



COGNITIVE  
DECLINE  
PARTNERSHIP  
CENTRE

# **CLINICAL PRACTICE GUIDELINES FOR DEMENTIA IN AUSTRALIA**

**Administrative Report**

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## **Guideline Development**

The development, publication and dissemination of this Guideline was funded by the NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People. The Partnership Centre receives support from the NHMRC and Funding Partners, including HammondCare, Alzheimer's Australia, Brightwater Care Group and Helping Hand Aged Care.

## **Guideline Adaptation Committee Membership**

Efforts were made to invite individuals who (1) had relevant practical experience in the management of dementia in Australia, (2) were highly respected in their fields, (3) were skilled in the appraisal of scientific evidence, (4) represented the various geographical areas across Australia, and (5) were able to make the necessary time commitment. In addition, the organising committee approached the Australian Association of Social Workers for representation. Carer representatives were sought via the Consumer Dementia Research Network (within Alzheimer's Australia), which contributes to the work of the NHMRC Partnership Centre.

In addition to carer representation on the guideline committee, three additional people provided comments on drafts of the guideline from the perspective of the consumer (two people living with a diagnosis of dementia and a carer).

The Guideline Adaptation Committee was supported by an organising committee. The organising committee was responsible for determining the scope of the guidelines, appointing a Chair and members of the Guideline Adaptation Committee and developing terms of reference for the committee.

The role of the Guideline Adaptation Committee was to

- assist in refining the scope of the Guideline
- comment on the process of selection of Clinical Practice Guidelines to be adapted and clinical questions to be addressed within the new Guideline
- consider new evidence from updated literature searches
- review the evidence and develop recommendations
- refine and review the draft Guideline before public consultation
- review public consultation comments and consider revising the Guideline as necessary
- approve a final draft of the Guideline to be submitted to the NHMRC for consideration of approval.

GUIDELINE ADAPTATION COMMITTEE	
<b>Prof Robert Cumming</b>	Chairperson of the Guideline Adaptation Committee Professor of Epidemiology University of Sydney
<b>A/Prof Meera Agar</b>	Palliative Care Director of Palliative Care, Braeside Hospital Conjoint Associate Professor University of New South Wales
<b>Prof Kaarin Anstey</b>	Psychology Director, Centre for Research on Ageing, Health and Wellbeing Director, Dementia Collaborative Research Centre – Early Diagnosis and Prevention The Australian National University
<b>Prof Elizabeth Beattie</b>	Anthropology and Sociology Director, Dementia Collaborative Research Centre: Carers and Consumers Queensland University of Technology
<b>Prof Henry Brodaty</b>	Psychogeriatrics Director, Dementia Collaborative Research Centres (Assessment and Better Care) Scientia Professor of Ageing and Mental Health, University of New South Wales Consultant Psychogeriatrician, Aged Care Psychiatry and Head of the Memory Disorders Clinic, Prince of Wales Hospital
<b>Prof Tony Broe</b>	Geriatric Medicine Senior Principal Research Fellow, NeuRA Professor of Geriatric Medicine, University of New South Wales Scientific Director, Ageing Research Centre, Prince of Wales Hospital
<b>Prof Lindy Clemson</b>	Occupational Therapy Professor in Ageing and Occupational Therapy University of Sydney
<b>Prof Maria Crotty</b>	Rehabilitation Physician Professor of Rehabilitation Flinders University and Repatriation General Hospital
<b>Margaret Dietz</b>	Social Work Team leader, Monash Aged Persons Mental Health Service Community team
<b>Prof Brian Draper</b>	Psychiatry Director, Academic Department for Old Age Psychiatry Prince of Wales Hospital Professor (Conjoint), School of Psychiatry University of New South Wales
<b>Prof Leon Flicker</b>	Geriatric Medicine Professor of Geriatric Medicine University of Western Australia
<b>Meg Friel</b>	Carer representative Alzheimer's Australia Consumer Dementia Research Network
<b>Louise Heuzenroeder</b>	Carer representative Alzheimer's Australia Consumer Dementia Research Network
<b>A/Prof Susan Koch</b>	Nursing Principal Research Officer, Royal District Nursing Service Research Institute
<b>Prof Sue Kurrle</b>	Geriatric Medicine Curran Professor in Health Care of Older People, University of Sydney Director, NHMRC Cognitive Decline Partnership Centre Senior Staff Specialist Geriatrician, Hornsby Ku-ring-gai Health Service
<b>Prof Rhonda Nay</b>	Nursing Emeritus Professor in Nursing La Trobe University
<b>Prof Dimity Pond</b>	General Practice Professor, Discipline of General Practice University of Newcastle

GUIDELINE ADAPTATION COMMITTEE	
<b>Dr Jane Thompson</b>	Carer representative Alzheimer's Australia Consumer Dementia Research Network
<b>Yvonne Santalucia</b>	Multicultural Aged Officer South Western Sydney Local Health District
<b>A/Prof Craig Whitehead</b>	Chair of Organising Committee Geriatric Medicine Regional Clinical Director of Rehabilitation and Aged Care, Southern Adelaide Health Service
<b>A/Prof Mark Yates</b>	Geriatric Medicine Director of Clinical Studies, Grampians Clinical School Deakin University Ballarat Health Services

SCIENTIFIC	
<b>Dr Kate Laver</b>	Post-doctoral Research Fellow, Systematic Reviewer and Guidelines Coordinator Flinders University *Non-voting member of the Guideline Adaptation Committee
<b>Dr Suzanne Dyer</b>	Researcher and Systematic Reviewer Flinders University *Non-voting member of the Guideline Adaptation Committee
<b>Dr Deborah Chen</b>	Systematic Reviewer Flinders University
<b>A/Prof Tracy Merlin</b>	Methodological consultant University of Adelaide

Guideline Adaptation Committee Members received no reimbursement for their involvement. Travel and accommodation costs were covered to attend meetings.

The Guideline Adaptation Committee included two carer representatives recruited via the Consumer Dementia Research Network (Alzheimer's Australia), one consumer representing people of CALD backgrounds, one carer representative representing carers of people with dementia and one representative of people of Aboriginal and Torres Strait Island background.

The consumers and carer representatives attended all meetings and took part in discussions and voting on recommendations. In addition, evidence summaries were sent to two consumers (people with dementia) and feedback was received from these consumers via Dr Jane Thompson as a member of the Guideline Adaptation Committee.

Consumer and carer representatives on the committee were individually consulted regarding particular sections. Efforts were made to ensure that consumers' views were heard and incorporated into the Guidelines via additional communication (email, in-person and phone conversations). The Chairperson ensured that these representatives were engaged in the face-to-face committee meetings. Consumers who were attending Committee Meetings outside of their paid work were reimbursed for their time. There were no out of pocket costs for the consumer or carer representatives (travel costs to attend the meetings were covered).

## Declaration of conflicts of interest policy

Members of the Guideline Adaptation Committee were required to declare their conflicts of interest in writing, prior to appointment.

All members of the Guideline Adaptation Committee completed the NHMRC Form for Disclosure of Interests (Guideline Development) prior to the first committee meeting. This information was collated and checked for accuracy by Committee members at the first meeting.

The Chairperson considered all potential conflicts of interest. The Chairperson asked committee members to identify any new or changed conflicts of interest at each meeting.

Where a committee member was identified as having a real or perceived conflict of interest, the Chairperson asked the Committee Member to step out of the room during that particular conversation. The person had no subsequent input into the recommendation or presentation of information in the Guideline for an area where there was a conflict therefore three committee members were excluded from discussions on the use of Souvenaid®.

## Disclosures of Interest

GUIDELINE ADAPTATION COMMITTEE	
<b>Prof Robert Cumming</b>	Honorarium payment to run a short course for Eli Lilly on appraisal of andrology journal articles (2013) Funding from NHMRC Author of publication cited by the guidelines
<b>A/Prof Meera Agar</b>	Employed by Hammondcare, a specialist dementia care provider Received research funds for projects exploring end of life care in dementia
<b>Prof Kaarin Anstey</b>	Director, Alzheimer's Australia Dementia Research Foundation Director, Dementia Collaborative Research Centre – Early Diagnosis and Prevention
<b>Prof Elizabeth Beattie</b>	Member of the NHMRC Assigners Academy – payment for Academy duties on non-meeting days. Funded travel and accommodation to attend Assigners Academy meetings Member of the Alzheimer's Australia Dementia Research Foundation Scientific and Medical Panel 2013 (unpaid) Director of the Dementia Collaborative Research Centre: Carers and Consumers, Queensland University of Technology, Brisbane
<b>Prof Henry Brodaty</b>	Board Membership – Nutricia, Merck, Lilly & Baxter Advisory Board Member Consultancy fees from Nutricia, Lilly, Merck & Baxter Advisory Boards Grants from Servier, Lilly, Medivation & Sanofi & Tau Therapeutics Author of publications cited by the guidelines
<b>Prof Tony Broe</b>	None declared
<b>Prof Lindy Clemson</b>	Funding for dementia research Author of publications cited by the guidelines Member of the Alzheimer's Australia Dementia Research Foundation Panel
<b>Prof Maria Crotty</b>	Funding from NHMRC (dementia research) Received support from Eli Lilly to attend a meeting regarding a pharmaceutical trial (trial focussed on sarcopenia)
<b>Margaret Dietz</b>	None declared

GUIDELINE ADAPTATION COMMITTEE	
<b>Prof Brian Draper</b>	Payment for an article on Young Onset Dementia Funding from NHMRC Funding from other sources related to dementia research (Dementia Collaborative Research Centre, New South Wales ADHC, Mason Foundation) Travel & Accommodation paid for by Zhejiang University and Worldwide University Network to attend Dementia Care in China Symposium as Keynote Speaker Author of publications cited by the guidelines
<b>Prof Leon Flicker</b>	Author of publications cited by the guidelines
<b>Meg Friel</b>	None declared
<b>Louise Heuzenroeder</b>	None declared
<b>A/Prof Susan Koch</b>	Funding from NHMRC (Partnership Centre)
<b>Prof Sue Kurrle</b>	Funding from NHMRC (Partnership Centre)
<b>Prof Rhonda Nay</b>	Received funds for research and consultancy from Dementia Training Study Centres and the Commonwealth Department of Health & Ageing for dementia related work
<b>Prof Dimity Pond</b>	Board Membership – Catholic Health Board (finished May 2014), Vic/Tasmania Dementia Study Training Centre Board Consultancy fees – Nutricia, Pfizer (2012) Funded travel – Dementia Congress, Dementia Training Study Centre, Alzheimer’s Australia Honorariums for presentations for Dementia Training Study Centres, Alzheimer’s Australia, Dementia Congress
<b>Dr Jane Thompson</b>	None declared
<b>Yvonne Santalucia</b>	Author of publications cited by the guidelines
<b>A/Prof Craig Whitehead</b>	Board membership (unpaid) Helping Hand Aged Care Funding from NHMRC
<b>A/Prof Mark Yates</b>	Board membership – Souvenaid Advisory Board Consultancy fees – Souvenaid Advisory Board Travel & Accommodation funded to attend Nutricia Alzheimer’s Association International Conference in Copenhagen

## Formulation of recommendations

### *Stage One – Review of the evidence*

Evidence summary documents for each systematic review question, including background information, description of the systematic review methods, narrative of results, Evidence Summary Tables and GRADE Evidence Profiles were circulated to all members of the guideline committee prior to the face-to-face meetings in which the recommendations were discussed. Members of the committee were asked to email any initial thoughts or questions directly back to the guidelines coordinator and these comments were addressed at the face-to-face meeting. This process ensured that all committee members were allowed time to consider the evidence and gave all members the opportunity to raise questions or provide comments.

### *Stage Two - Discussion*

At the face-to-face meeting the Chairperson guided the committee through the proposed recommendations and answered any questions regarding the body of evidence.

The Chairperson opened discussions and addressed questions or comments. The committee then made a decision for each proposed recommendation regarding whether they accepted the existing NICE recommendation, rejected it or wished to modify it.

#### *Stage Three – Formulation of draft recommendations*

The committee discussions were used to inform recommendations. Changes were prompted by updated evidence in the evidence review or where the committee felt that changes were needed to ensure the wording was specific, unambiguous and clearly described the actions taken by users, that wording matched the strength of the body of evidence and when required to suit the Australian setting or current standards of practice. Recommendations supported by the body of evidence were classed as evidence based recommendations. Where evidence was systematically reviewed but considered insufficient to inform a recommendation, expert opinion was sought from the committee and used to make consensus based recommendations. The committee also developed practice points to provide guidance in areas that were outside of the scope of the systematically reviewed literature. In one case (Souvenaid), where the intervention had not been previously considered by NICE, the GRADE evidence-to-decision framework (which incorporated considerations of values, cost and equity) and automated voting was used. This recommendation was later modified in response to feedback received in the public consultation phase.

#### *Stage Four – Call for agreement*

The Chair called for agreement and facilitated discussion where there was disagreement. Where consensus was gained the committee moved to the next section of the guideline. Where consensus was not gained, differences in opinion were discussed and in all cases resolved. Differing opinions were noted.

#### *Stage Five – Draft recommendations circulated to committee*

The guideline manuscript, containing the recommendations, was circulated to the committee for review prior to public consultation.

#### *Stage Six – Public consultation*

The Guidelines and the Technical report were released for public consultation on the 3<sup>rd</sup> of April 2015.

#### *Stage Seven – Revisions based on public consultation*

Revision of recommendations and the Guideline after public consultation.



## Assessment of the Guidelines

The guideline was assessed by two reviewers independent of the guideline using the AGREE II Instrument. The reviewers were Christopher Etherton-Beer and Saravana Kumar. Feedback provided by the reviewers was addressed by the committee and some changes made to the Guideline in response to their comments.

## Public consultation

The process for public consultation on the draft guideline complied with Section 14A of the Commonwealth National Health and Medical Research Council Act 1992 and accompanying regulations. Public consultation was conducted between the 3<sup>rd</sup> of April 2015 and the 15<sup>th</sup> of May 2015. A notice inviting submissions was published in The Australian newspaper on the 11<sup>th</sup> of April 2015. The draft Guideline and Technical Report were placed on the NHMRC Cognitive Decline Partnership Centre website (<http://sydney.edu.au/medicine/cdpc/news-events-participation/draft-guidelines.php>). A document summarising all feedback and the responses to this feedback will be provided at the end of the public consultation period. The following organisations were formally notified and invited to provide feedback. All responses received during public consultation are detailed in the Public Consultation Submissions Summary.

Organisation	Response received
The Commonwealth Department of Social Services	Yes
The Commonwealth Department of Health	Yes
State departments of health (NSW, Vic, SA, Qld, WA, Tas, NT)	Feedback received from NT and SA Health
The Therapeutic Goods Administration	No
The Pharmaceutical Benefits Advisory Board	No
The Medical Services Advisory Board	No
*Aged and Community Services Australia	Yes
*The Royal College of General Practitioners	Yes
The Pharmacy Guild of Australia	No
*The Royal College of Nursing, Australia	Yes
*The Royal Australian and New Zealand College of Psychiatrists	Yes
Palliative Care Australia	Yes
*Occupational Therapy Australia	Yes
*Carers Australia	No
*Australian Medical Association	No
*Australian College of Rural and Remote Medicine	Yes
*Australian and New Zealand Society for Geriatric Medicine	Yes
*Australasian Faculty of Rehabilitation Medicine	No
*Alzheimer's Australia	Yes
*Australian Association of Social Workers	No
Australian Physiotherapy Association	No
Psychology Association	No
*COTA	No
Consumers Health Forum	No
*Leading Aged Care Services Australia	Yes
*National Aged Care Alliance	No

Organisation	Response received
CDPC DSBI's	No
Dementia Training Study Centres	No

Organisations marked with an asterix were invited to endorse the Guideline.