Welcome to the first edition of the NHMRC CDPC News

It is with great pleasure that I write the welcome message for the first NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People Newsletter. We have all been looking forward to its arrival and I encourage all the CDPC members to read the newsletter to find out about the wonderful work we have been doing since the start of 2014. This is going to be a great opportunity for us to share in our successes, find out what’s hot in the field of dementia research as well as exciting news and events.

One event that I look forward to every year is the Annual Meeting, and last year’s meeting in Melbourne was an occasion for a large number of our Network to come together, hear about our progress as well as consolidate our links with government and consumer representatives.

With all our projects now well and truly under way, and some near completion, this edition of the newsletter includes information on projects examining, caring for the confused older person in hospital, the impact of a diagnosis of dementia on young people in the family, quality use of medicines, adapting to ageing for Australian doctors and the effectiveness of powers of attorney as a decision making tool. I hope find it interesting to read about these projects and contact us if you would like further information.

Finally, I would like to welcome Carol Bennett to the CDPC Network. Carol recently took over from Glenn Rees as CEO of Alzheimer’s Australia and therefore becomes a member of the CDPC Governance Authority. You can read a short background piece on Carol in this newsletter and I very much look forward to working closely together in the future.
A Partnership Centre is all about creating a collaborative environment that fosters links between researchers, consumers, clinicians, industry partners and policy makers to ensure translation of knowledge and research into enhanced health care practice.

The 2014 NHMRC Cognitive Decline Partnership Centre Annual Meeting confirmed we are all working towards the common goal of improving the lives and care of people living with dementia and their families.

Held at the Hilton on the Park, Melbourne on November 11, the annual meeting was a rare opportunity for the CDPC Network to come together and share not only in project successes over the past 12 months, but to hear from consumers and government representatives regarding their links with the Centre.

CDPC Director and Chief Investigator, Professor Susan Kurrle opened the meeting by “Setting the scene”. The Centre’s achievements during 2014 of over ninety per cent of milestones met with over one hundred public presentations, workshops, journal articles and other forms of research dissemination were highlighted.

Professor Kurrle also provided an overview of current research areas impacting on incidence of dementia and rates of decline and cited specific case studies to emphasize the importance and relevance of the CDPC research priorities.

The Annual Meeting “hot topic” sessions provided project groups an opportunity to work collaboratively to showcase their research. These sessions highlighted the broad cross section of projects addressing priority areas in dementia and related cognitive decline including timely diagnosis, identifying risks, legal issues, better hospital care and environment, medication management, and different models of care.

Dr Susan Koch, a Lead Investigator at the CDPC and Director of the RDNS Research Institutes presented on behalf of three related activities about “Supporting Families Through Services”.

“Many people experiencing memory loss or other symptoms of dementia including cognitive impairment have no idea that services are available, or what services are available,” said Dr Koch. “Even when they do learn of services it is difficult to navigate the health and aged care services.”

Dr Susan Koch went on to describe how the Centre is evaluating the Key Worker and Weavers model as alternative respite models for people with cognitive decline and their carers in the community setting. Both models work to support the carer in how to assist in developing strategies to build resilience, enhance their strengths, and empower them to take control of their situation.

“We propose a ‘support for life’ approach to care coordination of health care, community and social engagement for people with dementia and their carers and families.”

Consumer engagement within the CDPC is integral to the operations of the Centre. This was highlighted by the Consumer Dementia Research Network’s involvement in the day from a detailed presentation to active panel discussions and Q and A.

Attendees of the meeting gained a greater understanding about the CDRN and their active role in research and knowledge translation through Alzheimer’s Australia over the past 5 years, which has brought real-life insights as a driver to improve the quality of care.

Dr John McCallum from the NHMRC outlined the mechanism for setting Government priorities for dementia research through the new National Institute for Dementia Research (NIDR), announced in 2014.

With the CDPC Activities now well and truly underway we look forward to hearing about further achievements in Adelaide on the 16-17 November at the 2015 CDPC Annual Meeting.
Activities in Action

Improving the experience of the confused patient

Confusion or cognitive impairment is a common condition for older people in hospital. More than 30% of older people present with or develop confusion during their admission. This confusion is most commonly due to dementia and/or delirium.

A CDPC project that is already making a real difference in improving the experience and outcomes for older people with confusion is the Care of the Confused Hospitalised Older Persons Program (CHOPs), a collaborative project with the NSW Agency for Clinical Innovation.

Confusion is distressing for older people. Caring for an older person with confusion in hospital can also be distressing for staff, carers and families. As a result of the confusion an older person in hospital can experience numerous adverse events. They may be disorientated, fearful and anxious, may not recognise their carers or families, be agitated, suffer hallucinations, and generally display behaviours that are not usual for them. The older person with confusion may refuse care, attempt to leave, be disruptive or aggressive.

If left unrecognised and untreated, confusion can result in serious health consequences including increased risks of medical and surgical complications, falls, institutionalisation following hospitalisation, increased mortality, increased length of hospital stay and readmission rates, and functional decline.

“Early identification of dementia and delirium in the hospital setting, allows us to treat the underlying cause and manage symptoms, so that we reduce adverse effects, minimise their duration and severity and improve the emotional support and wellbeing of patients, carers and families,” said Professor Susan Kurrle Lead Investigator of CHOPs.

CHOPs was chosen by the CDPC as one of a number of activities to promote research and best practice for people with dementia in Australia. Seven key principles have been developed and a range of resources (including a website) have been produced to assist in the roll out of CHOPs and promote best practice care for older people within NSW Hospitals. Some of the numerous benefits derived from the implementation of the CHOPs program include better hospital design and priority setting for best practice care, a program specifically tailored to the needs of the older person, their carers and families as well as the hospital teams, and a shared knowledge during the implementation process that embeds systems into practice to sustain and spread improvements in the care of confused people in hospital.

The CHOPS program is currently being rolled out in 12 sites across NSW, as nominated by interested facilities, and is planned for other selected Australian states during 2015.

For further information:

Dementia experience – carers perspective short film – A resource for staff working in acute care to increase their understanding of the needs and experiences of carers of individuals with dementia http://www.aci.health.nsw.gov.au/chops/education/dementia-carers-video
Activities in Action

Study reveals lack of support for young people

A CDPC research program looking at the experiences of young people with parents with a diagnosis of younger onset dementia has found that they are extremely impacted by the diagnosis, and that society contributes to their distress.

Younger onset dementia (YOD) describes any form of dementia in people under the age of 65, with the latest figures indicating that it affects approximately 25,100 Australians. There has been very little research to date about the impact on the young person having a parent with YOD, so gaining the young person’s perspective in a qualitative research study has been very important to develop greater insight and understanding.

The purpose of this research, which started in April 2012 at The University of Sydney, was to develop an understanding of the experiences of young people between the ages of 10 to 24 years having a parent with YOD, and the role society plays in contributing to the emotional distress, stigma and marginalisation faced by all family members.

The research study:

Young people who had a parent with YOD volunteered for confidential interviews in this qualitative research study. A thematic analysis was conducted from the transcripts of the interviews and the social model of disability was used as a framework to help inform our understanding on the societal influences experienced by these young people.

The research highlighted the emotional distress experienced by many young people often feeling isolated and alone with inadequate education tools or support available from health and social care service providers. Often young people failed to be recognised by services, many feared unwanted scrutiny by the outside world as they faced stigma and discrimination having a parent with YOD as well as the burden of being a young carer within the family.

These results demonstrated the need for a shift within the present service delivery and support system that acknowledged individual family members age appropriately. The social model of disability directed consideration of the environmental influences on individuals and how this impacted on their ability to be a part of their social world, as is their right. Collaboration across sectors that include youth services are important to ensure young people remain connected to their social networks and family.

As a consequence of these research findings, a workshop was facilitated to provide a platform for cross-sectorial collaboration and networking from representatives of government, general practice, aged care, researchers, youth mental health and support service providers in partnership with consumers, namely young people and their parents living with a diagnosis of YOD.

The young people described, through sharing their emotional personal journey, the challenges they encountered in their social world. For many attendees this provided clarity on how the young people had been socially disadvantaged to date. Working in partnership and harnessing the expertise of the young people, ideas were explored on the design and delivery of services and support opportunities that would be more age appropriate.

As a group ideas were shared on new ways for including and supporting young people within families so they no longer felt invisible and alone. The potential for the social model of disability as a framework to influence the way services and models of care are designed and implemented that are more socially orientated was acknowledged. Wide reaching options such as the role of social media and web based tools were considered valuable for connecting and informing these family members.
Study reveals lack of support for young people (- cont)

Both the research study and the workshop confirmed more opportunities need be made available for young peoples’ engagement with health and social care service providers. There needs to be greater respect and understanding of their roles within families, as well as recognition of their individual needs and wants. More collaboration between youth, family support and dementia sectors in partnership with the families facing these situations, would enable a whole family approach to support and education.

This study entitled “The psychosocial impact on the young people having a parent with younger onset dementia,” was funded through the CDPC and carried out at the University of Sydney, Northern Clinical School – Hornsby with CDPC Investigators: Karen Hutchinson, Professor Susan Kurrle and Associate Professor Chris Roberts.

Please see the workshop summary highlighting some recommendations for future consideration in this area. (Link to the summary of workshop report)

For more information on this subject please read the article ‘The emotional well-being of young people having a parent with dementia’ which was published online in the journal Dementia. (dem.sagepub.com DOI: 10.1177/1471301214532111)
Optimising the quality use of medicines for people with cognitive and related functional decline

Medication use can provide great benefits to people with cognitive and related functional decline, such as disease prevention, disease management and symptom control. Unfortunately medications can also cause harms, particularly in older people.

While medication prescribing is a common interaction between older adults and doctors, cessation of medications is less common. Consequently, older people commonly take multiple medications (polypharmacy). Up to 50% of older adults with cognitive impairment take a medication that is considered unnecessary or high risk (inappropriate).

Through the CDPC project, ‘Optimising the quality use of medicines for people with cognitive and related functional decline’ we are researching the effects of medications and combinations of medications on important clinical outcomes such as functional independence and frailty.

One of our projects based in Sydney aims to discover how older adults and non-paid carers of older adults feel about medication changes. Optimisation of medication use in older adults will include initiation of medications as well as cessation of medications (also known as deprescribing).

The process of deprescribing is as complicated as prescribing, however, how to conduct it safely and effectively is not yet known. Understanding how older adults and carers feel about deprescribing will help clinicians implement medication withdrawal in practice.

Some of the first phases of this project at Sydney University involve gaining insight into the beliefs, attitudes and experiences of older adults with and without cognitive impairment and non-paid carers of these people. This will then be used to inform the development of interventions to ensure that existing medication review services and prescribing practices are person-centred, safe and effective.

What has been achieved so far?

So far we have conducted focus groups with both older adults and carers to explore how they feel about medication use, in particular how they would feel about having medicines stopped. This along with a literature review and discussions with experts in the field was used to develop a questionnaire. We are currently collecting data with this questionnaire to explore these attitudes and beliefs on a larger scale. The next phase of this study will involve exploring the views of people with mild cognitive impairment.

Project highlights to date.

We have been very pleased with the level of interest in our research with the opportunity to present at several national and international conferences. Prof Hilmer presented our Activity plans at the Hammond Care Risky Business Conference in Sydney in June 2014, and led a symposium on ‘Prescribing and Deprescribing in Older Adults’ at the Gerontological Society of America conference in Washington DC in November 2014.

A/Prof Bell led a symposium on ‘Prescribing for People with Dementia’ at the Australasian Society of Clinical and Experimental Pharmacologists and Toxicologists Annual Scientific Meeting in December 2014, which included presentations from three lead investigators from the CPDC. Dr Reeve published an article entitled, ‘Deprescribing antipsychotics in older adults’ in the Australian Doctor journal, which provides clinical guidance to general practitioners.

Project Lead: Prof Sarah Hilmer and A/Prof Simon Bell

Postdoctoral Research Associate: Dr Emily Reeve and Dr Kris Jamsen

University of Sydney and Monash University
Healthy ageing in Australian doctors

Doctors are a shrinking resource for an expanding population in most developed countries. In Australia we are seeing the ageing of our medical workforce, with a large percentage of doctors already at retirement age. Doctors and other health professionals experience the inevitable effects of the normal ageing process, the same as everyone else. Normal ageing affects physical and cognitive modalities that are integral to the practice of medicine – sight, hearing, reflexes, joints, fine motor skills and cognition.

What we don’t know is how these changes affect doctors in the workplace and how they are able to adapt to these changes.

The “Healthy Ageing in Australian Doctors” Activity aims to understand and document the ways in which Australian doctor’s experience and adapt to the ageing process including changes in cognition, as well as the physical changes. We hope to inform and contribute to the development of an evidence based approach to maintaining healthy, safe and sustainable medical practice.

To date, we have engaged doctors, in both metropolitan and regional areas, in focus group discussions. We have collected what we believe, are extensive and valuable data related to ageing in the medical workplace and insightful approaches to dealing with cognitive and physical changes. We invited the doctors to identify strategies for working towards retirement and their attitudes towards older colleagues.

We have also engaged consumers in focus groups and asked them to share their experiences with older doctors and identify what they felt were advantages and disadvantages of seeing an older doctor. Similarly we have spoken with other health professionals who have worked with older doctors and asked them to share their experiences and thoughts.

By collecting information from doctors, other health professionals and the clients of older doctors we have begun to build up a picture of how ageing affects doctors in the workplace. We are well on the way to delivering reports that will inform practice. Our ultimate aim is to develop a “Healthy Ageing Tool Kit” for doctors and health professionals.

This activity takes a slightly’ left of field” look at the issues for the Cognitive Decline Partnerships Centre. We are thinking about how ageing including cognitive changes affects health professionals and consequently how that affects their clients. We want to promote healthy ageing and preventive health care in our colleagues. To do that we need to understand more about how we adapt to ageing in the workplace. Our work is continuing in 2015.

Lead Investigators: Prof Susan Kurrle and Dr Narelle Shadbolt

Project Officer: Kerri Lockwood

University of Sydney
The complexity of decision-making in dementia care

A diagnosis of dementia does not mean an individual loses the right to make decisions for themselves. However, as the disease progresses, there may be limited or diminished mental capacity, making decisions about personal, health and financial matters difficult.

If older people lose mental capacity these decisions need to be made for them, in other words a substitute decision maker may need to be appointed. Therefore it is crucial that older people have access to adequate and appropriate substitute decision making tools.

The focus of this project was on the policies and practices of financial institutions in respect to the decision making tool, powers of attorney, and the experience of consumers, the attorneys, when exercising or attempting to exercise their authority in accordance with this tool.

Thinking and planning for the possibility of cognitive decline (and the financial consequences of this) is not common practice. Consequently, only a small proportion of people have in place a formal substitute decision making tool.

Substitute Decision Making (SDM), that is making decisions on behalf of someone else, is governed by state and/or territory legislation. SDM can be for personal and health matters, and in NSW this is governed by the Guardianship Act 1987 or it can be for financial matters, which are governed by the Powers of Attorney Act 2003.

Powers of Attorney can be either General or Enduring. The major difference between the two is that a General Power of Attorney ceases to have effect once the principal loses mental capacity. On the other hand an Enduring Power of Attorney continues to be effective.

One of the many problems associated with powers of attorney is that in NSW these instruments are not required to be registered, unless the attorney wishes to engage in property dealings. Therefore, no-one knows how many are in existence, or if the document is the most recent, or even if it is actually a valid document.

This study involved two major banks who provided information on the policies and practices of their organisations in respect of substitute decision making instruments. In addition, 15 attorneys agreed to participate in one to one and a half hour face to in-depth interviews with regard to knowledge and/or recognition of financial institutions of substitute decision making tools.

The findings of the project, to be released in early 2015, have highlighted a number of issues relating not only to the problems experienced by the attorneys and the banks but also fundamental problems with the legislation, the lack of harmonisation between the jurisdictions and the absence of any form of registration process, either federal or state/territory and a general lack of awareness associated with substitute decision making.

A significant outcome of this pilot study has been the development of an education package for the frontline staff in financial institutions. The aim of this package is to assist staff to understand the relevant instruments used in substitute decision making in respect of financial transactions.

Lead Investigator: Ms Sue Field

University of Western Sydney
Consumer involvement in the Cognitive Decline Partnership Centre

The phrase ‘A Magical Mystery Tour’ springs to mind when reflecting on our first full year of involvement, as consumers, with this first NHMRC Cognitive Decline Partnership Centre.

When Sue Kurrle first enthusiastically presented the proposed Cognitive Decline Partnership Centre (CDPC) Work Plan to the Consumer Dementia Research Network (CDRN) as a group in mid-2012, with a short-list of 14 Projects summarised for us, it was the beginning of our excitement and inspiration to be actively involved in this unique and innovative Centre – this NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People.

Alzheimer’s Australia as one of the Funding Partners and an organisation of which actively advocating for the Consumer ‘Voice’ to be heard, is core business, created the opportunity with Sue Kurrle for the CDRN Members to bring the consumer voice to the work of the CDPC. This included the funding of a part-time Consumer Investigator (CI) position, together with the support of a CDRN Member Sub-Group (6 members) and the broader membership.

The CI represents Consumers on the Executive Committee and facilitates, co-ordinates and supports the involvement of Consumers in all CDPC Activities as members of the Activity teams. With the support of Sue Kurrle, the Project Leads and Alzheimer’s Australia, we now have at least two Consumers involved in all current 17 major Activities. Initial involvement was through aligning Consumers to Activities based on their expression of interest and their availability. Then, in February 2014, the CDRN was structured into an Enabling Sub-Unit, consistent with the CDPC organisation structure approved in the original Work-plan. Involvement in further Activities is now by invitation from the Project Leads.

The interest and enthusiasm of the Consumers has also extended to contributing to Activity Focus Groups, Reference Groups and also to the Scientific Sub-Committee established in 2014, as well as selectively reviewing project proposals in the formative stages of development.

Apart from contributing the ‘consumer voice’ to Activities, the CDRN Members also recognise their need for broadening their skills and experiences in a range of theoretical domains, with some welcoming the opportunity to attend the Health Economics Workshop and also welcoming the Change Management experts to our August Meeting in Melbourne. Our only disappointment with these opportunities being with the limitations on financial support for a greater number of Members to attend.

We consider the CDRN is a unique group of people. It has been an innovative initiative of Alzheimer’s Australia, created in 2010, with 25 Consumers (people with a dementia or people who look after a person with a dementia) from each State & Territory. All have varied personal and professional backgrounds, who have a lived experience of dementia, as well as an interest in research and its potential to contribute to change! Expertly supported by AA Senior staff, the CDRN Members have become increasingly involved in a range of research-related initiatives, including the National Quality Dementia Care Initiative, Alzheimer’s Australia’s Dementia Research Foundation, and the Dementia Collaborative Research Centres’ research proposals. Members contribute as Volunteers to research priority setting and funding decisions; to Steering and Advisory Committees; to Project Teams – and a variety of other opportunities where the ‘Consumer Voice’ is valued and invited.

Extending our involvement as Consumers to the CDPC has been an interesting and enlightening learning experience for us all. A ‘Magical Mystery Tour’? – not altogether perhaps, as our understanding and appreciation of what and how we can most effectively contribute to the CDPC has matured over this past year. Our expectations when we initially leaped into the CDPC were naïve at best, but we have come to better understand and work with the complex process of research and continue to gain in respect for the experience, skill and expertise of the Project Leads and Project Officers, an awesome bunch!! Above all else, we have had to learn patience and harness our passions and energy to...
contribute effective and vigilant consumer perspectives for all the Activities / Work in which we are involved. We look forward in 2015 to evaluating how effectively we achieve this and if/how we are making a difference to the work of this unique Centre & the opportunities it has been given.

One of our members, Christine Bryden, has always strongly advocated that there be ‘Nothing About Us, - Without Us’!! ……

For Consumers - this means Research for us, - with us!! – “as a basic social and human rights issue …… to create a better future for people with dementia and for the people who look after them”!

For Researchers - as Christine also stated at the PC Annual Meeting in 2014, “Consumers can be effective in advocacy for research funding and in providing real-life insights for research and Knowledge Translation – as a driver to improving the quality of care”.

Quite simply …….. they bring the lived experience of dementia!!

TOGETHER - we make a powerful PARTNERSHIP!!

Thank you everyone for valuing the Consumer Voice and for being wonderful colleagues with whom to work. - BRING ON 2015 - and a very creative, productive year together!!!!

Joan Jackman CDPC Consumer Investigator, Alzheimer’s Australia CDRN member

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CDPC Member Profile

**Carol Bennett- Alzheimer’s Australia**

Carol Bennett is the Chief Executive Officer of Alzheimer’s Australia – the peak national organisation for all forms of dementia promoting advocacy, policy, support services, education, awareness, information and research.

Over the past fifteen years, Carol has worked at a senior executive level in peak national and state health organisations, most recently for five years as CEO of the Consumers Health Forum of Australia.

Carol has been appointed to numerous national and international policy bodies including recent appointments as a council member of the National Health and Medical Research Council, and a Board Director of the International Alliance for Patients Organisations.

She has worked with many stakeholders from health consumers to Prime Ministers in driving positive change for health consumers in Australia.
Where can you find the CDPC?

30th International Conference of Alzheimer’s Disease International

15 - 18 April 2015, Perth, Australia
Care, Cure and the Dementia Experience - A Global Challenge

Karla Seaman (Activity 9) “Residential aged care: Stagnant or stimulating for future graduates?” 16 April 2015, session: Developing Dementia Friendly Communities.

Karen Hutchinson (Activity 17) “Young people collaborating for social change so they no longer feel alone in the journey with their parent’s dementia” 18 April 2015, session: Engaging People Living With Dementia.

Dimity Pond (Activity 14) “Revision of the 2003 Australian ‘Care of Patients with Dementia in General Practice’ Guidelines” 17 April 2015, poster session: Policy, Practice and Economics.


Katrina Anderson (Activity 10) “Improving quality of residential dementia care and promoting change by supporting and caring for staff: What can we learn from the literature?” 17 April 2015 poster session: Residential Care Models of the Future

For more information on upcoming events go to our Events page on the CDPC website.

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CDPC Intranet
https://workspaces.usyd.edu.au/sites/partnership/

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