

Dementia Clinical Practice Guidelines and Principles of Care Review

Dementia Australia Policy Position Summary (full submission begins page 2)

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What needs to change?

- The revised Guidelines include many positive improvements, with new questions addressing issues such as diagnostic developments and driving, and include a strong focus on health equity, accessibility, and the involvement of people with living experience
- Greater emphasis is needed on risk reduction, person-centred decision-making, rehabilitation, palliative care, pain management, equitable access to specialist services, and accessible companion resources.
- The shift in terminology between the 2016 and 2026 Guidelines (for example, from "evidence-based recommendations" to "conditional recommendations") may create confusion for clinicians, people living with dementia and carers.
- Key terms such as "routinely" are used throughout the draft Guidelines but are not clearly defined, which may lead to inconsistent interpretation and implementation.

What is Dementia Australia recommending?

- A clear explanation of how the 2016 and 2026 Guidelines should be interpreted together, including a crosswalk between recommendations.
- Clearly defined conditional recommendations and key terms such as "routinely", with practical guidance and examples to support shared decision-making.
- Strengthen guidance on risk reduction by recognising the broader benefits of multidomain interventions, including improved cognition, brain health, and reduced exposure to modifiable dementia risk factors.

- Ensure guidance on disease-modifying therapies supports informed, person-centred discussions and does not unintentionally restrict access to treatment options for eligible people.
- Promote individualised approaches to driving assessments, rehabilitation, changed behaviours, deprescribing, pain management, and end-of-life care.
- Expand guidance on palliative care, advance care planning, workforce capability, culturally safe care, and equitable access to specialist services.

If actioned, what impact could these recommendations have?

- Improve consistency and confidence in how the Guidelines are interpreted and applied in Australian clinical settings.
- Support clearer, informed, and person-centred decision-making for people living with dementia, carers, and clinicians.
- Reduce the risk of therapeutic nihilism and variation in access to treatment and care.
- Strengthen focus on quality of life, independence, rehabilitation, symptom management, and palliative care throughout the dementia trajectory.
- Improve equity, accessibility and culturally safe care for diverse communities and people living with dementia across metropolitan, regional, rural, and remote Australia.

How has Dementia Australia advocated for this position?

- Through direct contribution to the review process by representation on the Guidelines Steering Committee, Living Experience Advisory Group and stakeholder focus groups.
- Submitted detailed feedback and recommendations on the draft guidelines including companion resources, informed by Dementia Advocates, Dementia Australia subject matter experts and the Supportive Care and Clinical Governance Committee.

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Introduction

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia and their carers across Australia (1). A growing number of Australians are affected by dementia. Dementia prevalence is set to increase to more than a million people across the country by 2065 (2). Dementia is the leading cause of death for all Australians, as well as the leading contributor to disease burden for those aged over 65 (3). An estimated 1.7 million people in Australia are involved in the care of people living with dementia (4). Dementia remains a challenging and often misunderstood condition and Dementia Australia responds to this challenge with trusted information, education and support services, advocacy to government and in the community for positive change, and support for vital research and health workers providing essential care.

Dementia Australia welcomed the opportunity to contribute to the revision of the Dementia Clinical Practice Guidelines and Principles of Care through representation on the Steering Committee, the Living Experience Advisory Group, and stakeholder focus groups, including groups for people identifying as LGBTQIA+ and people living with young onset dementia.

We commend the extensive and inclusive consultation process, particularly the involvement of people with living experience, First Nations peoples, CALD communities, LGBTQIA+ communities, and people living with young onset dementia. We support the strong focus on health equity and accessibility throughout the draft Guidelines.

The development of accessible companion resources for people living with dementia and carers is a welcome innovation. We have provided specific feedback on the draft companion resources later in this submission.

We also welcome the inclusion of a Practical Information section to support accessibility and understanding, although we note inconsistent use of the terms “Practical Information” and “Practical Info” throughout the document. In addition, Dementia Australia recommends the consistent use of the term “*young onset dementia*”, reflecting current international practice.

This submission draws on feedback from Dementia Australia Dementia Advocates, subject matter experts and the Supportive Care and Clinical Governance Committee. It begins with general observations on the draft Guidelines before outlining specific recommendations.

Recommendations

1. Interpreting Recommendations across the 2016 and 2026 Guidelines

Dementia Australia is cognisant of the extensive research and consultation undertaken in the development process of the draft Guidelines and equally, we understand that recommendations for or against for each question were carefully considered in the light of the evidence base. We note the shift in language from the 2016 Guidelines to the current draft. The 2016 Recommendations are classed as ‘evidence-based recommendations’, ‘consensus-based recommendations’ or ‘practice points compared with the draft Guidelines’ ‘conditional recommendations’ and ‘good practice statements’. The language in the original Guidelines arguably gives more certainty and guidance and we are concerned that given two documents will be either combined or consulted together in some form, this shift in language may cause confusion.

Dementia Australia recommends that the final Guidelines include both:

1. a summary of how the evidence recommendations should be interpreted across both guidelines and
2. a clear crosswalk between the 2016 Guidelines and the revised recommendations, including which 2016 recommendations remain current, which have been updated, and which areas were out of scope for this review.

2. Clarity of conditional recommendations and use of the term “routinely”

The conditional recommendations could be read as overly contingent, and the cautious wording could impact on the core remit of the Guidelines to provide clear information and guidance. Feedback from a Supportive Care and Governance Committee member observed that *“Conditional recommendations may create some ambiguity in practice and grey areas for clinicians. While the intent is to appropriately reflect evidence limitations, this may also create variability in implementation and interpretation and confusion.”*

The contingent language also creates a discouraging rather than encouraging tone in a document with the central purpose of supporting clinicians, people living with dementia, and their carers to make informed decisions about treatment and care. There is a risk that such language will contribute to clinical nihilism.

“Routinely” is used consistently throughout the document but is never defined in a clinical context and this compounds the sense of imprecision in relation to the guidance on the questions and recommendations given.

Dementia Australia recommends that the final Guidelines include a clear explanatory statement describing the meaning and intended application of conditional recommendations, including how clinicians, people living with dementia and carers should interpret and use them in practice. This should be accompanied by a clear definition of key terms such as “routinely”, examples of circumstances where a

recommendation may or may not apply, and guidance on how conditional recommendations support shared decision-making rather than preclude particular treatment or care options.

Dementia Australia further recommends that the Guidelines explicitly acknowledge that a conditional recommendation reflects uncertainty or variability in the evidence base rather than a lack of value or appropriateness of an intervention for every individual. This would help minimise unintended variability in interpretation, reduce the risk of therapeutic nihilism, and support more confident, person-centred and evidence-informed decision-making by clinicians, people living with dementia and carers.

3. Guideline Updates

The draft guidelines note that “The NHMRC recommends that Guidelines should be reviewed and updated after five years. Some questions may need to be updated earlier if new evidence becomes available that could change current recommendations.” Has a mechanism such as a ‘living guidelines’ document been considered, enabling real time updates to be incorporated to reflect the changing the evidence base and research findings? If yes, has the funding been secured to maintain the Guidelines and associated resources? Given the rapid pace of development in dementia research, the Guidelines must be maintained in a timely fashion, or they risk being out of date very quickly.

4. Risk reduction

There was limited attention given to risk reduction in the 2016 Guidelines and we support the increased focus in the revised draft. We note the statement in the revised Guidelines that “Interventions addressing fewer than three domains were outside the scope of the evidence review and as such, this Guideline does not make recommendations regarding single-domain or dual-domain interventions.” Given there was some discussion of “evidence supporting individual components of multidomain interventions,” we are interested in the rationale for limiting the scope of this question to three interventions or more.

In relation to Recommendation 2, and the conditional recommendation against multidomain interventions for people who are cognitively healthy or are cognitively healthy and at risk of dementia, the rationale for this appears to be due to the short follow up period of the trials. We strongly support reframing the impact of these interventions as the potential benefit in changing and reducing exposure to modifiable risks. This would have been more helpful than an outcome measure of a diagnosis of dementia.

The focus on incident dementia as the primary outcome may understate important and clinically meaningful benefits associated with multidomain interventions, including improvements in cognition, functional health, cardiovascular risk profiles and other modifiable risk factors that are themselves associated with future dementia risk.

Dementia Australia recommends that the final Guidelines provide greater transparency regarding the rationale for limiting the evidence review to interventions addressing three or more risk domains and explain how evidence relating to individual domains was considered in the development of Recommendation 2.

Dementia Australia further recommends that the discussion accompanying Recommendation 2 more clearly acknowledges the demonstrated benefits of multidomain interventions in improving cognition, supporting brain health and reducing exposure to modifiable dementia risk factors, even where current trial follow-up periods are insufficient to determine effects on incident dementia. While Dementia Australia acknowledges that the available evidence may not yet support conclusions regarding dementia incidence, the current wording risks undervaluing a growing body of evidence demonstrating cognitive and broader health benefits associated with multidomain interventions. International studies, including the Finnish FINGER trial, Australia's Maintain Your Brain (MYB) study and the recent U.S. POINTER trial, have demonstrated improvements in cognitive outcomes and risk-factor modification through multidomain approaches incorporating physical activity, nutrition, cognitive stimulation, and vascular risk management. We note and strongly support the submission on this issue from Professor Henry Brodarty.

Dementia Australia therefore recommends that the Guidelines frame multidomain interventions not solely through the lens of preventing a future dementia diagnosis, but also through their capacity to reduce modifiable risk factors, support cognitive health, delay symptom progression and contribute to healthy ageing.

5. Diagnosis and therapies: disease modifying therapies

As written, the recommendations are against prescribing either donanemab or lecanemab for people diagnosed with mild cognitive impairment or mild dementia due to Alzheimer's disease.

However, the discussion goes on to note that “a conditional recommendation against the intervention does not preclude treatment,” and further, “the decision should be informed by careful discussion of potential benefits and harms, as well as cost and feasibility considerations.” It was also noted that in the case of both medications, “the evidence base is rapidly evolving and will be impacted by emerging research.”

These qualifying observations, in conjunction with the lack of definition of “routinely”, contribute to interpretative obfuscation. If the recommendation against does not preclude treatment as stated in the document, for consumers consulting the Guidelines, this potentially undermines the value and authority of the recommendation. Consumers may reasonably interpret a recommendation against routine prescribing as indicating that a treatment should not be considered. The Guidelines should therefore clearly articulate when and under what circumstances discussion, assessment and treatment may remain appropriate despite a conditional recommendation against routine use.

Furthermore, given the recommendation is against routinely prescribing either medication, there is the potential risk of medical gatekeeping. Eligible patients may not have the opportunity to explore all possible treatment options because of paternalistic approaches to prescribing. Dementia Australia strongly supports the right of every person who is eligible for treatment to be provided with appropriate information and the opportunity to consider that treatment option.

Dementia Australia recommends that the final Guidelines clearly explain the intended meaning of “routinely” in the context of prescribing disease-modifying therapies and provide practical guidance on how Recommendations 7 and 8 should be interpreted and applied in clinical practice.

Dementia Australia further recommends that the accompanying explanatory text explicitly state that a conditional recommendation against routine prescribing does not preclude eligible individuals from being informed about, assessed for, or considered for treatment. The Guidelines should reinforce the importance of shared decision-making, ensuring that people living with mild cognitive impairment or mild dementia due to Alzheimer’s disease have access to balanced information regarding potential benefits, harms, monitoring requirements, eligibility criteria, feasibility considerations and costs.

Given the rapidly evolving evidence base for disease-modifying therapies, Dementia Australia recommends that the Guidelines distinguish clearly between a recommendation against routine use and a recommendation against treatment altogether. This distinction is important to minimise unintended variation in interpretation and to support equitable access to evidence-informed discussions about available treatment options.

Dementia Australia notes and supports the submission from Dementia Trials Australia regarding Recommendations 7 and 8 and encourages the Guideline Development Group to ensure that the final wording promotes informed, person-centred decision-making while accurately reflecting the current evidence base.

6. Driving assessment and the potential impact on diagnosis and help-seeking

The issue of driving was identified in the 2016 Guidelines as an area requiring further research and Dementia Australia supports its inclusion in the revised Guidelines. Driving has important implications for safety, independence, social participation and quality of life and is often one of the most sensitive issues discussed following a dementia diagnosis. As noted by one of the people living with dementia who provided feedback for this submission, *“this is an emotionally and socially sensitive issue for many people.”*

There is a well-documented delay in dementia diagnosis in Australia, with some estimates suggesting an average delay of 3–5 years, and longer delays for some people living with young onset dementia. One factor contributing to delayed diagnosis is concern about the potential consequences of a diagnosis, including impacts on driving and independence. In this context, care should be taken to ensure

that recommendations do not unintentionally create additional barriers to assessment, diagnosis and timely access to treatment, support and care.

We acknowledge that the draft Guidelines appropriately note the importance of contextual factors when assessing fitness to drive and indicate that ongoing monitoring may be appropriate in some circumstances. Dementia Australia supports an individualised approach that takes into account the person's symptoms, functional abilities, stage of disease, driving history, insight, risks and personal circumstances. Not every person diagnosed with dementia will require an immediate practical driving assessment, however all should have a discussion about driving as part of ongoing clinical care.

We strongly support the recommendations under “Having the conversation” and the emphasis on respectful, person-centred discussions about driving. These conversations should support informed decision-making, address potential risks, and assist people living with dementia and their families to plan for future changes where required.

“I don't think that every person who has dementia has to have a driving assessment. It depends on the individual person's dementia and progression when seen by their doctor. It is possible to monitor some people over time and refer others immediately for assessment. Irrespective of the outcome, discussions need to be sensitive to how the person living with dementia is likely to feel. We are individuals, therefore we can't have a blanket statement on this.” — Person living with dementia

Dementia Australia recommends that the final Guidelines clarify that a diagnosis of dementia should trigger consideration of driving safety and fitness to drive, but that decisions regarding referral for practical driving assessment should be guided by an individualised clinical assessment rather than diagnosis alone. The Guidelines should emphasise person-centred discussions, ongoing review where appropriate, and shared decision-making that balances safety, independence, wellbeing and access to timely diagnosis and care.

7. Post diagnostic care

7.1 Physical and cognitive rehabilitation for people living with dementia

There are some general references to the benefits of cognitive and physical rehabilitation in relation to supporting quality of life and wellbeing for the person living with dementia and/or their care partner (for example p.111 and p.123 respectively) but the Guidelines would be improved with a stronger emphasis on the importance of these broader benefits.

Dementia Australia notes and supports the submission from both the ADNET Cognitive Intervention Working Group and from CST Australia.

Dementia Australia recommends expanding the discussion accompanying rehabilitation recommendations to explicitly recognise maintenance of

function, participation, independence and quality of life as clinically meaningful outcomes, as well as measurable functional improvement.

Offering physical and cognitive rehabilitation for people living with dementia is balanced by the equal importance of identifying rehabilitative futility. Our specialist palliative care team suggested that the Guidelines would benefit from clearer guidance on when rehabilitative interventions become clinically disproportionate or futile in the context of a progressive, terminal neurodegenerative condition. Clinicians require clear criteria or indicators to support decision-making around when rehabilitation shifts from functional gain to comfort focused care.

7.2 A more expansive focus on palliative care and End-of-Life Care

Dementia Australia supports the inclusion of interventions that facilitate communication about end-of-life care and recognises the importance of supporting conversations between health professionals, people living with dementia, and those involved in their care. However, the current discussion would benefit from greater clarity regarding who is encompassed by the phrase “people directly affected by end-of-life care.” We recommend explicitly recognising that effective end-of-life communication should involve not only the person living with dementia wherever possible, but also family members, carers, substitute decision-makers, and others identified by the person as significant participants in care and decision-making. Such an approach is consistent with person-centred care and acknowledges the central role that families and carers play throughout the dementia trajectory.

Dementia Australia supports the observation that further research is required to identify the most appropriate communication interventions for people living with dementia. However, research alone will not be sufficient to improve practice. The successful implementation of communication interventions will also require targeted education and training for health professionals, ensuring that conversations about advance care planning, goals of care, dying and bereavement are undertaken with confidence, sensitivity and clinical competence.

More broadly, Dementia Australia recommends a stronger focus on palliative care throughout the revised Guidelines. Although palliative care is discussed, the current treatment is not commensurate with the prevalence and complexity of palliative care needs experienced by people living with dementia and their families. Dementia is a progressive, life-limiting neurodegenerative condition, and palliative principles should be integrated throughout the dementia trajectory rather than being confined to the final stages of life. The Guidelines provide an important opportunity to reinforce that palliative care is not solely about the last days or weeks of life but encompasses the ongoing optimisation of quality of life through symptom management, psychosocial support, advance care planning, and support for families and carers.

This broader palliative approach is also relevant to the discussion of rehabilitation. Physical and cognitive rehabilitation can provide important benefits through maintaining function, independence, participation and quality of life. Equally, as dementia progresses, the balance of care may increasingly shift towards symptom management, comfort, dignity and quality of life. Dementia Australia recommends that the Guidelines provide clearer guidance on how clinicians can support transitions in goals of care over time, ensuring that rehabilitative, supportive and palliative approaches are integrated and tailored to individual needs, preferences and clinical circumstances.

Dementia Australia's palliative care specialists further recommend that the Guidelines explicitly recognise that advanced dementia care frequently aligns more closely with palliative principles. This includes prioritising pain and symptom management, addressing complex behavioural and physical symptoms, supporting comfort and dignity, reducing distress, and ensuring that treatment decisions are informed by the person's wishes, values and goals of care. The Guidelines should reinforce that high-quality dementia care includes both rehabilitative and palliative approaches, with the relative emphasis on each changing over time according to individual needs.

Equity of access should also receive greater attention within the palliative care discussion. Many Australians living with dementia, particularly those in rural, regional and remote communities, have limited access to geriatricians, dementia nurse specialists, palliative care clinicians and allied health practitioners with expertise in advanced dementia care. Dementia Australia recommends that the Guidelines acknowledge these disparities and emphasise the importance of equitable access to specialist support for advance care planning, complex symptom management, end-of-life decision-making and family support.

The Guidelines would also be strengthened by recognising the importance of specialist involvement in multidisciplinary case conferences addressing end-of-life planning. Where such case conferences are used to facilitate discussions about goals of care, treatment preferences, symptom management or care transitions, people living with dementia and their families should have access to appropriately qualified clinicians who can support informed, evidence-based decision-making.

Finally, Dementia Australia recommends a stronger emphasis on workforce capability and culturally safe care. The Guidelines should highlight the need for education and training in the assessment and management of complex symptoms commonly experienced in advanced dementia, including pain, agitation, swallowing difficulties, reduced oral intake, delirium and terminal restlessness. Public facing resources should also be expanded to ensure information about palliative and end-of-life care is culturally safe, linguistically appropriate and accessible for Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, LGBTIQ+ communities,

people living with young onset dementia, families impacted by childhood dementia and other priority populations.

Dementia Australia recommends that the final Guidelines incorporate a more comprehensive discussion of palliative care across the dementia trajectory, including stronger guidance on advance care planning, end-of-life communication, transitions in goals of care, symptom management, family support, equitable access to specialist services, workforce capability and culturally safe care.

7.3 Non-Pharmacological Approaches, Deprescribing and Pain Management

Dementia Australia supports the emphasis on non-pharmacological approaches as the foundation of care for people experiencing distress, changed behaviours and behavioural symptoms associated with dementia. Language and terminology in this area are both clinically and personally significant, and people with living experience of dementia express a range of preferences regarding how their experiences are described. While recognising that this remains a contested and evolving area of practice, Dementia Australia recommends that the Guidelines promote the use of the term changed behaviour wherever possible, as it is generally regarded as more person-centred and less stigmatising than alternative terminology.

In a clinical guideline, references to the “management” of changed behaviour and the use of “interventions” are understandable. However, Dementia Australia recommends a less biomedical framing of these experiences. Changed behaviours are often expressions of unmet physical, emotional, environmental or psychosocial needs, and care should focus on understanding, responding to and supporting the person rather than managing the behaviour itself. Similarly, many non-pharmacological responses are not medical treatments but supportive approaches that help meet individual needs, preserve wellbeing and enhance quality of life. Consistent use of terms such as “approaches”, “strategies” and “supports” may better reflect the intent of contemporary person-centred dementia care.

The Guidelines would also be strengthened by more clearly reflecting the hierarchy of clinical responses to changed behaviour. Under the current structure, restrictive practices are discussed before non-pharmacological approaches, despite restrictive practices being recognised as measures of last resort. Dementia Australia recommends that the discussion be reordered so that comprehensive assessment, understanding potential causes of distress, and implementation of individualised non-pharmacological approaches are presented first. Restrictive practices should then be discussed separately and clearly identified as options that should only be considered when other approaches have been exhausted and where required to prevent harm, consistent with legislative and regulatory requirements. The

structure of the Guidelines should reinforce the principle that personalised non-pharmacological approaches are the first-line response to distress and changed behaviour.

Dementia Australia also supports the conditional recommendation regarding deprescribing of cholinesterase inhibitors and memantine when aligned with the person's clinical circumstances, preferences and goals of care. However, successful implementation of this recommendation requires recognition of the practical challenges faced by clinicians and people living with dementia. In particular, many people living in residential aged care, rural and regional communities, and remote locations have limited access to neurologists, geriatricians and other specialist prescribers. Dementia Australia recommends that the Guidelines acknowledge these inequities and encourage alternative models of specialist support, including telehealth, outreach services and shared-care arrangements where appropriate.

In addition, there is considerable variability in clinician confidence and expertise regarding the monitoring of withdrawal effects following deprescribing. Clinical deterioration, symptom recurrence and changes in function may not always be recognised promptly. Dementia Australia recommends that the Guidelines place greater emphasis on monitoring requirements following deprescribing and identify the competencies, education and clinical support required to undertake deprescribing decisions safely and effectively.

Dementia Australia broadly supports the recommendation against the routine prescribing of opioids for chronic non-cancer pain in people living with dementia and the safeguards outlined in the accompanying discussion. As noted elsewhere in this submission, the interpretation of recommendations against routine prescribing would be strengthened by a clear definition of the term “routinely” and guidance regarding circumstances in which prescribing may remain clinically appropriate.

The management of pain in people living with dementia warrants particular attention. Pain is frequently under-recognised and may be expressed through behavioural, functional or psychological changes rather than verbal reporting. Dementia Australia recommends that the Guidelines place greater emphasis on comprehensive, multidimensional pain assessment and encourage the use of validated pain assessment tools designed for people with cognitive impairment. Assessment should consider the broad range of factors that may contribute to pain, discomfort and distress, including comorbid conditions, physical frailty and disease progression.

Finally, the Guidelines should recognise the importance of ongoing review and monitoring of both opioid and non-opioid pain management plans. People living with dementia in community settings frequently lack consistent clinical oversight, increasing the risk of ineffective treatment, adverse effects and

delayed adjustments to care. Dementia Australia recommends that the Guidelines promote structured follow-up, regular review and multidisciplinary involvement in pain assessment and management to support safe, effective and person-centred care.

Dementia Australia recommends that the final Guidelines adopt more person-centred terminology when discussing changed behaviour, reinforce non-pharmacological approaches as the first-line response to distress, strengthen guidance regarding equitable and safe deprescribing practices, and provide more comprehensive direction on pain assessment, monitoring and management for people living with dementia.

8. Feedback on Companion Resources

There is an appropriate balance of concise, text-based content and visual representations in the design of the Cognitive and Physical Rehabilitation companion resources. The colour palette could be reconsidered in terms of enhancing the accessibility for all the proposed companion resources. Using black text on a cream or soft yellow rather than a completely white background is helpful.

While there is variability in colour perception, blue, green, and purple can be difficult to distinguish for some people living with dementia and these colours predominate in both resources. Brighter colours like yellow, pink, and orange could contribute to increased legibility.

Both draft companion resources lack an emphasis on working with the person with dementia in planning and undertaking rehabilitation activities. The draft Guidelines correctly note the importance of shared or supported decision-making in identifying goals and planning activities, so it is important that this collaborative approach is reflected in resources aimed at people living with dementia and carers. This could be included under the heading of “What the Guidelines say” or in one of the bullet points under “What does recommendation mean?”.

Some people living with dementia have told us they dislike the use of “help’ in relation to rehabilitation and reablement and prefer “support”. They suggest that the former implies dependence whereas the latter suggests the person with dementia is actively engaged in the planning and undertaking of the activity.

8.1 Cognitive Rehabilitation companion resource

We note the disclaimer that these are general recommendations, but many people do not have a clear understanding of what cognitive rehabilitation entails. “Goal setting and problem-solving” is a broad descriptor, so including one or two examples of cognitive rehabilitation would be helpful i.e. cooking a meal or learning how to use new device.

This resource exclusively features representations of older people, and we suggest using a mix of older and younger people in all companion resources where possible to indicate that dementia can occur across the life span.

On a minor note, under “What do the Guidelines say”, the sentence is missing “their” and would benefit from the addition of “to them” as in bold below.

Consider offering cognitive rehabilitation to people living with mild to moderate dementia to optimise **their** ability to engage in and carry out the activities that are meaningful and important **to them**.

In addition to providing accessible, companion resources for people living with dementia and those supporting them, we would also support the Guidelines linking to other resources providing information about dementia and consumer facing resources detailing best practice principles of care. This could include for example, Dementia Australia’s pages on **About Dementia**, **Younger onset dementia** and **What next? After your diagnosis**.

Conclusion

Dementia Australia strongly supports the clear necessity to revise the 2016 Dementia Clinical Practice Guidelines and Principles of Care and recognises the extensive research and consultation that has been undertaken in drafting the revised Guidelines. We look forward to more information on how the 2016 and revised Guidelines will be implemented. Given the detailed nature of both documents, the way in which the respective documents will be accessed individually or in combination will be an important consideration for potential consumers.

Dementia Australia would welcome the opportunity to discuss any of the issues raised above in more detail and to engage with the ongoing development of the companion resources.

The Policy and Advocacy team can be contacted at:
policyteam@dementia.org.au

References

1. Dementia Australia, *Commissioned AIHW Dementia Prevalence Data 2024-2054*. 2023, Dementia Australia.
2. Australian Institute of Health and Welfare (2025) Dementia in Australia, AIHW, Australian Government, accessed 15 January 2026.
3. Australian Bureau of Statistics (2025) Causes of Death, 2024, ABS, Australian Government, accessed 15 January 2026
4. Based on Dementia Australia’s analysis of the following publications - National Dementia Action Plan; Australian Institute of Health and Welfare (2024) 2023 Aged Care Provider Workforce Survey: Summary report, AIHW, Australian Government.

5. Australian Institute of Health and Welfare. Reduction of the average time taken for people to receive a diagnosis of dementia from the first onset of symptoms. <https://www.aihw.gov.au/reports/dementia/ndap-indicators-dashboard/contents/action-4/measure-4-5-time-from-symptom-onset-to-diagnosis>
6. Ambikairajah A, Foxe D, de Lange A-M, et al. A Bayesian analysis of diagnostic timelines across Alzheimer's disease, frontotemporal dementia, and other neurodegenerative conditions. *Alzheimer's Dement.* 2025;17: e70184. <https://doi.org/10.1002/dad2.70184>
7. Power MC, Willens V, Prather C, Moghtaderi A, Chen Y, Gianattasio KZ, Grodstein F, Shah RC, James BD. 'Risks and Benefits of Clinical Diagnosis Around the Time of Dementia Onset.' *Gerontol Geriatr Med.* 2023 Nov 22; 9:23337214231213185. doi: 10.1177/23337214231213185. PMID: 38026091; PMCID: PMC10666707.