FULL REPORT

ROUNDTABLE ON YOUNGER ONSET DEMENTIA with INTERNATIONAL EXPERT CLINICIAN AND RESEARCHER, CHRISTIAN BAKKER
12 March 2013

On 12 March 2013, Ageing, Disability & Home Care (ADHC) and Alzheimer’s Australia NSW hosted a Roundtable event in Sydney, with Christian Bakker from the Netherlands.

About Christian Bakker:

Christian Bakker is an international expert on younger onset dementia. He is a Health Care Psychologist and Researcher at Radboud University, Netherlands, researcher on the Needs in Young Onset Dementia (NeedYD) study and co-founder of the Florence Centre for Specialized Care in Young Onset Dementia in The Netherlands.

Christian has been instrumental in the development of services specifically for younger people with dementia and their families in the Netherlands and was involved in the development of the Dutch National Young Onset Dementia Care Program. Christian is a senior researcher with the Needs in Young Onset Dementia (NeedYD) longitudinal research project aimed at exploring the course of young onset dementia and investigating the care needs of younger people with dementia and their relatives. The NeedYD study is mainly targeted at:

- delineating the course of early onset dementia;
- the functional characteristics and needs of people with younger onset dementia and their families;
- the risk factors for residential placement; and
- the interaction with the caring environment.

Christian has authored and co-authored several articles in peer reviewed scientific journals and chapters in books on younger onset dementia.

Who attended the Roundtable?

The Roundtable, held at the Sydney Mercure Hotel, was attended by 50 participants comprising policy makers, researchers, service planners and service providers from NSW Health, ADHC, Universities and non–government organisations, in areas of dementia policy, mental health, disability, aged care, psychiatry, community care and residential care.

What was the aim of the Roundtable?

The aim of the Roundtable was to provide an opportunity for policy makers, service planners and service providers to come together and discuss approaches to the design and delivery of service supports to meet the specific needs of people with
younger onset dementia and their families. Christian shared his experiences from The Netherlands Younger Onset Dementia Care Program operating out of the Florence Centre, which is being informed by longitudinal research conducted in the Netherlands. The research explores the course of younger onset dementia and the care needs of younger people with dementia and their relatives.

The Roundtable discussion focused on a number of key themes:

- raising awareness of younger onset dementia;
- integrated diagnostic services;
- integrated approaches to care planning and management of younger onset dementia – service design and models of care;
- family and community support – holistic approaches;
- predictors of residential placement in younger onset dementia; and
- residential support – respite, supported living.

**Experiences from the Netherlands in addressing younger onset dementia**

**National policy informed by evidence:**

Christian informed participants of the National Taskforce for Younger Onset Dementia that was set up in the Netherlands with representatives from government, service providers and Alzheimer’s Association Netherlands.

The Taskforce led the establishment of a National Care Program for Younger Onset Dementia, with a legislated care governance framework and evidence based best practice guidelines. Service providers that wish to deliver services to people with younger onset dementia must demonstrate compliance with the best practice care guidelines.

The Needs in Young Onset Dementia (NeedYD) Study is a longitudinal research study that has provided good evidence to inform service development. NeedYD investigates the course of younger onset dementia (cognitive functioning, behaviours of concern, caregiver functioning) and explores the needs of people living with younger onset dementia and their carers. The study explores factors related to the use of informal and formal care, carer burden, the time to residential placement; and compares these issues with late onset dementia.

Some key research findings from the NeedYD Study include:

- most often unmet needs for people with younger onset dementia are in relation to meaningful daytime activities, social company, verbal and non-verbal language and comprehension, information and psychological distress;
- the more unmet needs in a person with younger onset dementia, the lower the carer’s health related quality of life; the least unmet needs, the higher the carer’s health related quality of life;
- there is a clear relationship between increased unmet care needs and increased
behaviours of concern;
- predictors of higher levels of formal care use are: severity of dementia; loss of initiative; and increasing behaviours of concern;
- time to residential placement for people with younger onset dementia in the NeedYD Study averaged 107 months compared to 50 months for late onset dementia; and
- increases in apathy increased the risk of residential placement in younger onset dementia. Reduced risk is predicted by having a female carer, a spousal carer, a high sense of competence, fronto-temporal dementia and less severe forms of dementia.

Further Reading:


Raising awareness of younger onset dementia

Christian reported on research findings that showed the time to diagnosis in younger onset dementia is on average 4.4 years compared to 2.8 years for late onset dementia (van Vliet D, de Vugt ME, Aalten P et al, 2013).

Some strategies proving to be effective in the Netherlands for raising awareness of younger onset dementia amongst the general public include:
- periodic interviews or editorials in local newspapers;
- media coverage of events for people with younger onset dementia; and
- promotion of a dedicated helpline telephone/email service for people with younger onset dementia.

For health care professionals, strategies include:
- training programs for occupational physicians and insurance company doctors; and
- inclusion of younger onset dementia in the curriculum of general practitioner and elderly physician education program, with basic and advanced modules tailored to the individual needs of health professionals.
Service design and delivery that responds to and meets the needs of people with younger onset dementia

Christian presented on the specialised services for younger onset dementia that have been established at the Florence Centre in the Netherlands. The Roundtable provided discussion opportunity on the essential elements of service design for delivering successful outcomes for people with younger onset dementia and their families.

Critical elements for service design and delivery include:

- **Integrated diagnostic services** – ensuring causes of dementia and neuropsychiatric symptoms can be determined and involve a team of experts (e.g. neurologists, psychiatrists, geneticists and a case manager) who can provide immediate follow up to ensure provision of information and psycho-social support, holistic comprehensive needs assessment and initiate services that may be required.

- **Early intervention** to maximise the person’s functional capacity and to strengthen the informal supports provided by family carers;

- **Individualised service planning** – designing a service mix that supports comprehensive care and is flexible to meet individual needs of the person with dementia and their family, and can be modified over time. The service mix ideally includes medical care; psycho-social support including individual counselling; allied health interventions including physiotherapy, occupational therapy, psychology, speech therapy; group fitness programs; and non-verbal therapies e.g. art, music; outdoor activities.

- **Employment support** is critical for people diagnosed who are still working – it is important to utilise occupational physicians and allied health specialists to maximise function and workplace participation through therapy interventions, job redesign and environmental supports.

- **Integrated approaches to care planning and management** facilitated by a case manager/key worker approach and ensuring regular reviews and monitoring of changing needs.

- **Consumer directed approaches** supporting choice and putting the person and their family in control of the care and the support they receive, based on their needs.

- **Whole of family approaches** are especially important as often the primary carer is still working and there may be younger children still living at home. Quality of life is decreased when there are unmet care needs for both the carer and the person with younger onset dementia.

- **Programs, particularly social, recreation and day programs designed to fit the needs** of people with younger onset dementia. Providing meaningful and
normalising activity; ensuring programs have a component of physical activity; providing opportunities to maintain existing and build new social networks; tailoring programs to specific needs such as for a person with advanced aphasia, and drawing on allied health services to address speech, mobility, and functional activity impairments in order to increase the person’s participation and maintain their independence.

- **Ensuring neuropsychiatric symptoms are addressed**, particularly loss of initiative which can lead to an increase in formal care. Non-pharmaceutical interventions such as physical exercise, non-verbal activities such as art and music, and meaningful engagement activities can help reduce neuropsychiatric symptoms.
- **Providing social opportunities** where people with younger onset dementia and their families can meet, share experiences and socialise in non-demanding environments.
- **Staff who are trained** to work with people with younger onset dementia.
- **Programs operating with flexible service hours**, including longer hours, early evening and weekends, to cater for needs of working families, carers and families with children living at home.
- **Respite services that can be accessed when needed**, including overnight and weekends, with capacity to provide acute interventions.
- **Supported Accommodation models** that can address changing needs, catering for step up and step-down support that is matched to need.

**Aspects of the Netherlands experience that participants found relevant to the current Australian context**

The Roundtable provided participants with opportunity to reflect on the experiences of the Netherlands in the Australian context. The areas participants agreed could be implemented or improved in Australia include:

- **Integrated service and diagnostic supports need improvement in Australia** - participants discussed how the new key worker model (to be implemented nationally by Alzheimer’s Australia, funded by Commonwealth) and the new ADHC pilot, *Younger Onset Dementia Program* can facilitate improved integration between services.

- **Improving knowledge and skills of service providers in the disability, health, acute care, primary care, aged care and community care sectors on the specific needs of people with younger onset dementia** - participants discussed the strengths of the approaches in the Netherlands where younger onset dementia is included in the curriculum of the elderly care physician education program and the general practitioner education program; and there are training programs for occupational physicians, insurance company doctors
as well as for service providers working with people with younger onset dementia. The new national Younger Onset Dementia Key Worker program in Australia will provide opportunity for further development of an integrated competency based training program, along with other initiatives such as the ADHC Disability and Dementia education program for the disability and community care sector.

- **Service design, particularly social, recreation and day programs designed to fit the needs of people with younger onset dementia and their families** - recognizing that this group is physically more active than the older group with dementia, and their family, carers and peers are more likely to be still in paid employment. Participants discussed the service design model in place at the Florence Centre in the Netherlands as an excellent example of a design mix that supports comprehensive care and is flexible to meet individual needs of the person with dementia and their family, and can be modified over time. Flexible operating hours, highly trained staff, and programs that fit the needs of people with younger onset dementia are the key features.

- **An increased focus on early intervention to help people with younger onset dementia to pursue their goals and mitigate, alleviate or prevent the deterioration of their functional capacity** - participants discussed the importance of initiating multi-dimensional needs assessment and individual support and service planning as soon as possible following diagnosis, and how the new national younger onset dementia key worker model and the NSW Younger Onset Dementia Program can facilitate this. Participants reflected on the importance of multidisciplinary approaches and in particular the role of allied health such as physiotherapy for improving/maximising physical functioning and mobility and speech therapy for increasing capacity in speech and communication.

- **Enabling approaches** build on strengths and offer people with younger onset dementia and their families the opportunity to be actively involved in identifying goals that are important and meaningful to them and to participate alongside service providers to achieve their goals. Participants identified that NSW Community Care Supports Program and Home and Community Care Program in Australia provides valuable supports to enable people to live at home in their community, however more can be done to improve the implementation of enabling approaches in service delivery more broadly.

- **Consumer directed care** provides people with younger onset dementia and their families/carers with greater control over their lives by allowing them to make choices about the types of care they access and the delivery of those services, including who will deliver the services and when. Participants reflected on the introduction of the National Disability Insurance Scheme (NDIS) in
Australia, the Living Longer Living Better reforms, the new Commonwealth Younger Onset Dementia Key Worker program and the NSW Younger Onset Dementia Program and how these reflect a philosophy and approach to individualised care and support that will facilitate improved individualised service planning and the design of a service mix that supports choice, is flexible to meet individual needs, and can be modified over time.

- **Employment support needs** for the person with younger onset dementia who is still working and for family/carers. Participants discussed opportunities to educate and engage employers and work peers, liaise with employment support services such as those that specialise with people who have disabilities and to involve allied health professionals to maximise function and workplace participation through therapy interventions, job design, and environmental supports. It is noted that the Commonwealth Living Longer Living Better reform package provides funding over the next five years for initiatives that will enable people with younger onset dementia to access better coordinated care and support. Included in the funding is a new program to increase dementia awareness in the workplace. To better meet the needs of working families, participants identified the need for services such as respite and day programs, to be more flexible with their operating hours including longer hours, early evening and weekend. Issues in transitioning out of work and in particular access to Centrelink entitlements were also identified as areas for improvement.

- **Respite services** - providing more flexibility and responsiveness to changing needs and in particular to support working families and the person with dementia who has behavioural and psychological symptoms. Participants reflected on the Florence Centre (the Netherlands) respite model where the service can be accessed when needed, including overnight and weekends, with capacity to provide acute interventions by allied health and other specialist staff. Participants noted that many of the respite services in Australia have limited capacity to offer emergency or short term notice respite or regularly planned respite in settings that are appropriate for the younger person.

- **Accommodation support options** that provide alternatives to residential aged care are needed in Australia. Participants reflected on the models at the Florence Centre which provide both short term and long term accommodation in a home like environment with access to specialist service supports nearby. In Australia, supported accommodation models in the disability sector, particularly those for people with progressive neurological conditions provide good frameworks for models to support people with younger onset dementia.
The Dementia Behaviour Management Service (DBMAS) in Australia provides specialist support for management of behavioural and psychological symptoms of dementia and participants discussed the strengths of this program and noted that there were opportunities to improve the integration of the program with other service supports.

Practice based on evidence is an area that participants recognised for improvement in Australia. The Netherlands experience demonstrates how research findings have been used to inform national policy and service development for people with younger onset dementia and their families. Programs demonstrating effectiveness are evaluated on an ongoing basis for both clinical and quality of life outcomes. Participants identified that having an evidence based best practice service guide would assist in securing resources and support from funding agencies, policy makers, service providers and members of the targeted population.

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