participants advocated for:

- **Parity in funding** between NDIS and aged care systems, based on assessed need rather than age
- **Legal recognition of dementia as a disability** at all ages, with the right to remain in the NDIS where appropriate
- **Flexible transition policies** that prioritise continuity of care and individual preferences
- **Investment in dementia-specialist services within aged care**, ensuring these environments are suitable for younger people

This theme demonstrates how arbitrary system divisions produce real-world inequities. In the context of young onset dementia, age—not need—continues to determine access to care, autonomy and quality of life.

Theme 10: Restrictive Practices and Risk Aversion

Reforms to restrictive practices—particularly the use of chemical restraint—in aged care and disability settings were designed to protect human rights and reduce the inappropriate use of sedation. However, for people with young onset dementia, these policies have sometimes produced unintended harms, especially when interpreted narrowly or applied without flexibility.

Service providers in the roundtable described situations where residents were experiencing significant behavioural and emotional distress—yet staff were prevented from intervening with clinically indicated medications because of regulatory and guardianship barriers. In these cases, the emphasis on avoiding restraint could result in prolonged suffering and a failure to provide compassionate care.

One provider described residents who were clearly in distress but unable to receive timely support:

"They were terrified of their environment, hiding under their bed, unable to eat and drink because of their high levels of anxiety… To leave a resident in a highly stressed, anxious, unsupported state is not just cruel, it's inhumane." (service provider)

Participants acknowledged that oversight is necessary and that medication can be misused. However, they also emphasised that when used appropriately, medication can dramatically improve quality of life.

"There are individuals that their quality of life is so much better… It is a significant issue… Sometimes GPs can be a bit lazy and just go, 'Oh, here you go, have that for agitation,' and that triggers restraint as opposed to the real reason for giving [the medication]." (service provider)

Frustration was particularly acute when substitute decision-makers—such as public guardians—refused to approve medications even in situations where the care team and family supported their use.

"In previous decisions where… it is beneficial that they have a restrictive chemical restraint… [the public guardian] will not approve that practice." (service provider)

These scenarios create an ethical dilemma for providers, who are caught between legal compliance and their duty of care. Participants described the moral injury associated with witnessing ongoing distress without having the authority to intervene.

Participants recommended:

- **Case-by-case decision-making** grounded in clinical ethics and knowledge of the individual's history and preferences
- **Clearer clinical protocols** that enable experienced health professionals to act promptly and ethically, in acute situations, with appropriate safeguards
- Timely, informed, and responsive guardianship decisions where consent is required
- Policy reform that balances human rights protections with quality of life, comfort and symptom relief

This theme illustrates one of the core tensions in modern dementia care: the need to protect individuals from harm without stripping away the supports that can reduce suffering. For some, dignity means avoiding medication—but for others, it means receiving appropriate medication promptly, respectfully and without bureaucratic delay.

Theme 11: Carer Responsibilities and Lack of Coordinated Support

Carers play an essential but often unsupported and under-recognised role in the lives of people with young onset dementia. Across both interviews and the roundtable, participants described the emotional, physical and administrative responsibilities of caring for someone with a progressive neurocognitive condition. This caring role is intensified by the lack of coordinated support and the assumption that families will navigate complex systems—health, disability, legal, financial—on their own.

One carer reflected on the early period after diagnosis:

"If you've got younger onset dementia, you're told you've got a diagnosis and 'run away and get your things in order.' Somebody needs to help them get through that sort of stuff… You actually need a coordinator who's got a finger on the pulse for what young onset dementia needs are." (carer)

Carers frequently described acting as the system navigator, legal advocate, emotional support, crisis responder, and informal care coordinator—all while managing jobs, parenting responsibilities or their own health. Even families with resources and knowledge of the health system found the processes reactive and fragmented.

Service providers also highlighted the scale of misinformation and lack of guidance carers face.

"Improving access to legal services and advice would probably have the greatest amount of change in the shortest period of time. … Most of those referrals, I'm on the phone with them—sometimes over an hour—just clearing the misinformation and the misguidance that people have been given." (service provider)

Others noted the challenge of communicating the level of support required, particularly when assessments focused narrowly on mobility or physical abilities. One carer explained that the system often failed to grasp the reality of 24-hour supervision and behavioural risk, not just physical assistance.

The emotional aspects was equally profound. Carers described living in a constant state of alert—always monitoring, redirecting, explaining. There were moments of grief, guilt, and emotional exhaustion, especially when care needs escalated rapidly or when carers had no option but to advocate repeatedly just to be heard.

Service providers acknowledged these concerns and were candid about the system's reliance on informal, unpaid care.

"The system is built on the assumption that carers will just pick it up and keep going. Without them, it would fall apart." (service provider)

Participants called for a reimagining of carer support—not as an optional add-on, but as a core element of good dementia care. Recommendations included:

- Dedicated case coordination for families from the point of diagnosis
- Funding for specialist dementia navigators or "care quarterbacks"
- Flexible respite models tailored to working-age carers and complex family dynamics
- Emotional and peer support programs specifically designed for spousal and parental carers
- Formal recognition of carers as expert partners in care planning and decision-making

This theme makes clear that systems built without carers in mind will inevitably fail. If carers are expected to carry the weight of responsibilities, they must be equipped, supported, and recognised for the role they play.