Aged Care Research & Industry Innovation Australia

An environmental scan summary: Australian dementia resources

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Key Points

- An interactive desktop environmental scan was undertaken to identify Australian dementia care resources of potential use to the aged care sector.
- The scan used several search strategies, a quality appraisal process (using QUEST), and invited advice from an Expert Advisory Group to identify high quality items to be made accessible via the website of the Aged Care Research and Industry Innovation Australia (Knowledge and Implementation Hub)
- The environmental scan identified a total of 325 resources for inclusion in the dementia section of a new Knowledge and Implementation Hub.
- Australian resources on dementia are targeted at a wide audience range with only a subset directed at care workers (n=132). Those resources specifically for care workers were mostly judged as being of low to medium quality.

Background

The aim of this environmental scan was to undertake a limited desktop review to identify existing dementia resources available within Australia for use by the aged care sector. These might include educational, informational or support tools. High quality resources will eventually be made available to the sector through the website of the Aged Care Research and Industry Innovation Australia (Knowledge and Implementation Hub). This report presents the methods and findings of a preliminary scan completed by the Knowledge and Implementation Hub team.

Methods

The environmental scan followed a structured method for identified resources. This included a replicable search strategy, eligibility checking against inclusion criteria, and quality appraisal check.

These processes are explained in further detail below.

Search strategy

The scan adopted a three-pronged approach to identifying relevant resources.

Google Advanced searches

Structured searches for Australian dementia resources were conducted between the 17th and 29th of November 2021 using the Advanced Search version of Google (Chrome browser in incognito mode to avoid previous search history impacting results). Searches for both dementia and Alzheimer* were run to identify webpages, websites, and PDF resources originating from Australia, including each of its states and territories.

The search was structured as follows:

- The search terms dementia and Alzheimer* were individually entered in the all these terms box in Google Advanced Search
- Australia was selected from the Region drop-down menu.

For each search term variant run in Google Advanced, we aimed to retrieve relevant resources from up to 50 pages of search results (10 results per page, i.e., up to a total of 500 webpages would be assessed).

Scanning dementia and key Australian aged care websites

A list of key dementia and aged care organisations was compiled for more targeted website searching. Organisations were identified during the scan process or were already known to the researcher group. They included:

- Dementia Australia
- Australian Dementia Network
- Healthdirect: Dementia overview page
- Help with Dementia
- Dementia Support Australia (Hammondcare)
- National Dementia Support Program
- Dementia and Aged Care Services (DACS) Fund projects
- Dementia Training Australia
- Dementia research: NHMRC
- Dementia Centre for Research Collaboration
- Dementia, Ageing and Aged Care Mission (MRFF)
- Forward with Dementia
- Australian Commission on Safety and Quality in Health Care (ACSQHC)
- Aged Care Quality and Safety Commission
- Department of Health and Aged Care
- COTA
- OPAN: Older Persons Advocacy Network
- Australian Ageing Agenda
- Australian Association of Gerontology

Expert Advisory Group

An Expert Advisory Group was established to inform the direction, approach, and scope of the overall project. This comprised people researching and working in dementia care within the aged care setting. The group was presented with preliminary results from the environmental scan and given the opportunity to provide feedback and advice on additional resources and current research initiatives to be followed up.

The details for all resources identified as potentially relevant at this point (including URL) were entered into an Excel spreadsheet. Each resource was then checked against the environmental scan's eligibility criteria.

Eligibility criteria

Resources were considered for inclusion if they:

- Were available online or could be ordered online, providing resource is free of charge.
- Provided information on care of the person living with dementia, either in the community or within residential aged care.
- Addressed people living with dementia, their family, care workers, or health professionals
- Were created since 2010
- Were of an informative, educational, or instructional nature

- Could be easily understood by a non-academic audience
- Were produced by a peak body or a reputable dementia or aged care organisation.

Quality assessment of resources

To gain a sense of the quality of available resources, a selection of potentially-relevant resources were appraised using the QUality Evaluation Scoring Tool (QUEST). This tool grades resources on author information such as credentials, sources cited, conflicts of interest, currency, and tone of message. Possible scores range from 0-28, with higher scores reflecting higher quality. Following quality appraisal, these resources were presented to an Expert Advisory Group for feedback.

Data extraction

The following data fields were captured for included resources:

- Resource name
- URL
- Year published
- Audience
- Resource type
- Provider of care/service/support
- Description of resource(s)
- Funding source
- Whether the website displayed a universally recognised indicator of quality (e.g., HONcode)

Results

The dementia and Alzheimer* searches produced 44 and 13 pages of results, respectively. Of these, 325 resources were identified as potentially useful and annotated in the Excel spreadsheet. The links within each resource were also further investigated with additional resources being added to the spreadsheet.

Target audience

It was found from mapping the resources by target audience that there are multiple populations to consider when providing information about dementia and/or Alzheimer's disease. These differ by relationship to people living with dementia (PLwD), cultural background, and whether the PLwD may have additional needs, conditions, or disorders. The following populations were identified within the Australian context.

- General population
- Persons living with dementia
- Family of PLwD
- Family carers of PLwD
- Service providers
- Aged care workers
- Health professionals (e.g., general practitioners, nurses, allied health professionals)
- Researchers/policy makers

Types of resources found

Most resources provided information, education, support, opportunities to network, and suggestions for improvement of care. Most resources were intended for more than one audience (e.g., PLwD, their families, and aged care workers). Some resources focused on specific issues such as advanced care planning, palliative care, COVID-19, or specific populations such as those from Aboriginal and Torres Strait Islander, or culturally and linguistically diverse backgrounds.

Resources written for care workers

A subset of resources (N = 132) included care workers as a potential target audience. Selected resources from this set are described in Table 1. Most resources consisted of information/guidelines regarding diagnosis, certain types of dementia, delaying functional decline, managing symptoms, and palliative care. There were also multiple education resources including online courses and podcast series/episodes to inform greater understanding of dementia. There is also the Dementia Support Australia App, which provides on-demand resources, strategies and advice to aged care providers/workers. Of the resources assessed using QUEST, website quality ranged from 10 to 25 (possible range 0–28; M = 15.08, SD = 4.68).

Websites displaying quality indicators

Twenty-one websites displayed HONcode certification. These resources mostly consisted of general information about dementia and diagnosis, as well as more specific information about certain populations (e.g., Alzheimer's disease, younger-onset dementia), topics (e.g., driving, depression) or strategies to improve care (e.g., medicines management, home environment). QUEST website quality ranged from 9 to 24 (possible range = 0-28; M = 16.42, SD = 3.80).

Ongoing dementia research

As part of the scan, we also looked for research initiatives underway across Australia focused on improving outcomes for PLwD. Currently, HammondCare is running studies focusing on Specialist Dementia Care Program Units, delivering training to aged care workers aiming to encourage conversations about advance care planning, and examining models of care. The Dementia and Aged Care Services (DACS) fund also have funded ongoing projects such as the Dementia and Behavioural Management Advisory Service, the Dementia Training Program, Dementia-Friendly Communities, the National Dementia Support Program, Severe Behaviour Response Teams, and the Specialist Dementia Care Program. Recently announced National Health and Medical Research Council grants include research which more closely focus on causes and diagnosis of dementia (e.g., Vascular contributions to dementia, promoting brain health in Aboriginal and Torres Strait Islander peoples, and enhanced dementia diagnosis).

There are also some current projects funded by individual states/territories. In South Australia, there are currently projects underway such as (1) building an innovative cottage-style dementia care home, and (2) the Australian Dementia Network (ADNeT): Bringing Together Australia's Dementia Stakeholders, and (3) the Harmony in the Bush program which incorporates individualised music/ art and movement interventions with the aim to reduce challenging behaviours and improve well-being. The Victorian Government is currently running the Changing Minds Carer Support Group, which is an informal, social group of people who care for family members or friends who are experiencing memory loss or living with a diagnosis of dementia.

While research across Australian universities is mostly focused on dementia prevention and detection, there are some projects currently underway which relate to improving outcomes for PLwD and/or carers. The University of Queensland are currently running a clinical trial examining the role of exercise in the cognitive function of older adults. The University of Tasmania has multiple ongoing dementia research projects such as (1) Work4Dementia, focusing on the development of an evidence-based intervention to build capacity and resilience for the Australian dementia care workforce, (2) a project focusing on reducing aspiration pneumonia risk through evidence-based oral care for PLwD, as well as (3) multiple other projects with more information expected to be provided soon (MENU project, Dementia Care Support worker, TACFP Projects, Dem Care Steps, Korongee Dementia Village, REDUSE, and Restraint).

Conclusion

This summary report describes the initial process used to identify resources capable of informing, training, educating, or generally supporting the aged care sector in its work. This is the first part of an ongoing process to build the resources of the Knowledge Hub. We will repeat the scan process on a scheduled basis to ensure new resources are identified and included so that Hub content remains relevant to the sector's needs.

Table 1. A selection of resources aimed at aged care workers

Resource name (Responsible organisation)	Description	QUEST quality rating (Range 0-28)
Clinical practice guidelines and principles of care for people with dementia (Cognitive Decline Partnership Centre)	Provides recommendations to health and aged care staff to apply in their workplaces.	25
Clinical practice guidelines for dementia in Australia (Laver et al. Medical Journal of Australia)	Guidelines emphasising 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.	23
Dementia among aged care residents (Australian Institute of Health and Welfare)	This report outlines the demographic characteristics and care requirements of permanent residents with a diagnosis of dementia and other residents in Australian Government subsidised residential aged care facilities in 2008–09, as identified by information from the Aged Care Funding Instrument (ACFI).	19
LGBTI fact sheets (Dementia Centre for Research Collaboration)	Multiple resources about the LGBTQIA+ community, varying in the degree in which they relate to dementia (but all funded by DCRC)	17
Innovation to implementation - Australia (Dementia Centre for Research Collaboration)	The I2I approach is built around the concept of innovation: products, actions, services or relationships that can potentially enhance health outcomes. The guide will help you work out how to move from innovation to implementation in a thoughtful manner to achieve the desired outcomes of a project or initiative best suited to your context and needs.	17
Dementia awareness: A resource reference for personal care workers (Department of Veterans' Affairs)	General information regarding dementia (including symptoms, communication, supporting the person living with dementia, activities, behaviours, behaviour management and delirium)	15
How to support everyday decision- making for people living with dementia in residential aged care: A guide for care workers (Australian Centre for Evidence Based Aged Care)	A booklet written to help carers understand the importance of supporting people with dementia make everyday decisions. Provides practical examples.	13
Good care in a residential aged care home (Dementia Australia)	This help sheet lists some of the important aspects of good care for people with dementia who are living in residential aged care homes, including the involvement of relatives and friends	12
Lewy body disease information for home care workers (Dementia Australia)	This sheet is designed to give you some basic information about Lewy body disease and its associated disorders. It will help you understand what is happening in the home that you are visiting. It also gives you some tips so that you can assist both the client and their carer.	12

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ARIIA was established as an independent, not-for-profit organisation, set up to lead the advancement of the aged care workforce capability by promoting and facilitating innovation and research to improve the quality of aged care for all Australians.



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