Younger Onset Dementia: International Literature Review and Needs and Feasibility Assessment of Services

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Younger Onset Dementia project

- Australian Government funded, July 2012 – Feb 2013

- Two elements:
  - International literature review; and
  - Consultations concerning a needs analysis and feasibility assessment of services for people with younger onset dementia

- Examined the service and care needs of people with younger onset dementia

- Identified guiding principles for service design and development, and examples of good practice
Needs and Feasibility Study

Methodology

- National consultations and online surveys
- Working closely with Alzheimer’s Australia
- Broad definition of younger onset dementia
  - primary condition – Alzheimer’s Disease, Fronto-Temporal Dementia
  - secondary condition – HIV/AIDS, Parkinson's, Huntington’s, drug and alcohol
- Broad definition of needs
  - Living arrangements, social, economic and environmental factors that enable and support people with younger onset dementia
Re-framing ‘dementia’

- Meeting with Alzheimer’s Australia National Dementia Consumer Advisory Committee Sept 2012
- Highlighted gaps in usual ‘dementia journey’ frameworks
- Two dimensions: longitudinally as well as systemically

**Five Stages of Dementia**

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Stage 5</th>
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</thead>
<tbody>
<tr>
<td>Risk Reduction, Awareness &amp; Recognition</td>
<td>Assessment, Diagnosis &amp; Post Diagnostic Support</td>
<td>Adjustment, Enablement &amp; Engagement</td>
<td>Management Care, Support &amp; Review</td>
<td>Later stages of dementia</td>
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Re-framing our approach \textit{cont’d}

\textbf{Circles of impact of younger onset dementia}
Results

- 215 people interviewed nationally
  - All States and Territories (except Tasmania)
  - Metro, rural and remote
  - Special interest groups:
    - Aboriginal and Torres Strait Islander
    - Cultural and Linguistically diverse
    - Homeless
    - Care leavers – unavailable at that time

- 97 survey responses; 29 complete
Consultations

- People with dementia and carers: 33
- Special interest groups: 21
- Service providers: 77
- Peak body representatives: 54
- Researchers: 19
- Policy and program officials: 11
Service delivery: best practice

- Key Service Attributes
  - **Individualised model of service** (listening, person-centred, whole of family, ongoing needs assessment, recognise diversity)

  - **Staff attributes** (skilled; holistic, enabling, & consumer centred approaches; effective communication, flexibility, capacity building)

  - **Organisational attributes** (facilitate access to relevant services, integrated and coordinated interagency partnerships & pathways, dementia friendly & timely service provision, respect & consideration, cultural safety, address needs of people in rural & remote areas, manage risk effectively, capacity for organisational change)
Service delivery: best practice cont’d

- Address all elements of the ‘circles of impact’,
  - starting with a focus on the person with younger onset dementia and working outwards to facilitate the enablers within the surrounding spheres of influence.

- Requires different emphases of effort across the five stages of dementia support.
What we found

- Unsurprisingly … relatively few services nationally
- Most in aged care sector – extension of existing models to meet the different needs of younger clients:
  - Risk factors - clients more active and physically strong
  - Client interests - vocational, purposeful, meaningful activities
  - Relationship factors – partners/spouses and children
- Some arising from within disability service sector
  - More ‘enabling’ philosophy, community engagement
What we found cont’d

- Many used a mix of aged care and disability program funding applied ‘flexibly’
  - E.g., combining transport and respite funding for outings
- Partnerships with generic community services
  - Health and fitness, ‘gym clubs’, swimming, walking groups
  - Vocational – gardening services, Men’s Sheds, art groups
  - Health pathways – links with health and aged care services, localised agreements re priority referrals, cross-sector education and training
Examples

- **Gardening on the Tram Tracks**: *(Adelaide SA)*
  - Men with younger onset dementia are supported and supervised by a council worker and a volunteer to beautify the nearby Black Forest Tram Stop gardens.
  - Also provides an opportunity for them to speak to commuters about the issues relating to younger onset dementia.

- **BANCPASS**: *(Melbourne, Vic)*
  - Collaboration between health and aged care service
  - Clients remain ‘on books’ even after entry to residential care
  - Priority referral pathway, in return for ongoing education of aged care staff
Implications for service delivery

- Timely and accurate diagnosis - health professionals and community awareness
- Focus on the individual – tailored to interests, needs, context
- Integrated – capacity building approach, flexible, networked with specialist services
- Continuity – case manager/co-ordinator who works with the client and their family for tailored support across ‘journey’
- Respite services – meaningful, vocational activities; offered in ‘blocks’ of sufficient time to enable carers continue family, personal and employment activities.
Organisational implications

- Most innovative service models driven by commitment of *individuals* – risks re sustainability
- Organisational support needs to be explicit – philosophy/mission, resources, staff skills and support, policies and processes.
- Underpinned by philosophy of partnership - Inclusion of clients and their families in development, design and delivery
- Commitment to quality e.g., evidence based assessment and care
- Capacity for advocacy
Policy implications

- **Promote Independence**
  - No ‘prescribed disengagement’ - i.e., arbitrary cessation of particular activities upon diagnosis;
  - Focusses on assessment of attributes and capacity rather than loss and disability.

- **Facilitate Interdependence**
  - Program eligibility and funding to include interdependence of people with dementia and their carers. E.g., NDIS
  - Cross-sector and inter-jurisdictional approaches to supporting people with dual diagnoses and complex health, care and accommodation needs.
Acknowledgements

This project was funded by the Department of Social Services.
The project was very much the result of the professional and personal commitment of my colleagues at CHSD.
Our sincere thanks to:

- Alzheimer’s Australia Younger Onset Dementia Key Workers, who facilitated much of our face to face consultations, and
- the service providers we met with, who are at the forefront in service development and advocacy for their clients.

Most importantly we are thankful for the generosity in time and insights of the people with younger onset dementia who contributed to this project, their carers and family members.
Want to know more?

Reports are available on University of Wollongong website:


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