



Dementia Capability for the Legal Profession



Why is dementia capability relevant to the legal profession?

The Australian population is ageing¹ and more people are living longer with chronic diseases, including conditions that affect their cognitive abilities. Dementia is of particular concern as a major cause of disability. Over 420,000 people in Australia have a dementia diagnosis, including nearly 30,000 people under the age of 65 with younger onset dementia. The prevalence of dementia is expected to triple by 2050. Most people with a diagnosis – around 70 percent – live at home.² In addition to the number of people living with a diagnosis, around 1.6 million people in Australia are carers of someone living with dementia.

A diagnosis of dementia is a common prompt for people to seek legal advice to organise their affairs and put plans in place for future financial, health and lifestyle decisions.³ The diagnosis alone does not preclude people from participating in legal processes or accessing their rights. Australian clinical practice guidelines for the care of people with dementia recognise the importance of legal advice following a diagnosis, especially for advance planning purposes.⁴ National guidelines for Memory and Cognition Clinics recommend that clinics refer clients to a range of services with 'dementia expertise', including legal services.⁵

Developing **dementia capability** is important for the legal profession.⁶ This term describes a practitioner whose knowledge, skills, attitudes and behaviours enable them to work effectively with people living with dementia, and those who support them, as well as other clients seeking to plan ahead for their future.

The importance of legal planning

Dementia capability in the legal profession has relevance to a range of clients, not just people who have a dementia diagnosis. Developing and applying the attributes of dementia capability can improve access, inclusion and person-centred services for all clients?

All adults have legal rights to plan ahead for future incapacity and the end of life. Many Australians make wills and appoint decision-makers, such as an enduring financial power of attorney. Advance care planning includes appointing a legally authorised decision-maker to be involved in future medical treatment decisions. Effective legal planning may help to prevent financial exploitation, unwanted medical care and estate disputes and reduce stress and conflicts around substitute decision-making.⁸

Dementia is a major cause of disability, particularly among older people. It is the leading cause of death for women in Australia, and the second leading cause of death for men.⁹ This means that, for many people, legal planning for future illness, loss of capacity and the end of life means planning for the risk of dementia.





The concept of dementia capability is a lens to focus attention on the importance of legal planning for all adults. Legal practitioners can encourage earlier engagement with advance planning for their clients. Doing so will ensure clients have plans in place that safeguard their preferences and interests and help to prevent problems in the event of developing dementia or another condition that affects their capacity.

LEGAL PRACTITIONER "We need to get a grip on our ageing population and the increasing numbers of clients with dementia. We just need to have a much broader, a much more detailed understanding of how to support clients with dementia."

PERSON LIVING WITH DEMENTIA "Having an educated legal group could make a big difference to a lot of people."

LEGAL PRACTITIONER

"There's been an increase [in clients with a dementia diagnosis] ... people come to us because their doctor has recommended it ...
So that's really good, but of course, it would be far better if they came before they had a diagnosis."

A note on the development and intention of this document

This document is to be understood in the context of a legal practitioner's ethical and professional responsibilities. It does **not** replace existing guidelines for the legal profession, such as practice guides on client capacity or elder abuse. Rather, the intent is to complement existing resources.

In particular, this document complements the <u>National Dementia Action Plan</u>. This Plan is a joint federal, state and territorial initiative that sets out priority areas to improve services, policies and systems for people living with dementia, their carers and families.

One of the objectives of the National Plan is to increase dementia capability in workforces and professions. This document advances that objective by setting out attributes that focus on the legal profession. This document is not a tick box exercise. Rather it encourages reflection on current knowledge, skills, attitudes and behaviours, followed by action to continuously develop and strengthen those attributes.

This statement of attributes was developed as part of a research project led by Nola Ries and Karen Donner, Faculty of Law, University of Technology Sydney. Legal practitioners from across Australia, people living with dementia and support persons of someone with dementia took part in this project. Participants shared their views and experiences in a process that led to the development of this statement of the attributes of a dementia capable legal practitioner. Illustrative quotations from participants are highlighted throughout this document.

For more information about the project, contact Professor Nola Ries, <u>nola.ries@uts.edu.au</u>.





Relevant terms

Dementia capability

This term describes a practitioner whose knowledge, skills, attitudes and behaviours enable them to work effectively with people living with dementia, those who support them, as well as other clients seeking to plan ahead for their future.

Dementia inclusive

This term is used in the National Dementia Action Plan to describe a 'society where people living with dementia and their carers can fully participate, feel safe and empowered to live independently with respect and dignity, free from stigma and discrimination.'10

Dementia positive

This term describes 'positivity towards dementia with an intentional emphasis on strength finding, manifesting through attitudes, beliefs, communication, and behaviors.' Being dementia positive can be demonstrated in practice in various ways. For example:

- Using respectful language when communicating with and about people living with dementia.
- Applying strategies that enable clients to express their wishes and make decisions about what is important to them.
- Encouraging legal planning in an empowering way that gives people control over what matters to them, rather than giving control away to others.

Dementia friendly

This term describes communities and places 'where people living with dementia are supported to live a high quality of life with meaning, purpose and value.¹² For example, the Dementia Friendly Community Program is an initiative of Dementia Australia funded by the Commonwealth Government.¹³ It supports local dementia alliances and helps organisations and businesses be more inclusive of people with dementia. Dementia capable professions play an essential role in dementia friendly communities.¹⁴

ATTRIBUTES

This document sets out attributes in relation to:

- knowledge;
- · legal rights and risks for the client;
- · capacity;
- · communication; and
- · advocacy.

The term 'attributes' refers to a person's characteristics, qualities or features in their professional role. These attributes should be understood within the professional boundaries of a legal practitioner; they do not imply medical knowledge or acting outside a lawyer's professional role.





KNOWLEDGE

PERSON LIVING WITH DEMENTIA "There's a stereotype that people think ... you're going to be really vague, and very old, and maybe not be able to communicate. So, there needs to be an understanding that dementia is more than that."

SUPPORT

"The person's abilities will change and [dementia] is a progressive disease ... [but they] will still have lots of other skills and strengths."

LEGAL PRACTITIONER

"I think it's useful, certainly, to know information about dementia. ... I think sometimes the trouble, too, is that we can be misled by labels. And rather than deal with the issue in front of us and the actual person, we can think, well, all right, that person's got Alzheimer's therefore they're not capable of doing this, that or the other. Whereas, of course, it may well be that they are [capable]... because the symptoms don't affect them in the way that it may affect somebody else."

Improving knowledge about dementia across professions – and society generally – is essential to reducing stigma and improving access to services and quality of life for people living with dementia and those who support them. There are many misconceptions about dementia that lead to an emphasis on deficits rather than strengths.



- Knows current information about dementia relevant to legal practice, including being aware that:
 - a. Dementia is a broad term that encompasses a number of progressive conditions that affect brain functioning.¹⁵
 - b. Dementia involves a range of signs and symptoms that may involve changes in cognitive abilities, behaviour, communication and personality. Dementia is not only or always about memory loss.
 - c. Cognitive and other changes will vary for each individual; a person-centred approach is required to identify and meet each client's unique needs and abilities, which will vary depending on their diagnosis and symptoms.





LEGAL RIGHTS AND RISKS FOR THE CLIENT

PERSON LIVING WITH DEMENTIA "From the minute a person is diagnosed, a pathway [to legal advice is needed]. There is a big gap here, because we need the legal side to come in, in a big way for people with dementia. And it covers every aspect from the day we are diagnosed ... the legal side is the priority."

LEGAL PRACTITIONER

"We're thrown into the deep end where everything's just about to blow up [for a person with dementia and their family], and everything's become urgent. My view is that if we had more skilled practitioners in the area, it wouldn't get to that point. We don't need to be dealing with a crisis all the time. We could actually ensure that these clients have the ability to put documents in place" to plan for the future.

SUPPORT

"It's really important that the person who is the substitute decision maker, or who has been given the power of attorney, that they understand what their role actually is. That it's not to decide for themselves, that they're actually standing in the shoes of the other person, and ... that's the line between acting for them, and abusing them."

Providing comprehensive advance planning advice is a key aspect of being a dementia capable legal practitioner. Taking steps to prevent, identify and respond to situations of abuse and exploitation is also important when working with clients with dementia, especially those experiencing multiple sources of vulnerability.



- Provides comprehensive and accessible advice on advance planning to enable clients to maintain the maximum possible level of independence, choice and control in their lives, which may include:
 - planning for estate matters, such as making a will and an enduring power of attorney;
 - b. planning for future health-related decisions, such as:
 - i. appointing a healthcare decision-maker;
 - ii. informing clients of the right to make an advance care directive, and encouraging clients to seek medical guidance on making an advance care directive, as necessary;
 - c. planning for future accommodation needs, such as contractual agreements for family or residential care arrangements;
 - d. planning for other decisions with legal implications, such as driving cessation (eg, explaining the law relevant to driver licensing for people with medical conditions);
 - e. planning to take part in medical research, such as making an advance research directive, signing up to a dementia research registry, and/or body donation for medical science after death.





- Uses preventive strategies to reduce a client's risk of exploitation and abuse, for example:
 - advising on the prudent selection of support persons (informal and formal) and enduring representatives;
 - b. careful drafting of legal documents, including instruments to appoint representatives for the client;
 - c. providing information on the legal role of appointed representatives, including responsibilities and limits on their authority.
- 3. Knows how to identify potential situations of exploitation or abuse and is able to respond appropriately to such situations, with awareness of the different types of abuse, including:16
 - a. emotional, psychological or social abuse;
 - b. financial abuse;
 - c. physical abuse;
 - d. sexual abuse;
 - e. neglect;
 - f. coercive control.¹⁷
- 4. Recognises the needs of diverse persons with dementia, or at risk of dementia, and is able to provide relevant legal assistance or referrals, including for:
 - people with younger onset dementia (under age 65), who may have legal issues concerning employment, family relationships and National Disability Insurance Scheme (NDIS) supports;
 - b. people from culturally and linguistically diverse backgrounds;
 - c. Aboriginal and Torres Strait Islander people, who have rates of dementia three to five times higher than non-Indigenous Australians;
 - d. LGBTIQ+ people;
 - e. people living in residential aged care facilities;
 - f. people who do not have trusted family members or friends available to take on decision-making roles;
 - g. people living in rural and remote areas;
 - h. people with other vulnerabilities (eg, people with co-existing disabilities; people without secure housing).
- 5. Is aware of and has professional networks and referral pathways to relevant services and programs. These may include networks and pathways to:
 - a. suitable health professionals to seek formal assessments of capacity, when necessary;
 - b. professionals who may assist in working effectively with a client with dementia (eg, speech pathologist input for a client with communication difficulties) or provide guidance on matters that may assist their legal planning (eg, a financial planner);
 - agencies or organisations to whom a client may be referred to address specific issues, such as disclosures of elder abuse or complaints about quality of aged or disability care services.





CAPACITY

PERSON LIVING WITH DEMENTIA

"[My solicitor] has been very empathetic and understanding and helpful ... one of the things was checking on capacity. He said to me early on that he needed to do that, but he was very respectful."

LEGAL PRACTITIONER

"We [the legal profession] have such significant challenges with people understanding capacity. They don't know the dementia-specific needs... [They think] this person's got dementia and they don't have capacity."

LEGAL PRACTITIONER

"[O]ur obligation is to see them [clients] on their own, and be willing to listen to them and take instructions, and not rush them. And then at the end of the day, make an assessment [of capacity] ourselves, and understand that we are qualified to make that assessment."

SUPPORT

"Ensure the person [with dementia] feels comfortable. ... you've got to build rapport with them. You've got to remind them about confidentiality. You have to really encourage [the person], because there's a massive tendency for people with dementia to sit back and let other people do the talking - and do the deciding. And you really have to actively encourage people to participate in the process and in the decision-making."

Dementia affects each person in a different way. A diagnosis of dementia should not, on its own, give rise to an assumption of incapacity. However, being able to deal appropriately with capacity issues is a key attribute of a dementia capable legal practitioner.



- 1. Understands principles of decision-making capacity, for example:
 - a. Capacity is decision-specific.
 - b. Capacity may fluctuate over time.
 - c. Capacity may be influenced by a range of factors, such as acute illness, changes in medication and environmental conditions, such as time of day, noise and other distractions.
 - d. Capacity can be enhanced with appropriate supports.
- 2. Identifies when client capacity may be in question and carries out appropriate steps to assess client capacity, which may include seeking an assessment from a suitable health professional.
- 3. Applies strategies that enhance capacity and support decision-making for people with dementia. Strategies may include:
 - a. Effective meeting set-up (eg, attentive to the client's preferred time of day, sending an agenda and other relevant material ahead of time to help the client be prepared);
 - b. Appropriate physical environment (eg, good lighting, uncluttered to avoid visual distraction, quiet and away from background noise);
 - c. Effective communication strategies during the meeting (eg, speaking in a conversational manner, addressing one topic at a time, using plain language to explain legal concepts or terms);
 - d. Giving the client time to consider options and make decisions;
 - e. Appropriate involvement of the client's support person, in line with the practitioner's ethical obligations.
- 4. Recognises and responds appropriately when they cannot act for a person due to a lack of capacity to give instructions.





COMMUNICATION

PERSON LIVING WITH DEMENTIA

"The emphasis should be on the communication. [The lawyer] taking time to actually make sure that they're understood, and they don't get carried away with too much, for want of a better word, technical language."

PERSON LIVING WITH DEMENTIA "You can have people [lawyers] who have plenty of knowledge, but if you haven't got the empathy which you need, then the knowledge is pretty dry."

PERSON LIVING WITH DEMENTIA "If he [solicitor] took it slow for me and explained the benefits of each thing [legal document], no, I wouldn't have a problem. But if he rushed me into signing something ... I would just say ... I need to find somebody that will actually listen to me."

LEGAL PRACTITIONER

"When I start the interview, I talk to people about what form of communication they like. Some people prefer written. Some people, I find, don't return your phone calls, and that's because they're not good on the phone. So I think it's really important to understand different communication styles, and then how dementia affects that. ... And also, to get feedback during the interview: 'Anything else you want to say? How are you going? Do you need a break?'"

Communication is central to the lawyer-client relationship and is of heightened importance for a dementia capable practitioner. People living with dementia commonly experience changes in communication, which may include changes in reading and writing skills and difficulties in finding words. Effective and respectful communication is vital when working with a client with dementia, especially to support self-expression, capacity and freedom to make choices.



- 1. Communicates effectively with clients, including:
 - a. Seeks and is guided by the client's preferences for effective communication;
 - Explains information in plain language and checks for understanding (eg, by asking open ended questions);
 - c. Listens to and treats clients with empathy;
 - d. Elicits the client's will and preferences;
 - e. Focuses on communicating with the client in situations where a support person is involved;
 - f. Maintains a written record of communication, which is shared with the client.
- 2. Uses respectful communication, including:
 - a. Uses inclusive and non-stigmatising language when communicating with or about people with dementia;
 - b. Is guided by resources such as Dementia Australia's Language Guidelines¹⁹ and the person-centred language guide from the Canadian Alzheimer's Society.²⁰





ADVOCACY

LEGAL PRACTITIONER

"That advocacy space, I think that's probably one of our most important functions."

LEGAL PRACTITIONER

"Promoting healthy lifestyles and wellbeing amongst practitioners, if the practitioner can actually identify in some way with the issue [of dementia prevention] and they can relate it to themselves or their future self ... then it's something that's going to get their attention and they're going to be more interested in doing it."

The legal profession has a powerful advocacy role in society, especially in promoting access to justice and reforms to improve the law. Legal and policy frameworks help to create and regulate societal conditions that support physical and mental health and reduce the risk factors for dementia.²¹

The profession maintains high standards of conduct and ethical practice and also attends to the wellbeing of practitioners.



- l. Considers, and when appropriate and possible, acts on opportunities to advocate for changes to laws, legal systems and practices that:
 - a. promote and protect the rights of people living with dementia;
 - b. support prevention and reduce the risk factors for dementia, including strategies that reduce dementia risks for members of the profession (eg, promoting healthy lifestyles and wellbeing among practitioners).





RESOURCES

Dementia Australia is a source of up-to-date information and resources about dementia: https://www.dementia.org.au/

Dementia Australia, How to Talk about Dementia: https://www.dementia.org.au/about-dementia/how-talk-about-dementia

Canadian Alzheimer's Society person-centred language guide: https://alzheimer.ca/sites/default/files/documents/Person-centred-language-guidelines_Alzheimer-Society.pdf

Law Council of Australia, <u>Best Practice Guide for Legal Practitioners on Assessing Mental</u> Capacity (June 2023)

Law Council of Australia, <u>Best Practice Guide for Legal Practitioners in Relation to Elder Financial Abuse</u> (September 2020)

Compass – Guiding Action on Elder Abuse, https://www.compass.info/, including guidance on:

- enduring powers of attorney, https://www.compass.info/featured-topics/powers-of-attorney/
- family agreements, https://www.compass.info/featured-topics/family-agreements/

Forward with Dementia – A guide to living with dementia: https://forwardwithdementia.au/

Courses for further learning

UTS Open, dementia-focused short courses for legal professionals:

- Understanding Dementia: Facts and Foundations
- Planning Ahead: Focus on Advance Care Planning
- Elder Abuse: Strategies for Prevention

University of Tasmania, Wicking Dementia Research and Education Centre offers free online courses:

- · Understanding Dementia
- · Preventing Dementia

Dementia Training Australia – Communication Strategies, https://dta.com.au/online-courses/the-view-from-here-racf/communication-strategies-racf/





ENDNOTES

- 1 Australian Institute of Health and Welfare, 'Older Australians, Demographic Profile', *Australian Institute of Health and Welfare* (2021) https://www.aihw.gov.au/reports/older-people/older-australians/contents/demographic-profile.
- 2 Dementia Australia, 'Dementia Facts and Figures' (February 2024) https://www.dementia.org.au/about-dementia/dementia-facts-and-figures.
- 3 Nola M Ries et al, 'How Do Lawyers Assist Their Clients With Advance Care Planning? Findings From a Cross-Sectional Survey of Lawyers in Alberta' (2018) 55(3) Alberta Law Review 683; Karen A Sullivan et al, 'Public Awareness of Legal Decision– Making Capacity and Planning Instruments in Dementia: Implications for Health Care Practitioners' (2023) 30(4) Psychiatry, Psychology and Law 565.
- 4 Cognitive Decline Partnership Centre, Clinical Practice Guidelines and Principles of Care for People with Dementia (Guideline Adaptation Committee, 2016).
- 5 Australian Dementia Network, 'ADNeT Memory and Cognition Clinic Guidelines: National Service Guidelines for Specialised Dementia and Cognitive Decline Assessment Services in Australia' (2021) 63, 67 https://www.australiandementianetwork.org.au/initiatives/memory-clinics-network/adnet-memory-and-cognition-clinic-guidelines/.
- 6 James H Pietsch, 'Becoming a "Dementia-Capable" Attorney Representing Individuals with Dementia' (2015) 19(13) *Hawaii Bar Review* 1; David Godfrey, 'Developing Dementia-Friendly Communities and Dementia-Capable Professionals' (2015) 36(3) *Bifocal* 79.
- 7 S Rahman & K Swaffer, 'Assets-Based Approaches and Dementia-Friendly Communities' (2018) 17(2) Dementia 131, 132.
- 8 Amy Waller, Rob Sanson-Fisher, Nola Ries & Jamie Bryant, 'Increasing Advance Personal Planning: The Need for Action at the Community Level' (2018) 18 BMC Public Health 606.
- 9 Australian Institute of Health and Welfare, Dementia in Australia (2023) https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary.
- 10 National Dementia Action Plan. See also World Health Organization, Towards a Dementia-Inclusive Society WHO toolkit for dementia-friendly initiatives (Geneva: World Health Organization, 2021) https://www.who.int/publications/i/item/9789240031531.
- 11 S Lin & F Lewis, 'Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future' (2015) 55(2) Gerontologist 237.
- 12 See https://www.dementia.org.au/dementia-friendly-communities
- 13 See https://www.dementiafriendly.org.au/about-us
- 14 C Hebert & K Scales, 'Dementia Friendly Initiatives: A State of the Science Review' (2019) 18(5) *Dementia* 1858, 1859. See also S Lin & F Lewis, 'Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future' (2015) 55(2) *Gerontologist* 237.
- 15 Over 100 diseases may cause dementia. Alzheimer's disease is the most common dementia diagnosis. Other diagnoses include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.
- 16 For definitions and examples, see https://www.compass.info/elder-abuse/understanding/defining-elder-abuse#section-abuse-types-explained.
- 17 For more information, see https://www.compass.info/featured-topics/coercive-control/understanding-coercive-control-as-elder-abuse/#section-what-is-coercive-control. Coercive control 'describes patterns of behaviour where a person seeks to control and manipulate the life of another person.'
- 18 See https://www.dementia.org.au/about-dementia.
- 19 See https://www.dementia.org.au/about-dementia/how-talk-about-dementia.
- $20 \; See \; \underline{https://alzheimer.ca/sites/default/files/documents/Person-centred-language-guidelines_\underline{Alzheimer-Society.pdf.} \\$
- 21 Dementia risk factors relate to diet, exercise, sleep, smoking, alcohol use, heart health, high blood pressure, diabetes, social interaction, cognitive stimulation, depression, hearing impairment, head injury and exposure to air pollution. See https://www.dementia.org.au/brain-health/reducing-your-risk-dementia.





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