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Younger Onset Dementia Services

A review of three services in Europe against best practice standards, with recommendations as to how we could work to develop and/or improve services in Aotearoa.

The CHURCHILL fellowship
Darral Campbell 2024



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EXECUTIVE SUMMARY

1. Aotearoa with over 5.2 million people, struggles to develop quality accessible services for people living with Younger Onset Dementia (YOD)
2. 90% of the population lives in urban areas, and three-quarters are in the North Island, leading to uneven service availability.
3. YOD services often lack clear differentiation from those for older individuals, failing to address the specific needs of younger people with dementia
4. Our health system does not see dementia, and in particular Younger Onset Dementia as a priority.

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BACKGROUND

Traditional health services target older retired people

1. On average 2-5 different consultants before diagnosis
2. Average time to diagnosis
   - Younger people = 4.4 years
   - Over 65s = 2.2 years
3. GPs often attribute symptoms in younger people to stress, anxiety, depression or menopause
4. People with YOD more likely to be diagnosed with an inherited dementia or a rarer dementia

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DEMENTIA CANTERBURY

- Traditional models offer post-diagnostic support designed for older people
- We need to think differently for active younger people offering support that is:
  - Holistic
  - Knowledgeable about are dementias
  - Family-centred
- Our YOD research shows a specialised programme can make a difference



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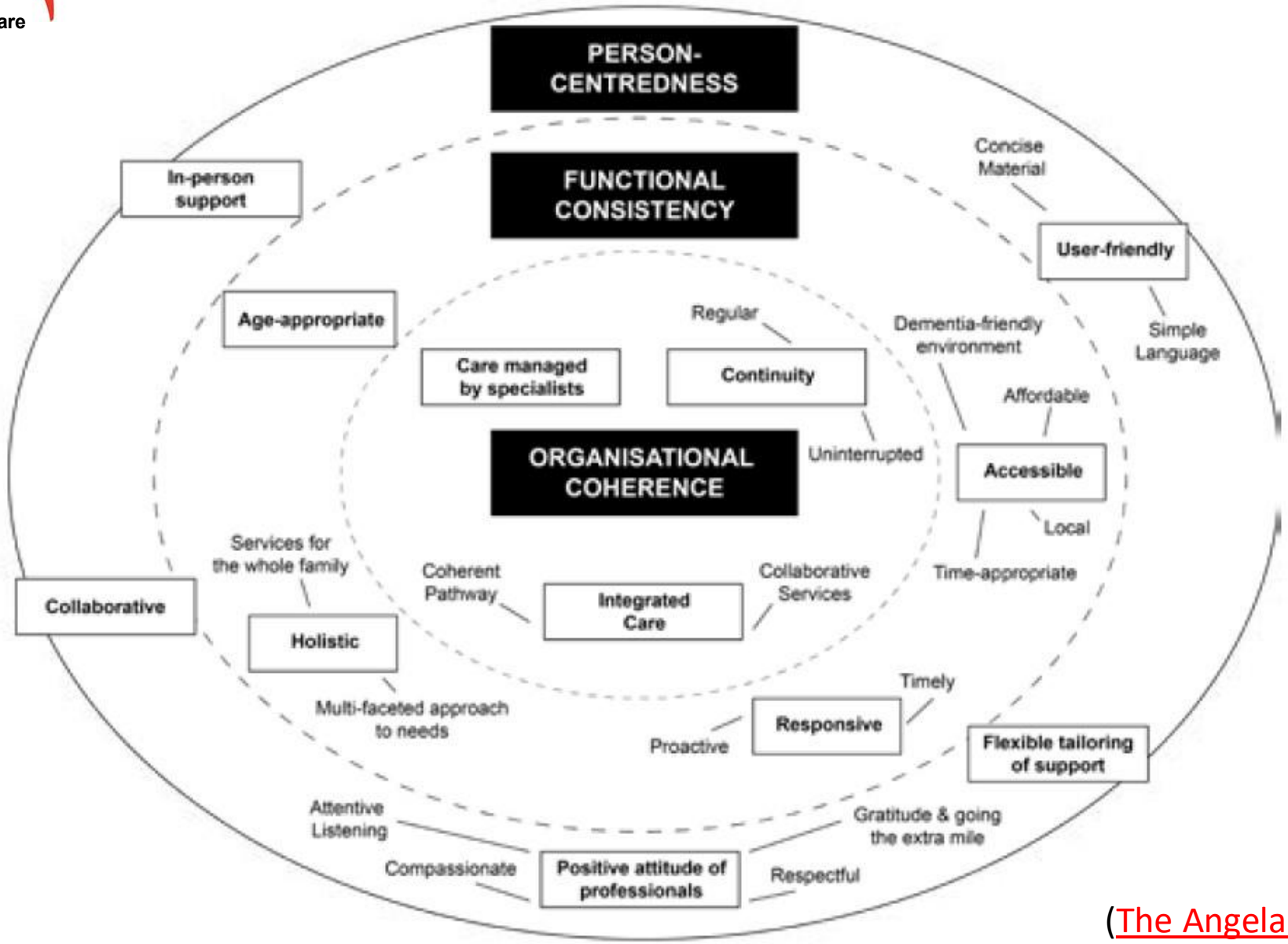
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- Aotearoa New Zealand has inconsistent and underfunded services for Younger Onset Dementia (YOD), with no best practice guidelines in place.
- Key organizations like Dementia Canterbury, Dementia Auckland, and YODAT are working to address these gaps but face challenges.
- International reviews, including the UK's Angela Project and Ireland’s National Dementia Office, highlight significant gaps in post-diagnostic support for younger individuals with dementia.
- Dementia Canterbury advocates for specialized, holistic support for younger people, contrasting with traditional models aimed at older adults.
- Research, supported by the Winston Churchill Memorial Trust, compares YOD services in Canada, the Netherlands, and Scotland, offering insights on improving support in New Zealand.

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THE ANGELA PROJECT'S MODEL



(The Angela Project, 2022)

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HOW KEY QUESTIONS WERE ADDRESSED

Countries / organisations visited

- Alzheimers Canada, British Colombia
- Alzheimers Scotland (Glasgow)
- Netherlands (Florence Centre for Specialized Care in Early Onset Dementia)

Focus:

- Diagnosis and referrals
- Range, extent of services
- Access and accessibility
- Specific community and residential services
- Funding



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Level	Facet	Description
Meso level: *Organisational coherence*	Integrated care	Services provided collaboratively, rather than in silos, organised in a way that enables a coherent tailored care pathway
	Care managed by specialists	Care provided and co-ordinated by specialist services and professionals who are trained and experienced with YOD
	Consistent	Services that give the person regular and continuing contact with a known person and/or service, who remains in touch as needs change over time
Macro level: *Functional Consistency*	Age-appropriate	Services that provide support to fit the younger age profile and needs of people with YOD and their families, and involve approaches/ activities appropriate to age, life stage and lifestyle
	Holistic	Services that consider and address the multiple facets of YOD and the needs of all in the family who are affected, including children and young people
	Responsive	Services that are proactive in response to changing needs and which respond to these in a timely manner
	Accessible	Services that are easily accessible in terms of being local, affordable, dementia friendly and delivered at convenient times

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CONCLUSIONS AND RECOMMENDATIONS

- **Desire for Best Service:**

  All visited programs aim to offer the best service for clients and families, understanding the unique needs of those with Younger Onset Dementia (YOD)

- **Need for Specialist YOD Services:**

  Research and practice indicate a need for specialized YOD services distinct from mainstream dementia services to cater to the entire dementia journey

- **Model of Best Practice:**

  The Angela Report provides a model of best practice that can be adapted to create YOD guidelines tailored for Aotearoa, including the needs of tāngata whenua, Pacifika, and other cultures

- **Specialist Programs in Major Cities:**

  Evidence supports the availability of specialist YOD programs in all major cities across New Zealand

- **Specialized and Interdisciplinary Staffing:**

  YOD programs should be staffed with professionals who are specialized in YOD and work in an interdisciplinary manner



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CONCLUSIONS AND RECOMMENDATIONS

- **Multi-Layered and Multi-Dimensional Programs:**

  Programs should be designed to be adaptable to the changing needs of individuals and families throughout the dementia journey, including options for respite care that allow continued involvement in community-based YOD programs

- **Challenges of Single-Site Models:**

  While a single-site model like Mariahoeve is ideal, replicating this in NZ may be challenging due to existing service structures. However, future planning should consider integrating YOD services with residential care environments to maintain community connections

- **Role of Neurologists:**

  Neurologists specializing in cognitive disorders may offer quicker and more age-appropriate diagnoses for those not suited to older adult services,

- **Designated Funding Needed:**

  Specific funding for YOD services is essential to prevent them from being merely adjuncts to older adult dementia services, ensuring comprehensive care from diagnosis through to end-of-life



	Canada British Colombia	**Scotland** Glasgow	**Netherlands** Mariahoeve
Population	Vancouver : 5,519,013 (Country : 38 million+)	Glasgow : 627,000 (Country : 5,436,800)	The Hague / Den Haag : 514,861 (Country : 17,646,000)
			

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Netherlands, Mariahoeve



Staffing:

- Interdisciplinary team includes Physio, Occupational and Speech Language Therapists, Social Work, Psychology, Art and Music Therapists, and Medical professionals.
- Team works with individuals and groups as needed.

Case Manager:

- A social worker performs initial assessments and engages with clients at home.
- Maintains regular home visits and liaises with care providers for home support.
- Other team members provide specialist assessments and advice as needed.

Respite Services:

- Overnight stays available for community-dwelling clients.
- Offers carers a break while maintaining existing service connections.
- Helps clients become familiar with supported living environments, preparing for potential full-time transitions.
- Regular stays (e.g., one night per week) can enhance home care and support family caregiving.

Residential Care:

- Two floors of Florence YOD service dedicated to residential care.
- Units accommodate 16 ..but also some smaller units of 8 people each, totaling 60 clients.
- Clients are grouped by functionality and need.
- Features 3 lounges and living areas per unit.
- Private rooms with ensuites, space for larger beds, lounge furniture, and personal items.
- Rooms resemble bedsits rather than traditional bedrooms.

Care Planning and Access:

- Individual care plans are tailored to each client's needs.
- Clients can continue accessing day groups, the café, and gardens if able.

Service Continuity:

- Same therapists involved in day services remain engaged when clients move to sheltered or residential care.
- Ensures continuity of care and maintains relationships and knowledge of clients and their families.

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Are they inclusive of care partners, families, and children?

- Not formalised education delivered in a variety of settings for care partners or families.
- Social worker offers education and support during home visits.
- Support groups with educative components and meetings are available for partners and children of individuals with YOD (Young Onset Dementia).
- Groups are led by a psychologist and social worker.
- Informal meetings are held in the café every 6 weeks, with health professionals present.
- Interdisciplinary Team (IDT) maintains ongoing involvement with families.

What criteria do you use to access services and remain in the YOD service arena?

- Access to Mariahoeve services is based on individual needs.
- Available services include supported living, sheltered accommodation, and nursing home care.
- At age 70, clients can transition to older persons' care floors or move to facilities closer to family, or receive hospital care.
- Service choices are influenced by the needs of both the client and their family.

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Are there specific services [community and residential] based in your area?

- Mariahoeve provides community support, day support, respite care, sheltered living, nursing home care, and hospital care all on one site.
- Similar services are available in the wider region and Amsterdam, but not all are located on a single site.
- The facility is situated in a mixed housing area with parks, community shops, and other services.
- A café and garden are open to the community; YOD clients can join a gardening group.

How are YOD services funded in your country/region?

- Services are typically fully covered by mandatory insurance.
- Additional specialist or residential care requires a government funding assessment.
- Cost is generally not a barrier; income testing is available if financial situations change.
- Funding levels increase with the level of care needed.

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CLIENT STORIES

Client 1 [NAME WITHHELD] said

He attends the community YOD program 3x per week on average but as he feels like. He travels by bike and train. He lives at home with his wife who is in fulltime work and their dogs.

His motivation to come to the program is because he is very isolated at home as his wife and all his friends are at work and he generally does not have anything to do each day other than walk the dogs. He enjoys being with people his own age and socially connecting. He has an individualised gym program and enjoys the gardens and other groups on site. He enjoys having lunch or a coffee in the café.

He has used the respite service on site when his wife needs to go away or have a break. He knows all the staff and other program attendees well and enjoys the camaraderie and sense of fun they all have together.

He said “If I wasn’t coming here coming here, I would just be sitting at home watching television, being nothing.”



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Client 2 [NAME WITHHELD] lives in one of the small, supported care units.

He previously attended most of the day services, and loves the fact that he can still go to things he enjoys, including being in the café and gardens at any time he wishes…. he has freedom to move about on site.

He has the same team of health professionals involved in his care… “they know me” he says. He started having periodic respite before eventually moving into the unit.

His room is like a bedsit, and he proudly shows me through. It includes a double bed, sofa, stereo /speakers and music collection, colourful posters and pop art on the walls, and bed with colourful bedding. The unit has small kitchen and dining areas seating up to 8 as well as lounge areas of similar size . He like his space and life in the unit, and most especially that he can continue to see the friends he has made attending the community day program and move through the building and gardens with freedom.

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Thank you
Darral Campbell

Research report available on request:
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Thank you to the Winston Churchill Memorial Trust for supporting this project and enabling international examples of best practice in services for people living with Younger Onset Dementia to be shared and potentially shaped for an Aotearoa context.