

LEE LI MING
PROGRAMME IN
AGEING URBANISM

Support Programmes for People with Young-onset Dementia

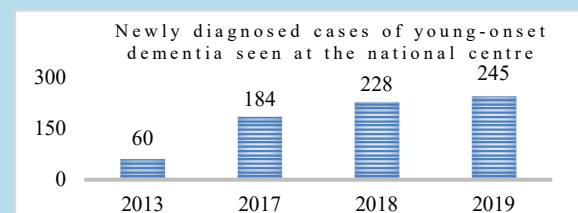
Need-supportive
interventions¹

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Rising trend of young-onset dementia

Although more common among those aged 65 and over, dementia is on the increase among younger people in Singapore. According to the National Neuroscience Institute, there are at least 4,000 people aged between 35 and 65 diagnosed with young-onset dementia (PYOD) (see Box 1).

Box 1: Prevalence of Young-onset Dementia in Singapore



Source: National Neuroscience Institute (2020, June 21) More here diagnosed with young onset dementia, says NNI. <https://www.nni.com.sg/news/patient-care/more-here-diagnosed-with-young-onset-dementia-says-nni>. Accessed on 18 October 2021.

¹ This is an evolving database. We will be adding more examples and cases over time.

Timely diagnosis and interventions are vital to slow cognitive decline and lower mortality for PYOD. However, most existing dementia care and support programmes are designed for older adults and might not be entirely suitable for PYOD given their distinct characteristics, preferences, and needs.

There is an urgency to look for more effective and age-appropriate support programmes for PYOD. This web post note reviews some interventions that are focused on meeting the needs of PYOD and their carers.

Interventions centred on the needs of PYOD and their carers

Caring for PYOD involves challenging and stressful tasks. As PYOD's cognitive abilities deteriorate, carers' burdens of managing behavioural changes and other health issues increase (van Vliet et al., 2010). It is important to understand the needs of both PYOD and carers, their possible coping strategies, and design need-supportive interventions. There are several interventions that demonstrate how PYOD cope and address their issues and problems (see Box 2).

Box 2: Balancing and assessing the needs of PYOD and carers

When coping with the condition, PYOD and carers need to find a fit on available healthcare support services, consider the lifestyle/behavioural changes, and make timely adjustments. They require:

- a. An understanding of dementia.

- b. Age-appropriate interventions that increase their ability to make decisions in daily living.
- c. Involvement of family members and friends for care support.
- d. Practical goals such as completing simple routine tasks.

Source: Bakker, C., de Vugt, M. E., Vernooij-Dassen, M., van Vliet, D., Verhey, F. R. J., and Koopmans, R. T. C. M. (2010) Needs in early onset dementia: A qualitative case from the NeedYD study. *American Journal of Alzheimer's Disease and Other Dementias*, 634–640.

Social clubs

The Boomers Club in Canada was set up as a social club with the support of the Alzheimer Society of Toronto. Started off as a pilot programme for 10 participants in 2019, it has become an 8-week session programme held 3 times a year and presently organized all year round (Oliverio, 2019). The Club provides weekly programmes of physical activities, cognitive stimulation, and creative therapies, free of charge for PYOD. From intergenerational bonding sessions to culinary classes, PYOD are consistently engaged. These activities enable participants with young-onset dementia to preserve their dignity while giving them the agency to select their preferred activities. Participant feedback from the programme has been positive (Oliverio, 2019, slide 34),

This group has a great benefit for me. I feel more grounded and happy. (person with YOD)

I come here to make friends – I'm lonely outside. (person with YOD)

I can take time by myself and have a coffee or run errands. This is such a lifeline for me. (caregiver)

With the onset of the COVID-19 pandemic, the programme is held online via Zoom. Efforts are made to maintain existing participants' interests and to recruit more participants through virtual activities and online registration respectively.

Co-design

Co-design engages PYOD in meaningful development of commercial products (Rodgers, 2018). A tartan project in Scotland in November 2014 has sought to empower participants to create the design of a tartan using simple materials. The physical design is digitised using an internet-based tartan design tool and uploaded onto an online platform where unique designs are chosen for production. PYOD were actively involved throughout the process, such as designing the tartan and real product.

The project attracted the participation of 17 Alzheimer Scotland Dementia Resource Centres where over 20 co-design workshops were held, 130 PYOD participated, and over 120 unique tartan designs were produced.² Participants remembered their own tartan design and were able to identify it. This process boosts their sense of ownership and participation in the creative process.

The project was exhibited in 2016 at the Verdant Works in Dundee, showcasing

² Rodger, P. A. (2016, February 17) Designing with people living with dementia. Alzheimer Scotland Tartan.

that PYOD can continue to contribute to society after diagnosis. The project gave rise to a number of “spin-off” discussions, themed activities and outings, instilling a sense of bonding among members.

Participation in community-based activity groups

A football group organised by the Nottingham County Football Club provides weekly sessions of the sport with professional training for men with YOD. Carone et al. (2016) have found this intervention beneficial to individuals with YOD as it creates a non-discriminatory environment for independent learning of new skills and keeping socially connected with others with similar condition. The study participants feel enjoyment and anticipation in the process,

But when he got here... it was like a great big weight off his shoulders... 'I really enjoyed that', which is very positive, because he hadn't got much happening other than me in his life. (caregiver) (Carone et al., 2016, p. 10)

I wanted something physical to make me sweat... It's getting the physical exercise, the mobility; it's getting, um, mental release of the pressures that's at home. (person with YOD) (Carone et al., 2016, p. 6)

Engaging PYOD through work

In Singapore, a Therapy Through Work Programme enables participants to regain their independence and rekindle their

<https://alzheimerscotlandtartan.wordpress.com/2016/02/17/designing-with-people-living-with-dementia/>. Accessed on 18 October 2021.

hope and purpose through activities like gardening, laundry folding, and packing cutlery.³ Participants and carers are given the choice to choose the type of work they wish to participate in. By accomplishing such tasks, PYOD build their sense of confidence and achievement. There is also increased social activity and interest; PYOD anticipate the next session and have shown improved mood, memory and social interaction. The experience also helps them to gain a sense of normality and relive their youth.⁴

Crucially, the programme provides a safe space where PYOD have the chance to earn some work allowance, and socialise with others, including workers and volunteers. Their carers also get to meet and befriend other carers and exchange caregiving tips. While PYOD are engaged, carers are freed up to focus on other tasks besides caregiving as well, like household chores and grocery shopping.

Conclusion

Closing the gap on community care through programmatic co-creation

While there are various approaches to address the needs of PYOD and carers, more research is still needed to measure the programme impact, e.g., on emotional and mental stress reduction, and improved social support. Scaling up community care efforts require customisable solutions that support and facilitate the process of co-creation and

conduct of suitable activities according to PYOD's preferences and conditions.

Of importance is access to the right support and resources which opens opportunities for more creative approaches. PYOD's participation in social activities can relieve caregiving burden and crowdsource community resources. Building and strengthening partnerships in caregiving is another key area of support and intervention.

Sources:

Carone, L., Tischler, V., and Dening, T. (2016) Football and dementia: A qualitative investigation of a community-based sports group for men with early onset dementia, *Dementia* Vol 15(6):1358–1376.

Oliverio, R. (2019, February 21) The importance of social programs for people living with young onset dementia. Alzheimer Society of Toronto. <https://brainxchange.ca/Public/Files/Early-Onset/Social-Programs-for-those-with-Young-Onset-Dementi.aspx>. Accessed on 18 October 2021.

Rodgers, P. A. (2018) Co-designing with people living with dementia. *CoDesign* Vol 14(3):188–202.

van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans, R.T.C.M. and Verhey, F.R.J. (2010) Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry* Vol 25(11):1091–1100.

³ City of Good. (2017, January 15) Instilling a sense of purpose in persons with dementia. <https://cityofgood.sg/articles/instilling-a-sense-of-purpose-in-persons-with-dementia/>. Accessed on 18 October 2021.

⁴ Apex Harmony Lodge. (2018, November 2) Therapy through work for persons with dementia. Youtube. https://youtu.be/m_SkH1F_-9A. Accessed on 18 October 2021.