

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.

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EXECUTIVE SUMMARY

Aotearoa has struggled in a population of just over 5.2 million to develop quality accessible services for people living with Younger Onset Dementia (YOD). With 90% of people living in city/urban areas, and three quarters of the population living in the north island, the development of Younger Onset Dementia services has been piecemeal, with no clear delineation between the needs of people who have dementia at an older age, and within a health system that has not seen dementia, and in particular Younger Onset Dementia, as a priority.

Dementia Canterbury established a program 5 years ago, Dementia Auckland 2 years ago, and Younger Onset Dementia Aotearoa Trust (YODAT) in 2015 - these organisations have been working towards developing programs that are specifically constructed to meet the differing needs of people experiencing Younger Onset Dementia, however these efforts are largely unfunded.

The purpose of this research is to see how programs in Europe offering specific Younger Onset services are in line with the above research and best practice, how they are funded and delivered, and how successful they are in meeting client and whānau needs.

This report was made possible with the support of the Winston Churchill Memorial Trust. It describes the services available in the three different countries; Canada, the Netherlands, and Scotland. I met with fourteen people including those working as frontline and managerial staff, and several people living with Younger Onset Dementia. Discussions with all parties provided valuable opportunity to look at specific YOD services, including the challenges of funding, geography, cultural diversity, accessibility, and to review what worked well and why. Additionally, to share what we did that was similar and what was different, with a view to looking at what we can learn and potentially implement in a New Zealand context to better support our Younger Onset Dementia Community.

PART 1: INTRODUCTION

BACKGROUND

Traditional health services for people with dementia have been targeted almost exclusively for older people who are mostly retired, without reference to the needs of those living with YOD and their whānau. Younger Onset Dementia is defined as dementia that is diagnosed before the age of 65. Due to their younger age, dementia impacts differently on work and family circumstances, and financial future planning.

Dementia UK (Dementia UK, 2024) reports that:

1. On average a person may see between two and five different consultants before a diagnosis is made.
2. The average time to diagnosis is 4.4 years in younger people compared to 2.2 years for people aged over 65
3. Awareness amongst GPs is relatively low when people are younger, symptoms are often attributed to stress, anxiety, depression, or menopause.
4. People with Younger Onset Dementia are more likely to be diagnosed with a genetically inherited dementia or a rarer dementia that may be difficult to recognise.

The Angela Project (The Angela Project, 2022) is the largest study ever conducted in the UK regarding young-onset dementia. In 2021, this study reported on the features of helpful services for people with young-onset dementia and their families. Based on this, a three-tiered set of recommendations for good practice was developed, referred to here as the Angela Model. The first micro tier focuses on person-centredness at the one-to-one level of person-professional interactions. The other two tiers relate to how the service is structured. The meso or group-level recommendations focus on “functional consistency” and highlight the importance of services being organized consistently with needs - age-appropriate, holistic, responsive, and accessible. The macro or organisational level recommendations focus on “organizational coherence” and emphasize the need for service integration, specialist services, and service continuity. A more detailed description of these structural recommendations are provided in Table 1.

This project enables an exploration of how these somewhat abstract concepts can be seen operating in real-life settings. As the Angela Model itself notes:

“The Younger Onset Dementia-related essence of our themes may become diluted when raised to high level labels. However, ...first-hand words and examples demonstrate that these vital services attributes apply distinctively in the context of YOD” (Stamou, et al., 2022)

KEY QUESTIONS:

How have overseas dementia services operationalised the recommendations of the Angela Model and what are the implications for services in Aotearoa New Zealand?

HOW THE KEY QUESTIONS WERE ADDRESSED.

To maximise comparability, I identified countries, or regions within countries, that are of roughly similar size to the population of Aotearoa New Zealand and Ōtautahi Christchurch. Visits were planned to Alzheimers Canada, University of British Columbia Clinic for Alzheimers and Related Disorders , Alzheimers Scotland (Glasgow) and

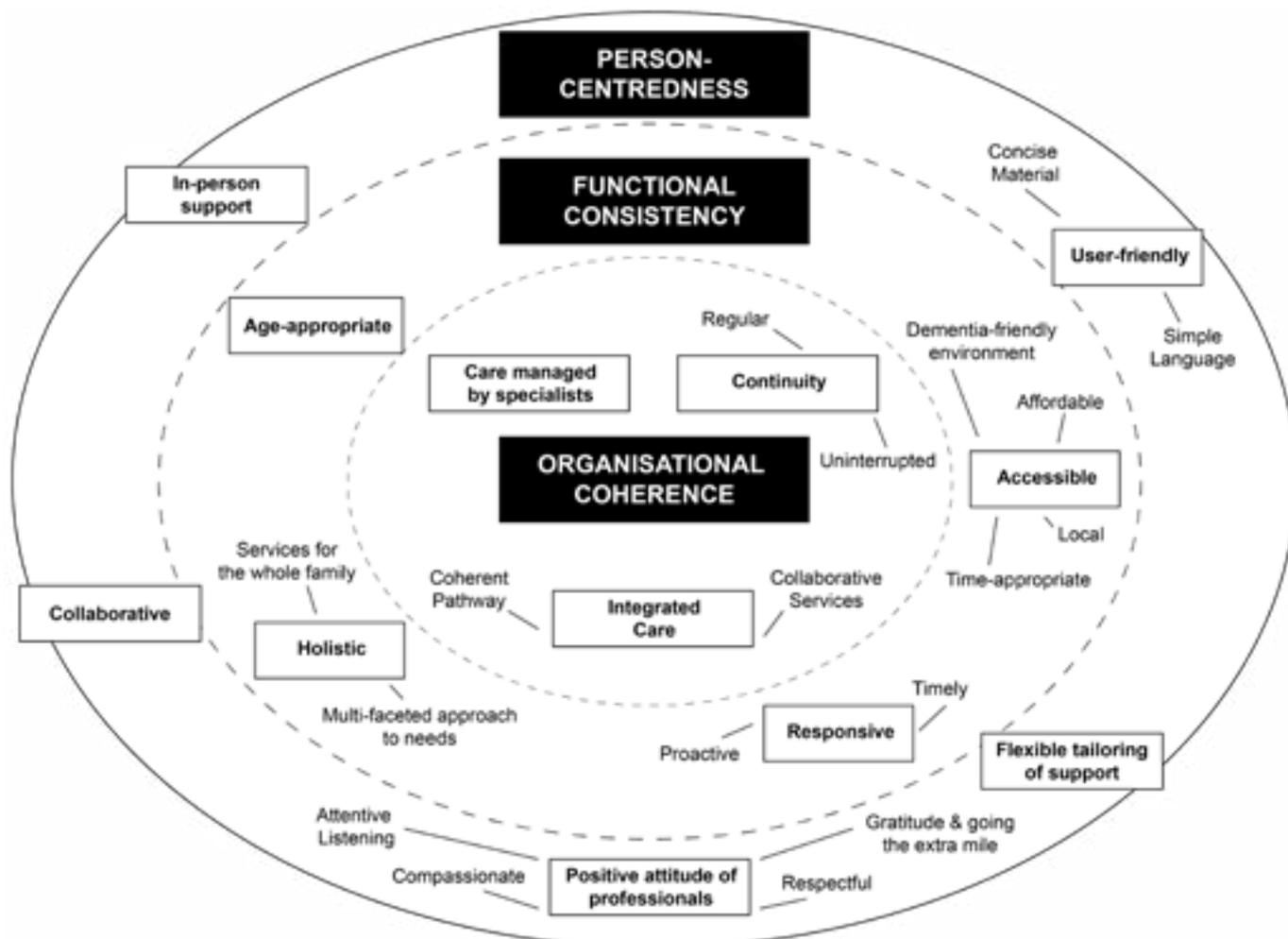


Table 1: The Angela Project's Model: Structural components of helpful post-diagnostic services for young onset dementia (Stamou, et al., 2022)

the Florence Centre for Specialized Care in Early Onset Dementia at the Mariahoeve Nursing Home, Netherlands. At each location I conducted interviews with key informants from the organisation. My questions for staff were based broadly around the process for diagnosis and referral, the range and extent of services provided, access and accessibility, criteria and/or challenges, specific community and residential services, and funding of services. My overview of services provides an overview of the services visited as well as a summary of the information gleaned from the interviews (see Appendix A). Information from all three sites were reviewed to draw out examples of the organisational and functional facets of best practice set out in the Angela Model.

Level	Facet	Description
Meso level: <i>Organisational coherence</i>	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: <i>Functional Consistency</i>	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

PART 2: KEY FINDINGS

Of the three services visited, the Netherlands example at Mariahove was the most comprehensive with seamless movement through the services at every stage of the dementia journey. Additionally, they provided a significant range of services in all settings including; community, respite, and care, and provision of services for both people living with YOD as well as for their families and whānau. However, the Scottish and Canadian services both had some good examples of best practice within the Angela Model of YOD. Below are examples of best practices from all three of the localities visited that demonstrate best practice within the Angela Model.

EXAMPLES OF MESO LEVEL: ORGANISATIONAL COHERENCE

Integrated care

Mariahove in the Netherlands provides the most integrated service with a clear pathway for all affected by YOD (clients and families) to access a specific tailored suite of comprehensive services under one umbrella. The services are geared to the needs of people throughout the changing journey and ensure that the same team of interdisciplinary professionals are involved over time. This extends to collaboration around home support, Neurologist and or GP review, family education and support, care planning and service delivery from initial diagnosis through to entry into nursing home care are all provided on one site.

The YOD service in Glasgow Scotland offers a great one year of wrap around service, and some ongoing programs and support, but does not provide a continuum of care throughout the journey. A particular strength of the program is the funding for two designated YOD link workers and a counsellor, and their involvement in the YOD programs and individual support. However, the reach in terms of postcode is more limited, as is the range of services.

Likewise, the program based in British Columbia, Canada, provides some services but not the range, and the service is limited.

Care managed by specialists.

Mariahove in the Netherlands has the most comprehensive range of YOD specialists. It includes a dedicated case manager for every person with YOD and their family/whānau, as well as a strong interdisciplinary team working exclusively in the YOD area which consists of Neurologist/GP service, Physiotherapy, Occupational Therapy, Social Work, Psychology, Speech /Language Therapy, Nursing, Music and Art Therapy. The team are experts in the delivery of YOD services.

Glasgow in Scotland provide designated link workers who specialise in YOD as well as a psychologist/counsellor. Their referral pathway is via Older Persons Health/Psychiatry rather than Neurologists, and for most YOD clients takes longer. They do not have an interdisciplinary team of professionals specifically working with YOD clients/whānau.

British Columbia have a dedicated Centre for Brain Health where specialist diagnosis happens and service navigation commences, but there are no specialist staff working within a YOD program in Alzheimer's BC. Some support and service does exist, but it is not a clear pathway to gain access and appears very dependent on where a person lives.

Consistent

Both Mairahove and Glasgow provide programs that offer consistent or regular known staff for contact over time, though Glasgow's time is more limited. Because Mairahove offer community, respite and designated nursing care on one site, the consistency of the same staff and case manager throughout the journey is one of the significant strengths of the service and differentiates it from other services.

MACRO LEVEL: FUNCTIONAL CONSISTENCY

Age-appropriate, Holistic, Responsive, Accessible.

Mariahove offers services in all stages of the dementia journey that are based entirely on younger age. The range of activities and specialist disciplines ensure a very wide variety of activities and services geared for all, including children, care partners and families, and the person living with dementia. This was supported by comments from the two clients I met who talked so positively about why the program works for them/their families, and how different their needs are to older people living with dementia. They mentioned the impact of spouses, their friends and contemporaries all still working for example, and the sense of isolation and loneliness that results, as well as the impact of having to give up their work/careers long before they had planned, impacting on their sense of self-worth and confidence.

The service developments are both holistic and responsive to the needs of all with rounded programs offering a variety of ways to connect, support, stimulate, educate, and care. Mariahoeve also seemed to have no issues with accessibility with people travelling relatively short distances, via a variety of means, no waiting lists, and having adequate funding to meet the diverse range of needs of the YOD population in the area. Staff described that universal mandatory insurance, with access to government funding for specialist care means finance is not a barrier to access services.

The other services offer mixed models with some age specific services, and other services that are generic to any age dementia. The services also have more limited support for the specific educational and support needs of families and care partners throughout the entirety of the dementia journey. Some had online options, but few opportunities for direct connection in an ongoing and systematic way, able to respond to changing need throughout the various stages of the journey.

Accessibility was an important issue for many in both Glasgow and Vancouver, with postal code limiting options. Finances were also one of the factors that had a bearing on uptake of services, range of services and or ability to access the services that did exist. With partners often working, transport or the lack of was a limiting factor. There was certainly a clear connection between the range of services available and the funding stream to create, grow and develop services. The service providers clearly articulated the inherent challenges they faced because of this, and their concerns about the unmet need given the lack of resources to develop and sustain services.

PART 3: CONCLUSIONS AND RECOMMENDATIONS

All three programs that I visited had, at their heart, a desire to offer the best service for clients and families with the resources that they had available. All programs understood why people living with YOD need specialist services that are different from mainstream services for people with dementia.

1. Both research and current practice support the need for the development of specialist YOD services that meet the needs of those living with or caring for someone throughout the dementia journey.
2. A model of best practice exists (Angela Report, Model attached) and can be applied to any YOD context. The use of this to enable Aotearoa to develop one of its own YOD best practice guidelines inclusive of the needs of tāngata whenua, Pacifica and other cultures, is a positive way to move forward, and the direction that should be encouraged.
3. There is enough evidence to suggest that specialist programs based on population mass should be available in all the major cities in New Zealand.
4. Programs need staffing that is YOD specialised and interdisciplinary.
5. Programs need to be multi-layered and multi-dimensional to ensure services and staff can remain alongside the person with dementia and family throughout the changing dementia journey. There is real potential to develop specialist YOD teams that could follow people throughout the journey even when in differing environments such as respite and rest home/dementia level care. There are also cost savings to be made both financially and in terms of quality of life if respite options were age appropriate and allow for the continuation of attendance at community based YOD programs, and flexible use; e.g. the man in Maraihoē that went into respite on site once a week for a night or sometimes two to ensure respite for his partner, but the ability to remain involved in the YOD community based program. This option enables families/care partners to continue to support and care for their person at home for longer.
6. Whilst a model where all services are on one site as evidenced in Mariahoeve is highly desirable, it may be difficult to replicate in New Zealand currently given the way Aged Care/Residential and Respite services are structured. However, there is scope to consider this as a concept to work towards in future planning of YOD specialist services inclusive of/in partnership with residential care environments, ensuring ongoing connection with the relationships already established in the community based interdisciplinary teams. To that end, presenting findings to both Te Whatu Ora commissions and residential care providers to discuss how such a service could work in Aotearoa New Zealand is planned. This is best achieved via some of the platforms below.
7. Diagnosis via Neurologists (specialising in cognitive disorders/brain health) appear to offer the potential for faster diagnosis, and a more age-appropriate option for people who are not a good fit within services designed for older adults.
8. Designated funding for YOD services is needed to avoid services simply being an adjunct to older person-based dementia services, enabling the development of an entire suite of services covering the journey from diagnosis to end stage care/death.

Plan for disseminating information and recommendations

1. Present report and recommendations at the Dementia New Zealand Hui for CEOs and Clinical Managers in Wellington in August 2024, looking at how all affiliates can develop recommendations in their areas.
2. Present report and recommendations at the Dementia Foundation Hui in July 2024. This is the organisation that supports the New Zealand Dementia work forum and acts as the secretariat for the National Dementia Leadership group. Attendees include frontline workforce as well as researchers, policy makers, and senior health officials from Te Whatu Ora.
3. Write an article for Dementia Canterbury and Dementia New Zealand's newsletters which are sent out across Aotearoa.
4. At a local level, we intend to try and seek funding to extend our existing services with a wider range of disciplines, and we will meet with local Te Whatu Ora commissions.
5. Present to Canterbury Aged Care Forum convened by Te Whatu Ora. Discuss with providers the scope to extend services in Aged Care environments.
6. Abstract submitted to present at the New Zealand Psychiatry of Old Age conference in November 2024.
7. Use our local and national social media channels to promote the report and its findings.
8. Meet with Younger Onset Dementia Aotearoa Trust (YODAT) to discuss research paper and ways to advocate for recommendations to be activated in a New Zealand context.

APPENDIX A: OVERVIEW OF SERVICES

1. CANADA: VANCOUVER BRITISH COLUMBIA

Organisation met with:	Alzheimers Society British Columbia University of British Columbia
Population:	Vancouver British Columbia Population 5,519,013 (Country population 38 million+)
Interview participants:	Michelle McCabe - <i>Senior Manager Community Programs and Practice Support</i> Laura Feldman - <i>Manager Community Services Vancouver Coastal region</i> Sarah Wagner - <i>Community Services Manager Fraser Region</i> Amy Freeman - <i>University of British Columbia Clinic for Alzheimers Disease, and related disorders.</i>



How are YOD clients diagnosed and referred to you?

Most people with Young Onset Dementia (YOD) are diagnosed at Djavad Mowafaghian Centre for Brain Health at the University of British Columbia by a neurologist following referral from a GP. They will make an initial referral for social work support and counselling post-diagnosis within the university services provided by Amy Freeman, the interviewee. Then, the university staff may refer on to Alzheimers Society British Columbia and Pauls club (see specific services below). The University of British Columbia centre will also provide ongoing medical review throughout the journey as needed in conjunction with the person's GP. This may include several members of the team depending on need/resource.

What YOD services do you provide?

Alzheimers Society British Columbia provides some support groups that focus on specific areas such as Frontotemporal Dementia. Alzheimers Society British Columbia does not have designated YOD education or CST programs, or workers. While there are some specific day program services for YOD in the region, these are not run by Alzheimers Society British Columbia.

General comments:

- The Brain Wellness Program is also available in BC.
- Patients can also be referred to Home and Community Care for a needs assessment.
- Partners of patients do not receive counselling from a qualified person, but the Alzheimer's Society runs some online support groups for caregivers
- The Minds and Motion program is being offered, which includes generic fitness and social connections.

However, it is mandatory for both partners to attend. This program is not age-specific and is not tailored to the needs of those with YOD. In fact, many people who participate in this program are significantly older than those with YOD.

- While there are support groups available, most are exclusively online due to the COVID-19 pandemic and remain so. As noted, some support groups focus on specific areas such as Frontotemporal Dementia. Educational sessions are also available online but are limited in scope.
- There is a national helpline available 24/7 to provide assistance to anyone who needs it. However, wrap-around services for those living with YOD or their care partners and families are not provided.

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

Support for families is limited and this is seen as a significant gap. The University of British Columbia does have a neuropsychologist who offers some individual sessions to support children's understanding of the changes that happen to the brain in YOD. Most opportunities for connection appear to be through online groups, with little if any face-to-face service.

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

Initial Diagnosis Service

The interviewees note that there is little ongoing support and counselling for grief and loss. They report that families struggle, and it is hard on children and care partners, many of whom have to give up work to care for their person if they do not have significant insurance. Dementia is not often covered by insurance.

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

The following services were noted:

- Alzheimers Society British Columbia provides online groups for YOD support.
- Pauls Club [YOD program]. This is a private Not for Profit service with some federal funding and a daily charge of \$150.

There were no specific YOD residential services.

The Alzheimers Society British Columbia does not partner with the community to run activity or social programs.

There are some local indigenous community services, but there are no specific services for indigenous people living with Younger Onset Dementia

The size of the British Columbia region is seen as a challenge to providing services that are consistent across all areas. (Note British Columbia is 944,735 km² compared to 268,021 km² for Aotearoa New Zealand)

How are YOD services funded in your country/region?

It is expected that individuals have a Medical Services Plan (MSP) in place for insurance purposes. However, the coverage provided by this plan may not extend to dementia.

The Alzheimer's Society of British Columbia receives funding from both the Provincial and Federal governments, as well as donations. They generally do not charge for their services.

2. SCOTLAND

Organisation met with:	Alzheimers Scotland (Office for Glasgow and northern regions including Inverness)
Population:	Glasgow population 627,000 Total country population 5, 436,800
Interview participants:	Fiona Kane - <i>Head of Commissioned Services/Localities Directorate</i> Alison McNair - <i>Locality Leader</i> Jane Brown - <i>Younger Persons Post Diagnostic Support Link Worker</i> Henry Simmons - <i>Chief Executive Alzheimers Scotland</i> Maureen Taggart - <i>National Dementia Nurse Consultant Alzheimers Scotland</i>



How are clients diagnosed and referred to you?

Most clients are diagnosed by a general psychiatrist and then referred to Older Persons Health psychiatrist. They are initially seen by Alzheimers Scotland Dementia Advisor who acts as a map and compass to services and can act as an advocate both giving information referring and linking to appropriate services and support. Advisors do not carry a caseload, and YOD clients are then referred on to one of two link workers . Alzheimers Scotland is funded to provide one year minimum of wrap around support for every new client. Clients tend to remain well engaged past the one-year period via the link worker and specific YOD services This is part of a fully funded commissioned service to provide health and social care planning.

What YOD services do you provide?

- 2 x link workers.
- Weekly YOD café
- Counsellor one to one
- Community based day program runs throughout the week with participants planning their activities in house as well as going out for day trips. [Around 80 people per week across 5 days.]
- Funded for 110 hours of staff time per week for the day program and or for support at home if they cannot able to attend the day program.
- Initially there is opportunity to engage in a therapeutic group run by a counsellor and link worker with an emphasis on understanding and coming to terms with diagnosis.
- People may then go on to a 12-week CST course with link workers.

- Link workers [two in total with the program] continue to try and support people at home as their dementia advances and group attendance may be less suitable.
- There is some service geared around employment liaison for YOD clients who are still in the workforce.
- A partnership exists with Kelvingrove Art Gallery and Museum involving a small group looking at Achieves.
- Clients attending the day program are actively involved in planning the activities they engage with, and the places they go.
- Struggling to deliver services that meet cultural needs and to provide more service to families.

Inverness.

An innovative outdoor program has been developed in partnership by Alzheimers Scotland and Cairngorms national Park. Though not specifically for YOD clients it does attract many people living with YOD . The development recognises that the people of the Inverness region often have a strong connection with the outdoors, resulting in the opening the first Outdoor Dementia Resource Centre in the UK. The service is provided in the forest under a large canopy and encompasses many outdoor activities within a green environment. There are opportunities to learn new skills or connect with old ones, as well as all important social connections

Are they inclusive of care partners children and families.

Currently the organisations offer support groups, and a counsellor, but no specific YOD education or social programs for families and care partners. Dementia Advisors may provide one on one support and education, information advice and sign posting. They may also provide some dementia education in schools.

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

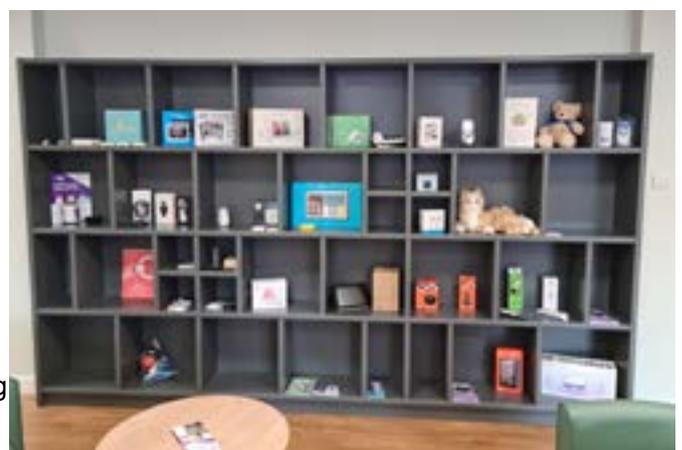
Referrals come from specialist Older Person's Health psychiatrist, community team and self-referrals. Much of the support is self-directed and the interviewees describe it as a post code lottery in terms of specific YOD support in some areas.

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

- YOD café weekly
- Counsellor 1 -1
- Community based day care program/support at home
- CST
- Support group to come to terms with diagnosis.
- Employment Liaison
- No specific residential care for YOD clients

How are YOD services funded in your country/region?

All people living in Scotland and diagnosed with Dementia, are fully funded for a year of comprehensive wrap around services. While most people with YOD remain involved post the one-year period, only some areas provide ongoing service/specific YOD programs.



How are clients diagnosed and referred to you?

Nearly all clients are diagnosed by a Neurologist, who has engaged in a full range of testing including CT head scan. They are usually referred to the service directly by their neurologist. Other specialist services and providers can also refer. Clients with alcohol /drug related dementia are not eligible, as other services are available for them.

3. NETHERLANDS

Organisation met with:	Florence Centre for specialized Care in Early Onset Dementia at the Mariahoeve Nursing Home [covers The Hauge and surrounds]
Population:	The Hague / Den Haag population 514,861 Total country population 17,646,000
Interview participants:	Jeffrey Slijfer - <i>Case Manager /Social Worker</i> Saskia Leiwakabessy - <i>Team Leader</i> [name withheld] - <i>Client attending day program</i> [name withheld] - <i>Client in sheltered living facility</i>

if their addictions are current and or they are recovering . As those who are recovered generally improve, they are not seen as a fit alongside others with YOD who will continue to deteriorate. The service at Mariahove works alongside the specialist Neurology and Neuropsychology services and GP in a collaborative and consultative process.

What YOD services do you provide ?

- Case Management
- Interdisciplinary team service and support including some individualised plans throughout the journey
- Support Groups, therapeutic groups
- Informal meetings [6 weekly café]
- Home Care [The wider Florence group also have practical home support services]
- Day Care Centre
- Overnight stay facility
- Sheltered accommodation.
- Living with nursing home care.
- Centre café and garden open to all.
- Day program provided 5 days per week 9.30 to 3 on site. Provides regular program of activities as well as lots of outings which are around social and cognitive stimulation. People opt to attend as many of the day sessions as they like. They can accommodate up to 20 people per day in the program, with around 40 people in total. They are met at the door having found their own way there. Either by bike, train, taxi, bus or being dropped off. There is no waiting lists, can usually accommodate. Additionally, they have access to Music, Dance and Art Therapy, a gym program, and a facilitated support group [run by a psychologist]
- People who do not attend the day program can and do attend the therapeutic groups, gym and support group.

The service is staffed by an interdisciplinary team that includes, Physio, Occupational and Speech language therapy, Social Work, Psychology, Art and Music therapists and Medical who can work with individuals and groups depending on need. The case manager, who is a social worker, does all the initial assessment and engagement within the persons home, and maintains regular home visiting, and liaison with care providers to ensure appropriate



support at home. Other interdisciplinary team members can also be involved to provide specialist assessment and advise as needed.

For those needing respite who are still living in the community, there is opportunity for overnight stays, enabling carers to have a break. This also provides an opportunity to be on the same site receiving a different type of service whilst maintaining all the existing connections to service delivery and attending any services they are engaged with as usual. This option provides a mechanism for clients to become familiar with the supported living environment, great preparation if they then need to move into this environment full time as their dementia progresses and needs change. It can also augment the care received at home and with a regular stay [i.e., one night each week] allowing some care partners /families to support their younger person at home for longer with a respite element built in to their week.

Two floors of Florence YOD service are residential specific and arranged in units accommodating 16 people. [60 people in total] Clients are clustered based on functionality and need. There are 3 lounges and living areas in each. All clients have their own rooms with ensembles and space to accommodate larger beds, lounge furniture and personal items such as bookshelves, sound systems etc . They resemble bedsits rather than bedrooms. Every client has a care plan which indicates the kind of help they need. This model means care as the client need dictates, rather than there being one size that fits all.

If people are able, they can continue to access some of the day groups, the café and the gardens. A particular strength is that the same group of therapists that provide the day service, remain engaged when the person moves into sheltered and or residential care. This provides a high level of service continuity, fostering existing relationships and knowledge about each person's situation and that of their family.

Are they inclusive of care partners , families and children?

Currently there are no formal education program for care partners or families, but the social worker does a lot of education and family work within visits. Support groups for partners, and meetings for the children of parents living with YOD are organised by the centre . These groups are facilitated by a psychologist and social worker. Informal meetings open to everyone take place in the café every 6 weeks with health professionals present to answer questions. The IDT continue to work with families throughout the persons involvement at Mariahoeve.

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

Clients can remain within the differing services offered by Mariahoeve throughout the entire dementia journey if they wish depending on their needs. This ranges from supported living in the community, to sheltered accommodation and nursing home care, clients once they reach 70 can either move on to the older persons care floors above, or other nursing home care in other centres closer to their family , or if they need hospital care, they can stay on in the hospital level facility onsite or go to an alternate hospital facility. This give choice for families based on both their needs and their younger person with dementias needs.

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

Mariahoeve is unique in that it provides community, day support, respite, sheltered living and nursing home care all on site. It also provides hospital care that is generic. Whilst some of these services are available in the wider region, this is not all on one site /by one organisation. Some similar services are available in Amsterdam.

The setting for Mairahove is in a community housing area [mixed housing with some for older people and some for families] with parks, community shops and services. It blends in with the other buildings around it. The centre's café and garden are open to the community as well as the clients and families visiting or living in the centre. A group of YOD clients have a gardening group and grow produce.

How are YOD services funded in your country/ region?

Costs for services are generally fully covered by insurance which is mandatory for all in the Netherlands. Any specialist care beyond this, and/or into residential care requires assessment to access government funding. Cost is therefore not a barrier to access service. There is some income testing, and this can be reviewed when /if income changes. Funding increases as care levels change.

Client Stories.

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. "
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 in to 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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