YOUNGER ONSET DEMENTIA: A FRAMEWORK FOR BEST PRACTICE IN SUPPORT SERVICES

Alzheimer’s Australia National Conference

Kylie Sait
Policy, Research & Information
Alzheimer’s Australia NSW
OUTLINE OF PRESENTATION

- Background to research project
- Research aims
- Research methodology
- Key findings
- Policy and service implications
- Framework for best practice
ALZNSW RESEARCH

- Research project about the service and support requirements of people with younger onset dementia

- Younger onset dementia identified as a ‘special needs’ group in the NSW Dementia Services Framework yet little research about the support needs or ‘best practice’ in services

- Funded by Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC)

- Partnership approach
  - Alzheimer’s Australia NSW
  - Social Policy Research Centre, UNSW
  - UnitingCare Ageing
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  - Angie Robinson (formerly UnitingCare Ageing)

- Project steering committee members

- The people with younger onset dementia and their families members who shared their stories with us

- Ageing, Disability and Home Care (ADHC)
RESEARCH AIMS

- Understand the experiences of people with younger onset dementia and their families including their experiences of accessing the service system in NSW
- Identify barriers to timely diagnosis of younger onset dementia
- Identify their service and social support requirements
- Identify appropriate models for early intervention, support services, respite and community-based accommodation options for people with younger onset dementia
LITERATURE REVIEW

- Reviews national and international literature on community based service models for people with younger onset dementia and their carers

- Identifies ‘good practice’ rather than ‘best practice’
  - Lack of service evaluations

- Published in 2011 and available at: http://www.sprc.unsw.edu.au/publications/reports/
METHODOLOGY

INTERVIEWS

- 54 people interviewed in single, dyad and group interviews
  - 34 carers – majority female
    - 2 former carers
    - 3 adult children carers
  - 20 people with younger onset dementia
  - Range of diagnoses - AD, FTD, vascular, MS

- 9 service providers
  - Younger onset dementia specific services
  - Mainstream dementia services
  - Community care services
  - Aboriginal specific service
  - CALD service
  - Co-morbidities
METHODOLOGY

SURVEYS

- People with younger onset dementia
  - Option of short or full survey

- Carers/family members

- Responses
  - People with younger onset dementia = 18
  - Carers/family = 48

ROUNDTABLE DISCUSSIONS

- Discussions were conducted with key stakeholders in June 2011 to inform the fieldwork
  - 6 carers; 7 people with dementia; 6 service providers

- A second set of roundtable discussions were conducted in May 2012 at the conclusion of the fieldwork to confirm research findings
  - 12 carers; 10 service providers
KEY FINDINGS

- Diagnosis – complex, lengthy, insensitive delivery
- Lack of understanding and awareness
- Impact on lifestyle and families
- Navigating the service system
- Good practice in service provision
- Unmet needs – residential respite and accommodation options
IMPACT OF DELAYED DIAGNOSIS

“Not all marriages are great when people come to the point of diagnosis. A lot of people have gone through some pretty horrendous times reaching that diagnosis, so it’s those problems around misdiagnosis and the time it takes to reach a diagnosis and in the meantime often marriages are really strained to breaking point”

(service provider)

“Because my husband is younger and because it wasn’t picked as early as I really felt it should have been…and where my husband…was self-employed, he made lots of financial decisions that were really bad, and because of that we’re pretty deep in debt…I’m still working and struggling to keep us where we are, pay off the debt”

(carer)
“He said: diagnosis to death, seven to ten years, then he turned around to make a phone call”

“Both neurologists were extremely unhelpful and useless, if I could dare to be so bold”

“I wasn’t particularly impressed with the gentleman who gave us the diagnosis because he basically bluntly said ‘yes, you’ve got Alzheimer’s, go back to your own doctor and they’ll look after you.’ I felt it could have been a little bit more sympathetic, a little bit gentler”

“The experience to me was appalling…there was no empathy when giving the diagnosis and the lack of information made things particularly difficult, as I had no idea what I was dealing with and no idea how to explain it to the family and Mum’s friends”

(carers)
LACK OF AWARENESS AND UNDERSTANDING

“In the community I’ve found that with a person with older dementia…people seem to have an understanding, ‘Okay, they’ve got dementia’, so they make allowances. But people with younger onset dementia…there’s not the same understanding…They don’t seem to recognise that this person has Alzheimer’s or dementia”

(carer)

“We get questioned more as people have never heard of younger onset dementia. I’ve found even some medical professionals fall into this category, particularly emergency departments. This makes it hard to get assistance sometimes, because it seems they don’t believe the diagnosis when you tell them your parent’s age”

(carer)
IMPACT ON LIFESTYLE AND FAMILY RELATIONSHIPS

“The carer role for me is very lonely, you’ve got no one to talk to...loneliness is an issue. I’ve got lots of other stuff in my life, but at the end of the day, there’s a person you’ve been with for most of your life, and now you’re not going to be together...Most of the time I’m strong, but sometimes it just catches you”

(carer)

“It’s not just about services for the person with dementia. It is also about the impact on the children and the spouse. We need support too. If dementia was not in the picture, what we experience would be seen as child abuse or domestic violence. Because it is seen as coming from the dementia we are expected to simply suck it up. The cause of it doesn’t change what we experience, especially so for the children”

(carer)
NAVIGATING THE SERVICE SYSTEM

“People get their diagnosis through the health system…and getting health to recognise that the community care services can actually help is still problematic…it’s very frustrating to think that people are missing out because a health professional has made a diagnosis but then not sent them on anywhere else”

(service provider)

“The whole process for somebody who has never been ill, never used any social services of any description or any government services, it’s a complete mess trying to navigate through…especially in the early days, you don’t know…for someone who is an outsider…doesn’t understand it, it’s very confusing”

(carer)
GOOD PRACTICE IN SERVICE PROVISION FOR YOD

- Living with Memory Loss and Support Groups
  “In terms of receiving support…it’s wonderful, absolutely wonderful…and that’s been an amazing help along the way…being inspired by people who care so lovingly” (carer)

- Dementia advisors
  “[She] does such a good job, she’s so active. There’s stuff for us to do every week; there’s something we could go to every week and that’s younger onset specific. And my worry is if we don’t support it, it will go away” (carer)
GOOD PRACTICE IN SERVICE PROVISION FOR YOD

“We need to] normalise their life…need something that is going to give them some sort of meaning and connection, rather than being isolated out of the community, which is what happens when you go to a bricks and mortar day care centre”

(service provider)

Wife: But your most favourite thing is going out on the bus, isn’t it?
Husband: Definitely.
Interviewer: You go out and have lunch somewhere?
Husband: Yes, and it’s all so nice. We go to good places.
Wife: He likes going on Tuesday, because it’s an older men’s group, not dementia.
Husband: I’m the only person [with dementia].
UNMET NEEDS

“[We need] more respite centres for people with younger onset dementia – not in a nursing home. Some sort of group house, as a respite service…houses could be used as retreats for both carers and people with dementia”

(carer)

“[We need] access to residential care that is not aged care. Some services will not assist with future care needs and planning as my husband is under 65. They say he is not suitable despite having a diagnosis of Alzheimer’s. Other services stated a Board would have to give permission for entry into the facility”

(carer)
### Figure 9: Summary of Vision, Principles and Implications for Service System Development

<table>
<thead>
<tr>
<th>Goal/Vision</th>
<th>Principles to Guide the Provision of Services</th>
<th>Younger Onset Dementia Service System Development</th>
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| Best practice in person-centred approaches for people with younger onset dementia and their families | • Holistic  
• Enablement  
• Whole of Family  
• Timeliness  
• Flexibility  
• Coordination and collaboration  
• Dementia-friendly environments  
• Effective communication  
• Skill  
• Cost effective | • Service and funding models  
• Skilled workforce attracted and retained  
• Collaboration and capacity building  
• Service system responsiveness  
• Building evidence based best practice |

### Key Areas of Focus  
| 1. Barriers to Timely Diagnosis |  
- Conduct a community education campaign to increase understanding of younger onset dementia and reduce stigma  
- Engage Medicare Locals to work collaboratively with GPs and other primary health providers to raise awareness of younger onset dementia  
- Conduct a GP education campaign about younger onset dementia  
- Train GP practice nurses to screen for younger onset dementia |

| 2. Diagnosis and Referral |  
- Streamline the process of diagnosis and referral to services through the use of clinical and referral pathway documents  
- Encourage GPs to include the carer in the diagnosis process to provide important information  
- Improve access to and navigation of the NSW service system for people with younger onset dementia and their families through the implementation of a key worker model  
- Provide a ‘one-stop-shop’ for information about younger onset dementia |

| 3. Early Intervention |  
- Proactive follow-up after diagnosis by key worker to develop individual service and support plans  
- Use whole of family approach to provide opportunities for peer support and counselling  
- Acknowledge and promote remaining capacities, functional independence, community engagement and quality of life of the person with younger onset dementia  
- Instigate planning ahead processes to ensure inclusion of person with younger onset dementia in the decision making while they still have capacity |

| 4. Support for Transition Periods |  
- Support people with younger onset dementia to transition out of employment with education for employers and opportunities to participate in meaningful alternatives  
- Support working carers via the provision of long day program models and promote the importance of workplace flexibility  
- Support the person with younger onset dementia and their carer to transition from driver to non-driver via planning, education and provision of transport options  
- Increase community awareness to strengthen community capacity building |

| 5. Behaviour Management |  
- Develop an understanding of the causes of behaviours and increase the use of effective communication and dementia-friendly environments  
- Provide appropriate and timely carer respite and in-home support with younger onset dementia trained staff  
- Provide access to specialised multi-disciplinary support services to assist the management of behaviours of dementia |

| 6. Avoiding Premature Entry to Residential Care |  
- Promote strategies to alleviate or reduce carer stress to prevent premature entry to residential care  
- Develop processes and protocols for a planned transition to residential care if required  
- Provide alternative care and accommodation options for people with younger onset dementia  
- Train hospital staff to support people with younger onset dementia and their families to enable them to return home if appropriate rather than placed in residential care |

| 7. People with Additional Needs |  
- Aboriginal communities  
- CALD communities  
- Co-morbidities  
- Rural and remote  
- GLBTI  
- Living alone |

This figure summarises the relationship between the vision for person-centred approaches for people with younger onset dementia, their families and carers; the principles to guide the provision of services; implications for service system development; and strategies to implement change, as outlined in Sections 7-9.
Best practice in person centred approaches for people with younger onset dementia and their families
10 PRINCIPLES
TO GUIDE THE PROVISION OF PERSON CENTRED SERVICES FOR YOD

Holistic
Enablement
Whole of Family
Timeliness
Flexibility
Coordination and collaboration
Dementia-friendly environments
Effective communication
Skilled staff
Cost effective
DEVELOPMENT OF A YOUNGER ONSET DEMENTIA SERVICE SYSTEM

- Service and funding approaches
- Integrated service delivery
- Collaboration and capacity building
- Workforce skills
- Evidence based practice
KEY ISSUES AND STRATEGIES

- Timely Diagnosis
- Diagnosis and Referral
- Early Intervention
- Support for Transition Points
- Behaviour Management
- Supporting People to Live at Home
- People with Additional Needs
service and support requirements of people with younger onset dementia and their families

released in november 2012 and available on the adhc website

THANK YOU
QUESTIONS?

Email: kylie.sait@alzheimers.org.au
Phone: (02) 8875 4641