

AUSTRALIAN NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL
COGNITIVE DECLINE PARTNERSHIP CENTRE

COLLABORATIONS IN CARE: AN INNOVATIVE APPROACH TO IMPROVING THE LIVES OF PEOPLE WITH DEMENTIA

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WHAT IS THE NHMRC COGNITIVE DECLINE PARTNERSHIP CENTRE (CDPC)?

- Partnership between Australia's National Health and Medical Research Council (NHMRC), Dementia Australia (consumer advocacy), and aged-care providers Brightwater Care Group (WA), HammondCare (NSW and Vic), and Helping Hand Aged Care (SA)
- Focus is on **improving care for people with dementia**
- Partners and consumers drive research agenda which is carried out by a team of research based and system based investigators (clinicians and aged-care providers)
- Approximately \$AUD25 million funding over 5 years
- Funding for projects began in Feb 2014, with 31 underway or completed, with funding finishing in Dec 2018



Brightwater



HammondCare
An independent Christian charity



dementia
australia™

The new voice of Alzheimer's Australia

WHO IS THE CDPC?

- Investigator team is a mixture of clinicians, researchers, consumers, and aged-care providers and practitioners
- Investigators include:
Medicine, nursing, physiotherapy, psychology, occupational therapy, pharmacy, social work, law, sociology, health economics, change management
- Consumers include people with dementia and carers of people with dementia
- The team covers 5 states, 11 universities, other institutions (Health Districts, Primary Care Networks, health and aged care providers), and 15 professions, and includes urban and rural sites



HOW IS THE CDPC DIFFERENT TO OTHER RESEARCH CENTRES?

- **Our main focus is on implementation: knowing to doing**
- Research projects are Partner initiated and approved
- Consumer involvement occurs from conception to completion - all projects are developed together with consumers, and reviewed by consumers
- Enabling sub units – advice and assistance available for:
 - health economics
 - research methodology
 - change management
 - policy development
 - technology and telehealth
- **Clinicians and providers are involved in research and can translate the findings immediately into practice**



EXAMPLES OF CDPC ACTIVITIES

- **Implementation:**

- Care of the confused hospitalised older persons program (CHOPs)
- Vit D administration in aged care facilities
- Telehealth enabled prescribing for people with dementia in aged care facilities
- Implementing the COPE intervention in community living older people with dementia and their carers (a “dyadic intervention”)
- Implementing Interprofessional Education across the aged care sector

EXAMPLES OF CDPC ACTIVITIES

- **Synthesis and dissemination:**
 - Development of Clinical Practice Guidelines and Principles of Care for People with Dementia
 - Development of Consensus Guidelines for Dementia in Primary Care
 - Development of a national approach to Advance Care Planning in People with Dementia
 - Review of the Role of Key Workers in Dementia

EXAMPLES OF CDPC ACTIVITIES

- **Collaborative new research:**
 - Investigating services provided in the residential care environment for people with dementia (INSPIRED)
 - Effect of regulations on the quality of aged care
 - Optimising the quality use of medicines in people with dementia
 - Understanding public attitudes to dementia and developing interventions to address these
 - Understanding falls risk and preventing falls in older people with cognitive impairment

EXAMPLES OF CDPC ACTIVITIES

- **Capacity building:**
 - PhD and Masters scholarships
 - Development of research capacity in staff working in health and aged care
 - Development of skills and confidence in consumers to work within a research environment
 - Providing workshops on health economics, policy engagement, technology and telehealth, and change management

COGNITIVE DECLINE PARTNERSHIP CENTRE

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**COGNITIVE DECLINE PARTNERSHIP CENTRE**

The NHMRC Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (Cognitive Decline Partnership Centre) aims to improve the lives of people with dementia by developing, communicating, and implementing research that improves care. Our approach is guided by our commitment to working together, diversity, and translating rigorous research into practice.

Dementia is the second leading cause of death in Australia and there are currently 353, 800 Australians living with dementia. An estimated 1.2 million people are involved in the care of a person with dementia.

To achieve our aim we bring together consumers, industry partners, researchers and clinicians to develop relevant research questions and ensure findings are applicable to the current care environment for people with dementia.

CONTACT US

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COLLABORATIONS IN CARE: INVOLVEMENT OF CONSUMERS

LESSONS LEARNT ABOUT INVOLVING CONSUMERS EFFECTIVELY

Six key areas have been identified as important for successful embedding of consumers in a research and implementation model like the CDPC:

- Respect from researchers and clinicians for experience of consumers (some living with dementia, some carers) including use of appropriate language
- Understanding of their needs (eg quiet rooms, easy to read material, adequate preparation time, frequent breaks)
- Having a paid consumer lead position to provide coordination and support
- Strong communication skills (in both directions)
- Training for consumers in how to advocate successfully, and to build confidence in dealing with researchers and clinicians
- Appropriate resourcing with expenses for travel and accommodation, and for accompanying people if necessary. CDPC has a Travel Support Policy.



CONSUMER INVOLVEMENT

BENEFITS

Consumers assisted across a range of aspects:

- Providing feedback on research questions
- Giving ideas about research instruments
- Providing feedback on outputs and resources produced by research teams
- Assisting in translation of research into practice.



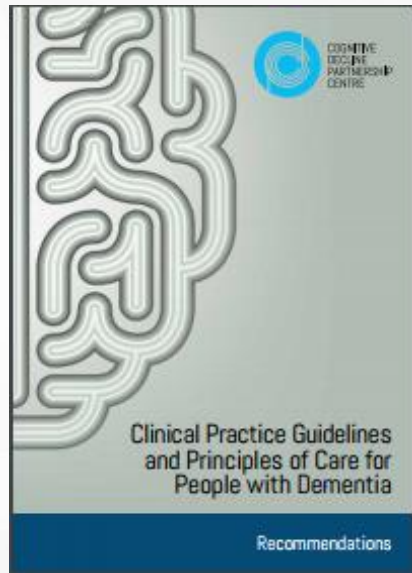
CHALLENGES

- Some difference across activities regarding the extent to which researchers are open to altering the research questions, methods, and outputs based on consumer feedback
- some hesitancy from consumers themselves about the impact their involvement has had on the research.

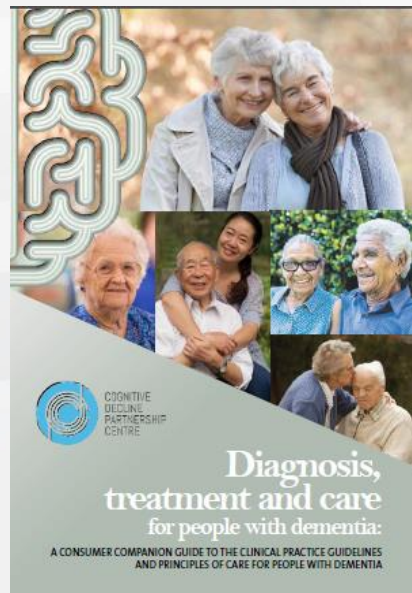
EXAMPLE OF CONSUMER INVOLVEMENT (1)

CLINICAL PRACTICE GUIDELINES AND PRINCIPLES OF CARE FOR PEOPLE WITH DEMENTIA

- Dementia Australia initiated this Activity
- Membership on the Organising Committee (1 consumer)
- Membership on the Guidelines Adaptation Committee (4 consumers)
- Consumers as members of the public, involved in the public consultation process.



- Subsequent involvement of 5 consumers in the development of the Consumer Companion Guide to the Clinical Practice Guidelines and Principles of Care for People with Dementia.
- Consultation on, and recommendations for, the marketing of the Guidelines and Consumer Companion Guide to consumers throughout Australia via print media, conference marketing, online media, doctors surgeries, community organisations for older Australians.



HOW HAS THIS ACTIVITY AND INVOLVEMENT EMPOWERED CONSUMERS?

- Consumer Companion Guide has been distributed across Australia in both hard and soft copies.
- Consumers are using information to direct their care or that of their family members eg saying to their doctor that “memory problems are not part of normal ageing”, asking about treatments that are available eg medication, or requesting a referral for exercise
- Consumers are questioning what is being suggested in terms of management eg in the management of behavioural problems associated with dementia, they are asking about what non-pharmacological strategies are available rather than going straight to medication, they are requesting referral of their family member to the Dementia Behaviour Management Assessment Service

MRS BROWN

- 78 year old lady with moderate Alzheimer's disease, recently moved to a dementia specific residential aged care facility after the death of her husband
- Very agitated and aggressive towards staff, wanting to call the police, trying to get out the door, pushing people out of the way
- Daughter told to stay away until she had "settled down", but was telephoned to say her mother was "dangerous" and she was being started on risperidone to "calm her down", and was physically restrained in a chair.
- Daughter visited Nursing Director with copy of Clinical Practice Guidelines and requested urgent review of her mother's situation by external team.
- Result of external review:
 - Mother's room made more homely with her own furniture and photos
 - Individual nursing assistance organised together with family members to provide 24 hour company for mother over 3 weeks until she gradually settled in, then reduced to several hours a day and finally ceased after 12 weeks

EXAMPLE OF CONSUMER INVOLVEMENT (2)

THE POLICIES AND PRACTICES OF FINANCIAL INSTITUTIONS AROUND SUBSTITUTE DECISION MAKING

- People with dementia are encouraged early in their illness to consider the appointment of substitute decision makers to protect their interests in financial matters (enduring power of attorney)
- Many older peoples' advocacy and consumer organisations noted that banks, other financial institutions, and even some government bodies did not always recognise these.
- Consumer organisations also noted that many older people did not understand powers of attorney, and whom they should appoint, what their obligations were, and how they might be open to financial exploitation.
- This Activity involved 3 consumers on the steering committee, and 5 more in designing an education package for staff of financial institutions, and more recently in developing workshops for older people together with a large older people's advocacy organisation (Council on the Ageing).

HOW HAS THIS ACTIVITY AND INVOLVEMENT EMPOWERED CONSUMERS?

- The workshop content is relevant to older people generally, and particularly to the carers of people with dementia, because of the involvement of consumers in content development
- The banks and financial institutions are aware that their customers were receiving education and therefore that education of their staff is high priority
- Older people are being made aware of how important it is to appoint someone they trust, who is available, and has some financial acumen.
- Older people are now also aware of the potential for financial abuse and the resources to protect themselves against this abuse have been made available, including direct advice



**Substitute Decision Making Instruments
Policies and Practices**
Substitute Decision Making Pilot Education Package



MR ANDREWS

- 81 year old man, carer for wife with mild dementia, living in own home
- He and his wife had appointed their son as their power of attorney. Son had begun to move bank accounts into his own name, saying that it was in his parents' best interests
- Mr Andrews attended a workshop on Powers of Attorney, and learnt that his son was not actually legally able to do this, and what he could do about it.
- He immediately went to his lawyer and revoked the Power of Attorney and visited the bank to investigate retrieval of his money.
- He has now appointed his 2 daughters as his power of attorney.

EXAMPLE OF CONSUMER INVOLVEMENT (3)

CARE OF OLDER PEOPLE WITH DEMENTIA IN THEIR ENVIRONMENT (COPE)

- Functional decline is one of the core features of dementia and is associated with reduced quality of life, negative impact on carers, and increased chance of institutionalisation
- COPE is an evidence based bio-behavioural program where an occupational therapist works with the person with dementia and their carer together to improve function, reduce dependency, and increase engagement, concentrating on the strengths and preferences of both.
- COPE (US version) has been adapted to the Australian context with the assistance of five consumers (including a person with dementia)
- It is being implemented with community living older people through health and aged care organisations in two Australian states



Gitlin 2010

HOW HAS THIS ACTIVITY AND INVOLVEMENT EMPOWERED CONSUMERS?

- Carers are very comfortable that this program has been developed with people who are living with dementia themselves, and are more likely to be happy to participate
- Carers are given the skills and the confidence to continue to manage the care of a person with dementia at home
- Carer stress and the possibility of physical and psychological abuse are covered in the training, and management of stress is a major part of the intervention
- Early evaluation has provided carer feedback that they are better able to cope with difficult behaviours and are less likely to become angry and frustrated, and they have learnt how to manage these feelings.



MRS WHITE

- 79 year old lady caring for her husband who has moderate dementia
- Very stressed with caring for her husband. She was quite bossy and critical of his memory lapses, and constantly corrected any mistakes. He became frustrated and angry and shouted at her, and occasionally pushed her.
- They were referred to COPE for assistance with managing at home.
- Occupational therapist spent time understanding Mr White's likes (his dog, his grandchildren, and going for walks), and a lot of time with Mrs White to try and change her behaviour towards her husband, teaching her how to distract him rather than correct him, and how to take him for a walk with the dog if he became frustrated, how to talk about their grandchildren and look at photos if he became sad.
- Situation at home much calmer, and husband, wife and dog have all lost weight with regular walking

INVOLVEMENT OF CONSUMERS IN OUR WORK HAS GREATLY BENEFITED THE CDPC AND HAS ENABLED US TO BE MORE RELEVANT AND MORE EFFECTIVE IN IMPROVING THE LIVES OF PEOPLE WITH DEMENTIA AND THEIR CARERS



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Thank you