

# EVIDENCE FOR CHANGE

CDPC FINAL REPORT 2019



COGNITIVE  
DECLINE  
PARTNERSHIP  
CENTRE



# involve

the people impacted by research in

# research



COGNITIVE  
DECLINE  
PARTNERSHIP  
CENTRE



# EVIDENCE FOR CHANGE

CDPC FINAL REPORT



COGNITIVE  
DECLINE  
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CENTRE

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IMPROVING THE  
LIVES OF PEOPLE  
WITH DEMENTIA  
BY DEVELOPING,  
COMMUNICATING,  
AND IMPLEMENTING  
RESEARCH THAT  
IMPROVES CARE



## DIRECTOR'S REPORT

The CDPC was the first NHMRC Partnership Centre for Better Health: Dealing with Cognitive and Related Functional Decline in Older People. The NHMRC Partnerships for Better Health Initiative was set up in 2011 to produce quality research that answered complex questions faced by decision makers about issues that impact the health of Australians. At that time cognitive decline was identified by government, aged care providers (Brightwater Care Group, HammondCare, Helping Hand Aged Care) and Dementia Australia, as a major health challenge facing Australia, and a new approach was needed to tackle this important area. This research model required engaging not just academic researchers but also industry partners and end users in the development and implementation of all research to ensure translation of research into policy and practice.

Over the six years of its existence the CDPC has done exactly this.

The CDPC's success has been due to the collaborative approach and shared vision of the whole investigator team which included the original Investigator Team of clinicians, academics, investigators working within aged care, and consumers, who were people with dementia and their carers and families. The consumer advocates have been integral to the success of the CDPC, and their involvement has enhanced the reach and impact of our work. Their lived experience has provided an expertise that has influenced not only our research outcomes but our individual project teams' approach to the research process.

Underpinning our achievements has been the CDPC Directorate team who ensured that projects remained on track, funding flowed, reports were written, and communications occurred. This team supported the CDPC network, keeping all members informed and promoting our research findings and resources.

Our vision was to improve care for people with dementia. A number of our CDPC projects have assisted in delivering that vision. The Clinical Practice Guidelines and Principles of Care for People with Dementia are changing practice in different settings including primary care and residential care and impacting dementia care education. New research examining different models of care for people with dementia, medicine use in older Australians, delivering programs that work to maintain an individual's independence, producing resources that enable people with dementia to make their own decisions and plan for their future, and implementing aged care staff education and training programs, are all evidence that we have gone a long way towards achieving our aim to *"improve the lives of people living with dementia by developing, communicating, and implementing research that improves care."*

It is unfortunate that the momentum achieved by the CDPC is now coming to an end, however many collaborative partnerships created during this time will continue. There is still much more to do for advancing and improving care for people with dementia in Australia, and I look forward to seeing CDPC research findings continuing to impact improvements in care for people with dementia and their families.



**Professor Susan Kurrle**

*CDPC Director and Chief Investigator*



THE UNIVERSITY OF  
SYDNEY

# EXECUTIVE SUMMARY

The CDPC developed, communicated, and implemented research that improves the care of people living with dementia and their families.

## Clinical Guidelines

- Australia's first clinical practice guidelines for people with dementia
- Layperson's guide on best practice dementia diagnosis, treatment and care
- Informed Vietnam's National Dementia Plan.

## Care Environments and Quality of Life

- Evidence on best models of residential care from the consumer perspective
- Consumer rated quality of care instrument for people with dementia and their families
- Quality of life instrument based on people's preferences
- Hospital programs that improve outcomes of people with dementia.

## Medication Management

- Tool to simplify medication procedures in aged care
- National action plan for quality use of medicines in older Australians
- Clinical practice guideline for doctors on how to trial withdrawal of Cholinesterase inhibitors and memantine
- Web-based medication review platform tailored to older Australians
- Vitamin D implementation program in residential aged care.

## Attitudes to Dementia

- Awareness of how dementia influences relationships materially, physically, psychologically, and socially
- Understanding use of regulation in the aged care industry
- How children are impacted when a parent has dementia.



### Planning, Decision-Making and Risk

- Supported decision-making policy guidelines for residential aged care
- Guide to support decision-making for families and people with dementia
- Advance care planning recommendations for people with dementia
- Community awareness of financial decision-making documents for older Australians
- Training of bank staff on financial decision-making tools for people with dementia.

### Maintaining Function

- Exercise Physiology program to improve aged care environment for people with dementia, families and staff
- Reablement resources to increase function and independence of people with dementia
- Home occupational therapy and nurse-led support program
- Evidence on fall risk factors for older people with dementia.

### Sustainable Workforce

- Evidence on staff factors that influence good quality care for people with dementia
- Interprofessional education toolkit in residential aged care
- Pain management resources for aged care staff
- Quality Improvement Collaboratives to improve translation of clinical guidelines.

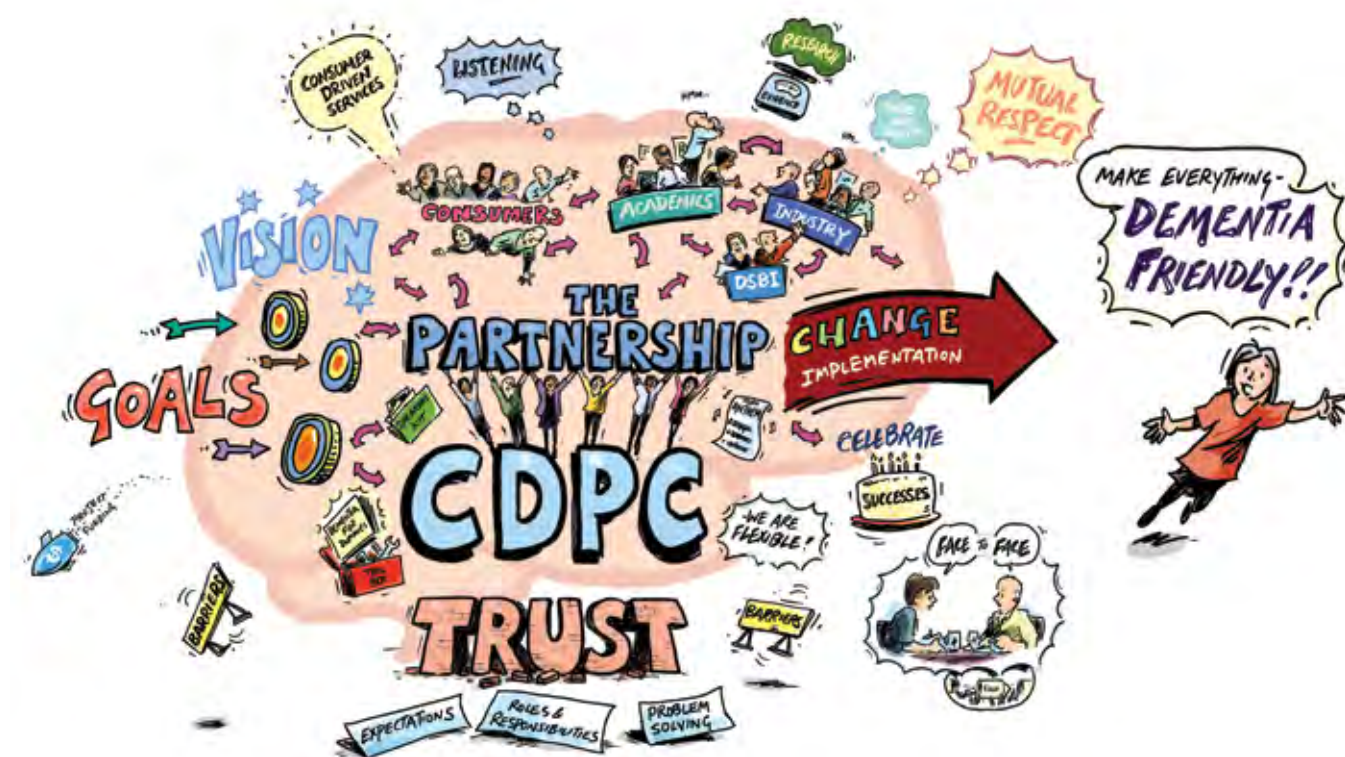
### Care Service Pathways

- Dementia support worker model for people with dementia and families
- Respite model to support the carer of a person with dementia
- Real-life and 'ideal state' map of dementia diagnosis and life after diagnosis
- Evidence on GP care for people with dementia.



# THE CDPC RESEARCH MODEL

For CDPC research outcomes to have the greatest opportunity to influence systems change in the care for people with dementia required a co-design research approach.



The CDPC brought together academic and systems-based researchers, consumers, and industry partners to develop prioritised research questions, and translate research into improved care for people with dementia and their families.

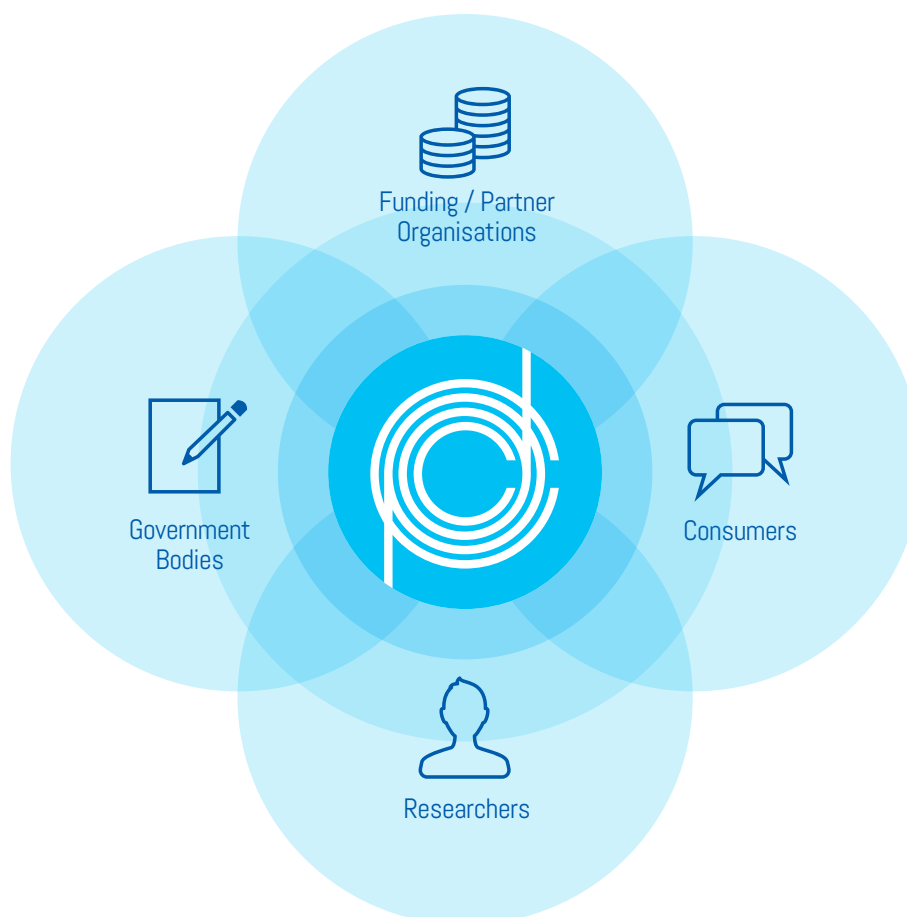
All research, funded through the \$25M NHMRC Partnerships for Better Health Initiative, was conceptualised, conducted and disseminated by all partners. Projects were required to be of high scientific standard and fit within NHMRC objectives.

The first fourteen research projects were generated by an academic investigator team, and aligned to the priorities of industry partners, Brightwater Care Group, HammondCare, Helping Hand Aged Care and Dementia Australia. A meeting with the then Alzheimer's Australia Consumer Dementia Research Network (CDRN) members, representing people with dementia and carers, resulted in a final consensus-based list of research and implementation activities that were funded in 2014.



Post-2014, funding was granted based on the outcomes of a Proposal Development and Review Protocol that ensured alignment to the objectives and strategic priorities of the CDPC, engaged consumers in the decision-making process, and were of a high standard of scientific quality, significance, feasibility, relevance, and economic value.

The CDPC created a research environment for optimal research impact. During development and conduct of CDPC projects, teams were supported by Subject Matter Experts in methodology, policy engagement, change management, technology, and economic modelling. In addition, consumers and industry partner staff provided vital linkages between projects and end-users.



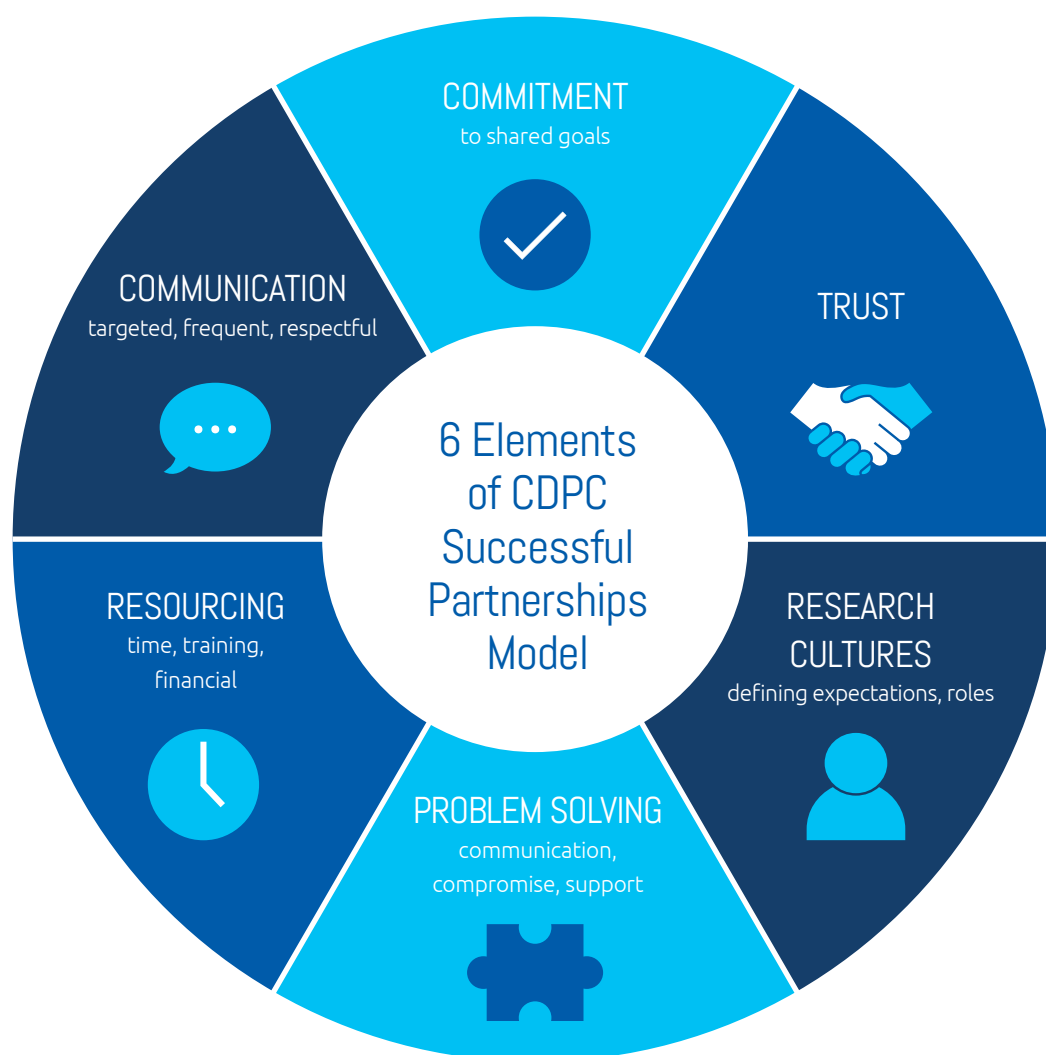
Dementia Advocate and person with dementia, Christine Bryden, stated 'researchers are critical to ensuring research is of high quality; consumers are critical to ensuring that research is of high relevance. Both are needed for excellence in Knowledge Translation.' The CDPC collaborative involvement of 'consumers' in all stages of its research, supported targeted, relevant research outcomes, to improve the care of people with dementia. Involving 'consumers' in broad dissemination of its research findings and outputs, including to the public, has supported a spread beyond academia of the Centre's research benefits and influences. The CDPC Research Model has effectively embraced the 'consumer' priority of 'Research for Us – With Us!'

*(Joan Jackman: consumer advocate, lead of the CDPC Consumer Enabling Sub-Unit and Executive Committee Member)*

The role of industry partners Brightwater Care Group, HammondCare, Helping Hand Aged Care and Dementia Australia ensured that research outcomes could be implemented to benefit clients of aged care services, as well as the staff and volunteers that supply those services. The value to the Australian aged care sector from CDPC activities will be sustained well beyond the life of the current CDPC entity. It is vital that industry continue to engage in research activities to assist in being able to respond to, and prepare for, changing consumer and regulator expectations. The CDPC model of industry engagement with academic research teams, supported by consumer representatives, in the initial development, conduct, evaluation and implementation of research ideas has relevance for the rapidly ageing global population.

*(Jan Van Emden: Designated System-Based Investigator (Helping Hand Aged Care) and Executive Committee Member)*

## 6 Elements of CDPC Successful Partnerships Model



## Measuring our impact

Being able to tell the community, care organisations, and policymakers about outcomes of publicly funded research is important. The CDPC understood the need to demonstrate the impact or potential impact its program of work has for creating new knowledge, improvements in health and quality of life, and creating understanding of social, and economic benefits.

A major reporting requirement of the Partnership for Better Health Initiative has been the ability to demonstrate success against four NHMRC Partnership Centres objectives: collaborative new research; synthesis and dissemination of research; implementation of research informed change; and capacity building. Narration of impact required increasing researcher capacity, administrative support, and targeted reporting to diverse research partners including government, consumers, and aged care providers.

Demonstrating how CDPC research is influencing care systems and policy required quantitative and qualitative data collection and reporting that informed a longitudinal, mixed methods

five-year internal evaluation. With the evaluation project completed in 2019, data collection continued with a focus on stories of impact.

Throughout its funding term the CDPC provided capacity building opportunities through workshops, webinars, conferences and seminars. For academic and systems-based researchers these increased understanding of the importance of demonstrating research impact and how to apply this in the research process.

The collected stories of impact (Research Impact) give evidence that bringing stakeholders with a shared interest in improving care for people with dementia together, is an effective avenue for implementation of changed practice and policy. As this NHMRC funded program of work completes, the CDPC's evidence of success will continue through the ongoing partnerships developed over the past six years.



## CDPC internal evaluation

The [internal evaluation](#) project examined CDPC operations, partnerships, communications of findings, and evidence of impact achieved to the end of 2018, using qualitative and quantitative measures.

### Milestones

Milestones achieved by the end of 2018 across all CDPC funded Activities:

838

TOTAL MILESTONES DUE

808

TOTAL MILESTONES ACHIEVED

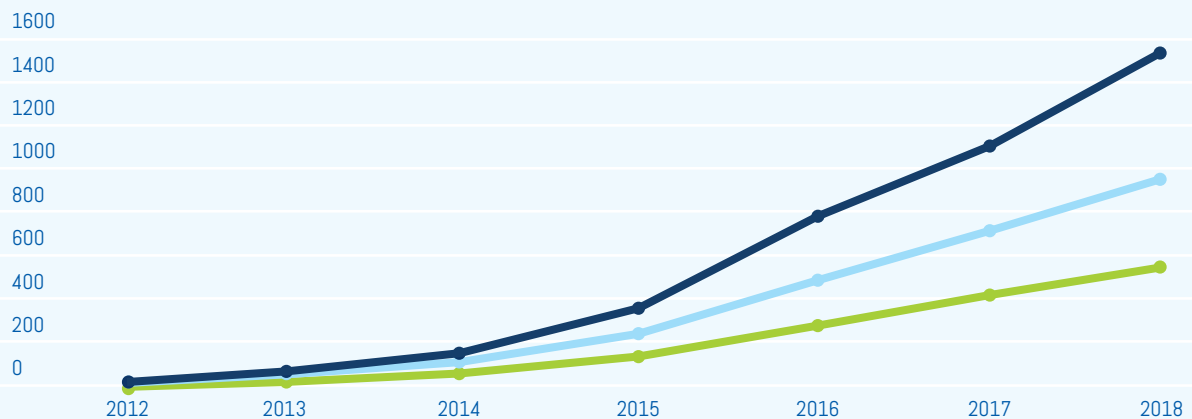
96%

TOTAL ACHIEVEMENT RATE BY END OF 2018

## Total outputs (traditional and non-traditional)

The number of outputs where CDPC research findings have been delivered has increased over the life of the CDPC

- Traditional
- Non-traditional
- Cumulative total outputs



Traditional outputs (e.g. peer-reviewed)

Non-traditional outputs (e.g. publication editorials, radio interviews, technical reports)

Scale of CDPC Implementation	Description	Impact and Case Study: Theme
Large scale implementation	Project outcomes have been disseminated and changed policy or practice in: <ul style="list-style-type: none"> <li>Federal government, national non-government or advocacy organisations, or</li> <li>Multiple organisations across most Australian states and territories</li> <li>Foreign national governments or international peak bodies.</li> </ul>	Clinical Guidelines Care Environments and Quality of Life Planning, Decision-Making and Risk
Medium scale implementation	Project outcomes have been disseminated and changed policy or practice in: <ul style="list-style-type: none"> <li>Organisations across 3–4 Australian states and territories</li> <li>More than one organisation in two or more international sites.</li> </ul>	Care Environments and Quality of Life Medication Management
Small scale implementation	Project outcomes have been disseminated and changed policy or practice in: <ul style="list-style-type: none"> <li>Organisations in 1–2 Australian states</li> <li>One organisation in one international site.</li> </ul>	Sustainable workforce
Pre-implementation	Collaborative research has been conducted and disseminated. Future implementation of this research is likely.	Attitudes to dementia

## Promoting the CDPC and its research outcomes

Active communication facilitates collaboration and acceptance of research outputs by end-users (industry, policymakers, public). Targeted communication has been central to achieving the CDPC aim of improving care of people with dementia, carers and families.

A comprehensive strategy of formal/informal and internal/external communication maximised the CDPC's effectiveness in achieving its overarching goals and objectives. Of importance were: exposure of CDPC's brand, vision; encouraging and seeking input via consultation and engagement; and communicating information in a way that is appropriate regarding language, context and message.

The collaborative nature of the CDPC meant it was essential that communication occurred both between and within CDPC internal and external stakeholders. Creating and strengthening relationships provided an environment for sustainability of CDPC funded initiatives and resources. Co-production and co-promotion with industry partners, consumers and external organisations meant many research findings are implemented into practice.

A challenge of communication was the diversity of stakeholder groups involved in the CDPC. To address this, the CDPC adopted the values of mutual respect and cooperation and adapted communications to ensure multiple perspectives were addressed.

### Through the life cycle of the CDPC the key messages were:

- Promote CDPC research findings and outcomes; increasing the likelihood of improving the lives of people with dementia and their carers
- The importance of the CDPC's unique structure involving end-users, including consumers and industry partners in the conception, design, conduct, dissemination and implementation of research; and the CDPC's influence as a facilitator of collaboration.

In addition to an overarching CDPC Communication Strategy, CDPC lead researchers were asked to complete a project specific communication plan. These increased the likelihood that projects would reach their full potential in practice and policy change. Embedding development of plans into reporting requirements ensured project teams considered the dissemination and implementation aspects of their project early.



## EVIDENCE FOR CHANGE (as of July 2019)

## CDPC Network

**200+**RESEARCHERS  
(ACADEMIC, SYSTEMS  
AND CONSUMER BASED)**4**INDUSTRY  
PARTNERS**32**RESEARCH  
PROJECTS**1675**

OUTPUTS

**800+**ORGANISATIONS REPORTED  
AS IMPLEMENTING CHANGE  
AS A RESULT OF CDPC  
RESEARCH

## Resources

GUIDELINES AND  
ASSOCIATED CONSUMER  
GUIDELINESPROJECT  
REPORTSACADEMIC  
PUBLICATIONSONLINE  
TRAINING  
PACKAGES

VIDEO



WORKSHOPS



WEBINARS

## Promotion

**109K**SITE VISITS TO  
THE CDPC WEBSITE  
(CDPC.SYDNEY.EDU.AU)**846**TWITTER  
FOLLOWERS**100+**LIKES ON  
FACEBOOK**50**POSTS ON  
YOUTUBE**1010**E-NEWSLETTER  
SUBSCRIBERS**560+**CONFERENCE  
PRESENTATIONS**33**

MEDIA RELEASES

**569**MEDIA COVERAGE  
(RADIO, ONLINE PRESS,  
TV AND TRADE PRESS)**10+**INDIVIDUAL  
RESEARCHER  
AWARDS, PRIZES**12**CONFERENCES AS  
SPONSOR/EXHIBITOR

## Every Three Seconds

CDPC research was highlighted in the international program, 'Every Three Seconds' that reached a global audience of millions. The program brought together international experts in the dementia field and was premiered at the 33rd International Conference of Alzheimer's Disease International (ADI).

[youtu.be/QcgUOER1KTW/](https://youtu.be/QcgUOER1KTW/)



## Evidence of need for change



# EVERY 3 SECONDS

A PERSON AROUND THE WORLD IS DIAGNOSED WITH DEMENTIA



## 447,115

AUSTRALIANS LIVING WITH DEMENTIA



## 2ND

LEADING CAUSE OF DEATH OF AUSTRALIANS



## 1.5 MILL

AUSTRALIANS ARE INVOLVED IN CARING  
FOR SOMEONE WITH DEMENTIA



## 50%+

OF PEOPLE IN RESIDENTIAL AGED CARE  
HAVE A DIAGNOSIS OF DEMENTIA



## 70%+

OF PEOPLE WITH DEMENTIA  
LIVE IN THE COMMUNITY



## 3%

OF AUSTRALIA'S CURRENT  
WORKFORCE IS IN AGED CARE

*(Dementia Australia Statistics 2019, Australian Institute of Health and Welfare, Services and places in aged care, 2016–17)*

# CLINICAL GUIDELINES FOR DEMENTIA

The Clinical Practice Guidelines and Principles of Care for People with Dementia give health professionals and carers access to recommendations reflecting current evidence on best practice dementia care. An associated companion guide allows people with dementia, families, and carers, to be fully informed.



Website: [cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/](https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/)

A photograph of three women at a conference booth, looking at a document. The image is overlaid with a blue tint. The woman on the left is holding the document, while the other two are looking at it. They are all wearing lanyards. In the foreground, there are stacks of the 'Clinical Practice Guidelines and Principles of Care for People with Dementia' booklet, which features a stylized brain graphic on the cover.

“

These clinical practice guidelines, in both formats, are invaluable for patients, carers and the public as they outline the type of care they should expect and ask for. They inform and enable people to ask questions; they can help people to anticipate what to expect when seeing a healthcare professional or having an intervention. And, ultimately they can facilitate implementation of best available evidence into practice.”

*Jane Thompson (Dementia Advocate)*

# CLINICAL GUIDELINES FOR DEMENTIA

The release of the 'Clinical Practice Guidelines and Principles of Care for People with Dementia' in 2016 was a major and early outcome for the CDPC.

These first Clinical Guidelines for Dementia in Australia continue to inform clinicians on what constitutes quality and consistency of treatment and care of people with dementia.

Approved by the National Health and Medical Research Council, the Guidelines detail optimal diagnosis and management in community, residential and hospital settings; guiding practice in treating people with dementia. The Guidelines facilitate adoption of the latest evidence and research by synthesising current information on dementia care for clinical practitioners, to deliver an agreed standard of practice.

The 'Clinical Practice Guidelines and Principles of Care for People with Dementia: Recommendations' outlines 109 clear and concise recommendations relevant for health and aged care professionals to apply in their workplaces to respond to the needs and preferences of people with dementia and their carers. The recommendations are classed as 'Evidence-based recommendations', 'Consensus based recommendations' or 'Practice points.'

## Accessible guide for people with dementia and their carers

A consumer companion guide entitled 'Diagnosis, treatment and care for people with dementia: A consumer companion guide' was also developed with substantial input from people with a lived experience with dementia. It provides practical guidance for people with signs and symptoms of dementia and their carers and/or advocates on what to expect with diagnosis, treatment and care options.



## Guidelines build clinical and community knowledge

Dr Linda Xu, a doctor and a Geriatrics Advanced Trainee at Hornsby Ku-Ring-Gai Hospital, knows the guidelines through its promotion at conferences, registrar training and lectures from Professor Kurrle.

"The guidelines have become a foundation that I can build further clinical knowledge on for the management of dementia".

"They are evidence-based and easy to read," she said.

The Consumer Companion Guide provides the public with the latest knowledge on how to treat people with dementia and how to understand their behaviour and promote social inclusion. CDPC Network Members have presented the Dementia guidelines and Consumer Companion Guide around Australia at Community Council Forums, Church Groups, Community Organisations, and Public Lecture Tours.



## Recommendations at a glance

**Person-centred** – individualised care responding to the needs and preferences of people with dementia and their carers.

**Timely diagnosis** – early signs of dementia such as memory loss are not dismissed as normal ageing and should be investigated.

**Symptom management** – use of pharmacological and non-pharmacological interventions

**Living well** – good nutrition, enjoyable exercise, staying involved with work or other mental activity, and being as independent as possible.

**Appropriate training of staff** – has shown to reduce symptoms such as agitation, reduce the use of physical restraints, and improve quality of care.



## EVIDENCE FOR CHANGE

# 1.5K

HARD COPIES OF CLINICAL  
GUIDELINES RECOMMENDATIONS  
DOCUMENT DISTRIBUTED  
NATIONALLY TO AGED AND  
HEALTH CARE ORGANISATIONS

# 200+

ORGANISATIONS REPORTED  
AS IMPLEMENTING CHANGE  
ASSOCIATED WITH THE  
GUIDELINES

# 300+

PAGE VIEWS/WEEK, MOST  
VIEWED PAGE ON CDPC  
WEBSITE SINCE LAUNCH

# 2<sup>IN TOP</sup> 5%

OF ALL RESEARCH OUTPUTS  
SCORED BY ALTMETRIC

# 60+

CONFERENCE PRESENTATIONS/  
MEETING AND WORKSHOPS  
(NATIONAL AND INTERNATIONAL)

# 100+

(103) MEDIA COVERAGE/  
DIGITAL CONTENT/INDUSTRY  
MAGAZINES



## RESEARCH IMPACT

- ▶ Referenced in Background Papers released by the Royal Commission on Aged Care Quality and Safety
- ▶ Referenced in Ireland's National Clinical Guideline: Appropriate Prescribing of Psychotropic Medication in People with Dementia
- ▶ Directed government funding initiatives: NHMRC call-out for funding applications to implement the Guidelines in 2016
- ▶ Influencing clinical practice: Guidelines included in the NSW Health Dementia Care Competency Framework online training resource for clinicians, GP Health Pathways, TAFE Certificate III in Aged Care, Resource for Aged Care Quality Standard 3, many university health science and medicine courses
- ▶ Informing health and aged-care services: Guidelines embedded into the Cabrini Aged Care Integrity Guidelines for Care, Montefiore Aged Care Policies and Practices, used by Dementia Support Australia, Australian Aged Care Quality Industry, on My Aged Care website
- ▶ Adapted for the development of Dementia Guidelines in Colombia, Vietnam and Germany
- ▶ Improvements in health systems practice with the guidelines used by Vietnam as a basis for their National Dementia Strategy.

## Australian Clinical Guidelines form basis for International Dementia Plan (Vietnam)

With one person every three seconds diagnosed with dementia worldwide, countries are developing policies and strategies to align with the World Health Organization's aim for every country to have a Dementia Plan.

The Australian Clinical Guidelines were translated into Vietnamese, and the Australian team were invited to a conference in Vietnam to inform development of a National Dementia Plan in response to the growing number of people (1.3M at 2018) with dementia in Vietnam.

“ The guidelines are a great resource... during the process of 'Administrative and policy assessment and intervention alignment' of our plan development, the guidelines will be a key reference to develop the potential packages of interventions for dementia in Vietnam.”

*Dr Tuan Anh Nguyen*

The Vietnamese government brought together the country's leading geriatricians, health policy and international experts on dementia to the September 2018 conference in Hanoi entitled, 'Dementia as a public health priority – the need for the development of Vietnam's national dementia plan'.

CDPC Director Professor Kurrle accompanied Dr Tuan Anh Nguyen, Professors Maria Crotty and Associate Professor Craig Whitehead. They provided an overview of dementia services in Australia, the Clinical Practice Guidelines and Principles of Care for people with Dementia and the latest evidence on dementia prevention and management.

The Australian team continues to work closely with Vietnamese researchers and policy makers.



Website: [cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/](http://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/)



# CARE ENVIRONMENT & QUALITY OF LIFE

The environment where care is delivered greatly impacts quality of life. CDPC researchers have examined community, acute, and residential care environments to inform policymakers, care providers, and people with dementia and their families about what are optimal care environments.



Website: [cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/](https://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/)

The background of the lower half of the page is a photograph of two people, an older man on the left and a woman on the right, both smiling warmly. The image is overlaid with a semi-transparent teal filter. A large white opening quotation mark is positioned to the left of the quote text.

“

Regardless of the physical position of where people live, it is their home. The physical environment, and the support and care they receive to assist them to maintain their everyday activities will result in the best Quality of Life opportunities.”

*Glenys Petrie (Dementia Advocate)*



# MODELS OF RESIDENTIAL CARE FOR PEOPLE WITH DEMENTIA

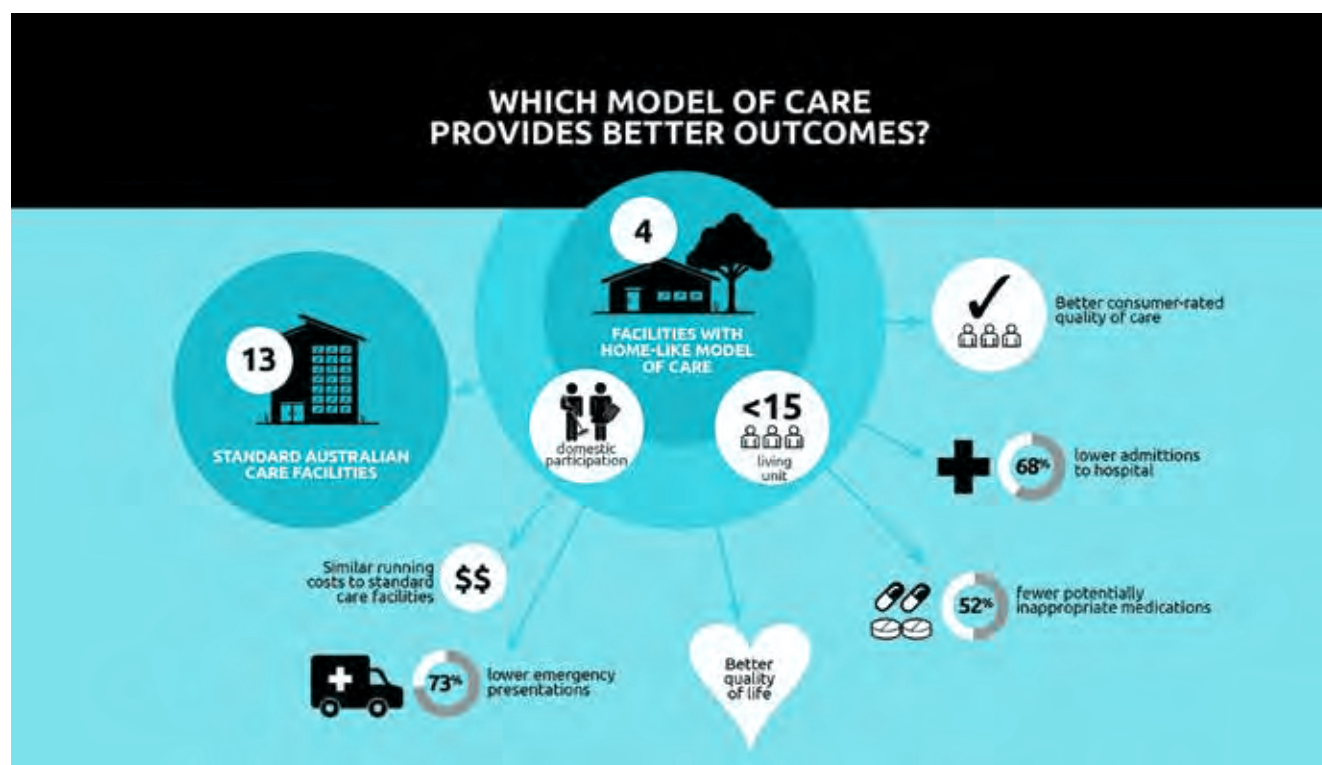
Where we live as we get older is not a question that many Australian's consider until there is a change in health status or cognitive ability.

A diagnosis of dementia can mean that as the disease progresses the person will no longer be able to stay at home and decisions to move into an environment where increased level of care is needed.

The environment in which we live and receive care impacts our quality of life. The CDPC project *'Investigating Services Provided in the Residential care Environment of Dementia in Australia (INSPIRED)'* by Professor Maria Crotty and her team (Flinders

University) compared home-like or cluster model of care with a standard residential aged care model and examined resource use, medication use, hospitalisation and quality of life.

The study collected data in 17 residential aged care organisations (13 standard and 4 home-like care facilities) from 541 participants including those with a diagnosis of dementia.





A key finding was that living in smaller home-like models was associated with a better quality of life for residents of aged care. Residents were less likely to be prescribed inappropriate medication or be admitted to hospital or emergency departments.

Researchers found that going outside daily was associated with a better quality of life for people living in residential aged care. A review of the views of residents, staff and family members examined the barriers to getting outdoors and found the design of the outdoor areas were important. Easy access from inside, unimpeded doorways, outdoors paths, appropriate seating areas with plants and vegetation were found to be important. Perceptions of safety was also important.

## Medication use in aged care

Inappropriate prescribing can adversely affect a person's quality of life and has been associated with an increased risk of hospitalisation and mortality. The Clinical Practice Guidelines and Principles of Care for People with Dementia recommend using non-pharmacological interventions in the first instance and avoiding the use of the antipsychotics where possible.

Medication data obtained from the INSPRED study showed ninety-eight percent of aged care residents were prescribed more than five medications, and 71% were prescribed more than 10 in a 12-month period. The paper [\*'Patterns of medication prescription by dementia diagnosis in Australian nursing home residents: a cross-sectional study'\* \(Liu et al., 2019\)](#) described what medications are more or less likely to be prescribed to people with dementia.

One quarter were prescribed the common antipsychotic drug risperidone and were nine-fold more likely to receive it over a 12-month period than residents without dementia. In contrast, residents with dementia were less likely to be prescribed medications used for the management of cardiovascular and respiratory disease.



### Guideline Recommendations 69–98

## Measuring quality of care from the consumer's perspective

Gaining an understanding of what quality of care means to people living in residential aged care is critical to provide optimal person-centred care. A CDPC research paper published in the International Journal of Quality in Health Care was the first to ask Australian residents living in a home-like or standard model of residential care to rate the quality of the care they receive.

Conducted at Flinders University, Rehabilitation and Aged Care, as part of the INSPiRED study, a simple questionnaire was developed and validated called the Consumer Choice Index – 6 Dimension (CCI-6D), to enable assessment of the quality of care from the perspective of residents or their family members.

The amount of the care time provided was rated as similar between types of care homes, however the residents and family members rated being able to get outside whenever they wanted, and flexibility of the care routines as better in clustered domestic models of care.

“ Given the majority of costs incurred by people living with dementia in residential care are borne by either the Australian or state governments, our findings are significant for informed, reliable policymaking.”

*Dr Emmanuel Gnanamanickam (Researcher)*



## RESEARCH IMPACT

- ▶ Recognised as significant new research through citation in three Background Papers released by the Royal Commission on Aged Care Quality and Safety and the Australian Financial Review.
- ▶ Data from Medical Journal of Australia publication **Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life** was shared through extensive media coverage ABC podcasts, radio interviews, broadsheet article (The Australian), online media including The Conversation.
- ▶ Referenced by Federal Minister in a speech at a national dementia conference as important research in the improvement of care for people with dementia.
- ▶ Referenced by International architect and design firm on designing residential aged care facilities at the LASA conference in Australia.
- ▶ Group Homes Australia used research findings as evidence their services are in line with best-practice
- ▶ Evidence from study adopted during the planning of aged care site (Montefiore) for improvements in quality of life and resource use.
- ▶ Evidence adopted by Independent Care Solutions
- ▶ Referenced in the International Design School training courses offered by The Dementia Centre, the Dementia Cottage Experience; and the virtual reality dementia tours.

### Uptake of the CCI-6D research tool

- Presentation at the South Australian Senate Inquiry into aged care quality assessment and accreditation
- Adopted by Dementia Training Australia as part of their aged care training packages
- Trialled by SA Health in a residential aged care facility.



## EVIDENCE FOR CHANGE



1

WEBSITE



30

ACADEMIC  
PUBLICATIONS



50

CONFERENCE  
PRESENTATIONS/  
WORKSHOPS



10

MEDIA RELEASES



100+

ONLINE AND PRINT MEDIA, RADIO  
INTERVIEWS, PODCASTS AND  
TELEVISION (MEDIA COVERAGE)



Website: [cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/models-of-care/](https://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/models-of-care/)



# IMPROVING HOSPITAL CARE OF OLDER PATIENTS

Some people may experience significant distress, anxiety and increased confusion when admitted to hospital and removed from familiar people and surroundings.

The Care of the Confused Hospitalised Older Persons Program (CHOPs) was undertaken to improve care, experiences and outcomes for people with dementia or delirium who are admitted to hospital.

The CHOPs project, led by Professor Kurrle (University of Sydney), in collaboration with the Agency for Clinical Innovation (ACI), developed a sustainable model of care that uses a framework derived from best practice evidence for identification, risk assessment and management of dementia and delirium in older people in hospital settings.

The CHOPs program educates health professionals on seven key principles of care. It includes: resources for carers and family members on delirium and antipsychotic medications; the 'Sunflower tool'; and 'This is Me' and 'My Story' templates, to assist staff in delivering person-centred care.

The approach of the CHOPs program of raising awareness, staff education, carer involvement and environmental modification has important health, social and policy impacts; providing hospitals with a framework to readily respond to people presenting with delirium and dementia.



## RESEARCH IMPACT

- ▶ Program adopted by at least 18 hospitals across multiple Australian states; improving service effectiveness and health outcomes
- ▶ CHOPs principles adapted by Monash Health to develop a Dementia and Delirium initiative with initial evaluation showing improved service effectiveness and patient outcomes
- ▶ Royal Brisbane and Women's Hospital adopted and adapted the CHOPs seven key principles, adding an additional principle
- ▶ CHOPs 7 key principles were adopted in the South German PAWEL study exploring patient outcomes and reduction of delirium risk and post-operative decline after elective surgery
- ▶ Hospitals RBK Stuttgart and Mannheim Hospitals in Germany plan to implement translated key principles.



## Guideline Recommendations 11–12



## Seven (7) Principles of Care

1. Cognitive Screening	Focus on clinical practice
2. Delirium risk identification and prevention strategies	
3. Assessment of older people with confusion	
4. Management of older people with confusion	
5. Communication to support person-centred care	Focus on enablers. To facilitate successful implementation
6. Staff education on caring for older people with confusion	
7. Supportive care environments for older people with confusion	



Website: [cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/care-environment-and-quality/](https://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/care-environment-and-quality/)

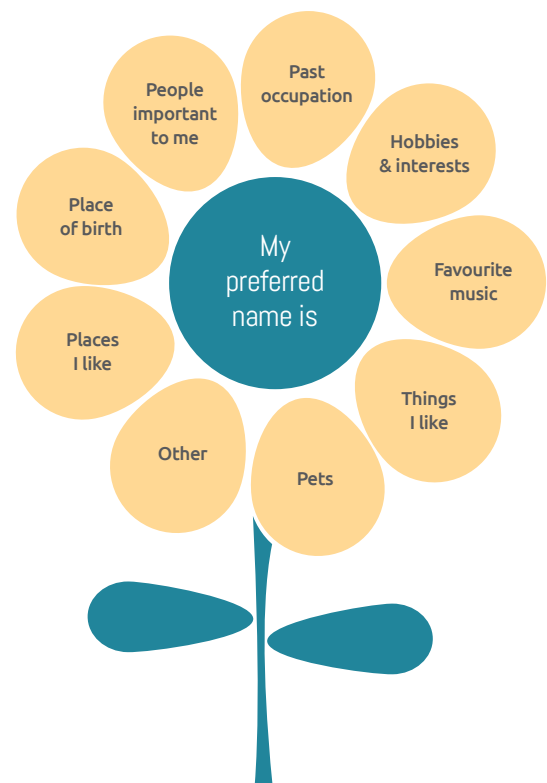
## Recognising the person not the illness

“ We are so passionate about the sunflower tool. It is not just a piece of paper on the patient's wall; that Sunflower represents the person we need to know to be able to care for.

The patient's preferred name is written in the centre of the flower and each of the petals (has details of family, interests, hobbies etc) is a prompt to start a conversation, that is, 'Were you born in Broken Hill or are you from far away? What are your hobbies and interests? Do you have a pet?

The tool is simple, it's visual and doesn't require a lot of writing by staff. We capture a lot of patient information this way and the Sunflowers are being completed 100% of the time. The feedback we hear from our patients is that we are interested in them.”

*Eureka van der Merwe, Nurse Manager*



# VOLUNTEER PROGRAM IMPROVES PATIENT WELL-BEING

Patients with dementia and delirium are highly vulnerable in hospitals, with greatly increased risk of adverse outcomes and death.

The fear and anxiety they experience in the unfamiliar environment and their acute medical conditions can often result in changed behaviours. This in turn can cause stress for both family carers and staff.

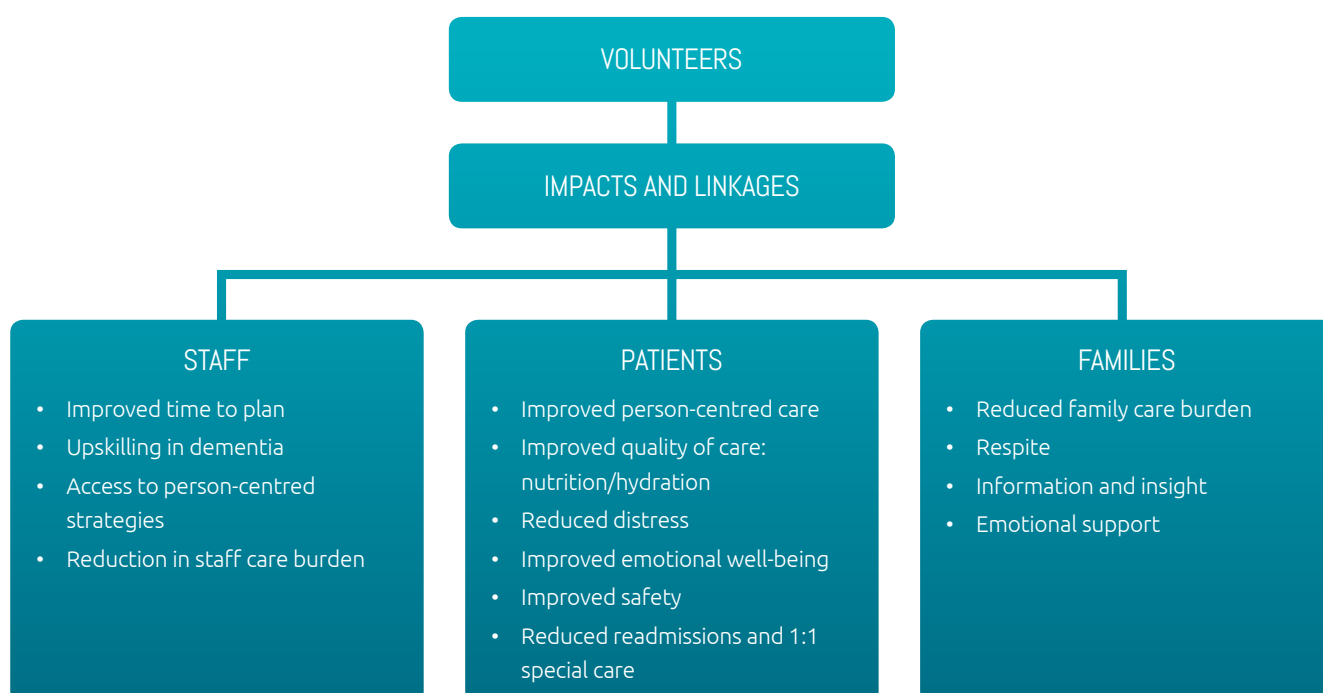
Nurses have highlighted lack of time as a barrier to supporting necessary emotional and safety care needs for these patients.

The Volunteer Dementia and Delirium Care program (VDDC) was implemented at Bega Hospital by Catherine Bateman (NSW Health) in 2009. The program recruits and trains volunteers to provide person-centred, one-to-one emotional and practical support to reduce risk and improve physical and emotional well-being of people with dementia or delirium.

In 2015 the CDPC supported program was further rolled out and evaluated in another seven NSW rural hospitals to determine the impact on patient outcomes, staff and families. Program implementation resulted in a decrease in the need for one to one nurse specials and reduced 28 day readmissions as well as a reduction in both staff and family care burden.



Guideline Recommendations 11, 12, 79



“ It is fantastic to have their wonderful support. It is really helping with the overall staff workload. Excellent.”

*Staff member*

“ Made me feel safe while I could not be with him. They were so caring, understanding and very patient. We cannot do without them. Bless them and keep the programme going.”

*Family member*



## EVIDENCE FOR CHANGE



70

FOLDER COPIES OF THE VDDC IMPLEMENTATION AND TRAINING RESOURCE HAVE BEEN DISTRIBUTED TO CLINICIANS IN NSW, QLD, WA AND SA



146

CLINICIANS HAVE ACCESSED THE WEB-BASED RESOURCE IN NSW, VIC, TAS, SA, QLD, WA AS WELL AS INTERNATIONALLY IN NZ, US AND UK



## RESEARCH IMPACT

- ▶ Adopted by 15 NSW hospitals and two in WA
- ▶ Adapted for the residential aged care setting at Bundaleer Aged Care Wauchope NSW
- ▶ Informed further research in implementation of the program in metropolitan acute settings in WA and in both acute and community settings in Victoria.



**Resource:** [aci.health.nsw.gov.au/resources/aged-health/confused\\_hospitalised\\_older\\_persons/dementia-and-delirium-care-implementation-training/](https://aci.health.nsw.gov.au/resources/aged-health/confused_hospitalised_older_persons/dementia-and-delirium-care-implementation-training/)



**Website:** [cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/care-environment-and-quality/](https://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/care-environment-and-quality/)



# ECONOMIC MODEL TO PREDICT FUTURE DEMENTIA CARE COSTS


As Australia's population ages, the number of people with dementia is expected to increase and this will result in an economic impact on the health care system.

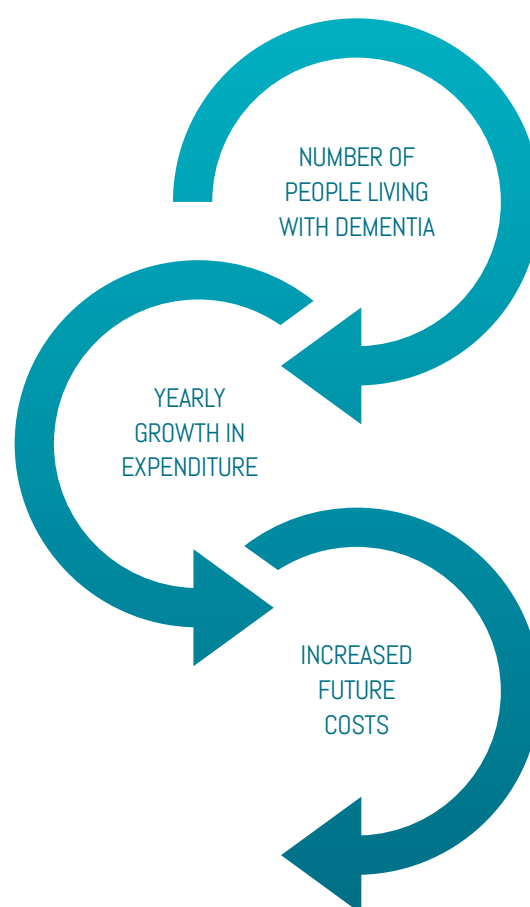
This project, by Associate Professor Tracy Comans and team (Griffith and University of Queensland), developed a validated model to predict costs associated with supporting the healthcare need for people with dementia. The model enables investigation of scenarios where there is a changing demand for resource use and resources available.

The study, published in the Australian Health Review, used large linked individual patient datasets to generate quantitative estimates of future demand on hospitals, permanent and respite residential aged care, transitional care and aged care assessment, and community care programs.

## RESEARCH IMPACT

- Policymakers setting resource and investment levels for the Australian health and aged care system have a tool to assist them in the decision-making process.

 **Website:** [cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/measuring-care-quality/](https://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/measuring-care-quality/)





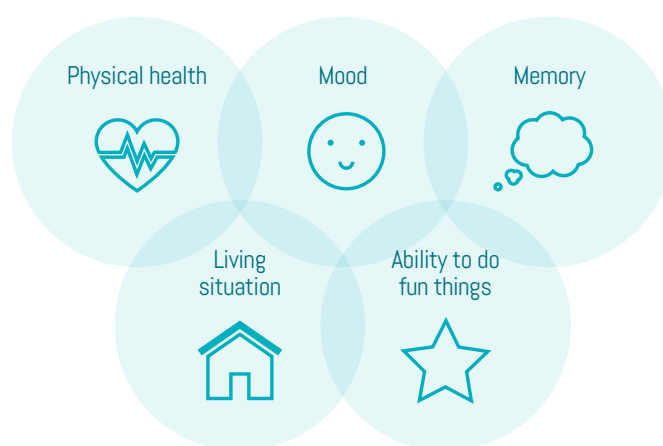
# MEASURING QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA

With the economic and social cost of dementia increasing, evidence-based interventions developed to improve the lives of people with dementia need to be cost-effective if they are to be sustainable.

The Quality of Life project team, by Associate Professor Tracy Comans and team (Griffith and University of Queensland), developed a new dementia specific quality of life classification system that captures aspects of quality of life that are important to people with dementia. Standard quality of life measures for people with dementia do not integrate economic evaluation of care interventions.

The AD-5D is a preference-based tool to enable people with dementia to rate the importance of five aspects of their daily life (AD-5D health states); physical health, mood, memory, living situation and ability to do fun things. Using survey results and one on one interviews with people with dementia, caregivers and the community, the study calculated the importance of the five domains allowing for a standard Quality of Life in Alzheimer's Disease to be applied to value interventions of people living with dementia.

## AD-5D health states



The study then used a qualitative think aloud approach to assess the decision-making processes applied by people with dementia and family carers as they participate in valuing the five health states.

Data collected using the AD-5D can help in economic decision-making and provide an assessment of dementia care services from the perspective of people with dementia and their carers.



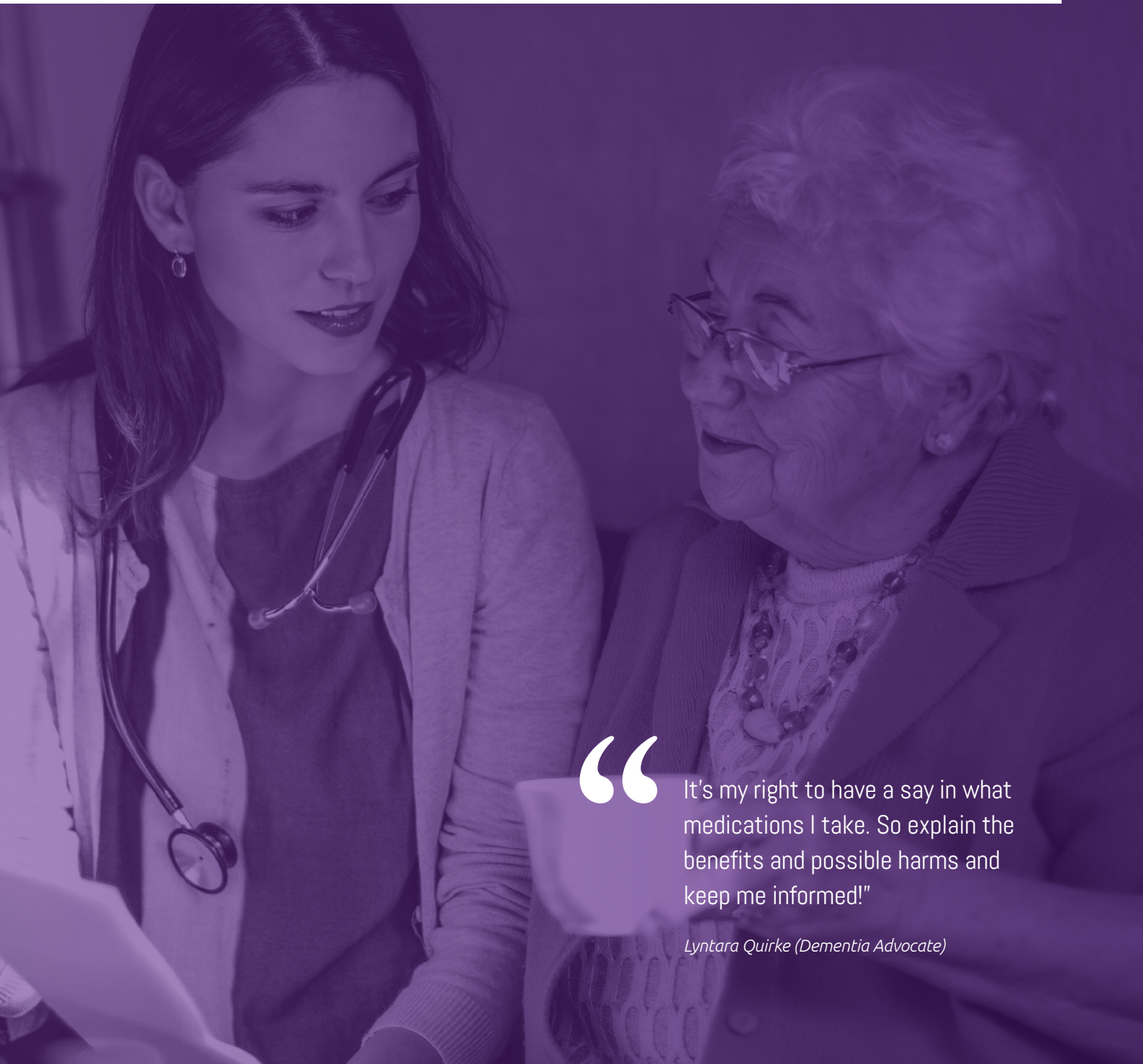
Website: [cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/measuring-care-quality/](https://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/measuring-care-quality/)

# MEDICATION MANAGEMENT

For people living with dementia, management of appropriate medication can be challenging. While medicines can control symptoms and prevent disease, they can also cause harm. The medication management research outcomes, resources and recommendations provide clinicians, pharmacists, aged care providers, policymakers, and people with dementia and their families with evidence-based information on medication management strategies in a variety of settings.



Website: [cdpc.sydney.edu.au/research/medication-management/](https://cdpc.sydney.edu.au/research/medication-management/)



“

It's my right to have a say in what medications I take. So explain the benefits and possible harms and keep me informed!"

*Lyntara Quirke (Dementia Advocate)*



# REDUCING UNNECESSARY MEDICATION ADMINISTRATION IN AGED CARE

Medication administration in residential aged care can be complex, and burdensome for residents and staff administering medications.

This collaborative research project, conducted by Professor Simon Bell and team (Monash University) brought together aged care providers, health professionals, consumers and carers to develop and trial a validated tool to reduce unnecessary medication complexity and consolidate medication administration times.

A five-step tool, the Medication Regimen Simplification Guide for Residential Aged Care (MRS GRACE), was developed. Validation of MRS GRACE by two pharmacists showed that medication regimens could be simplified for 3 out of 5 residents. The Simplification of Medications Prescribed to Long tErM care Residents (SIMPLER) study was a cluster-randomised controlled trial across eight residential aged care sites which investigated the application of MRS GRACE.

## What factors need to be considered when health professionals are looking to simplify medication administration using MRS GRACE

1. What are the resident, and family's, preferences with regards to medication administration
2. Regulatory factors that might impact on simplification
3. Interactions between medications that might prevent simplification
4. Different types of medication formulations available
5. Whether there are any potential unintended consequences as a result of simplification.

## Residents participating in the SIMPLER study



99 residents  
randomised  
to receive intervention



143 residents  
randomised to  
comparison group  
(usual care)

Medication  
simplification  
possible for 65%  
of residents

Significant  
reduction in no.  
of administration  
times at 4 months  
follow-up compared  
to comparison group

**242**

PARTICIPATING RESIDENTS

**9**

MEDICATIONS  
PRESCRIBED  
FOR REGULAR USE

MEDICATIONS ADMINISTERED

**4**

TIMES  
PER  
DAY

The study involved embedding Research Fellow, Dr Janet Sluggett (Monash University), within the aged care organisation that was participating in the research. Having the researcher embedded within the organisation supported co-design and collaboration, increasing the likelihood of implementation success and sustainability.

An economic analysis of the true costs and benefits of the medication simplification, and a process evaluation examining barriers and enablers to implementing this model in residential aged care more widely is also being investigated. This will provide aged care provider organisations with more detailed information about the impact of medication simplification and inform decisions about implementing new models of care.



**Website:** [cdpc.sydney.edu.au/research/medication-management/reducing-medication-complexity/](https://cdpc.sydney.edu.au/research/medication-management/reducing-medication-complexity/)





# DEVELOPMENT OF NATIONAL PLAN TO REDUCE UNNECESSARY MEDICATION USE

Taking too many medicines can have serious side effects, including falls, confusion, loss of independence, extra hospital admissions and deaths.

Over-prescribing also has an economic impact, adding hundreds of millions of dollars to annual medicine expenditure.

The report, *'Quality Use of Medicines to Optimise Ageing in Older Australians: Recommendations for a National Strategic Action Plan to Reduce Inappropriate Polypharmacy'*, developed by CDPC researchers at the University of Sydney, in collaboration with the Australian Deprescribing Network and NPS MedicineWise, aims to halve harmful or unnecessary medicines use by older Australians within five years.

A National Strategic Action Plan would address seven actions across four domains of health care: health policy and regulatory environment, health care organisations, health care professionals, and the broader public and recipients of care.

## It would:

1. Raise awareness of the significant challenges polypharmacy creates for individuals and society
2. Provide an integrated cohesive National Strategic Action Plan for a wide spectrum of stakeholders and settings to use when designing their own plans for reducing polypharmacy and optimising medicines use in their population
3. Highlight the activities and resources needed as part of an effective cohesive framework to inform funding and policy decisions.

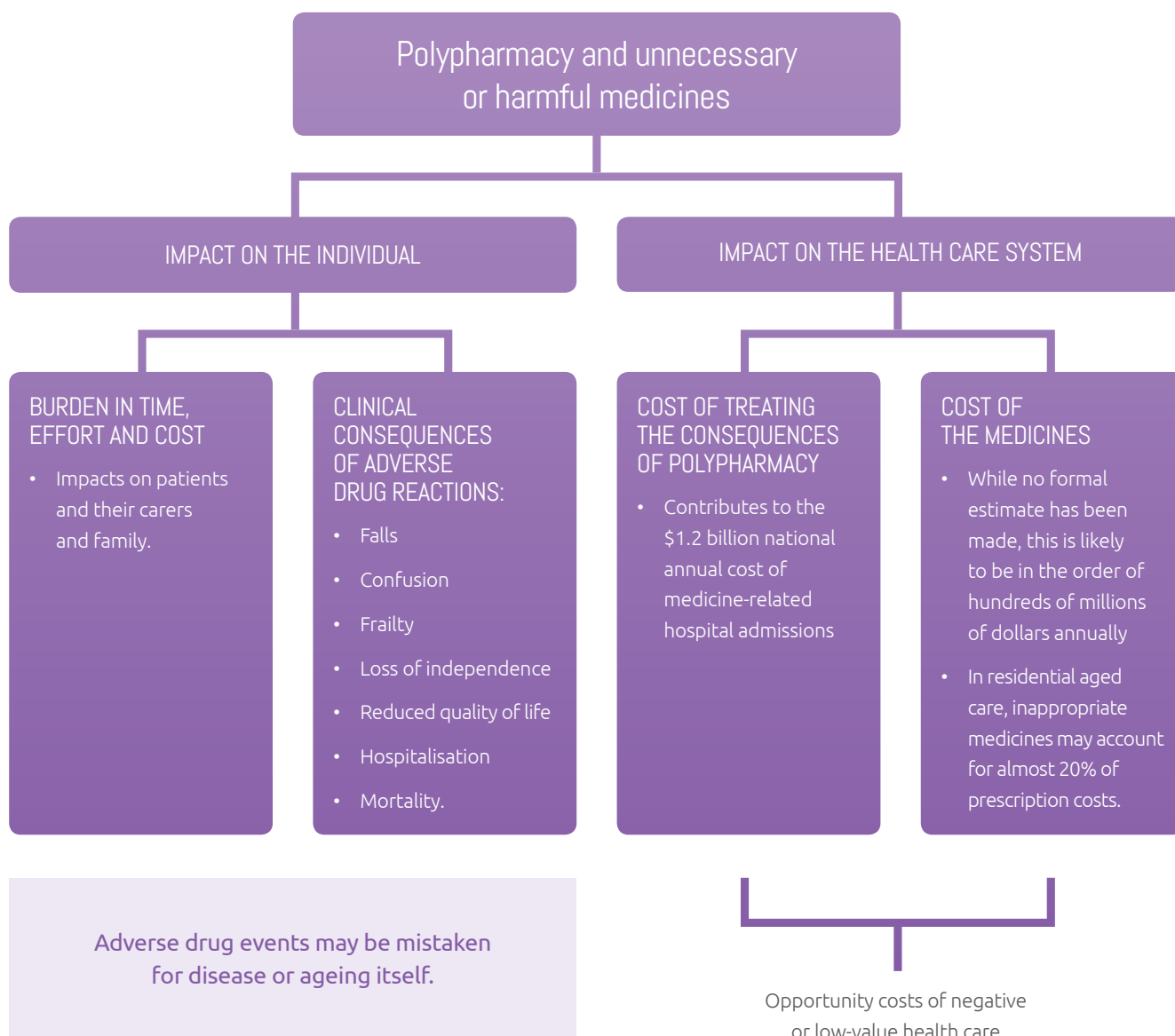


CDPC researcher Professor Sarah Hilmer believes change in medication use can only be widely achieved with a coordinated approach that integrates action by government, doctors, pharmacists and relevant stakeholders.

“ There is increasing evidence that withdrawal of harmful or unnecessary medicines is safe and benefits the individual and the community.”

*Professor Sarah Hilmer*

## Polypharmacy and unnecessary or harmful medicines



**Website:** [cdpc.sydney.edu.au/research/medication-management/quality-use-of-medicines/](https://cdpc.sydney.edu.au/research/medication-management/quality-use-of-medicines/)

## Guidelines to reduce medications

Cholinesterase inhibitors and memantine are the most commonly prescribed medications for dementia treatment. Use of these medications involves prescribing them for individuals who may benefit and withdrawing them for individuals where the harms may outweigh the benefits.

The 'Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine', developed by CDPC researcher, Dr Emily Reeve (University of Sydney), in conjunction with the Bruyère Research Institute (Canada), gives doctors and other healthcare professionals an important tool to navigate the complex process of optimising use of these medications for people living with dementia.

The guidelines are endorsed by The Australian and New Zealand Society for Geriatric Medicine; 'support the principles of appropriate use of medications in older people and welcome the development of these recommendations to guide clinicians and aid consumers in the goal of better, more individualised prescribing and deprescribing in older people with dementia'.

Recommendations reflect current evidence about when and how to trial withdrawal and emphasise the need to consider the individual as well as their values, preferences and goals of care. The recommendations were approved by the National Health and Medical Research Council (NHMRC) as meeting the NHMRC standard for clinical practice guidelines.

### Key recommendations

- Identify people suitable for a trial deprescribing of cholinesterase inhibitors and memantine
- Taper treatment and monitor people during the withdrawal process
- Deprescribing should involve shared decision making with individuals and their carers



Guideline Recommendations 69–75



Website: [cdpc.sydney.edu.au/research/medication-management/deprescribing-guidelines/](https://cdpc.sydney.edu.au/research/medication-management/deprescribing-guidelines/)



# NEW TOOLS PROVIDE PERSON-CENTRED APPROACH TO MEDICATION REVIEWS

Most older people report that they would like to stop a medicine if their doctor said they could.

Professor Sarah Hilmer and her team (University of Sydney) developed and validated tools that consider an older person's goals of care and facilitate shared decision-making about optimal medication use.

The Goal-directed Medication review Electronic Decision Support System (G-MEDSS) © is a web-based platform that allows healthcare practitioners, conducting medication reviews, to tailor care to meet their goals and preferences for older patients with and without dementia. G-MEDSS, allows pharmacists to use a Computerised Clinical Decision Support Systems (CCDSS) in combination with a pharmacist-led home medicines review (HMR) in collaboration with the patient and the GP to help reduce potentially harmful medications.

G-MEDSS includes The Drug Burden Index (DBI) Calculator ©, which measures exposure of older adults to anticholinergic

and sedative medications that can impair physical and cognitive function.

G-MEDSS includes the revised Patients' Attitudes Towards Deprescribing questionnaire that has been developed and validated for older people, their carers, and for people living with cognitive impairment. Understanding patient attitudes can inform and guide medication review decisions and this third tool in G-MEDSS helps clinicians identify their patients' goals of care at the time of medication review, both globally and those specific to medication management.



Website: [cdpc.sydney.edu.au/research/medication-management/med-review-tool/](http://cdpc.sydney.edu.au/research/medication-management/med-review-tool/)



2 OUT OF 3

AUSTRALIANS OVER THE AGE OF 70 ARE TAKING 5 OR MORE MEDICATIONS



63%

OF RESIDENTS OF AGED CARE FACILITIES TAKE 9 OR MORE MEDICATIONS REGULARLY



9 OUT OF 10

OLDER PEOPLE SAY THAT THEY WOULD LIKE TO STOP ONE OF THEIR MEDICINES IF THEIR DOCTOR SAID THEY COULD





## EVIDENCE FOR CHANGE (PROJECTS PAGES 30 – 35)



48

PEER REVIEWED  
PUBLICATIONS

8

MEDIA  
RELEASES

60+

MEDIA  
COVERAGE BOTH  
NATIONALLY AND  
INTERNATIONALLY

124

CONFERENCE  
PRESENTATIONS,  
MEETINGS AND  
WORKSHOPS

1

CLINICAL  
PRACTICE  
GUIDELINE

100+

COPIES OF THE NATIONAL  
STRATEGIC ACTION  
PLAN DISTRIBUTED  
TO UNIVERSITIES,  
ORGANISATIONS, OR  
HEALTH DEPARTMENTS

## RESEARCH IMPACT

- ▶ Summary of guideline published in Medical Journal of Australia sits in 2019 top 5% of all research outputs by Altmetric
- ▶ The guideline app (with the 4 other deprescribing guidelines) released in March 2019 had over 2000 downloads by August 2019
- ▶ The algorithm in the guideline has been translated into 3 different languages for use in research and teaching materials
- ▶ The guideline has been cited in international guides and publications including WHO Medication Safety in Polypharmacy technical report '*Medication Safety in Polypharmacy*'
- ▶ The revised Patients' Attitudes Towards Deprescribing questionnaire adopted in over 50 research studies and translated into 11 different languages
- ▶ National Action Plan is informing the government's response to the World Health Organisation's Third Global Patient Safety Challenge: Medication without harm.
- ▶ The project outcomes have been referenced in professional organisation publications and resources (Pharmaceutical Society of Australia, Dementia Training Australia)
- ▶ Chief Clinical Advisor to the Aged Care Quality and Safety Commission met with CDPC researchers to discuss implementation of strategies to minimise psychotropic use in Australia
- ▶ Pharmaceutical Society of Australia (PSA) expressed interest in exploring options for funding some of the action plan recommendations
- ▶ Implementation of G-MEDSS underway in Australia, Canada (hospitals) and the UK (outpatient clinics)
- ▶ Interest from aged care organisations to incorporate G-MEDSS into their medication review procedures
- ▶ Application made to University of Sydney Commercial Development and Industry Partnerships (CDIP) to facilitate widespread implementation of G-MEDSS
- ▶ This research was presented during expert witness testimony provided at a public hearing of the Royal Commission into Aged Care Quality and Safety
- ▶ The study is informing policy and practice about simplifying medication use in residential aged care facilities and among older people receiving community aged care services in their own home
- ▶ Discussions are continuing with clinicians, researchers and international pharmacy organisations regarding the application of the Medication Regimen Simplification Guide for Residential Aged Care (MRS GRACE)
- ▶ Medication simplification workshops have been held for pharmacists and GPs.

# COLLABORATIVE MEDICATION REVIEWS THROUGH TELEHEALTH

Finding the right balance between under and over-prescribing of medication for people with dementia living in aged care facilities is complex.

Medication reviews that involve collaboration between healthcare professions have been shown to optimise prescribing practices.

Professor Len Gray (University of Queensland) and his team's 'Telehealth enabled prescribing in dementia' explored using an existing telehealth system to deliver coordinated medication reviews through collaboration of pharmacists and geriatricians.

Geriatricians and pharmacists independently conducted medication reviews on 'virtual' cases using the telehealth platform and geriatricians then compared their results to those of the pharmacist's and reviewed their recommendations. Time taken and feedback on their experience with the telehealth system were recorded.

70%

AGREEMENT BETWEEN  
PHARMACISTS AND  
GERIATRICIANS

OCCASIONS OF DISAGREEMENT,  
AFTER VIEWING PHARMACISTS'  
REPORTS GERIATRICIANS  
CHANGED THEIR DECISIONS

10%

OF THE TIME AFTER VIEWING PHARMACISTS' REPORTS

Geriatricians	Pharmacists
Pharmacists reports were helpful	80% would be prepared to use this system
Potential for review and alter medication according to recommendation	Convenience of access to information
Prompted thought/ change of original recommendation	Access to more information
Minimise duplication effort	Reduced travel time and expense
Worthwhile to discuss together	Lack of discussions with staff
	Navigation of the telehealth system

Enablers Barriers

The tested telehealth system was found to be an effective way of delivering medication reviews and overcoming challenges of accessibility and timeliness. Telehealth based prescribing has additional benefits of enabling synchronous collaboration among health professionals, minimising duplication of effort, and optimising prescribing for people in long term care.



Website: [cdpc.sydney.edu.au/research/medication-management/telehealth-for-medication-management/](http://cdpc.sydney.edu.au/research/medication-management/telehealth-for-medication-management/)

# VITAMIN D SUPPLEMENTS IN AGED CARE



Vitamin D supplements have been shown to reduce the rate of falls in residential aged care, however only half of residents take vitamin D supplements.

New Zealand and Canada have successfully increased use of Vitamin D in aged care.

Professor Ian Cameron (University of Sydney) and his research team aimed to increase the use of vitamin D supplements in the Australian residential aged care setting.

“Vitamin D supplement use is the most effective single intervention for the prevention of falls for older people living in residential aged care.”

*Professor Ian Cameron*

The implementation program was trialled at 41 aged care facilities in NSW and SA, and resulted in an increase of the overall proportion of residents receiving adequate vitamin D supplementation by 4.6% over 18 months.

The study found uptake of vitamin D supplements varied widely across the various facilities and ongoing use of vitamin D supplements by residents in aged care facilities will require a multi-level approach.

## FACTORS INFLUENCING UPTAKE OF VITAMIN D SUPPLEMENT USE IN RACFS

- 1 Level of engagement of Staff, GPs, pharmacists, residents and family
- 2 Feasibility and effectiveness of strategies for uptake
- 3 Barriers to uptake

### Recommendations:

- Policymakers support community health campaigns to raise awareness about the role of vitamin D in falls prevention in the community and aged care settings
- Aged care organisations support implementation strategies including appointing and fostering local leadership for implementation
- Nurse practitioners, pharmacists and physiotherapists play a greater role in identifying residents for vitamin D supplementation.



**Website:** [cdpc.sydney.edu.au/research/medication-management/vitamin-d-study/](https://cdpc.sydney.edu.au/research/medication-management/vitamin-d-study/)



# ATTITUDES TO DEMENTIA

The attitude and perceptions of the community and health care professionals to dementia, and the care of people with dementia, has a profound impact on treatment and care. Under this theme, researchers evaluated attitudes to dementia, ageing, and care pathways to increase the understanding of dementia for policy makers, the health sector and public campaigners.



Website: [cdpc.sydney.edu.au/research/attitudes-to-dementia/](https://cdpc.sydney.edu.au/research/attitudes-to-dementia/)



“

Perhaps the time has come to expand our thinking about dementia to encompass not only cellular but cultural perspectives. Our society needs to recognize that dementia is not only a brain disorder of the person but also a social disorder that can be understood in a variety of different ways.”

*Danijela Hlis (Dementia Advocate)*



# REGULATION OF AGED CARE SERVICES

An understanding of what behaviour characterises optimal strategies for aged care organisations and care workers to manage the demands of dementia care is beneficial for aged care providers, care practitioners, care-users, policy makers and regulators.

This study led by Professor Simon Biggs and his research team (University of Melbourne) explored the complex, fragmented and multi-layered regulatory framework of the Australian aged care industry caring for people with dementia, and the regulatory compliance process.

'The organisation of risk: how do dementia care providers adapt to regulation' resource has important recommendations and systems analyses for dementia care at system, organisation and practice levels.

The study showed aged care organisations respond to the pressures of the complex regulatory environment in different ways, some using an innovative approach and others dominated by a risk aversion approach.

There are crucial benefits to be gained in care quality, particularly for people with dementia, if providers and care staff respond to the demands with a problem solving 'puzzle' approach, as opposed to one that is characterised by distancing and 'misattention'.

How employees respond to the pressures of many overlapping and often competing regulatory demands found a positive regulatory culture can provide quality, person-centred dementia care but an operational tension exists between innovative practice and risk avoidance.

## Recommendations:

- A national review to simplify areas of duplication and overlap
- Allow consumer engagement and innovation to streamline regulatory clusters
- Encourage organisational differentiation in risk management and a 'puzzle' approach
- Tailoring training to the demands on staff of different levels within an organisation
- Using a stacking approach to regulatory activity based on expertise
- Welfare market models and regulation need more consumer choice and engagement.



### MISATTENTION APPROACH

Emotional stress  
Mechanical, routine  
Bureaucratic and inflexible approach, tasks prioritised

### PUZZLE APPROACH

Engages emotionally  
Creative solutions  
Understanding person with dementia prioritised



## RESEARCH IMPACT

- ▶ The research has provided an understanding of the use of regulation within the aged care industry
- ▶ The report was forwarded to the Standing Committee on Quality of Aged Care and The Attorney General's Office
- ▶ Aged care organisation, Helping Hand Aged Care, cited the report in their submission to the Royal Commission on Aged Care Quality and Safety.



Website: [cdpc.sydney.edu.au/research/attitudes-to-dementia/aged-care-regulation/](https://cdpc.sydney.edu.au/research/attitudes-to-dementia/aged-care-regulation/)





# DEMENTIA IN THE PUBLIC DOMAIN

## After a dementia diagnosis, social exclusion can become a major challenge.

Social networks frequently shrink, and family, friends and professional helpers may be unsure of how to engage with the person with dementia.

'Dementia in the public domain' conducted by Professor Simon Biggs and team (University of Melbourne) examined the way international, national and local public health campaigns respond to end-user needs, and how they can influence policy and attitudes through creation of positive identities, empathy and understanding of people with dementia who live in the community.

The knowledge gained from this research is important because community-based care for older people is increasing, matching a desire to stay at home and in their community for as long as possible. This has created the need for better policy awareness of what it means to have a growing number of people living with dementia and to understand their life-course priorities.

The report facilitates improved understanding of how dementia influences relationships and families materially, physically, psychologically and socially and what support services are required to enable continued wellbeing.

Knowledge of the profile and voice of people with dementia and their carers can assist policy makers in designing and funding more effective health policy and support services.



**Website:** [cdpc.sydney.edu.au/research/attitudes-to-dementia/dementia-in-the-public-domain/](http://cdpc.sydney.edu.au/research/attitudes-to-dementia/dementia-in-the-public-domain/)

### Priority messages for campaigning:

- Reflect that dementia is part of normal social life
- Disadvantage and exclusion are experienced as a result of dementia
- Social inclusion and engagement need to be priorities
- Dementia awareness training needed for organisations
- Do not want to be viewed just as 'consumers'
- Multiple forms of intervention are needed
- Health services and prevention need more priority
- Use age-based perspectives and 'dementia voice' perspectives.



### RESEARCH IMPACT

- ▶ Research data shared with people with dementia, carers, people working with provider organisations, policy-makers, national and local campaigners on the social impacts of dementia
- ▶ Resource is being adopted by aged care and public health campaigning organisations to assist in development of campaigns and in changing public attitudes and behaviour.







# EMPOWERING YOUNG PEOPLE WHEN THEIR PARENT HAS YOUNGER ONSET DEMENTIA

There is limited understanding of how young people who have a parent diagnosed with younger onset dementia are impacted.

This qualitative research, led by Dr Karen Hutchinson (University of Sydney) applied the social model of disability framework, to investigate experiences of young people within the family environment; and the community supports available to the family. Three key themes emerged from the research.

## INVISIBILITY

Social isolation  
Neglect  
Stigma

## CONNECTIVITY

Need for social connectedness  
Engagement with  
health professional  
Acknowledgement by family,  
peers and society

## BEING EMPOWERED

Receiving age appropriate support  
Having control of their own future  
Understanding of what is out of  
their control  
Opportunities to share stories



## RESEARCH OPPORTUNITIES

Young people need support to cope in a family environment where a parent is diagnosed with younger onset dementia, however this requires a shift in understanding of their needs and linking of service providers across existing youth and dementia services. Engagement of young people in developing policies and procedures that focus on social inclusion and support of the whole family would help break down social barriers, driving social change.



**Website:** [cdpc.sydney.edu.au/research/attitudes-to-dementia/effects-on-children-of-parents-with-dementia/](https://cdpc.sydney.edu.au/research/attitudes-to-dementia/effects-on-children-of-parents-with-dementia/)

ENGAGEMENT OF  
YOUNG PEOPLE

DEVELOP POLICIES  
AND PROCEDURES

FOCUS ON SOCIAL  
INCLUSION AND SUPPORT  
FOR WHOLE FAMILY

RESULT:  
BREAK DOWN SOCIAL  
BARRIERS AND CREATE  
SOCIAL CHANGE

# PLANNING, DECISION-MAKING AND RISK

A diagnosis of dementia does not mean the person immediately loses their ability to make decisions. CDPC research teams developed evidence-based information and recommendations on how to best support the person living with dementia to make financial, health, and lifestyle choices now and in the future.



Website: [cdpc.sydney.edu.au/research/planning-decision-making-and-risk/](https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/)



“

It's about giving the person with dementia the opportunity to express their wishes in the best possible situation.”

*Theresa Flavin (Dementia Advocate)*

# SUPPORTING PEOPLE TO MAKE DECISIONS ABOUT THEIR OWN LIFE

It is a human right for people to be involved in decisions that affect their own care. However, when a person has a diagnosis of dementia, decisions are often made without any consultation.

The 'Supported decision-making in dementia care' project team, led by Dr Craig Sinclair (University of Western Australia) developed policy guidelines and training packages for residential aged care providers about the importance of supported decision-making and how to provide a person-centred approach to care.

The policy guide, *'Supported Decision-Making in Aged Care: A Policy Development Guideline for Aged Care Providers in Australia'* assists aged care providers in framing policies in line with human rights and National Decision-Making Principles. It also illustrates how embedding these Principles in policy and practice will assist in meeting the Aged Care Quality Standards introduced on 1 July 2019.

For a person with dementia, supported decision-making means creating an environment that encourages them to make their own decisions through assisting them to understand and weigh up issues.

In addition to training workshops a series of videos, webinars and help sheets were developed to support education of the aged care sector and the community about the principles and benefits of supported decision-making.

“ Our staff found the supported decision-making workshops invaluable when considering a person-centred approach to care, and the document is guiding our internal policies in this area”

“ We are also adapting the companion guide and using the videos in our step by step education program for staff”

*Jacqueline Wesson, Dementia Specialist and Research Coordinator at Montefiore*



Guideline Recommendations 4, 7







## RESEARCH IMPACT

- ▶ Lead Researcher, Dr Craig Sinclair, was called as an expert witness on person centred care and supported decision-making at the 2019 Royal Commission on Aged Care Quality and Safety
- ▶ Research papers and guidelines cited in community, state and federal government documents and websites
- ▶ NSW Public Guardian co-presented workshops, with CDPC researchers, for aged care providers across NSW
- ▶ Down Syndrome Australia adapted the companion guide resource to produce a document for people with Down Syndrome and their families
- ▶ Resources are being incorporated into residential aged care provider internal training programs specifically targeted for care managers and care workers (Montefiore, Churches of Christ QLD, Enrich living Services)
- ▶ Policy guideline has changed practice policy (Montefiore, BaptistCare)
- ▶ Dementia Australia has incorporated supported decision-making resources into their Certificate IV course in Dementia Practice
- ▶ Multiple licenses for use of the training material have been issued.

A companion guide for consumers entitled, "[Supported Decision-Making: A guide for people living with dementia, family members and carers](#)" was developed for national dissemination. This provides people with dementia and their families information about what it means to support a person with dementia to make decisions.



**Website:** [cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/](https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/)



## EVIDENCE FOR CHANGE



# FULL DAY

WORKSHOPS DELIVERED ACROSS AUSTRALIA.  
15+ WORKSHOPS, 200+ ATTENDEES

*Creating a better understanding of the key principles and concepts involved in supported decision-making and how to apply this in supporting people to make decisions in the aged care environment.*



# 1000+

COPIES OF THE POLICY GUIDELINE  
DISTRIBUTED AT WORKSHOPS, EVENTS,  
AND CONFERENCES



# 1000+

COPIES OF THE 'SUPPORTED DECISION-MAKING:  
A GUIDE FOR PEOPLE WITH DEMENTIA, THEIR  
FAMILIES AND CARERS' DISTRIBUTED



# 4000+

PAGE VISITS TO THE WEBPAGE DEVELOPED TO HOUSE  
RESOURCES WITH LINKS TO MULTI-LINGUAL HELP  
SHEETS, VIDEOS, WEBINAR SERIES, AND GUIDELINES



# WHY ADVANCE CARE PLANNING NEEDS TO BE DIFFERENT FOR PEOPLE WITH DEMENTIA

There is a general lack of awareness of Advance Care Planning in Australia and the benefit in ensuring your end of life wishes are known.

This CDPC research, by Professor Meera Agar and team (University of Technology Sydney/HammondCare) looked at how Advance Care Planning (ACP) systems can be improved to meet the needs of people with dementia, and other forms of cognitive decline.

Extensive consultation identified the key issues to be considered in developing an approach to advance care planning for those with dementia that could be applicable in a range of settings.

The final report includes recommendations that can be adapted into existing programs or used to develop new programs aiming to increase the uptake of ACP in a sustainable way.



## Guideline Recommendations 6

“ In developing this report, we spoke with a lot of stakeholders, including consumers...and identified that the most important part was supporting the person with dementia to have ongoing conversations with family about what is most valued.”

*Professor Meera Agar (University of Technology Sydney)*

### Recommendations:

- ACP should cover an extended period of time and include a wide range of issues
- Individuals should receive a timely diagnosis of dementia and information about the potential prognosis
- ACP should be done as soon as possible after diagnosis of dementia, if not done previously
- Effective ACP requires conversations that focus on understanding a person's values and beliefs, and what is important to them
- The appointment of one or more substitute decision-makers is critical
- People with dementia should be involved in discussions and decision-making as much as possible
- Particular care is needed with transfers between health and care settings.



## EVIDENCE FOR CHANGE

Acting on recommendations within the report, ACP awareness was raised through collaboration with key advocacy groups and organisations and development of accessible information for people with dementia, their families and the community.



# 400+

INDIVIDUALS AND ORGANISATIONS  
HAVE RECEIVED THE REPORT



# 21

NEWSLETTER ARTICLES WERE  
TAILORED WITH PRACTICAL  
INFORMATION FOR SPECIFIC  
DISTRIBUTION TO KEY INDUSTRY  
CONTACTS



# 28

MEDIA COVERAGE  
REPORTED



## RESEARCH IMPACT

- ▶ Dementia Australia houses the Start to Talk webpages, providing information and resources on ACP
- ▶ Report cited as resource on industry and community websites: Palliative Care Australia, Care Search, Dementia Training Australia, and Advance Care Planning Australia
- ▶ Report was received with thanks by state and territory health ministers and their representatives.



## RESEARCH OPPORTUNITIES

Cross jurisdictional change needs to occur to bring legislation into harmony between Australian states and territories, this has been highlighted over many years as a barrier to quality care for older Australians, most recently during the 2019 Royal Commission into Aged Care Safety and Quality. In addition, education of health professionals on the importance of ACP and access to funding for GPS to support ACP is needed.



“ Good advance care planning enables control in the future when you don't have a voice, and it releases family from the burden of decisions.”

*Dementia Advocate*



**Website:** [cdpc.sydney.edu.au/research/planning-decision-making-and-risk/advance-care-planning/](https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/advance-care-planning/)



# THE IMPORTANCE OF FINANCIAL DECISION-MAKING

Concerns about financial abuse of older Australians and the need for information on the legal documents associated with financial matters brought the CDPC and the Council on the Ageing (COTA) together to deliver a series of community seminars across metropolitan, regional and rural NSW.

The community sessions involved a two-hour presentation from Adjunct Associate Professor Sue Field (Western Sydney University) titled *'Powers of Attorney: Choose who manages your finances when you can't'*.

The CDPC project, *Policies and practices of financial institutions around substitute decision making*, led by Adjunct Associate Professor Sue Field examined substitute decision-making instruments and provided several recommendations for financial institutions to improve service particularly with respect to powers of attorney.

An evaluation of the close to 300 workshop attendees found 98% thought the information was relevant to their current situation, 93% believed their understanding of Powers of Attorney had improved, and 88% would look to find out more information about Powers of Attorney.

The need for public education on substitute decision-making involving financial matters was identified by Legal Aid NSW, and a second collaborative seminar series was delivered in the second half of 2019.

“ Your choice of Attorney is critical. The best person is not necessarily your partner, a child or the executor of your will. You need to appoint someone you can not only trust to act in your best interests but who is available, has advocacy skills and financial acumen.”

*Adjunct Associate Professor Sue Field*



## Guideline Recommendations 4–7





## Building an educated finance sector.

As part of the *'Policies and practices of financial institutions around substitute decision making'* project an education package was developed to assist bank staff understanding of the different documents used by people who are acting on behalf of someone else. The education package describes the concept of mental capacity; the impact of jurisdictional requirements on substitute decision-making instruments; the differences between Enduring Guardianship and Powers of Attorney; the differences between a General Power of Attorney and an Enduring Power of Attorney; and the purpose of a Financial Management Order.



## RESEARCH IMPACT

- ▶ Evidence shared with Australian Banking Association which was subsequently distributed to ABA member banks
- ▶ Commonwealth Bank of Australia (CBA) adopted evidence and developed community guide *'Safe & Savvy'* which provides the general public information about power of attorney, elder financial abuse, what abuse looks like, and how to protect yourself
- ▶ The CBA engaged researcher to implement training for CBA staff, based on the package developed within the project
- ▶ Acting on project recommendations, the CBA has examined handling of substitute decision-making policies, and developed education and training for frontline staff, customers, and the general public
- ▶ The researcher and CDPC staff were invited to a 2019 CBA Community Workshop to help the CBA develop an understanding of how to improve access to their products and services for people with cognitive decline requiring support from others to manage their financial affairs.



**Website:** [cdpc.sydney.edu.au/research/planning-decision-making-and-risk/financial-institutions/](https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/financial-institutions/)

# STAYING AT HOME LONGER

The ability for a person to live in their own home for as long as possible is known to positively influence their physical health and mental well-being.

The CDPC project '*Living with dementia in the community: assessing the risk*' led by Professor Constance Dimity Pond (University of Newcastle) culminated in two booklets. Booklet 1 provides a self-assessment tool, and Booklet 2 facilitates consultation with the health professional. Booklets cover the six key community care and disease management principles that assist people to maintain as much control over their health care decisions as possible.



**Website:** [cdpc.sydney.edu.au/research/planning-decision-making-and-risk/tools-to-assess-independence/](https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/tools-to-assess-independence/)

## Community care and disease management principles

1. Person-centred care
2. Consumer-directed care
3. Supported decision-making
4. Wellness/Healthy ageing
5. Risk enablement, and
6. Enablement/Wellness.



# MAINTAINING FUNCTION

A person's quality of life is positively impacted by their continued ability to perform their daily activities. Projects under this theme created evidence-based information, recommendations, and training programs for health and social care professionals in community and aged care settings to support a person, and their carer, to live well with dementia.



**Website:** [cdpc.sydney.edu.au/research/maintaining-function/](https://cdpc.sydney.edu.au/research/maintaining-function/)



“

It is vital for people living with dementia to be given the opportunity to maintain their level of cognitive and physical functionality at the time of diagnosis, and for this support to continue in an endeavour to function as independently as possible.”

*John Quinn (Dementia Advocate)*



# DEMENTIA AND EXERCISE PHYSIOLOGY PROGRAMS

Two thirds of people living with dementia experience significant functional decline.

Providing ways to maintain functional ability is a key recommendation of the Clinical Practice Guidelines for people with dementia.

Conducted in collaboration with CDPC industry partner Helping Hand Aged Care, this project, by Associate Professor Gaynor Parfitt and team (University of South Australia) evaluated a twelve-week activity program for people with dementia in residential aged care. The evaluation of the Commonwealth funded exercise physiologist-led program was carried out across four sites and included group and individual exercise sessions.

The evaluation demonstrated the positive impact of the program was not limited to the residents taking part, it also had positive effects on the care staff and family members.

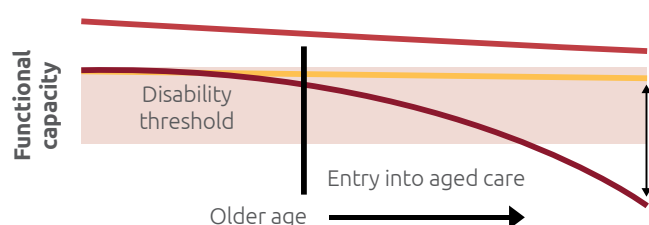
## Key findings were:

- **Residents** maintained physical and cognitive function during the program
- **Family members and Care staff** perceived an improvement in physical function, cognitive awareness, socialisation and communication
- **Care staff** reported that improved mobility and flexibility helped them (the care worker) perform their duties of care.

**Website:** [cdpc.sydney.edu.au/research/maintaining-function/aged-care-exercise-program/](http://cdpc.sydney.edu.au/research/maintaining-function/aged-care-exercise-program/)

Guideline Recommendations 66, 68

## Potential maintenance of function with introduction of Exercise Prescription



## KEY

- Natural decline of functional capacity in older adults
- Declining trajectory of functional capacity in aged care facilities
- Potential maintenance of functional capacity



## RESEARCH IMPACT

- ▶ Evidence of improved aged care environment for residents, their family members as well as the staff who provide aged care services
- ▶ Aged care providers are adopting evidence through employment of exercise physiologists in the care of older people with cognitive issues
- ▶ There is international interest in implementing the program.

# REABLEMENT PROGRAMS TO STAY WELL LONGER

For a person living with dementia the ability to perform everyday tasks often decreases as the disease progresses and they become increasingly dependent.

Reablement programs aim to delay decline or improve functioning and quality of life by addressing areas such as everyday abilities, or muscle strength and balance, which have the added benefit of improving mobility and reducing the likelihood of falls.

***Supporting independence and function in people living with dementia: A handbook of reablement programs for service providers and others with an interest in improving function***, developed by Professor Christopher Poulos and his team at HammondCare, is an evidence-informed resource containing practical reablement programs to support function in people living with dementia.

Directed at aged care providers, allied health and nursing professionals, managers and care workers, the *handbook* is supported by two additional resources, a *consumer information booklet*, and a *technical guide*. The *technical guide* contains a detailed synthesis of the published research evidence on reablement interventions for people living with dementia, and is a resource particularly aimed at health professionals delivering programs and researchers.

“ We developed the consumer information booklet to empower people living with dementia, along with their families and support persons, by providing them with the tools to make informed decisions about programs that could be of benefit.”

*Professor Christopher Poulos*

The research team included five Dementia Consumer Advocates to review and provide feedback on wording for final publication of the resources.



## RESEARCH OPPORTUNITIES

The project team was recently awarded a small grant to develop a standardised assessment guide for practitioners implementing the reablement programs. Further funding to undertake a specific dissemination and implementation project with the resources is now being sought.



**Website:** [cdpc.sydney.edu.au/research/maintaining-function/reablement-guidelines/](http://cdpc.sydney.edu.au/research/maintaining-function/reablement-guidelines/)





## INFORMATION BOOKLETS

# IN HOME SUPPORT PROGRAM

People want access to programs that help their family member living with dementia to remain at home.

Occupational therapy can promote healthy ageing through improving social participation, functional ability and independence, and is recommended in the Clinical Practice Guidelines for Dementia in Australia.

The COPE Program (Care of People with dementia in their Environments) is a proven occupational therapy and nursing dementia care program that promotes independence through individualised strategies so the individual with dementia can remain in their home longer.

COPE is a step by step approach to care using collaborative problem solving, skills building and activity prescriptions to improve participation in daily life for people with dementia and improve the wellbeing of their caregiver.

A total of 17 organisations and providers implemented 88 COPE interventions in South Australia and New South Wales over the course of this implementation project by Professor Lindy Clemson and team (University of Sydney /Flinders University). Training of 38 Occupational therapists and 17 nurses was also undertaken.

Evaluation showed that those taking part in the program, people with dementia and their caregivers, found stress reduction techniques invaluable, and carers had increased confidence in problem solving, and better ability to manage day to day caregiving to continue to support the person with dementia at home.

Occupational therapists highly valued the practical nature of the training and reported that it armed them with better tools, skills and confidence to work with their clients who often have complex symptoms.

The developers of the program, including Professor Laura Gitlin (USA), have generously licensed the COPE program to allow continued availability for occupational therapists and nurses in Australia. Further training opportunities will be offered from November 2019 and will take place in different states in Australia.



Guideline Recommendations 66–68



Website: [cdpc.sydney.edu.au/research/maintaining-function/cope-program/](https://cdpc.sydney.edu.au/research/maintaining-function/cope-program/)





## RESEARCH IMPACT

- ▶ The COPE Program will continue to be delivered by aged care providers post training.

“ We’re pleased to be offering our clients the opportunity to take part in this valuable program. We plan to continue to feature COPE as part of the suite of allied health services available through Help@Home.”

*Aged Care Manager*

- ▶ Involvement in the COPE program has changed behaviours.

“ Brainstorming and helping me come up with strategies has been extremely beneficial to me and my husband. Participation in the program has empowered me to take better care of my husband and myself.”

*Community member*



## EVIDENCE FOR CHANGE



THE NEW WEBSITE  
(COPEPROGRAM.COM.AU)  
PROVIDES INFORMATION ON ALL  
ASPECTS OF THE COPE PROGRAM



A SERIES OF FIVE VIDEOS FROM  
AUSTRALIAN FAMILIES DESCRIBE  
THEIR POSITIVE EXPERIENCES  
WITH THE COPE PROGRAM





# PREVENTING FALLS IN OLDER AUSTRALIANS

Each year more than 60% of people living with dementia at home will fall, resulting in injury, immobility, loss of independence and more rapid transition into residential aged care.

Professor Jacqueline Close and Dr Morag Taylor (NeuRA at UNSW) led the project 'Understanding risk and preventing falls and functional decline in older people with cognitive impairment' and identified several novel fall risk factors for older people living with dementia in the community.

This project added considerably to the academic literature examining the link between physical ability, cognition, and falls in older people with dementia and highlights potential fall risk assessment strategies, as well as opportunities for targeted interventions.

- Increased white matter hyperintensity volume predicts falls and is associated with poorer cognitive and physical function. White matter hyperintensities are small white areas on Magnetic Resonance Imaging (MRI) that are thought to be due to changes in the blood vessels in the brain
- Physical inactivity and decline in cognitive ability in areas such as problem solving and managing life tasks (executive function) were associated with physical decline and falls in a sample of older people that included people with dementia
- Individuals with dementia and poorer executive function, were less active and had physical impairments when compared to individuals with dementia and better executive function
- Exercise based programs can improve physical, cognitive and psychological risk factors associated with falls in people with dementia

- A home-based exercise program for people with dementia found improved balance, increased physical activity and reduced concern about falls. A program using iPads to deliver a tailored and progressive exercise program, StandingTall was trialled to determine if this would increase adherence.



## RESEARCH OPPORTUNITIES

In relation to fall risk, there is a need to determine if managing vascular risk factors like blood pressure can prevent development of white matter hyperintensities, and in turn preserve physical function and prevent falls.

In terms of fall prevention, StandingTall needs testing in a large randomised controlled trial to confirm this intervention can improve exercise participation and prevent falls in older people with dementia.



**Website:** [cdpc.sydney.edu.au/research/maintaining-function/falls-prevention/](https://cdpc.sydney.edu.au/research/maintaining-function/falls-prevention/)



# INNOVATIVE TECHNOLOGIES TO INCREASE SOCIALISATION

Social isolation or lack of social interaction can negatively influence both physical and cognitive abilities.

Aged Care residents, especially those with a diagnosis of dementia, can be socially isolated and lonely, and many residents have no family or friends visiting them.

A project led by Dr Angelita Martini and Karla Seaman from CDPC industry partner Brightwater Aged Care, and supported by University of Western Australia examined the use of a socialisation robot 'Alice' to enhance the wellbeing of people living with dementia.

The researchers investigated what impact incorporating Alice into activities, such as exercise groups, games, songs and storytelling, had on older adults with dementia and also explored staff attitudes to the use of Alice within a residential aged care setting.

Outcomes of the qualitative project provided evidence that the use of Alice in an aged care setting positively influenced social engagement and that residents developed new social connections with both each other and staff. Aged care staff also realised the benefit of incorporating Alice into the care program.

There were identified limitations when incorporating a new technology into an existing care environment and these included, staff time and training and the requirement for specialised technological support.



## RESEARCH OPPORTUNITIES

The use of a robot in residential aged care requires further research and the technology of Alice requires improvements to run effectively for staff and resident satisfaction. There is potential for Alice to be used for people from culturally and linguistically diverse backgrounds as well as for individual therapy and group therapy. These possibilities will be explored in future activities within the organisation.



**Website:** [cdpc.sydney.edu.au/research/maintaining-function/socialisation-robots/](https://cdpc.sydney.edu.au/research/maintaining-function/socialisation-robots/)



# SUSTAINABLE WORKFORCE

Having a workforce that can respond to a changing aged care environment, where consumer choice and expectations of high-quality care are the norm, requires innovation in the way care is delivered. CDPC research teams evaluated the aged care workforce in a variety of contexts that informs into building a sustainable aged care workforce.



Website: [cdpc.sydney.edu.au/research/sustainable-workforce/](https://cdpc.sydney.edu.au/research/sustainable-workforce/)



“

The people who can make a real difference to quality of care if they are empowered to do so.”

*Jenny Henderson (Dementia Advocate)*

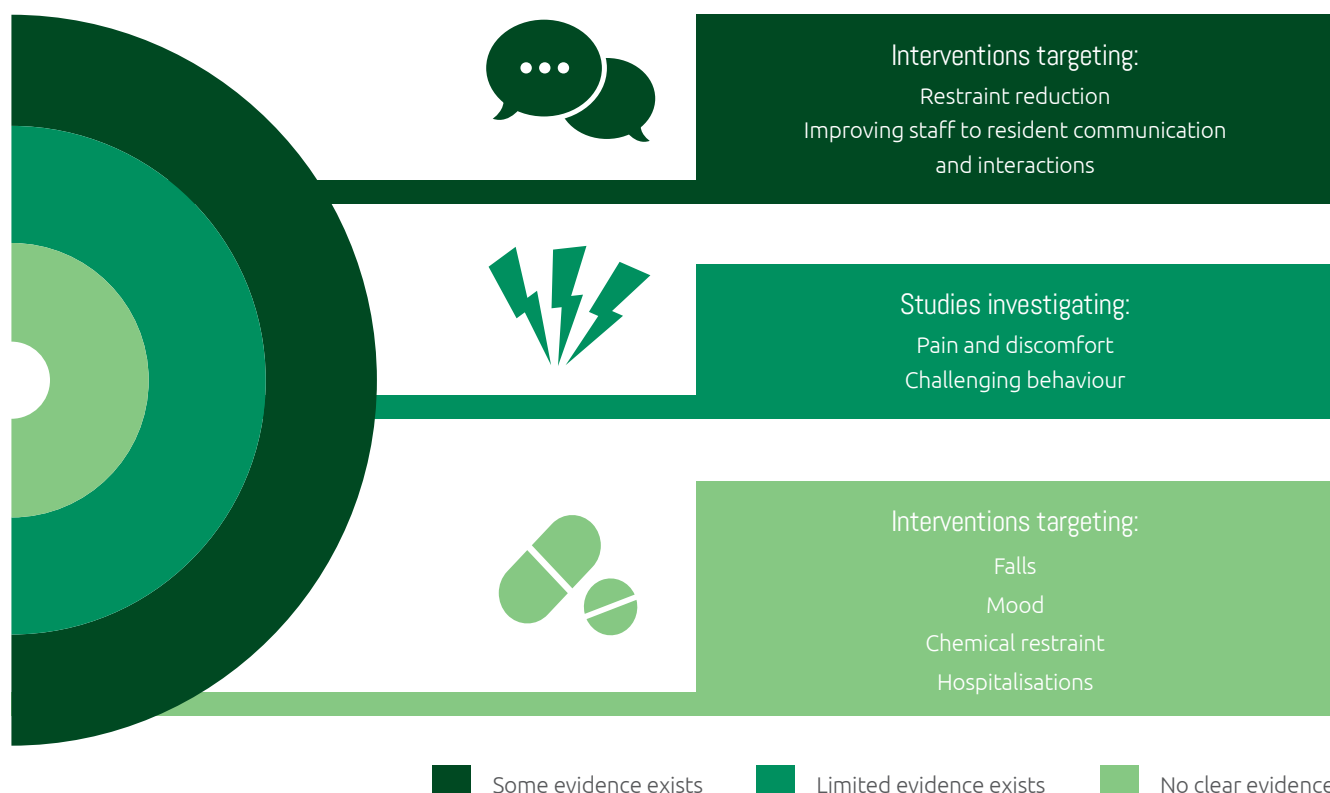
# IMPROVING RESIDENTIAL CARE THROUGH STAFF

How we care for our older Australians in residential aged care comes under regular scrutiny and has been a focus of a 2019 Australian Royal Commission on Aged Care Quality and Safety.

A project from researchers at NSW Health, led by Dr Katrina Anderson and Annaliese Blair, examined what factors influence staff providing good quality care for residents and how this will enable aged care organisations in better targeting interventions to improve care practices and quality of life for residents with dementia.

The first phase of the study involved a systematic review of current evidence about relationships between staff, quality of care and quality of life for residents and what staff interventions have been trialled to improve quality of care and quality of life.

## Improving residential quality of life and quality of care through staff: What the evidence tells us



In the second phase of the project, a longitudinal study with surveys, interviews, file audits and live observations was undertaken to rate the quality of the care provided and the effects of care on residents' quality of life and provide information on organisation variables including staff ratios, rostering practices and training.



#### Guideline Recommendations 59–63



## EVIDENCE FOR CHANGE (BASELINE)

- ▶ Quality of care is strongly associated the way residential aged care organisations structure and deploy staff, rather than some of the individual characteristics of staff
- ▶ Organisation factors have varying and complex effects on quality of care and quality of life. For example, a larger proportion of people with dementia in a facility, is associated with worse quality of care but better quality of life
- ▶ Staff concern about residents falling or being in pain is strongly associated with quality of care and quality of life outcomes
- ▶ Residents in facilities with higher levels of care assistant hours per resident are predicted to have better quality of care and quality of life
- ▶ Lack of physical and chemical restraint and higher engagement in activities are strongly associated with better quality of life.



## RESEARCH IMPACT

- ▶ Research into the determinants of quality of care and quality of life for people with dementia will provide vital information for the Royal Commission on Aged Care Quality and Safety and Aged Care workforce strategy recommendations
- ▶ Research evidence will assist aged care providers and policy makers to improve dementia care and meeting regulatory requirements and recommendations.



**Website:** [cdpc.sydney.edu.au/research/sustainable-workforce/improving-care-through-staff/](https://cdpc.sydney.edu.au/research/sustainable-workforce/improving-care-through-staff/)



# BUILDING A SUSTAINABLE AGED CARE WORKFORCE

The Australian aged care workforce is under pressure with an increasing workload, and changes to policy and regulation.

Building a sustainable workforce to meet these challenges is crucial to maintain a quality care environment.

The project 'Developing and implementing an interprofessional education toolkit in the aged care sector' led by Dr Angelita Martini and Karla Seaman from CDPC industry partner Brightwater Care Group developed the IPEAC Toolkit (Interprofessional Education in Aged Care Toolkit) in collaboration with Helping Hand Aged Care (SA).

A key finding of the implementation phase of the project was the benefits of staff team cohesion created by participating in the development of the toolkit, planning and facilitating IPE placements and seeing the benefits to students and residents.

The free online Toolkit provides an easy to use resource to facilitate interprofessional student placements and support interprofessional education programs within residential aged care.

## BENEFITS OF INTERPROFESSIONAL EDUCATION

- 1** Increased support and social contact for residents
- 2** Increased knowledge and capacity of facility staff through
- 3** Increased positive perceptions of working in aged care from students

The toolkit consists of four modules and can be used in part or whole.

- 1.** IPE in aged care
- 2.** Getting Started
- 3.** Running an IPE student placement
- 4.** Moving forward with IPE.



Guideline Recommendations 62–63



## RESEARCH IMPACT

- ▶ Uptake of IPEAC program and tools in six sites across Western Australia and South Australia in 2018
- ▶ Downloads of IPEAC Program from Brightwater website (January–July 2019) = 78
- ▶ Telstra Health cited IPEAC program and tools
- ▶ Eastern metropolitan region palliative care consortium (Victoria) provide link to the toolkit
- ▶ A cost-benefit analysis has estimated that uptake of the IPEAC could have significant social benefits.



Website: [cdpc.sydney.edu.au/research/sustainable-workforce/interprofessional-education/](https://cdpc.sydney.edu.au/research/sustainable-workforce/interprofessional-education/)



# PAIN MANAGEMENT IN AGED CARE

Training in pain management for staff is critical to bridge the gap between what is available to treat and assess pain and what is being used in aged care homes.

The Intervene Phase 2 project, conducted by Associate Professor Colm Cunningham and the research team (HammondCare), developed resources to bridge the evidence-practice gap in use of evidence-based pain management strategies. Intervene Phase 1 research pointed to the ongoing problem that people with dementia who are experiencing pain are often undertreated.

Intervene Phase 2 identified the most effective pain management tools and strategies and developed a three-part pain education video series, endorsed by Pain Australia.

The videos were developed in consultation with aged care health professionals to provide pain management education for frontline staff and explain current best practice in diagnosing, assessing, monitoring and treating pain.

The study identified issues of staff communication, limited interdisciplinary collaboration and inconsistent use of assessment tools as barriers to implement pain management strategies and mapped our plans for sustaining change.



## RESEARCH IMPACT

Resources and tools have been developed and are available for best practice pain management in residential aged care and include a pain management protocol, pain management model, a quick reference flip chart and pain assessment tools.



**Resource:** [dementiacentre.com/programs/intervene/](https://dementiacentre.com/programs/intervene/)



**Website:** [cdpc.sydney.edu.au/research/sustainable-workforce/intervene-pain-assessment/](https://cdpc.sydney.edu.au/research/sustainable-workforce/intervene-pain-assessment/)



Guideline Recommendations 78–83



## A pictorial of the Pain Management Model



*Intervene Phase 2 Project – a multidisciplinary team pain management model for residential aged care.*  
© The Dementia Centre, HammondCare 2019



Website: [dementiacentre.com/images/HammondCare\\_Pain\\_Management\\_Model.pdf](https://dementiacentre.com/images/HammondCare_Pain_Management_Model.pdf)

# NATIONAL QUALITY COLLABORATIVE TRANSLATES DEMENTIA GUIDELINES INTO PRACTICE

Occupational therapy, exercise and carer support have been shown to improve the lives of people with mild to moderate symptoms of dementia.

The CDPC project, 'Agents of Change' by Dr Kate Laver and team (Flinders University), is examining whether Quality Improvement Collaboratives (QIC) can provide a learning environment to increase adherence to evidence-based recommendations found in the Clinical Practice Guidelines for Dementia.

“The three guidelines focus on promoting independence, delaying functional decline and reducing carer stress and ill health and are relevant for up to 85% of people with mild to moderate symptoms of dementia who are living in the community.”

*Dr Kate Laver*

The researchers recruited health and aged care professionals, working in organisations that provide care for people with dementia in the community, to be part of the QIC and received training and support to build skills in designing quality improvements, managing stakeholders and fostering organisational change.

As with many of the CDPC research projects, consumers were involved with the project at all levels of the research process to provide expert advice on intervention improvement and adherence to the guideline recommendations.

Preliminary results indicated that prior to the QIC intervention there was only partial adherence (74%) to the guidelines in consultations by healthcare professionals with people with dementia and their carers, while post intervention there appears to be an increase toward guideline adherence.

## Organisational culture for implementation of a QIC intervention

Barriers	Facilitators
Lack of support from colleagues and management	Culture of innovation
Not considered core business	Resources devoted to quality improvement
Lack of consultation with people with dementia	More than one employee advocating for change

Adherence to Clinical Practice Guideline Recommendations through QIC will help people living with dementia in the community maintain their quality of life with evidence-based treatments in occupational therapy, exercise and carer support that delay functional decline.



## Guideline Recommendations 66–68

### Literature review found Quality Improvement Collaboratives **are** cost effective in:

- Translating clinical guidelines into practice
- Improving healthcare outcomes
- Reducing use of services
- Creating cost savings.



**Website:** [cdpc.sydney.edu.au/research/sustainable-workforce/agents-of-change-project/](https://cdpc.sydney.edu.au/research/sustainable-workforce/agents-of-change-project/)

# CARE SERVICE PATHWAYS

The journey after a dementia diagnosis can be challenging for both the person with dementia and their family and carers. CDPC research teams examined current and potential care pathways to identify gaps and provide potential strategies to address them.



Website: [cdpc.sydney.edu.au/research/care-service-pathways/](https://cdpc.sydney.edu.au/research/care-service-pathways/)



“

This research has emphasised the critical nature of individualised wellness and care programs for the person with the diagnosis of dementia as well as for their family and carers, and the role of the key worker or other supporters to ensure consumers are involved as far as practicable in all decisions about their care.”

*Ron Sinclair (Dementia Advocate)*



# NEW FRAMEWORK FOR DEMENTIA SUPPORT WORKER ROLE

Support workers are an important service for people with dementia, their carers and family living in the community setting, however in Australia there is little evidence of their value.

This project, by Susan Koch and team (Royal District Nurse Service), evaluated the role of dementia support workers currently in operation across Australia.

A systematic review of the literature and qualitative evaluation of dementia support worker roles found the support worker role was highly valued. As a result of the study, an evidence-based framework for implementation of a dementia support worker model was developed.

The framework informed and endorsed by people living with dementia and their carers, key workers, Australian industry experts, policy makers and researchers, outlines four key themes: organisational philosophies, organisational context, role definition and key worker competencies.

Findings from the study support the implementation and expansion of the dementia support worker role.

## Recommendations:

- Increase access to the support worker role within home care packages or other funding models
- Align dementia support worker model with Primary Health Networks to increase accessibility for diverse groups
- Utilise the framework developed as part of this evaluation as a human resources recruitment, service review and service development tool
- Actively include people with dementia in service development, improvement and awareness campaigns
- Undertake cost-effective analysis of dementia support models.



## Guideline Recommendations 51–53

“ I think it's not just the physical help that you need, it is this emotional and supportive role that is so important. It's definitely got us to where we are now.”

*Study participant (Consumer)*



## RESEARCH IMPACT

- ▶ Outcomes influenced the development of a proposal to undertake research into the needs of people living with cognitive impairment in the residential aged care setting
- ▶ Research evidence has informed government organisations regarding dementia support programs
- ▶ The Primary Health Care sector have acknowledged the benefits of community support programs in the delivery of care in the general practice setting. The framework provides a pathway for this approach to be implemented.



Website: [cdpc.sydney.edu.au/research/care-service-pathways/role-of-support-workers/](https://cdpc.sydney.edu.au/research/care-service-pathways/role-of-support-workers/)



# PROGRAM SUPPORTS FAMILY CARERS TO CARE FOR THEMSELVES

Caring for a person with dementia can be emotionally and physically challenging, affecting the wellbeing of the carer and their ability to provide care.

A CDPC project, led by Susan Koch (Royal District Nurse Service) evaluated the Weavers model as an alternative respite model to support the carer by assisting in developing strategies to build resilience, enhance their strengths, and empower them to take control of their situation.

The Weavers Program was originally co-designed by The Australian Centre for Social Innovation and CDPC industry partner Helping Hand Aged Care using an approach that involved both carers and service providers to better understand carer needs and challenges.

In the Weavers Program a past or present carer, or a 'weaver' provides volunteer support to other carers in the program.

The evaluation of the program was conducted in order to provide information for continued improvement and determine measures of change and impact on the carers or 'Weavers'.

The study found the Weavers Program had positive outcomes for carers, care recipients and volunteers.



## Guideline Recommendations 100–102

Carers	Care receiver	Weavers volunteers
Decreased depression	More attentive caring by the carer	Increased sense of purpose
Increased belief in their capability	Improved access to services	Increased confidence
Increased assertiveness of own needs		Training and professional development

“It's made me sit up and not mope around doing nothing... and get on with your life. I got that from the Weaver and that's what I'm very grateful about.”

*Carer*



Website: [cdpc.sydney.edu.au/research/care-service-pathways/carers-respite-program/](https://cdpc.sydney.edu.au/research/care-service-pathways/carers-respite-program/)





## RESEARCH IMPACT

- ▶ Evaluation evidence is assisting long-term sustainability of alternative respite models with the program being adopted nationally and internationally
- ▶ Uptake of Weavers open source model by aged care organisations.



Resource: [taksi.org.au/work/weavers-peer-to-peer-carer-support/](https://taksi.org.au/work/weavers-peer-to-peer-carer-support/)

# USING THE CONSUMER VOICE TO MAP THEIR HEALTH CARE JOURNEY

The personal experiences of the healthcare system from people living with dementia and their carers can focus current research efforts for opportunities to improve care for people with dementia.

This project, conducted by Professor Anneke Fitzgerald and team (Griffith University), provided real-life data on people's experiences of dementia diagnosis and life after the diagnosis, and how they would like it to be in the future or 'ideal state'.

Data was obtained directly from people living with dementia and their carers from a series of workshops around Australia. The researchers then proposed an 'ideal state' model, a dementia wellness plan that is customised to each person's journey and need.

Inclusion of consumers helped to identify what can be improved in the healthcare system but also in provided ideas on how current deficiencies and barriers can be overcome.



## Recommendations:

1. Better recognition of the early symptoms of dementia
2. Consistent assessment and diagnostic process
3. Allocation of a support person to assist with navigating the system pre and post diagnosis
4. Improved communication when delivering a diagnosis
5. Advocacy groups should provide individual assistance free of charge at the consumer level.
6. Development of an individual dementia wellness plan
7. Education of frontline staff (GPs).



Guideline Recommendations 50–53



## EVIDENCE FOR CHANGE

The project report, *'Understanding the Journey Better: an investigation of the current 'state of play' of the health care journey experienced by people living with cognitive decline and their carers'*, proposes a dementia wellness plan to enable consumers to live as well and independently as possible, and to be able to make choices.



## RESEARCH IMPACT

- ▶ People with dementia and their carers felt their inclusion in the research process had made them feel valued.
- ▶ Research organisations have asked for more information on the 'pathway model for diagnosis and post-diagnosis' to investigate further research opportunities.

“ A regularly updated wellness plan would help alleviate feelings expressed by consumers and their carers that they feel lost in the system, unaware of many services and what they can expect on their healthcare pathway.”

*Professor Fitzgerald*



**Website:** [cdpc.sydney.edu.au/research/care-service-pathways/future-health-care-journey/](https://cdpc.sydney.edu.au/research/care-service-pathways/future-health-care-journey/)



# DEMENTIA CARE GUIDE FOR GENERAL PRACTITIONERS

The pathway to a dementia diagnosis can take years and can be a stressful time for the person and their families.

A General Practitioner (GP) is often the first health professional a person will see when changes in behaviour are noticed.

This CDPC project, by Professor Constance Dimity Pond and the research team (University of Newcastle), examined what was needed for GPs to provide timely, accurate and effective support to older people with cognitive decline and their carers.

The project synthesised current evidence on GP care for people with dementia. The expertise of practitioners and researchers, along with robust literature reviews, informed Key Messages and Practice Points across six areas of care:

1. Communicating: Diagnoses and Consultations for People with Dementia
2. Caring for People with Dementia Experiencing Behavioural & Psychological Symptoms
3. Elder Abuse: Identification and Screening
4. Dementia in People with Intellectual Disability
5. Supporting Carers of People with Dementia



## Guideline Recommendations 23–49



## EVIDENCE FOR CHANGE



A booklet for GPs, and e-copy of that resource along with the background literature reviews, are available [cdpc.sydney.edu.au/research/care-service-pathways/primary-care-consensus-guide/](https://cdpc.sydney.edu.au/research/care-service-pathways/primary-care-consensus-guide/)

## How does ageing impact our doctors?

Approximately one quarter of Australian doctors are over the age of 55 years and how this group experiences the ageing process is not well understood. Dr Narelle Shadbolt (University of Sydney) investigated the current literature about how doctors maintain their own health as well as a safe and sustainable practice.

Limited research on the influence of ageing physicians on quality of care was found. While literature indicated older doctors perform less well than their younger counterparts, older doctors had lower levels of psychological distress, burnout, and an improved work-life balance. Older doctors also experience an increased level of credibility and respect from patients and have greater tolerance and respect of patients.



## CDPC PROJECTS AND RESEARCH TEAMS

Themes	Associated projects	Teams
<b>Clinical Guidelines for Dementia</b> <ul style="list-style-type: none"> <li>Clinical practice guidelines and principles of care for people with dementia</li> <li>Consumer companion guide</li> </ul> <a href="http://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/">cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/</a>	<b>1313</b> – Clinical Practice Guidelines and Principles of Care for People with Dementia	<b>1313</b> – <b>A/Prof Craig Whitehead</b> and <b>Prof Maria Crotty</b> , Kate Laver, Suzanne Dyer, Stephanie Harrison, Jan Van Emden, Jane Thompson, Christine Bryden, Louise Heuzenroeder, Joan Jackman, Meg Friel, Kate Swaffer, Graeme Brough
<b>Care environment and Quality of Life</b> <ul style="list-style-type: none"> <li>Models of care</li> <li>Dementia care in hospitals</li> <li>Measuring care quality</li> </ul> <a href="http://cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/">cdpc.sydney.edu.au/research/care-environment-and-quality-of-life/</a>	<b>1301</b> – Understanding long-term care configurations for older people with cognitive decline in Australia (INSPIRED)	<b>1301</b> – <b>Prof Maria Crotty, Dr Suzanne Dyer, Dr Stephanie Harrison, Dr Emmanuel Gnanamanickam, Dr Rachel Milte, Dr Enwu Liu</b> , Lua Perimal-Lewis, Wendy Hudson, Meredith Gresham, Rebecca Forbes, Megan Corlis, Colm Cunningham, Anglea Raguz, Tony Ramshaw, Louise Heuzenroeder, Elaine Todd, Kathy Williams
	<b>1302</b> – Confused Hospitalised Older Person Study (CHOPS)	<b>1302</b> – <b>Prof Susan Kurrle, Anne Cumming</b> , Cath Bateman, Ellie Shu, Anthea temple, Glen Pang, Wendy Hudson, Colm Cunningham, Rebecca Forbes, Catriona Lorang, Caroline Bulsara, Jan Van Emden, Christine Bryden, Louise Heuzenroeder, Jennifer Henderson, Anne Turner
	<b>1326</b> – Dementia Delirium Care with Volunteers	<b>1326</b> – <b>Dr Catherine Bateman, Dr Katrina Anderson, Ms Annaliese Blair</b> , Elaine Todd, Louise Heuzenroeder
	<b>1315</b> – The cost-effectiveness of aged care, dementia and dementia management in Australia	<b>1315</b> – <b>A/Prof Tracy Comans, Dr Lachlan Standfield</b> , Wendy Hudson, Megan Corlis, Jan Van Emden, Angela Raguz, Joan Jackman, Louise Heuzenroeder, Elaine Todd, Kathy Williams, Leo White
	<b>1333</b> – The AD-5D – a preference-based quality of life instrument	<b>1333</b> – <b>A/Prof Tracy Comans, Dr Kim-Huong Nguyen, Prof Susan Kurrle, Prof Julie Ratcliffe, Dr Donna Rowen, Prof Wendy Moyle, Dr Brendan Mulhern, Dr Sanjeeva Kularatna, Megan Corlis</b> , Lyntara Quirke, Elaine Todd
<b>Medication Management</b> <ul style="list-style-type: none"> <li>Quality use of medicines</li> <li>Deprescribing guidelines</li> <li>Reducing medication complexity</li> <li>Vitamin D study</li> <li>Telehealth for medication management</li> </ul> <a href="http://cdpc.sydney.edu.au/research/medication-management/">cdpc.sydney.edu.au/research/medication-management/</a>	<b>1311</b> – Optimising the quality use of medicines for people with cognitive and related functional decline	<b>1311</b> – <b>Prof Sarah Hilmer, Prof Simon Bell</b> , Emily Reeve, Janet Sluggett, Lisa Kouladjian-O'Donnell, Mouna Sawan, Esa Chen, Kris Jamsen, Amy Page, Colm Cunningham, Rebecca Forbes, Catriona Lorang, Meredith Gresham, Megan Corlis, Jan Van Emden, Michelle Hogan, Lyntara Quirke, Joan Jackman, Christine Bryden, Tracy Comans, Kim-Huong Nguyen
	<b>1312</b> – Implementation of Vitamin D in residential aged care facilities	<b>1312</b> – <b>Prof Ian Cameron</b> , Pippy Walker, Amanda Miller Amberber, Jan Van Emden, Wendy Hudson, Rebecca Forbes, Meredith Gresham, Lyntara Quirke, Joan Jackman, Les Leckie, Leo White
	<b>1320</b> – Telehealth Enabled Prescribing in Dementia	<b>1320</b> – <b>Prof Leonard Gray, Dr Ruth Hubbard, Prof Sarah Hilmer, Prof Simon Bell, Dr Christopher Freeman</b> , Nancye Peel, Liam Caffery, Joan Jackman, Les Leckie, Elaine Todd



Themes	Associated projects	Teams
<b>Attitudes to dementia</b> <ul style="list-style-type: none"> <li>Aged care regulation</li> <li>Healthy ageing in Australian physicians</li> <li>Dementia effects on children</li> <li>Dementia in the public domain</li> </ul> <a href="http://cdpc.sydney.edu.au/research/attitudes-to-dementia/">cdpc.sydney.edu.au/research/attitudes-to-dementia/</a>	<b>1307</b> – The effects of regulation on aged care services for people with dementia	<b>1307</b> – <b>Prof Simon Biggs</b> , Wendy Hudson, Meredith Gresham, Catriona Lorang, Rebecca Forbes, Angela Raguz, Megan Corlis, Lyntara Quirke, Joan Jackman, Jennifer Henderson
	<b>1316</b> – Healthy Ageing in Australian Physicians	<b>1316</b> – <b>Prof Susan Kurrle, Dr Narelle Shadbolt</b> , Kerri Lockwood, Jan Van Emden, Joan Jackman, Elaine Todd
	<b>1317</b> – The psycho-social impact of having a parent with younger onset dementia	<b>1317</b> – <b>Dr Karen Hutchinson, Prof Susan Kurrle, A/Prof Christopher Roberts</b> , Wendy Hudson, Megan Corlis, Caroline Bulsara, Christine Bryden, Kate Swaffer, Joan Jackman, Nadine Hedger
	<b>1318</b> – Dementia in the public domain	<b>1318</b> – <b>Prof Simon Biggs</b> , Irja Haapala Biggs, Ashley Carr, Meredith Gresham, Megan Corlis, Lyntara Quirke, Danijela Hlis, Joan Jackman, Tony Ramshaw
<b>Planning, decision-making and risk</b> <ul style="list-style-type: none"> <li>Advance care planning</li> <li>Financial institutions</li> <li>Assessing independence</li> <li>Supported decision making</li> </ul> <a href="http://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/">cdpc.sydney.edu.au/research/planning-decision-making-and-risk/</a>	<b>1305</b> – Advance Care Planning: systematic review and summary	<b>1305</b> – <b>Prof Meera Agar</b> , Adele Kelly, Gail Yapp, Joy Coker, Natalie Phrynowsky, Jan Van Emden, Kathy Williams, Jennifer Henderson, Christine Bryden, Kate Swaffer, Elaine Todd, Anne Cumming, Tracy Comans, Kim-Huong Nguyen
	<b>1306</b> – Financial Institutions Policy and Practice	<b>1306</b> – <b>Adjunct A/Prof Sue Field</b> , Lara Markovic, Sangita Bahtia, Jan Van Emden, Elaine Todd, Janet Brennan, Tony Ramshaw, Louise Heuzenroeder
	<b>1308</b> – Living with dementia in the community	<b>1308</b> – <b>Prof Dimity Pond</b> , Evelyn Mueller, Robin Scott, Nigel Catzikitis, Megan Corlis, Jan Van Emden, Ron Sinclair, Ian Gladstone, Danijela Hlis, Joan Jackman, Mick Carmody, Judy Wheaton, Christine Bryden,
	<b>1324</b> – Supported decision-making in dementia care	<b>1324</b> – <b>Dr Craig Sinclair, A/Prof Meera Agar, Adjunct A/Prof Sue Field, Prof Susan Kurrle, Prof Cameron Stewart</b> , Romola Bucks, Josephine Clayton, Meredith Blake, Kirsten Aurret, Sascha Callaghan, Helen Radoslovich, Meredith Gresham, Angelita Martini, Kathy Williams, Joan Jackman, Ron Sinclair, Theresa Flavin
<b>Maintaining function</b> <ul style="list-style-type: none"> <li>Falls prevention</li> <li>COPE program</li> <li>Aged care exercise program</li> <li>Reablement guidelines</li> <li>Socialisation robots</li> </ul> <a href="http://cdpc.sydney.edu.au/research/maintaining-function/">cdpc.sydney.edu.au/research/maintaining-function/</a>	<b>1319</b> – Understanding risk and preventing falls and functional decline in older people (Preventing Falls and Functional Decline)	<b>1319</b> – <b>Prof Jacqui Close, Dr Morag Taylor, Prof Susan Kurrle</b> , Roslyn Savage, Lyndell Webster, Jan Van Emden, Kate Swaffer, Joan Jackman, Elaine Todd, Ian Gladstone, Lyntara Quirke
	<b>1321</b> – Implementing COPE (Care of Older People in their Environments) (Improving the function of older people in their homes)	<b>1321</b> – <b>Prof Lindy Clemson, Dr Kate Laver, A/Prof Yun Hee Jeon, A/Prof Lee-Fay Low, Prof Susan Kurrle, Dr Justin Scanlan, A/Prof Tracy Comans, Prof Laura Gitlin, Prof Maria Crotty</b> , Sally Day, Miia Rahja, Jennifer Culph, Monica Cations, Meredith Gresham, Joan Jackman, Danijela Hlis, Glenys Petrie, John Quinn, Jane Thompson
	<b>1329</b> – Evaluation of Implementation of Exercise Prescription in Residential Aged Care Facilities (Exercise programs in residential aged care)	<b>1329</b> – <b>A/Prof Gaynor Parfitt, Megan Corlis</b> , Dannielle Post, Alison Pennington, Wendy Hudson, Chris Poulos, Ian Gladstone, Ron Sinclair, Joan Jackman, Tracy Comans, Kin-Huong Nguyen

Themes	Associated projects	Teams
	<b>1330</b> – Evaluation of the impact of socialization robots on social engagement of older adults with cognitive decline (Robots in aged care)	<b>1330</b> – Dr Angelita Martini, A/Prof Brett Robertson, Dr Karla Seaman, Wendy Hudson, Val Jenner, Joan Jackman
	<b>1337</b> – Development of evidence-based Dementia Reablement Guidelines and Programs deliverable to people with early to moderate dementia	<b>1337</b> – Prof Christopher Poulos, Dr Meredith Gresham, A/Prof Roslyn Poulos, Megan Corlis, Wendy Hudson, Prof Lindy Clemson, A/Prof Kathy McGilton, Prof Ian Cameron, Claire O'Connor, Helen Radoslovich, Rebecca Forbes, Joan Jackman, Ian Gladstone, Theresa Flavin, John Quinn, Glenys Petrie, Ron Sinclair
<b>Sustainable workforce</b> <ul style="list-style-type: none"> <li>Improving care through staff</li> <li>Interprofessional education</li> <li>Agents of change project</li> <li>Intervene – pain assessment</li> </ul> <a href="http://cdpc.sydney.edu.au/research/sustainable-workforce/">cdpc.sydney.edu.au/research/sustainable-workforce/</a>	<b>1310</b> – Improving quality of residential dementia care and promoting change by supporting and caring for staff	<b>1310</b> – Prof Michael Bird, Dr Katrina Anderson, Sarah MacPherson, Annaliese Blair, Meredith Gresham, Megan Corlis, Jennifer Henderson, Danijela Hlis, Val Jenner and Bob Page, Ron Sinclair, Christine Bryden.
	<b>1322</b> – Which staff factors influence the quality of long-term dementia care and quality of life of residents? A longitudinal study to identify the most critical staff variables to target in interventions	<b>1322</b> – Dr Katrina Anderson, Ms Annaliese Blair, Catherine Bateman, Maria Zylinski, Peter Davis, Margaret Nichols, Maaria Haaque, Janice Salzke, Meredith Gresham, Megan Corlis, Catriona Lorang, Jenny Henderson, Katrina Radford
	<b>1309</b> – Evaluating the outcomes of inter-professional education programs in residential aged care	<b>1309</b> – Karla Seaman, Caroline Bulsara, Angelita Martini, Jane Harrup-Gregory, Kylie Pratt, Aimee Hallsworth, Georgia Hett, Leigh Elliot-Davies, Elly Williams, Julie Citti, Megan Corlis, Kathy Williams, Les Leckie, Kate Swaffer, Lyntara Quirke
	<b>1328</b> – Developing and implementing an interprofessional education toolkit for staff in residential aged-care to better support the care needs of people with cognitive and functional decline.	<b>1328</b> – Karla Seaman, Dr Angelita Martini, A/Prof Rosemary Saunders, Megan Corlis, Kathy Williams, Joan Jackman, Jennifer Henderson
	<b>1327</b> – ‘Agents of Change’: Implementing occupational therapy as recommended by the Clinical Guidelines	<b>1327</b> – Dr Kate Laver, Prof Maria Crotty, Prof Anneke Fitzgerald, Prof Susan Kurrle, Prof Ian Cameron, A/Prof Craig Whitehead, Dr Jane Thompson, A/Prof Billingsley Kaambwa, Monica Cations, Lenore de la Perrelle, Megan Corlis, Meredith Gresham, Wendy Hudson, Gary and Mae Collins, Ian Gladstone, Nadine Hedger, John Quinn, Glenys Petrie
	<b>1338</b> – Intervene Stage 2 – Pain management best practice in residential aged care	<b>1338</b> – A/Prof Colm Cunningham, Linda Ferguson, Prof Christopher Poulos, Prof Phillip Siddall, Prof Anneke Fitzgerald, Dr Catriona Lorang, Dr Sharon Andrews, Rumbi Tichawangana, Raj Anand, Kate Hayes, Megan Corlis, Meredith Gresham, Wendy Hudson, Shirley Waldhunter, Lyntara Quirke, Ian Gladstone, Danijela Hlis, Joan Jackman

Themes	Associated projects	Teams
<b>Care service pathways</b> <ul style="list-style-type: none"> <li>• Role of support workers</li> <li>• Respite program for carers</li> <li>• Primary care consensus guide</li> <li>• Future health care journey</li> </ul> <a href="http://cdpc.sydney.edu.au/research/care-service-pathways/">cdpc.sydney.edu.au/research/care-service-pathways/</a>	<b>1303</b> – Evaluating the Dementia Key Worker Role	<b>1303</b> – <b>Dr Susan Koch</b> , Dianne Goeman, Catherine Standing, Emma Renehan, Claudia Slegers, Wendy Hudson, Megan Corlis, Kate Swaffer, Judy Wheaton, Ian Gladstone, Val Jenner, Bob Page, Jane Thompson
	<b>1304</b> – Prototyping an alternative respite model for older people with cognitive decline and their carers ('Weavers')	<b>1304</b> – <b>Dr Susan Koch, Megan Corlis</b> , Kerry Jones, Catherine Standing, Gill Westthorp, Vikki Booth, Carolyn Curtis, Val Jenner, Bob Page, Ron Sinclair, Elaine Todd
	<b>1314</b> – Development and implementation of a consensus guide on dementia in primary care	<b>1314</b> – <b>Prof Constance Dimity Pond</b> , Jill Philips, Evelyn Mueller, Jan Van Emden, Joan Jackman, Leo White, Danijela Hlis, Kathy Williams
	<b>1325</b> – Understanding the Journey Better: An exploration of the current 'state of play' of the health care journey experienced by people living with cognitive decline and their carers.	<b>1325</b> – <b>Prof Anneke Fitzgerald, Dr Joanne Curry</b> , Angelique Olde Meierink, Megan Corlis, Joan Jackman, Kate Swaffer, Louise Heuzenroeder, Ian Gladstone, Elaine Todd, John Quinn, Danijela Hlis, Glenys Petrie, Lyntara Quirke



**COGNITIVE DECISION PARTNERSHIP CENTRE**

# Diagnosis, treatment and care for people with dementia:

A CONSUMER COMPANION GUIDE TO THE CLINICAL PRACTICE GUIDELINES AND PRINCIPLES OF CARE FOR PEOPLE WITH DEMENTIA

**Recommendations**

**Clinical Practice Guidelines and Principles of Care for People with Dementia**

**Future planning and advance care planning**

**Diagnosis, treatment and care for people with dementia**

**Diagnosis, treatment and care for people with dementia**

**SUPPORTING DECISION-MAKING**

A guide for people living with dementia, family and carers

**SUPPORTED-DECISION-MAKING IN AGED CARE**

A Policy Development, Care Guidelines for Aged Care Providers in Australia

**DEMENTIA IN THE PUBLIC DOMAIN**

VOICE AND VISUAL REPRESENTATION IN PUBLIC SPACES

**Diagnosis, treatment and care for people with dementia**

**Learning experiences at home to help living with dementia**

**Diagnosis, treatment and care for people with dementia**

**Diagnosis, treatment and care for people with dementia**

**Diagnosis, treatment and care for people with dementia**



# PUBLICATIONS

## Clinical Guidelines

Dyer, S. M., Laver, K., Pond, C. D., Cumming, R. G., Whitehead, C., & Crotty, M. (2016). [Clinical practice guidelines and principles of care for people with dementia in Australia](#). *Australian family physician*, 45(12), 884.

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Laver, K., Cumming, R. G., Dyer, S. M., Agar, M. R., Anstey, K. J., Beattie, E., ... & Dietz, M. (2016). [Clinical practice guidelines for dementia in Australia](#). *Med J Aust*, 204(5), 191–193.

## Care Environment and Quality of Life

Blair, A., Bateman, C., & Anderson, K. (2019). [“They take a lot of pressure off us”: Volunteers reducing staff and family care burden and contributing to quality of care for older patients with cognitive impairment in rural hospitals](#). *Australasian journal on ageing*, 38, 34–45.

Comans, T. A., Nguyen, K. H., Mulhern, B., Corlis, M., Li, L., Welch, A., ... & Ratcliffe, J. (2018). [Developing a dementia-specific preference-based quality of life measure \(AD-5D\) in Australia: a valuation study protocol](#). *BMJ Open*, 8(1), e018996.

Crotty, M., Killington, M., Liu, E., Cameron, I. D., Kurrle, S., Kaambwa, B., ... & Ratcliffe, J. (2019). [Should we provide outreach rehabilitation to very old people living in Nursing Care Facilities after a hip fracture? A randomised controlled trial](#). *Age and ageing*.

Dyer, S. M., Gnanamanickam, E. S., Liu, E., Whitehead, C. and Crotty, M. (2018). [Diagnosis of dementia in residential aged care settings in Australia: An opportunity for improvements in quality of care?](#) *Australasian Journal on Ageing*.

Dyer, S. M., Liu, E., Gnanamanickam, E. S., Milte, R., Easton, T., Harrison, S. L., ... & Crotty, M. (2018). [Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life](#). *The Medical journal of Australia*, 208(10), 433–438.

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Farrer, O., Yaxley, A., Walton, K., Milte, R., & Miller, M. (2017). [The ‘diabetic diet’: a web based survey for determining the incidence, rationale, composition and implications in residential aged care facilities](#). *Journal of Nursing Home Research*, 3, 50–53.

Gnanamanickam, E., M Dyer, S., Milte, R., Liu, E., Ratcliffe, J., & Crotty, M. (2018). [Clustered domestic model of residential care is associated with better consumer rated quality of care](#). *International Journal for Quality in Health Care*.

Gnanamanickam, E. S., Dyer, S. M., Milte, R., Harrison, S. L., Liu, E., Easton, T., ... & Whitehead, C. (2018). [Direct health and residential care costs of people living with dementia in Australian residential aged care](#). *International journal of geriatric psychiatry*.

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Kurrle, S., Bateman, C., Cumming, A., Pang, G., Patterson, S., & Temple, A. (2019). [Implementation of a model of care for hospitalised older persons with cognitive impairment \(the Confused Hospitalised Older Persons program\) in six New South Wales hospitals](#). *Australasian journal on ageing*, 38, 98–106.

Laver, K., Gnanamanickam, E., Whitehead, C., Kurrle, S., Corlis, M., Ratcliffe, J., ... & Crotty, M. (2018). [Introducing consumer directed care in residential care settings for older people in Australia: views of a citizens’ jury](#). *Journal of health services research & policy*.

Milte, R., Ratcliffe, J., Chen, G., Miller, M., & Crotty, M. (2018). [Taste, choice and timing: Investigating resident and carer preferences for meals in aged care homes](#). *Nursing & health sciences*.

Milte, R., Ratcliffe, J., Chen, G., & Crotty, M. (2017). [What Characteristics of Nursing Homes Are Most Valued by Consumers? A Discrete Choice Experiment with Residents and Family Members](#). *Value in Health*.

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## Care Service Pathways

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## COMMITTEE MEMBERS AND COLLABORATORS

### CDPC Governance Authority (2012–2019)

The Governance Authority members are responsible for the performance of the CDPC against NHMR objectives and for ensuring the portfolio of research Activities reflect the desires of funding partners.

Members and Proxies of the Governance Authority between 2012 and 2019 were:

- Mr Glenn Rees, Alzheimer's Australia
- Dr Chris Hatherly, Alzheimer's Australia
- Ms Alison Kevan, Alzheimer's Australia
- Ms Carol Bennett, Alzheimer's Australia
- Ms Maree McCabe, Alzheimer's Australia / Dementia Australia
- Ms Kaele Stokes, Dementia Australia
- Ms Kanupriya Hehir, Alzheimer's Australia (Proxy)
- Ms Annette Moxey, Alzheimer's Australia / Dementia Australia (Proxy)
- Dr Penny Flett, Brightwater Care Group
- Ms Jennifer Lawrence, Brightwater Care Group
- Mr John Brearley, Brightwater Care Group (Proxy)
- Dr Stephen Judd, HammondCare
- Professor Christopher Poulos, HammondCare, CDPC Designated Systems Based Investigator
- Dr Meredith Gresham, HammondCare (Proxy), CDPC Designated Systems Based Investigator
- Mr Ian Hardy, Helping Hand Aged Care
- Ms Megan Corlis, Helping Hand Aged Care, CDPC Designated Systems Based Investigator
- Mr Jan van Emden, Helping Hand Aged Care (Proxy), CDPC Designated Systems Based Investigator
- Ms Sarah Byrne, NHMRC
- Mr Alan Singh, NHMRC
- Mr Chris Jennaway, NHMRC
- Mr Russell de Burgh, NHMRC
- Ms Marion Berry, NHMRC
- Ms Julie Glover, NHMRC (Proxy)
- Mr Michael Nutt, NHMRC (Proxy)
- Dr Chris Pettigrew, NHMRC National Institute for Dementia Research (NNIDR) and NHMRC (NHMRC Proxy)
- Ms Sarah Louder, NHMRC (Proxy)
- Ms Deborah Lopert, NHMRC (Policy Officer)
- Ms Jasmine Cribb, NHMRC (Project Officer)
- Dr Jonathan Lomas, NHMRC Knowledge Broker
- Professor Philip Davies, NHMRC Knowledge Broker
- Ms Janice Besch, NHMRC National Institute for Dementia Research (NNIDR) – Chairperson 2017–2019
- Professor John McCallum, NHMRC to 2015, NHMRC National Institute for Dementia Research (NNIDR) until 2017 – Independent Chairperson
- Ms Stephanie Ellis, NHMRC National Institute for Dementia Research (NNIDR) (Proxy)
- Representatives from the Department of Social Services and Department of Health (Dementia Policy Section)

### CDPC Executive Committee (2014–2019)

The Executive Committee is responsible for monitoring the progress of the CDPC's activities, as well as making key decisions regarding the approval of new research projects and the allocation of resources.

- Professor Susan Kurrle, CDPC Director – Chairperson
- Professor Simon Biggs, University of Melbourne and Brotherhood of St Lawrence
- Professor Maria Crotty, Flinders University
- Professor Anneke Fitzgerald, Griffith University and CDPC Management of Change and Workforce Enabling Sub-Unit Lead
- Ms Joan Jackman, CDPC Lead Consumer Investigator, Dementia Australia (was Alzheimer's Australia)
- Dr Susan Koch, Royal District Nursing Service (to 2015), Independent
- Ms Anne Cumming, CDPC Policy & Legislation Enabling Sub-Unit Lead

## CDPC Scientific Sub-Committee members (2014–2016)

- Professor Ian Cameron (Chairperson), The University of Sydney; CDPC Research Methodologies Enabling Sub-Unit Lead
- Professor Meera Agar, University of Technology, Sydney
- Associate Professor Caroline E Bulsara, University of Notre Dame Australia
- Dr Liz Gill, John Walsh Centre for Rehabilitation Research; Sydney Medical School Northern; The University of Sydney; Kolling Institute of Medical Research
- Dr Dianne Goeman, Royal District Nursing Service Institute
- Professor Leonard Gray, The University of Queensland, CDPC Technology & Telehealth Enabling Sub-Unit Lead
- Ms Karla Seaman, Brightwater Care Group, CDPC Designated Systems Based Investigator
- Dr Ron Sinclair OAM, Alzheimer's Australia Consumer Dementia Research Network (CDRN)
- Ms Elaine Todd, Alzheimer's Australia Consumer Dementia Research Network (CDRN)
- Professor Simon Bell, Monash University
- Dr Christine Bryden, Alzheimer's Australia Consumer Dementia Research Network (CDRN)
- Associate Professor Tracy Comans, Griffith University, CDPC Health Economics Enabling Sub-Unit Lead
- Professor Anneke Fitzgerald, Griffith University, CDPC Management of Change & Enabling Sub-Unit Lead
- Dr Meredith Gresham, HammondCare, CDPC Designated Systems Based Investigator
- Megan Corlis, Helping Hand Aged Care, CDPC Designated Systems Based Investigator
- Dr Hiltse Heemskerk (2014)
- Mr Leo White, Alzheimer's Australia Consumer Dementia Research Network (CDRN)
- Dr Kathryn (Kate) Hayes, Griffith University; Western Sydney University
- Dr Kate Laver, Flinders University
- Dr Janet Long, Macquarie University
- Dr Catriona Lorang, HammondCare, CDPC Designated Systems Based Investigator
- Mrs Kate Swaffer, Alzheimer's Australia Consumer Dementia Research Network (CDRN)
- Dr Katrina Anderson, Aged Care Evaluation Unit, Southern NSW Local Health District

## Enabling Sub-Unit Leads

Enabling sub-Units provided advice to CDPC research teams in their area of expertise.

- Professor Ian Cameron (Research Methodologies)
- Assoc Professor Tracy Comans (Health Economics)
- Ms Anne Cumming (Policy and Legislation)
- Ms Megan Corlis (CDPC Designated System Based Investigators 2013–15)
- Ms Rebecca Forbes (CDPC Designated System Based Investigators 2016)
- Professor Leonard Gray (Technology and Telehealth)
- Professor Anneke Fitzgerald (Management of Change and Workforce)
- Ms Joan Jackman (Consumer Enabling Sub-Unit)



## Designated System Based Investigators

Staff members of the Funding Partners who support in knowledge translation, dissemination and implementation of activity outputs.

### Brightwater Care Group

- Ms Wendy Hudson
- Dr Karla Seaman
- Dr Angelita Martini

### HammondCare

- Associate Professor Colm Cunningham
- Dr Meredith Gresham
- Ms Rebecca Forbes
- Dr Catriona Lorang
- Professor Chris Poulos
- Ms Angela Raguz

### Helping Hand Aged Care

- Ms Megan Corlis
- Mr Jan Van Emden
- Ms Samantha Giorgatzis
- Ms Helen Loffler
- Ms Helen Radoslovich

## Alzheimer's Australia Consumer Dementia Research Network and Dementia Australia Consumer Network members involved in CDPC Research (2013–2019)

The below members have been involved and contributed to CDPC activities:

- |                    |                       |                  |
|--------------------|-----------------------|------------------|
| • Joan Jackman     | • Jenner Henderson    | • Ron Sinclair   |
| • Janet Brennan    | • Louise Heuzenroeder | • Kate Swaffer   |
| • Christine Bryden | • Danijela Hlis       | • Jane Thompson  |
| • Theresa Flavin   | • Val Jenner          | • Elaine Todd    |
| • Ian Gladstone    | • Les Leckie          | • Anne Turner    |
| • Nadine Hedger    | • Leo White           | • Kathy Williams |
|                    | • Bob Page            | • John Quinn     |
|                    | • Lyntara Quirke      | • Glenys Petrie  |
|                    | • Tony Ramshaw        |                  |

## Original CDPC Lead Investigators

- |                          |                                |                                   |
|--------------------------|--------------------------------|-----------------------------------|
| • Professor Susan Kurrle | • Professor Ian Cameron        | • Dr Liz Gill                     |
| • Professor Meera Agar   | • Assoc Professor Tracy Comans | • Professor Len Gray              |
| • Dr Catherine Bateman   | • Professor Maria Crotty       | • Professor Sarah Hilmer          |
| • Professor Simon Bell   | • Anne Cumming                 | • Dr Susan Koch                   |
| • Professor Simon Biggs  | • Sue Field                    | • Professor Dimity Pond           |
| • Dr Michael Bird        | • Professor Anneke Fitzgerald  | • Assoc Professor Craig Whitehead |

## CDPC Operations Team

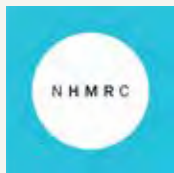
- |   |   |  |
|---|---|--|
| • Amy Boland, Operations Manager (2013–2015)        | • Sally Grosvenor, Communications Manager                         | • Alexandra Kitching, Project Officer        |
| • Jennifer Thompson, Operations Manager (from 2015) | • Honor Morton, Communications and Engagement Officer (2017–2019) | • Rebecca Tam, Finance Officer               |
|   |   | • Candida Blows, Director Personal Assistant |

## CDPC Evaluation Team

- |                        |                      |
|------------------------|----------------------|
| • Dr Shannon McDermott | • Alexandra Kitching |
|------------------------|----------------------|

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**Australian Government**  
**Department of Health**



**Brightwater**

**HammondCare**  
Champion Life



**dementia  
australia™**



**Helping Hand**  
new aged care

## AUTHORS

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Writing and editing support from:

- **Honor Morton**, Communications and Engagement Officer
- **Jennifer Thompson**, Operations Manager
- **Professor Susan Kurrle**, CDPC Director

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