

LEE LI MING
PROGRAMME IN
AGEING URBANISM

Harnessing Digital Resources For Dementia- Friendly Singapore

Digital Tools and
Information Resources¹

William Siew Jing Wen

Knowing the Impact of Dementia

On an individual level, dementia can put a heavy burden on families of persons living with dementia (PLWD). The World Alzheimer 2019 reported that 52% of caregivers of PLWD had deteriorated in health and 62% had their social life affected adversely because of caregiving responsibilities. Caregivers often feel that they are left out, ostracised and unsupported by their friends and even healthcare professionals. On a national level, the incidence of dementia can shrink the workforce and negatively impact the overall economy. The World Alzheimer Report 2015 estimated the economic cost of dementia to be US\$2 trillion worldwide by 2030.

Global research has shown that digital information resources can improve the quality of life of PLWD and their caregivers in various ways; these resources help PLWD and their caregivers stay in the know regarding dementia (Van Boekel, et al., 2019). Family members of PLWD who do not have digital resources

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

tend to delay seeking appropriate diagnosis and treatment. The use of digital platforms for social care support can improve dementia care; it is more effective with the presence of active online communities² and user-centric mobile solutions (Yousaf, et al., 2019). There is a small but growing evidence base for supporting PLWD and their caregivers with technology and digital resources to lower the costs of dementia care (Williams et al, 2019). While local research studies cover extensively on caregiver's burden and physical care (Philip & Seng, 2017), more research is needed on the use and effectiveness of digital technologies in Singapore in meeting the needs of caregiving of PLWD.

Examining Dementia Resources and Support in Singapore³

Launched in 2016, the Dementia-Friendly Singapore (DFSG) initiative aims to build a more caring and inclusive society for persons living with dementia and their caregivers. There are three key lines of development to engage, empower and enable PLWD and caregivers. Central to the development is awareness building and early detection through programmes such as dementia-friendly communities and digital resources.

² Pagan-Ortiz, M. E., Cortes, D. E., Rudloff, N., Weitzman, P., Levkoff, S. (2014). Use of an online community to provide support to caregivers of people with dementia. *Journal of Gerontological Social Work*, 57: 694-709. doi: 10.1080/01634372.2014.901998.

³ We thank AIC for their valuable input and for providing information on dementia digital resources and support in Singapore.



Ten Dementia-Friendly Communities (DFC) have been set up by community partners with support from the Agency for Integrated Care (AIC) to create public awareness about dementia and address the social stigma often associated with the condition and the lack of community support for PLWD and their caregivers⁴. The DFC is envisaged as a community of people who know about dementia and mental wellness and where people affected by dementia and mental health conditions and their families feel included, involved and supported within the community⁵.

With the launch of the Smart Nation initiative in 2014, the use of technology in dementia care has become more prevalent in Singapore. There are several platforms to disseminate digital resources to heighten dementia awareness and help families affected by dementia to cope better.

⁴ Yap, W. (2019). Nee Soon South Dementia-friendly Community. Notes on Age Friendly and Dementia Friendly Cities, Note 8. LKYCIC <https://lkycic.sutd.edu.sg/research/resources/>.

⁵ Tai, J. (2016, January 21). Yishun set to be first 'dementia-friendly' town. *The Straits Times*. Retrieved September 14, 2020, from <https://www.straitstimes.com/singapore/yishun-set-to-be-first-dementia-friendly-town>.

Digital Resources and Tools To Empower Caregivers and Public

The DFSG website and Dementia Friends mobile app (introduced in 2018) offer caregivers and the public digital resources and mobile tools on how to help PLWD. They add to the range of resources and tools provided by the Alzheimer’s Disease Association (ADA), Lien Foundation and others.

Dementia-Friendly Singapore Online Resources

The DFSG website is a one-stop portal that leverages technology to make dementia-related information more readily accessible to PLWD, caregivers and the community. The website hosts a range of resources including brochures, daily living tips, self-help kit, handy guides, advanced care planning workbook, bite-sized videos on caregivers’ stories and exercises (Box 1). The website receives an average of more than 70,000 clicks per month⁶.

Box 1: Bite-sized information resources and educational videos for public on dementia

Learn more about Dementia.

All About Dementia

If your loved one has dementia, you will notice changes in their behaviour. Caregivers like yourself may find it difficult to cope with these challenges.

Managing Dementia

Dementia affects not only your loved one’s ability to remember, but can cause them to behave differently. In certain cases, behaviour linked to dementia, such as aggression or wandering, can be a cause for concern.

Planning Care

Here are some tips, prepared in handy PDF formats, for caregivers on how they can offer care to their loved ones who wish to continue staying in the community and enjoy their regular activities.

Providing Care

Learn about the different ways a person in the different stages of dementia talks to others, and how you can respond when communicating with them.

Signs and Symptoms of Dementia

Keeping track of your loved one’s signs and symptoms of dementia can help you identify the condition’s progression.

Dementia-Friendly Singapore

Dementia affects 1 in 10 people aged 60 and older. As our population ages quickly, dementia is an issue we cannot ignore

How You Can Play A Part

Here are some different roles individuals and organisations can play to make Singapore and communities more supportive for persons with dementia and their loved ones.

DFSG YouTube Channel provides information on:

- Caregiver Support Network;
- Community Mental Health Support;
- Dementia Friends Mobile App;
- Signs and symptoms of dementia;
- “A day in the life of” videos;
- Communicating with persons living with dementia;
- Caregivers’ stories on available help; and
- Exercises for seniors.

Source: Dementia-Friendly Singapore. (2020, August 12). Healthy Mind, Healthy Life [Video]. <https://youtu.be/JsSe05hkqR4>.

⁶ Agency for Integrated Care. (2020, September 16). Data on Dementia Friends Singapore Website [Email].

In addition, DFSG utilises social media (Facebook: <https://www.facebook.com/DementiaFriendlySingapore>) to share bite-sized information about dementia. As of September 2020, it has over 5,700 followers, with the primary target audience being caregivers of PLWD. Information about upcoming events, new initiatives and news articles are also shared. Caregivers can use this platform to ask dementia-related questions, such as where to get dementia screening or how to manage behavior of concern in PLWD.

Since February 2020 (with the onset of COVID-19), DFSG has posted online resources about COVID-19 and dementia. These include talks/webinars, infographics, exercise videos, home-based activities such as word search puzzles, and news articles. It has also organised online forums such as the Online Support Group Series, Virtual De-Kopitiam, and Foreign Domestic Worker Support Group. The resources are available in English, Mandarin, Tamil and Malay, catering to Singapore's multi-ethnic communities. Feedback from the public indicates that these web-based and mobile-based resources are useful and comprehensive.

Dementia Friends App

The Dementia Friends mobile app enables caregivers to seek community support to help find missing family members with dementia. Developed by students from the Nanyang Polytechnic, School of Information Technology in collaboration with AIC, and supported by Tote Board, the app targets caregivers and the general public.



Between 25 October 2018 and 1 November 2020, over 9,600 users signed up as Dementia Friends and there were over 260 cases of calls for help on missing persons, an average of about 10 cases reported per month (Box 2).

Box 2: Greater peace of mind for families of PLWD

The Dementia Friends app offers a dedicated crowdsourcing platform for families to locate members with dementia who wander off and go missing. App users will receive a notification with details and photo when a PLWD is reported missing, thereby activating the community to keep a lookout and raising awareness about the situation of missing PLWD. Previously, doing manual searches, making police reports and publishing Facebook appeal posts were traditional ways of locating them. AIC noted a 5% increase in sign ups each month for the app, and more than 200 notifications about activities on dementia were pushed out. The app won the Lee Hsien Loong Interactive Digital Media Smart Nation Award 2019.

Source: Agency for Integrated Care. (2020, Sep 16). Data on Dementia Friends app [Email].

The app provides information on dementia and related resources like a list of services for persons living with dementia and updated news on DFSG initiatives, current events and volunteering opportunities for Dementia Friends. While online informational resources on dementia are available and Singaporeans rank top among mobile app use ⁷, it is still uncertain if mobile technologies are meeting caregivers' needs in managing daily challenges and difficulties.

A 2020 study on the usability of Dementia Friends app among caregivers found that more than 50% of the 69 online survey respondents did not know about the app (Siew, 2020). The study also revealed that,

- 80% of those who did not use the app said they were already digitally resourceful. Most of them stated that they were unlikely to download and use a mobile app unless it solved their direct needs.
- 80% of respondents using the app shared that they would go to other caregivers for dementia-related advice.

This suggests opportunities to further improve the communication of relevant information of the app. It also indicates the need to design mobile technologies that caregivers would use to address their need for communication with doctors, experienced caregivers, family members and friends for dementia case management, advanced care planning and

end of life care support. Even though conducted with a small sample, the study underscores the need for post-implementation evaluation of the effects of current and future digital initiatives, including mobile app solutions.

Digital Learning

Since September 2019, AIC offers e-learning modules on dementia awareness for the public, making learning more accessible and suitable for anyone who wishes to:

- a. Learn more about dementia and its risk factors,
- b. Identify the ABCD signs and symptoms of dementia, and
- c. Interact with people living with dementia better.

(This module is accessible at <https://ccmhdcomms.github.io/dementiaawareness20/>.)

Community support groups/ care partners can play a part in raising awareness about dementia by facilitating the sharing of knowledge through e-learning modules pegged at the para-professional level. These modules are available on AIC Learning Institute Platform, covering:

- a. Brain and dementia diagnosis,
- b. Person-centred care and behaviours of concern, and
- c. Activities that help enrich the lives of persons with dementia.

⁷ Kwang, K. (2019, January 24). Singapore tops mobile app use and downloads: App Annie. *Channel NewsAsia*. Retrieved September 14, 2020, from <https://www.channelnewsasia.com/news/technology/singapore-tops-mobile-app-use-and-downloads-app-annie-11157124>.

As of September 2020, over 1,600 frontline officers in enforcement (Singapore Police Force and Immigration & Checkpoint Authority) as well as 12,000 members of the public have completed these e-learning modules⁸.

During the COVID19 pandemic, the ADA has set up virtual Memories Café sessions and a series of webinars to provide specialised information on dementia. These are normally streamed live on YouTube and are also accessible via ADA website (<https://alz.org.sg>).

Co-designing Digital Resources

Co-designing digital resources offers a well-tested pathway in engaging the community on dementia. To ensure the Dementia Friends app stays relevant and useful, AIC continues to look for more co-designing opportunities of resources with others such as businesses, service providers, family caregivers and persons with dementia themselves. A multi-pronged approach is implemented including co-working with student groups to develop prototypes on engaging youths (on how to raise awareness and spread messaging), seniors (on staying cognitively active) and PLWD (on how to delay their cognitive decline) through gamification.

During COVID-19, AIC collaborated with ADA, supported by the Singapore Police Force and Ministry of Environment and Water Resources, which is leading 50 agencies across Government on ground enforcement of safe distancing measures

at public spaces in public housing estates on the “Support for Persons living with dementia over the COVID-19 period” (SPOC-19). The agencies took into consideration the challenge and stressed that caregivers face during safe distancing and COVID19 management measures, e.g., the PLWD may unknowingly flout the rules such as mask-wearing because of their condition.

Officially launched on 5 May 2020, SPOC-19 enables PLWD caregivers to apply for an official memo stating the condition of the PLWD. The memo application can be completed online and the digital memo would be sent to the applicant’s email. The initiative received good feedback from healthcare institutions, community service partners and caregivers. Close to 1,000 caregivers registered for SPOC-19.

The Lien Foundation in partnership with design firms --- Lekker Architects, Lanzavecchia + Wai Design Studio have created HACK CARE, a visual guide to engage, empower and enable PLWD to age in place. Styled like an IKEA catalogue, HACK CARE provides creative and practical improvisations, inspirations and instructions to assist caregivers develop their own hacks in caregiving. HACK CARE is available in print and e-copy (<https://hackcare.sg>); 2,500 copies have been given out.

In addition, the ADA has dedicated a blog to engage, empower and enable PLWD and their caregivers, providing them with information resources that are helpful during the COVID-19 pandemic. These include resources that help them to use

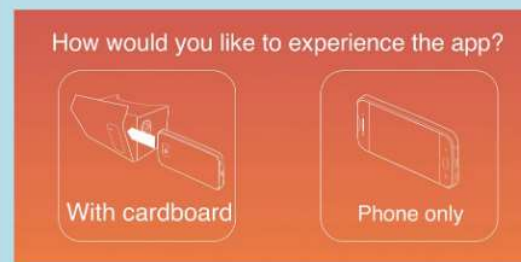
⁸ Agency for Integrated Care. (2020, September 16). Data on AIC’s digital learning outreach [Email].

social media safely, cope with the loss of loved ones living with dementia, keep abreast of ADA key milestones and World Alzheimer’s Month 2020.

Another potential development is to look at immersive educational experiences that can serve to strengthen the community’s understanding about the signs and symptoms of dementia. In March 2019, ADA introduced a Virtual Reality immersive experience workshop known as Enabling EDIE™ (<https://alz.org.sg/artc/edie/>), the first in Asia, to enhance participants’ knowledge on dementia⁹. Apart from enabling participants to experience the life of a PLWD, the 3-hour workshop supports care practitioners to work with PLWD and their caregivers to develop targeted needs support plan based on the challenges of the PLWD. Another similar reference is *A Walk Through Dementia* mobile app in the UK, where app users can look through the lens of a PLWD and learn to understand dementia conditions and their perspectives (Box 3).

Box 3: Wearing the shoes of persons with dementia

Alzheimer’s Research UK developed an app called “A Walk Through Dementia” using 360° immersive virtual reality technologies to allow users to empathise the PLWD’s point of view. In three scenarios (purchasing necessities at the supermarket, navigating their way home and handling basic tasks at home), the app educates its users on the signs and symptoms of dementia and allows them to experience the daily challenges of a PLWD. The app also briefly provided information on what dementia is and how can one make a difference.



Source: Alzheimer’s Research UK. (2016, June 2). *A Walk through Dementia - Launch film*. Retrieved September 14, 2020, from <https://youtu.be/nW1Y3Ffv7Mw>.

Conclusion

Access and availability of dementia-related information is critical to fostering public awareness, improving quality of life of PLWD and caregivers, and

⁹ Dementia Australia. (2019, April 15). EDIE launched in Singapore. Retrieved November 18, 2020, from <https://www.dementia.org.au/about-us/news-and-stories/news/edie-launched-singapore>.

ultimately, reducing the impact of dementia on society. With technology development, Singapore has increasingly developed information resource using digital platforms and tools including Dementia Friends app, e-learning and DFSG website. Digital participation can signpost people to support and help PLWD and caregivers to take charge of their health.

Digital does not, however, solve problems by itself; it can help provide information about services and wellbeing more quickly, saving time and helping PLWD and caregivers access the support they need to live well. But, this will require them to have digital skills like basic internet skills and access to technology and/or the internet in the first place. Community support is essential. It is important to continue to promote support services that are tailored to the needs of PLWD and their caregivers. Co-designing with PLWD and caregivers is the key to engaging with PLWD to get the right message across and improving their personal confidence and sense of wellbeing.

Sources:

Philip, Y., & Seng, B. K. (2017). Profiling the dementia family carer in Singapore. Alzheimer's Disease Association of Singapore. Retrieved September 14, 2020, from <http://alz.org.sg/wp-content/uploads/2017/04/Research-Profiling-Dementia-Family-Carer-SG.pdf>.

Siew, W. (2020). Harnessing mobile-based technologies for caregiving of persons with dementia. Master of Innovation by Design Thesis. Singapore University of Technology and Design Library Archive.

Van Boekel, L., Wouters, E., Grimberg, B., van der Meer, N., & Luijkx, K. (2019). Perspectives of stakeholders on technology use in the care of community-living older adults with dementia: A systematic literature review. *Healthcare*, 7(2), 73. doi: 10.3390/healthcare7020073.

Williams, K. N., Perkhounkova, Y., Shaw, C. A., Hein, M., Vidoni, E. D. and Coleman, C. K. (2019). Supporting family caregivers with technology for dementia home care: A randomized controlled trial. *Innovation in Aging*, 3(3), igz037, doi: 10.1093/geroni/igz037.

Yousaf, K., Mehmood, Z., Saba, T., Rehman, A., Munshi, A. M., Alharbey, R., & Rashid, M. (2019). Mobile-health applications for the efficient delivery of health care facility to people with dementia and support to their carers: A survey. *BioMed Research International*. doi: 10.1155/2019/7151475.