From: Dyer, Suzanne (Health)
To: Community Affairs, Committee (SEN)
Cc:
Subject: RE: Submission to the Senate Inquiry on Aged Care Quality Assessment and Accreditation
Date: Monday, 27 November 2017 5:06:25 PM
Attachments:

To the Senate Community Affairs References Committee

We would like to provide the committee with some additional information relevant to our submission (no 71) as follows

1. An additional academic peer-reviewed publication on the scoring algorithm for the CCI-6D which has been accepted for publication since our original submission. This is provided in confidence as it is currently in press but unpublished (Milte et al).
2. Link to the recent NHMRC guidelines for dementia in Australia which our research group developed, http://sydney.edu.au/medicine/cdpc/documents/resources/CDPC-Dementia-Guidelines_WEB.pdf . Please note recommendations 59 - 63 which are relevant to discussions at the senate hearing relating to staff training. Note also that two of these recommendations were prioritised for research translation by the guidelines adaptation committee (p66). A summary MJA article is also attached.
3. Information on the CCI-6D is now available online http://www.flinders.edu.au/sohs/disciplines/rehabilitation-aged-and-extended-care/research/dementia-care.cfm

Regards

Dr Suzanne Dyer, Associate Professor Craig Whitehead, Dr Rachel Milte & Professor Maria Crotty

Clinical practice guidelines for dementia in Australia

Kate Laver
PhD, MClinRehab, BAppSc(OT)[1]

Robert G Cumming
MB BS, MPH, PhD[2]

Suzanne M Dyer
PhD, GradCertPH[1]

Meera R Agar
FRACP, FAChPM, PhD[3,4]

Kaarin J Anstey
BA(Hons), PhD[5]

Elizabeth Beattie
PhD, MA, BA[6]

Henry Brodaty
MD, DSc, FRANZCP[4]

Tony Broe
MRACP, MB BS, BA[7]

Lindy Clemson
PhD, MAppSc, BAppSc(OT)[2]

Maria Crotty
MPH, PhD, FAFRM[1]

Margaret Dietz
BA, BSW, GradCertFamilyTherapy[8]

Brian M Draper
MB BS, MD, FRANZCP[4]

Leon Flicker
FRACP, GradDipEpid, PhD[9]

Margeret Friel
MEd, BJuris[10]

Louise Mary Heuzenroeder
BN, MBA, MPH[11]

Susan Koch
PhD, RN, MN[12]

Susan Kurrle
MB BS, PhD, DGM[2]

Rhonda Nay
PhD[13]

C Dimity Pond
MB BS, FRACGP, PhD[14]

Jane Thompson
BSc(Hons), MSc, PhD[15]

Yvonne Santalucia
BEd[16]

Craig Whitehead
FAFRM, FRACP[1]

Mark W Yates
MB BS, FRACP[17]

doi: 10.5694/mja15.01339

Online first 14/03/16

Summary

- About 9% of Australians aged 65 years and over have a diagnosis of dementia.
- Clinical practice guidelines aim to enhance research translation by synthesising recent evidence for health and aged care professionals.
- New clinical practice guidelines and principles of care for people with dementia detail the optimal diagnosis and management in community, residential and hospital settings. The guidelines have been approved by the National Health and Medical Research Council.
- The guidelines emphasise timely diagnosis; living well with dementia and delaying functional decline; managing symptoms through training staff in how to provide person-centred care and using non-pharmacological approaches in the first instance; and training and supporting families and carers to provide care.

Dementia is a National Health Priority Area in Australia. As our population ages, the number of people with dementia will increase.[1] People with dementia have deficits in one or more of the areas of memory, communication, attention, thinking and judgement.[2]

The quality of clinical practice in dementia care in Australia is variable. The availability of high-quality services to support workforce training, diagnosis and ongoing care, advance care planning and support for families to provide care is inconsistent.

Clinical practice guidelines can improve uptake of research findings by identifying, synthesising and disseminating evidence to clinicians.[3] Most importantly, adherence to clinical practice guidelines can improve the quality and consistency of care.[4]

The National Health and Medical Research Council (NHMRC) Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People was established in 2013 with funding support from the NHMRC, HammondCare, Alzheimer's Australia, Brightwater Care Group and Helping Hand Aged Care. One of the activities of the Partnership Centre was to develop Australian clinical practice guidelines for dementia. The guidelines were adapted from existing guidelines[5] using ADAPTE methodology[6] to reflect the Australian context and the latest evidence. A multidisciplinary guideline committee, which included consumers, was appointed to refine the scope of the guidelines and form recommendations based on systematic reviews of the evidence.

The purpose of the guidelines is to provide recommendations for an agreed standard of practice for the diagnosis and management of people with dementia in Australia. The guidelines address care of people with dementia in community, residential care and hospital settings and are relevant to medical practitioners, nurses, aged care workers and allied health professionals. They are also useful for researchers, educators, policy makers and decision makers.

The full guidelines can be accessed via the Australian Clinical Practice Guidelines portal (https://www.clinicalguidelines.gov.au).

Main recommendations

The guidelines provide 109 recommendations, categorised as evidence-based recommendations (formulated after a systematic review of the evidence), consensus-based recommendations (formed where a systematic review has failed to identify sufficient studies to inform a recommendation) and practice points (based on expert opinion). Key recommendations prioritised by the committee for implementation are presented in the Box.

Changes in management

Delays between the onset of symptoms and diagnosis of dementia are widely acknowledged.[7] There is currently a lack of information regarding the benefits and harms of population screening for cognitive impairment.[8] The guidelines focus on timely diagnosis by recommending that symptoms are explored when first raised by the person experiencing the symptoms and/or their carer or family and are not dismissed as "just a part of ageing". People with a possible diagnosis of dementia should be referred to a service or specialist in dementia diagnosis (eg, a memory clinic, neurologist, geriatrician or psychiatrist).[9]

The guidelines recommend a systematic approach to diagnosing dementia; this includes patient and informant history taking, cognitive assessment, medication review, blood tests and computed tomography or magnetic resonance imaging to exclude other cerebral pathologies. The use of single-photon emission computed tomography is not recommended.[10] More recent diagnostic techniques using biomarkers (including the use of positron emission tomography) are not recommended for routine use.[11]

Clinical cognitive assessment should include examination with a screening tool with established reliability and validity. A number of tools are recommended in the guidelines including the Mini-Mental State Examination. The Kimberley Indigenous Cognitive Assessment tool for

remote living Aboriginal and Torres Strait Islander populations and the Rowland Universal Dementia Assessment Scale for people from non-English speaking backgrounds are recommended for use where illiteracy, language or cultural considerations deem their use appropriate.

The committee recommended review of people with mild cognitive impairment after 6–18 months. This recommendation was formulated based on an existing systematic review which found that, in a clinic setting, the annual conversion rate of mild cognitive impairment to Alzheimer disease was close to 10%.[12]

At the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression, to ensure optimal management of coexisting conditions.

The guidelines recommend comprehensive role-appropriate dementia-specific training for health and aged care professionals. Such training can improve the quality of life for the person with dementia[13] and reduce restraint use[14,15] by teaching staff how to understand a person with dementia and to read body language and behaviour as signs of communication and respond appropriately. The evidence supports training models that focus on understanding symptoms and behaviours and providing person-centred care.[16]

The guidelines recommend a greater emphasis on promoting and maintaining independence through activities of daily living, continuing exercise and supporting the person to pursue activities that are meaningful and of interest to them. Adequate nourishment and hydration through maintaining a healthy, balanced diet should be encouraged and supported. People with dementia should have their weight monitored and nutritional status assessed regularly. Oral health is important[17] and, on diagnosis, the medical practitioner should recommend that the person with dementia (or their carer[s] or family) make an appointment to see a dentist to conduct an assessment and formulate a long-term treatment plan.

Acetylcholinesterase inhibitors and memantine are routinely prescribed for people with mild to moderate Alzheimer disease in order to delay functional decline, and the guidelines support their use.[18] Based on recent evidence, the guidelines also state that any one of the three acetylcholinesterase inhibitors (donepezil, galantamine or rivastigmine) could also be considered for people with dementia with Lewy bodies, Parkinson disease dementia, vascular dementia or mixed dementia.[19-22] The combination of an acetylcholinesterase inhibitor and memantine could be considered for managing the symptoms of functional decline for people with moderate to severe Alzheimer disease.[23] Clinicians should be aware that not all of these indications are reimbursed under the Pharmaceutical Benefits Scheme and that acetylcholinesterase inhibitors are associated with a number of side effects including (but not limited to) nausea, vomiting, diarrhoea, dizziness, increased urinary frequency, falls, muscle cramps, weight loss, anorexia, headache and insomnia.[24] Acetylcholinesterase inhibitors should not be prescribed for people with mild cognitive impairment.[25]

If people with dementia cannot express their needs through communication, they may communicate through their actions and behaviour. The guidelines recommend the need to understand the person and symptoms via a comprehensive assessment and analysis of the behaviour (eg, antecedent [triggers], behaviour description and consequence [ABC approach]). The objective measurement of behavioural and psychological symptoms of dementia should be undertaken using tools to monitor the type and patterns of behaviours. The provision of care that is consistent with the ten principles of dignity in care[26] and non-pharmacological interventions should be implemented before considering use of medications. Non-pharmacological interventions should ideally involve engagement in activities that are enjoyable for the person with dementia and individualised support. Working with the carer and family to build skills in managing symptoms, communicating effectively and problem solving have been shown to be effective in reducing symptoms.[27,28]

A number of pharmacological treatments are recommended to complement non-pharmacological approaches when the person with dementia is severely distressed or there is an immediate risk of harm. Analgesics are recommended when pain is suspected.[29] A trial of selective serotonin reuptake inhibitors is recommended for agitation; the strongest evidence is for citalopram.[30] The role of antidepressants in the treatment of depression in people with dementia is uncertain. Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se.[31] Nevertheless, the committee considered that those with a pre-existing history of major depression (before developing dementia) who develop a comorbid major depression should be treated in the usual way.

People with Alzheimer disease, vascular dementia or mixed dementias with mild to moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications, owing to the increased risk of cerebrovascular adverse events and death.[32] For people with severe symptoms who are distressed or causing distress to others, treatment with an antipsychotic may be offered following a full discussion with the person with dementia and/or their carer(s) or family about the possible benefits and harms. Treatment should be reviewed every 4–12 weeks, considering the need for antipsychotics and possible cessation of medication.

Care for people with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated. Treatment and care should be provided as per the person's advance care plan.

Carers and families should be included in the planning, decision making and care and management of people

1 Flinders University, Adelaide, SA
2 University of Sydney, Sydney, NSW
3 Braeside Hospital, Sydney, NSW
4 UNSW Australia, Sydney, NSW
5 Australian National University, Canberra, ACT
6 Queensland University of Technology, Brisbane, QLD
7 Neuroscience Research Australia, Sydney, NSW
8 Monash Health, Melbourne, VIC
9 University of Western Australia, Perth, WA
10 Department of Correctional Services, Darwin, NT
11 SA Heath, Adelaide, SA
12 Royal District Nursing Service, Melbourne, VIC
13 La Trobe University, Melbourne, VIC
14 University of Newcastle, Newcastle, NSW
15 Alzheimer's Australia, Canberra, ACT
16 Liverpool Hospital, Sydney, NSW
17 Ballarat Health Services, Ballarat, VIC
Kate.Laver@flinders.edu.au

Key recommendations identified by the committee as priorities for implementation*

- Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family. The 10 principles of dignity in care (http:/www.dignityincare.org.uk) should be used as the standard by which care is delivered and evaluated.
- People with a possible diagnosis of dementia should be offered referral to memory assessment specialists or services for a comprehensive assessment.
- The medical practitioner should be honest and respectful and use a gradual and individualised approach when communicating the diagnosis to the person with dementia and their carer(s) and family.
- Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carers and families from the time of diagnosis.*
- Health and aged care organisations should ensure that all staff working with people with dementia receive dementia-care training (attitude, knowledge and skill development) that is consistent with their roles and responsibilities. Training should reflect programs that have been shown to optimise care for people with dementia.*
- Training programs should be comprehensive and have a strong focus on communicating effectively with the person with dementia and his or her carer(s) and family and recognising, preventing and managing behavioural and psychological symptoms of dementia. Staff should be trained in the principles of person-centred care and how these principles are applied in practice.
- People with dementia living in the community should be offered occupational therapy interventions which should include: environmental assessment and modification to aid independent functioning; prescription of assistive technology; and tailored intervention to promote independence in activities of daily living.*
- People with dementia who develop behavioural and psychological symptoms should be offered a comprehensive assessment at an early opportunity by a professional skilled in symptom assessment and management. This should involve their carer(s) and families as appropriate and include; analysis of the behaviours, assessment of physical and mental health, pain or discomfort, side effects of medication, the influence of religious and spiritual beliefs and cultural norms, physical environmental and interpersonal factors, an assessment of carer(s) health and communication style, understanding the behaviour as a form of communication.*
- People with Alzheimer's disease, vascular dementia or mixed dementias with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications because of the increased risk of cerebrovascular adverse events and death.
- The person with dementia, their carer(s) and family should be offered respite appropriate to their needs.
- Carers and families should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be individualised, multifaceted and delivered over multiple sessions.*

*Note that some recommendations have been shortened in this publication. ◆

with dementia. Carers are often not provided with enough support or adequate training to effectively provide care.[33] There is evidence that tailored multifaceted programs involving both the carer and the person with dementia can improve quality of life for both.[34] Carers should have access to programs that include education regarding dementia; information regarding relevant services such as respite; information about support organisations such as Alzheimer's Australia; individualised care management strategies to overcome specific problems; training in providing care and communicating most effectively with the person with dementia; and support regarding coping strategies to maintain their own well-being, including stress management.

Competing interests: No relevant disclosures.

Provenance: Not commissioned; not externally peer reviewed. ■

References are available online at www.mja.com.au.

1 Australian Institute of Health and Welfare. Dementia in Australia. Canberra: AIHW, 2012. (Cat. No. AGE 70.) http://www.aihw.gov.au/publication-detail/?id=10737422958 (accessed Jan 2016).

2 Burns A, Iliffe S. Dementia. *BMJ* 2009; 338: b75.

3 Grol R, Grimshaw JM. From best evidence to best practice: effective implementation of change in patients care. *Lancet* 2003; 362: 1225-1230.

4 Grimshaw J, Thomas R, MacLennan G, et al. Effectiveness and efficiency of guideline dissemination and implementation strategies. *Health Technol Assess* 2004; 8: 1-72.

5 National Institute for Health and Care Excellence. Dementia: supporting people with dementia and their carers in health and social care. NICE guidelines [CG42]. London: NICE, 2006. https://www.nice.org.uk/guidance/cg42 (accessed Jan 2016).

6 ADAPTE Collaboration. The ADAPTE process: resource toolkit for guideline adaptation. ADAPTE, 2009. http://www.g-i-n.net/document-store/working-groups-documents/adaptation/adapte-resource-toolkit-guideline-adaptation-2-0.pdf (accessed Jan 2016).

7 Koch T, Iliffe S, EVIDEM-ED project. Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review. *BMC Fam Pract* 2010; 11: 52.

8 Lin JS, O'Connor E, Rossom RC, et al. Screening for cognitive impairment in older adults: an evidence update for the US Preventive Services Task Force (Evidence Synthesis No. 107). Rockville, MD: Agency for Healthcare Research and Quality, 2013. http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0063382/pdf/PubMedHealth_PMH0063382.pdf (accessed Jan 2016).

9 LoGiudice D, Waltrowicz W, Brown K, et al. Do memory clinics improve the quality of life of carers? A randomized pilot trial. *Int J Geriatr Psychiatry* 1999; 14: 626-632.

10 Dobert N, Pantel J, Frolich L, et al. Diagnostic value of FDG-PET and HMPAO-SPET in patients with mild dementia and mild cognitive impairment: metabolic index and perfusion index. *Dement Geriatr Cogn Disord* 2005; 20: 63-70.

11 Albert MS, DeKosky ST, Dickson D, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement* 2011; 7: 270-279.

12 Ward A, Tardiff S, Dye C, Arrighi HM. Rate of conversion from prodromal Alzheimer's disease to Alzheimer's dementia: a systematic review of the literature. *Dement Geriatr Cogn Disord Extra* 2013; 3: 320-332.

13 Clare L, Whitaker R, Woods RT, et al. AwareCare: a pilot randomized controlled trial of an awareness-based staff training intervention to improve quality of life for residents with severe dementia in long-term care settings. *Int Psychogeriatr* 2013; 25: 128-139.

14 Huizing A, Hamers JP, Gulpers M, Berger M. Short-term effects of an educational intervention on physical restraint use: a cluster randomized trial. *BMC Geriatr* 2006; 6: 17.

15 Testad I, Ballard C, Bronnick K, Aarsland D. The effect of staff training on agitation and use of restraint in nursing home residents with dementia: a single-blind, randomized controlled trial. *J Clin Psychiatry* 2010; 71: 80-86.

16 Chenoweth L, King MT, Jeon YH, et al. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol* 2009; 8: 317-325.

17 Chen X, Kistler C. Oral health care for older adults with serious illness: when and how? *J Am Geriatr Soc* 2015; 63: 375-378.

18 Centre for Health Economics Monash University, University of South Australia Veterans' Medicines Advice and Therapeutics Education Services, Department of Health and Ageing Pharmaceutical Policy Branch, Ahmed R. Post market review: Pharmaceutical Benefits Scheme anti-dementia medicines to treat Alzheimer disease. Canberra: Department of Health, 2012. http://www.pbs.gov.au/info/reviews/anti-dementia-report (accessed Jan 2016).

19 Birks J, Craig D. Galantamine for vascular cognitive impairment. *Cochrane Database Syst Rev* 2006; (1): CD004746.

20 Birks J, McGuinness B, Craig D. Rivastigmine for vascular cognitive impairment. *Cochrane Database Syst Rev* 2013; (5): CD004744.

21 Malouf R, Birks J. Donepezil for vascular cognitive impairment. *Cochrane Database Syst* Rev 2004; (1): CD004395.

22 Wang HF, Yu JT, Tang SW, et al. Efficacy and safety of cholinesterase inhibitors and memantine in cognitive impairment in Parkinson's disease, Parkinson's disease dementia, and dementia with Lewy bodies: systematic review with meta-analysis and trial sequential analysis. *J Neurol Neurosurg Psychiatry* 2015; 86: 135-143.

23 Schmidt R, Hofer E, Bouwman FH, et al. EFNS-ENS/EAN Guideline on concomitant use of cholinesterase inhibitors and memantine in moderate to severe Alzheimer's disease. *Eur J Neurol* 2015; 22: 889-898.

24 Bond M, Rogers G, Peters J, et al. The effectiveness and cost-effectiveness of donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (review of Technology Appraisal No 111): a systematic review and economic model. *Health Technol Assess* 2012; 16: 1-470.

25 Tricco AC, Soobiah C, Berliner S, et al. Efficacy and safety of cognitive enhancers for patients with mild cognitive impairment: a systematic review and meta-analysis. *CMAJ* 2013; 185: 1393-1401.

26 Dignity in Care [website]. http://www.dignityincare.org.uk (accessed Jan 2015).

27 Gitlin LN, Winter L, Dennis MP, et al. Targeting and managing behavioral symptoms in individuals with dementia: a randomized trial of a nonpharmacological intervention. *J Am Geriatr Soc* 2010; 58: 1465-1474.

28 Tremont G, Davis JD, Bishop DS, Fortinsky RH. Telephone-delivered psychosocial intervention reduces burden in dementia caregivers. *Dementia* 2008; 7: 503-520.

29 Pieper MJ, van Dalen-Kok AH, Francke AL, et al. Interventions targeting pain or behaviour in dementia: a systematic review. *Ageing Res Rev* 2013; 12: 1042-1055.

30 Porsteinsson AP, Drye LT, Pollock BG, et al. Effect of citalopram on agitation in Alzheimer disease: the CitAD randomized clinical trial. *JAMA* 2014; 311: 682-691.

31 Sepehry AA, Lee PE, Hsiung GY, et al. Effect of selective serotonin reuptake inhibitors in Alzheimer's disease with comorbid depression: a meta-analysis of depression and cognitive outcomes. *Drugs Aging* 2012; 29: 793-806.

32 Schneider LS, Dagerman KS, Insel P. Risk of death with atypical antipsychotic drug treatment for dementia:

meta-analysis of randomized placebo-controlled trials. *JAMA* 2005; 294: 1934-1943.

33 Black BS, Johnston D, Rabins PV, et al. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *J Am Geriatr Soc* 2013; 61: 2087-2095.

34 Olazaran J, Reisberg B, Clare L, et al. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord* 2010; 30: 161-178. ■