

LEE LI MING
PROGRAMME IN
AGEING URBANISM

Keeping Dementia at Bay in Australia

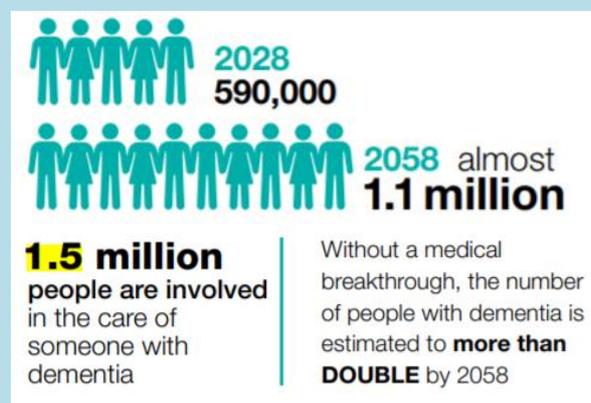
Digital Tools and
Information Resources¹

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Projecting Australia's Population with Dementia

Dementia can affect people of any age and is not limited to older adults. A 2018 national data shows that more than 436,000 Australians are affected by dementia, and three times the number, about 1.5 million caregivers are caring for them. The population with dementia is estimated to double in 2058 (Box 1). Caregiving is a heavy burden on family members, who are commonly the caregivers of persons with dementia, due to lack of awareness and self-efficacy to cope with the condition.

Box 1: Projection of Population with Dementia in Australia



Source: Dementia Australia's Strategic Direction 2018-2023, 2018.

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

In June 2013, a special committee began examining the quality of life of persons with dementia. They looked into increasing opportunities for social engagement and community participation, helping persons with dementia and caregivers to plan for care, and improving awareness and communication on dementia and dementia-related services through the community. The committee presented a full report in the Parliament of the Commonwealth of Australia, describing the key themes, barriers and comments on the need to better raise the awareness of dementia in the community and to create dementia-friendly communities².

The key areas to address are the lack of knowledge and better pipelines to support services from diagnosis to ongoing treatment and management to advance care planning. There is currently a knowledge gap in the use of digital information resources and how it translates to the use of support services that helps Australians to fight against the increasing incidence of dementia – which includes understanding the behavioural and lifestyle changes that one can adopt to reduce the risk of dementia.

² The Parliament of the Commonwealth of Australia (2013, 26 June). Thinking ahead. *Report on the inquiry into dementia: early diagnosis and intervention*. Standing Committee on Health and Ageing, Canberra. Retrieved September 8, from https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/dementia/report/fullreport.pdf.

Knowing Behavioural and Lifestyle Changes

Keeping dementia at bay involves understanding the risk factors of dementia and actively making lifestyle changes. According to a 2018 report on Dementia Australia's strategic direction for 2018-2023, 83% of Australians want to know how to reduce the risk of dementia. The factors that may influence a person's risk of having dementia are differentiated by non-modifiable and modifiable factors³. Non-modifiable risk factors are related to age, genetics (associated with specific genes) and family history of dementia, while modifiable risk factors are related to a person's lifestyle choices – to reduce the potential of developing dementia by taking care of the heart, body and mind (Box 2). Since there is currently no cure for dementia, an important risk reduction strategy is to address modifiable risk factors. Action starts with proactive adjustments to behavioural and lifestyle changes that improve one's physical, cognitive and psychosocial health.

³ Dementia Australia. (n.d.). Risk factors for dementia – information about lowering your risk of dementia. Retrieved September 6, 2020, from <https://www.dementia.org.au/risk-reduction>.

Box 2: Health Risk and Health Gain

The Australian Burden of Disease Study 2011 has shown that the top risk factors of dementia burden are contributed by chronic kidney disease (8.4%), physical inactivity (8.0%), and stroke (6.7%).

“The largest health gains are expected from reducing the prevalence of diabetes (48% reduction in dementia burden due to diabetes), obesity in mid-life (26%) and physical inactivity (15%).”

Source: Martin, F., Bishop, K., Dunford, M. & Prescott, V. (2016). Contribution of vascular diseases and risk factors to the burden of dementia in Australia: Australian Burden of Disease Study 2011. Australian Institute of Health and Welfare. Retrieved on September 12, 2020.

Increasing Self-efficacy through Digital Tools and Information Resources

As an effort to keep dementia at bay, technology-enabled online tools and information resources are readily accessible to the public in Australia.

Dementia Australia Website

On the Dementia Australia website, there is a range of resources for creating greater community awareness on risk reduction of dementia, e.g., digital library, online guides, bite-sized videos, booklets, community café toolkit and community information session (Box 3). It also contains self-help sheets that address the needs of caregivers and their family

members who are diagnosed with different types of dementia.

Box 3: Video on Purposeful Activities for Dementia

KEY MESSAGES CHAPTER 4

- A supportive environment is necessary to encourage people with dementia to engage in activities that are meaningful to them.
- The environment includes both physical surroundings and the relationships between everyone involved in supporting the person with dementia - carers, staff, friends, volunteers and others.

REFLECTION CHAPTER 4

- How can all people involved work together to share experiences, achievements and goals at home and in the social group?

Source: Alzheimer's Australia Vic. (2015, 27 May). Purposeful activities for dementia - Chapter 4 [Video]. Retrieved on September 14, 2020, from <https://youtu.be/HQpptGa7Kxw>.

Your Brain Health Matters

Your Brain Health Matters website offers a wide range of community education programmes and e-Health tools that are designed to inform people about what they can do in terms of ten health and lifestyle behaviours to reduce the risk of dementia. It offers evidence-based information on diet and nutrition, fluid intake, education, fitness routines and lifestyle strategies (mental, physical and social activity) to boost the brain's blood flow⁴. “Weekly brain engagement for a minimum of at least two hours, which is

⁴ Culler, K. L. (n.d.). Practical tips to help you stay in the know. Your Brain Health Matters. Practical Tips. Retrieved September 6, 2020, from <https://www.yourbrainhealthmatters.com/practical-tips>.

around 15 to 20 minutes per day, has benefits for ageing adults,” said Culler⁵.

The vision is that with greater awareness of behavioural and lifestyle factors to reduce risks of dementia, people can improve their health literacy with the help of e-Health tools and digital information resources that are readily accessible (Stormacq, et al., 2020).

BrainyApp

The Alzheimer's Australia Vic and Bupa Health Foundation launched the BrainyApp on 9 November 2011 in iOS and 23 July 2012 in Android respectively; it was downloaded over 41,000 times in the first 48 hours (Noone, 2012). The app won the Victorian Public Healthcare Award for innovation in e-health and communications technology on 21 November 2012⁶.

Through the mobile app, users monitor their physical, mental and dietary aspects in a fun way. Upon completion of a survey which encompasses the user's physical, social and mental activity as well as their lifestyle habits (smoking, drinking, etc.), users will receive their brain-heart health score and lifestyle areas for improvement. If the users engage in sufficient recommended

activities such as maintaining a healthy diet, their brain-heart health score may improve over time.

O'Connor et al. (2014) study suggests that the increase in exposure of interventions through technology-enabled mobile tools and online information resources helps to reduce dementia risk. Though there is little evidence on determining the effectiveness the BrainyApp, study participants used it more frequently than web-based tools because it can offer different features while monitoring their brain-heart health score, such as sharing information about dementia and ways to keep their brain active and healthy. These findings were echoed in other research on cognitive assessment tools, lifestyle programs and mobile health app usability to enhance dementia prevention and care (Carotenuto, et al., 2018; Wesselman, et al., 2019; Azad-Khaneghah, et al., 2020).

Advancing Dementia Care and Prevention

In addition, Australia has developed and executed an enhanced systemic plan to advance dementia care and prevention. Three priorities are identified: timely diagnosis and support, quality of dementia care, and reduction of discrimination.

Timely Diagnosis and Support

Timely diagnosis, screening and support are best practices in the care and wellbeing of people with dementia. In particular, the availability of clearer and well-defined pathways for affected families to have access to early diagnosis

⁵ Davis, L. (2020, 7 September). Try these easy mind games to improve your brain function and help prevent disease. *USA Today*. Retrieved September 8, from <https://www.msn.com/en-us/health/medical/try-these-easy-mind-games-to-improve-your-brain-function-and-help-prevent-disease/ar-BB18L02p>.

⁶ Alzheimer's Australia Vic. (2012, 21 November). BrainyApp wins Victorian Healthcare Award for innovation [Video]. YouTube. https://youtu.be/D4DS2HSFN_4.

and assistance. Useful information and support services would empower families and caregivers to be more prepared when faced with the diagnosis of dementia. Apart from the Medicare and Pharmaceutical Benefits Scheme, the national Commonwealth Home Support Program is established in July 2015 to provide a one-stop programme to all services, which include basic home support and community care services to reduce the barriers for families seeking support. In addition, community/residential aged care packages, respite services, and behavioural management advisory services are available for families to manage their caregiving journey better.

Quality of Dementia Care

With the presence of a robust system of timely diagnosis and support, the quality of care for persons with dementia can be measured through dementia-specific indicators. For example, acute care services and community aged care services targeted at providing necessary diagnosis, treatment and home care packages can help families to manage situations better when coping with change. With data analytics and stakeholder involvement, families of persons with dementia and dementia practice leaders can use the health and behavioural data to discover, define and develop effective models of care for different family profiles to deliver a better care plan for the recipient.

Reduction of Discrimination

The community plays a significant part in supporting engagement with people with

dementia. This necessitates understanding the challenges that caregivers, families and persons with dementia face when dealing with the condition and debunking myths and stigmatisation. More immersive educational experiences (e.g., seeing through the eyes of people with dementia) are used to provide useful perspectives when involving the community.

Winning the Fight with Dementia

Australia has developed plans and programmes to raise dementia awareness and prioritise actions to reduce dementia risk through digital platforms, learning programmes and immersive experiences. Digital tools and information resources such as online guides, videos, booklets, self-help sheets and community café toolkit are readily accessible on Australia Dementia website. Besides that, community education programmes and e-health tools are available online through other websites such as Your Brain Health Matters. Dementia prevention through mobile-based technologies also saw a successful adoption based on the huge number of users who downloaded the BrainyApp since its launch on iOS and subsequently on Android. Studies have shown the potential of mobile-based tools to help users to check their health score and make adjustments through the recommendation of brain activities and lifestyle changes on a mobile app. The community role in advocating the importance of brain health, physical health and other risk factors of

developing dementia also plays a part in their strategies forward. At all possible fronts, Australia shows their resolute in keeping dementia at bay with enhanced quality of care as well as timely diagnosis, community support and services through harnessing various forms of technology. Future research can focus on examining the effectiveness of mobile app interventions to realise opportunities for co-creation and innovation in the fight with dementia.

Sources:

- Azad-Khaneghah, P., Neubauer, N., Cruz, A. M. (2020). Mobile health app usability and quality rating scales: A systematic review. *Disability and Rehabilitation: Assistive Technology*, 1. doi: 10.1080/17483107.2019.1701103.
- Carotenuto, A., Rea, R., Traini, E., Ricci, G., Fasanaro, A. M., Amenta, F. (2018). Cognitive Assessment of Patients With Alzheimer's Disease by Telemedicine: Pilot Study. *JMIR Mental Health*, 5(2). doi: 10.2196/mental.8097.
- Dementia Australia. (2018). Designing a new future. Retrieved September 6, 2020, from <https://www.dementia.org.au/sites/default/files/documents/DA-2018-Strategic-Plan.pdf>.
- Noone, Y. (2012, 24 July). BrainyApp goes android. *Australian Ageing Agenda*. Retrieved September 8, from <https://www.australianageingagenda.com.au/technology/brainyapp-goes-android>.
- O'Connor, E., Farrow, M., & Hatherly, C. (2014). Randomized Comparison of Mobile and Web-Tools to Provide Dementia Risk Reduction Education: Use, Engagement and Participant Satisfaction. *JMIR Mental Health*, 1(1). doi: 10.2196/mental.3654.
- Stormacq, C., Wosinski, J., Boillat, E. & Van Den Broucke, S. (2020). Effects of health literacy interventions on health-related outcomes in socioeconomically disadvantaged adults living in the community: a systematic review. *JBIR Evidence Synthesis*. doi: 10.11124/jbisrir-d-18-00023.
- Wesselman, L. M. P., Hooghiemstra, A. M., Schoonmade, L. J., de Wit, M. C. J., van der Flier, W. M., & Sikkes, S. A. M. (2019). Web-Based Multidomain Lifestyle Programs for Brain Health: Comprehensive Overview and Meta-Analysis. *JMIR Mental Health*, 6(4). doi: 10.2196/12104.