

*25 years
of dedicated service
and beyond!*



25th Anniversary Symposium

Towards a Dementia-Friendly Singapore



FOCUS GROUP DISCUSSION FINDINGS

Nov 2015

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Executive Summary

Objectives

As a lead-up to the Alzheimer's Disease Association's 25th Anniversary Symposium, ADA brought together a wide spectrum of people in the community including people with dementia and family caregivers to exchange ideas, provide suggestions and to explore ways to make Singapore a dementia-friendly community.

Overview

Focus group discussions were conducted across eight groups from June to August 2015. A total of ten sessions were held. All sessions were facilitated by members of the Facilitators Network of Singapore. Each session began with a brief introduction to ADA and the reasons for the focus group discussion. Two videos were shown which depicted scenes of a dementia-friendly community vs one which was not. An entry survey was then followed by a thorough focus group discussion.

Summary of Results

- 44% of participants felt Singapore is not at all dementia-friendly.
- At the entry survey stage, the Media and the Arts group was the only one who felt they were not at all, or could contribute minimally, in creating a dementia-friendly Singapore.

Recommendations

The following recommendations are based on the more salient points which emerged. These need attention and action towards creating a dementia-friendly community:

Stigma: Misperceptions of violence and madness associated with dementia result in people living with dementia (PWD) being isolated by the community. To move towards an inclusive society, greater understanding of dementia and integration of PWD into mainstream community is necessary. Faith based organisations could do more to promote inclusivity of PWD.

Awareness – through school curriculum, at the tertiary level particularly through those in the health-care and architectural/design courses. Use of traditional and social media in creating this awareness. Sensitizing groups such as banks, transport operators and shop keepers on recognising signs of PWD and how to respond/communicate with them. Identify an influential goodwill ambassador.

Support and Collaboration – At an emotional, technological, social and infrastructural level by groups including the community/neighbours, government (on policies concerning Foreign Domestic Workers and flexi work hours), cross sectorial support in establishing integrated help such as a one stop-centre offering medical, social and other needs for PWDs and their caregivers.

Phase 2: Re-engage with groups soon to discuss the way forward

Focus Group Session Statistics

A total of 10 sessions were held over a period of three months, from June to August 2015:

Focus Group Discussion 1 – Persons with Dementia

Three persons who had been diagnosed with dementia for between one and three years participated. They were in the mild-moderate stage of dementia.

Focus Group Discussion 2 – Caregivers

Two sessions were held, one in English and one in Mandarin. A total of 21 primary and secondary caregivers participated.

Focus Group Discussion 3 – Dementia Design

One session was held, in English, with the following nine participants:

- Architects and town planners from private and public agencies
- Lecturer and Students from Architectural and Industrial Design (NUS)

Focus Group Discussion 4 – Healthcare, Social Services and Community Services

Two sessions were held, both in English, with a total of 19 participants from the healthcare, social service and community service sectors.

Focus Group Discussion 5 – Media and the Arts

One session was held, in English, with 10 participants from print, audio & visual media, social media, music industry, and theatre works public relations agencies.

Focus Group Discussion 6 – Legal, Business and Banking

One session was held, in English, with six participants, from the legal, business and banking sectors.

Focus Group Discussion 7 – Faith-based Organisations

One session was held, in English, with 16 participants from the various faith-based organisations in Singapore.

Focus Group Discussion 8 – Public

One session was held, in English, with six participants from members of the public.

(Please refer to Table 1 for the tabulation on the sessions held)

Table 1: Tabulation of Focus Group Sessions Held

S/No	Focus Group	Date	No. of Participants
1	Persons with Dementia	20 Jun 15	3
2a	Caregivers (Mandarin)	20 Jun 15	10
2b	Caregivers (English)	20 Jun 15	11
3	Dementia Design	9 Jul 15	9
4a	Healthcare, Community & Social Services	24 Jul 15 (am)	12
4b	Healthcare, Community & Social Services	24 Jul 15 (pm)	8
5	Media & the Arts	28 Jul 15	10
6	Legal, Business & Banking	1 Aug 15	6
7	Faith-based Organisations	20 Aug 15	16
8	Public	20 Aug 15	6
TOTAL			91

Conduct of the Sessions

All the sessions were facilitated by members of the Facilitation Network of Singapore. A brief introduction to ADA and the reasons for the discussion was done by the CEO of ADA.

Entry Survey

Each session began with an Entry Survey, to enable the facilitators to gauge the knowledge, understanding and sentiments of the participants towards the topic and dementia in general.

The entry survey covered the following topics:

For Focus Group Discussion 1 (FGD1)

1. How long have you been diagnosed with dementia?
2. Do you think Singaporeans know much about dementia?
3. Do you think that having dementia is a social stigma?
4. Do you find any assistance from the community?

For Focus Group Discussions 2 to 8 (FGD2 – FGD8)

1. How dementia-friendly is Singapore?
2. To what extent can you/the sector contribute to a dementia-friendly Singapore?

The survey entry results can be found on pages 7 to 9.

Focus Group Discussions

The topics were:

For Focus Group Discussion 1 (FGD1)

1. How has dementia affected your lifestyle?
2. What type of support are you getting? (example: family, friends, social, community, government)
3. What other support do you need? (example: legal, business, government policies, employment)
4. What changes should be made in your area of residence to make it friendlier for you?

For Focus Group Discussions 2 to 8 (FGD2 – FGD8)

1. What does it mean to be a Dementia-Friendly Community?
2. How can you/your sector contribute to a Dementia-Friendly Community?
3. What are the issues and challenges you foresee in supporting a Dementia-Friendly Community?
4. What suggestions do you have to address these issues and challenges?

The key findings from the discussions held are reported on pages 10 to 18.

Entry Survey Results

Focus Group Discussion 1 – Persons with Dementia

The results were as follows:

S/N	Question	Responses			
1	How long have you been diagnosed with dementia?	<1 year	1-3 years 3 persons	3-5 years	>5 years
2	Do you think Singaporeans know much about dementia?	Not At All All felt that Singaporeans are not familiar with dementia. People think it is part of normal ageing.	A Little	Some	A Lot
3	Do you think that having dementia is a social stigma?	Yes All think that dementia is a stigma.	Reasons All felt that their friends and relatives look down on them and think that persons with dementia do not behave normally.	No	Reasons
4	Do you find any assistance from the community?	Not At All One person said that only family members extended their helping hands, whilst another person felt that she does not need help from the community.	A Little One person felt that government provided little subsidies for medical bills.	Some	A Lot

Focus Group Discussions 2 to 8

How Dementia-Friendly is Singapore?

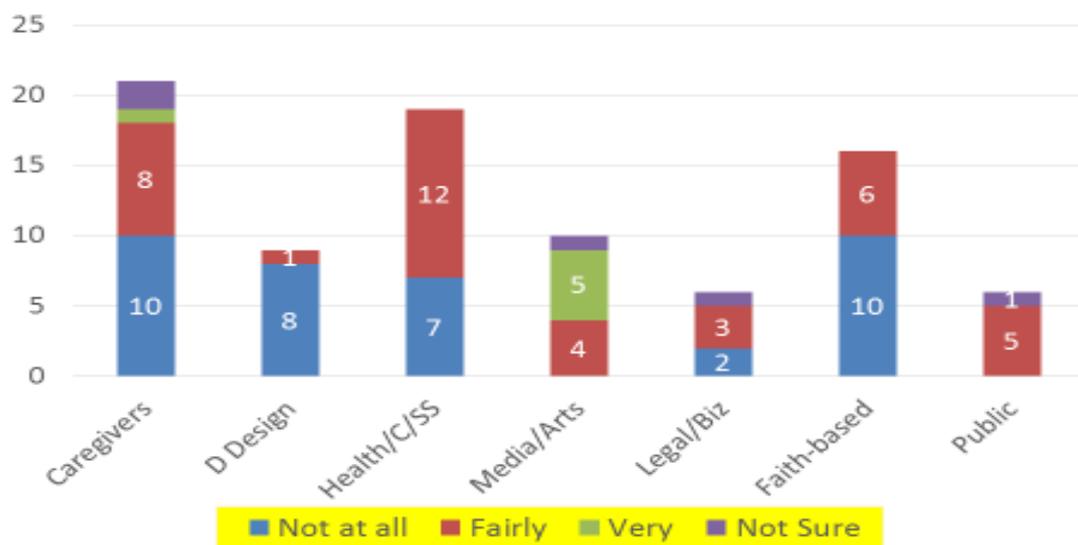
Out of the 90 participants polled (1 participant arrived only after the polling has ended)*:

- 40 (44%) felt that Singapore is not at all dementia-friendly;
- 39 (43%) felt that Singapore is fairly dementia-friendly;
- 6 (7%) felt that Singapore is very dementia-friendly; and
- 5 (6%) were uncertain

Table 2: How Dementia-Friendly is Singapore?

S/N	Focus Group	Not at All	Fairly	Very	Not Sure
1	Persons with Dementia	3	0	0	0
2	Caregivers	10	8	1	2
3	Dementia Design	8	1	0	0
4	Healthcare, Community & Social Services	7	12	0	0
5	Media & The Arts	0	4	5	1
6	Legal, Biz and Banking	2	3	0	1
7	Faith-based Orgs	10	6	0	0
8	Public	0	5	0	1
TOTAL: 10 sessions, 91 participants, 90 polled *		40 (44%)	39 (43%)	6 (7%)	5 (6%)

Chart 1: How Dementia-Friendly is Singapore?



To What Extent Can You/The Sector Contribute to a Dementia-Friendly Singapore?

Out of the 87 participants polled:

- 32 (37%) felt that they/the sector could contribute to some extent to make Singapore more dementia-friendly;
- 46 (53%) felt that they/the sector could contribute to a large extent;
- 5 (6%) felt that they/the sector would not be able to contribute at all or at most, contribute minimally; and
- 4 (4%) were uncertain

Table 3: To what extent can you/the sector contribute to a dementia-friendly Singapore?

S/N	Focus Group	Not at All/Min	To Some Extent	To a Large Extent	Not Sure
1	Caregivers	0	7	14	0
2	Dementia Design	0	6	3	0
3	Healthcare, Community & Social Services	0	4	15	0
4	Media & The Arts	5	4	0	1
5	Legal, Biz and Banking	0	3	3	0
6	Faith-based Orgs	0	8	8	0
7	Public	0	0	3	3
TOTAL: 87 polled		5 (6%)	32 (37%)	46 (53%)	4 (4%)

Key Findings (FGD1 Persons with Dementia)

Topic 1. How has Dementia Affected Your Lifestyle?

- Not able to continue driving – need to sell the car and to get used to travelling on public transport.
- Have lesser friends – people looked down on them; some were worried that they could become violent; some thought that they had gone crazy.
- Less mobility – they needed to be cared for by family members.
- Not really affected – has accepted it (from God), and carried on with life as per normal.

Topic 2. What Type of Support Are You Getting?

- Family support, for example, spouse and son. One said that her husband prepared her for dementia.
- Very little support from friends and relatives.
- Getting some subsidies from the government, in terms of medical fees.
- Religion.

Topic 3. What Other Support Do You Need?

(Legal, Business, Government Policies, Employment?)

- Two participants (pensioners) commented that their medical bill was not an issue.
- Social media, such as television and internet could be used to educate the public about the different types of dementia.
- Incorporate topics on dementia (signs and symptoms) into our current school curriculum.
- The public to understand their behaviours and their mood swings.
- Two participants commented that they have reached retirement age and since have children to look after them, they should retire completely.

Topic 4. What Changes Should Be Made in Your Area of Residence to Make It More Friendly For You?

- Two participants commented that they were doing well in their residential areas, hence did not require any changes to be made.
- One participant lives near a shopping mall and suggested that the mall puts up large directional signs.
- The people in the community to know that they (people with dementia) have a condition and to continue to accept them as part of the community.

Key Findings (FGD2 to FGD8)

Topic 1. What Does It Mean To Be A Dementia-Friendly Community?

General consensus amongst the groups: It is a community in which ...

1. There is societal awareness, empathy and acceptance of persons with dementia (PWDs):
 - a. People
 - take time to find out more about dementia and to prepare their next generation for it (life-long learning mentality).
 - are aware about dementia, know what the signs and symptoms are and how they affect the PWDs.
 - know where to access dementia-related resources.
 - are gracious, patient and respectful towards PWDs.
 - know how to identify PWDs and to assist them.
 - show acceptance for PWDs by including them in social events, organizing activities that are suitable for them, bearing in mind their intellectual limitations, and at the same time, allowing them to utilize/showcase their remaining capabilities, etc.
 - b. Both formal and informal publicity and education on dementia are in place.

2. The society recognises the important role played by caregivers and their families, shows understanding of the challenges faced by them and are attentive to their situation and needs. A strong community and workplace support exist for caregivers and their families, where ...
 - a. neighbours are supportive and provide practical assistance.
 - b. there is availability of support, such as emotional, technological, social, structural and infrastructural.
 - c. there is consistent service delivery from a well-structured and coordinated care system.
 - d. there is strong government support, for example, presence of policies to ensure public awareness and well-trained foreign domestic workers.
 - e. other family members and relatives are also understanding and supportive, and there are more family gatherings.
 - f. institutional support is available, for example, dementia helpline and respite care, be it short-term, ad-hoc, or 'dusk to dawn' care.

- g. flexi-work scheme is available for caregivers working full-time, for example flexi hours and 'work from home'.
 - h. there is existence of mutual support groups in the community.
 - i. caregivers themselves are understanding, patient and tolerant towards their loved ones with dementia.
 - j. caregivers enjoy a smoother caregiving journey and continue to have quality of life.
3. The PWDs are fully integrated into society. They ...
- a. are treated as normal persons – no more stigma and their dignity is preserved.
 - b. have easy access to treatment.
 - c. feel free and confident to move about and caregivers have peace of mind knowing that they would be safe and would be able to come home eventually, even if they had lost their way because someone would help them to get home.
 - d. are recognised for their strengths and remaining capabilities instead of their deficits. Those in the early stages and who are able to continue working are given the opportunity by their employers, through the redesigning of their work or reassignment of duties.
 - e. continue to be active (as far as possible), to contribute to the community and to enjoy a good quality of life.

Topic 2. How Can You/Your Sector Contribute To A Dementia-Friendly Community?

FGD2 Caregivers

1. To personally accept and face the fact.
2. Provide mutual support for other caregivers in the neighbourhood/community.
3. Share caregiving experiences with new caregivers, friends and other contacts.
4. Assist ADA & similar organisations raise public awareness.
5. Collaborate with ADA and the government to help caregivers in Singapore.

FGD3 Dementia Design

1. Provide cues for orientation in planning and design.
2. Adopt a user-centric philosophy in design, and incorporating therapeutic elements.
3. Create age-friendly, barrier-free and accessible facilities.
4. Design safer homes, to maximize independence.
5. Organize social activities and motivate PWDs and their caregivers to participate.
6. Integrate IT-enabled connections into dementia designs.

FGD4 Healthcare, Social Services and Community Services

1. Enable early treatment for PWDs.
2. Collaborate with community partners.
3. Educate on importance of early diagnosis and prevention.
4. Through the provision of healthcare, social services and community services, to empower PWDs to continue to lead an active life.
5. Be a voice for PWDs and their families and advocate for their interests.
6. Step up training programmes for family caregivers and domestic helpers.
7. Create public awareness through media and social media.
8. Conduct public forums and screening for dementia.
9. Customize social activities for PWDs.
10. Be a befriender to PWDs.

FGD5 Media and The Arts

1. Encourage more dementia specialists to work on the subject.
2. Encourage arts and media students to volunteer their services in dementia programmes.
3. Orchestras and music groups to collaborate and put in concerted efforts to launch initiatives to raise awareness, and to help PWDs and their families.
4. Print media to conduct workshops on dementia for editors, and award writers who write about dementia.
5. Approach platforms, such as Humans of Singapore, Night Owls, and Buzzfeed to publish dementia-related stories.

FGD6 Legal, Business and Banking

1. Create awareness in the industry/sector.
2. Educate families to be more prepared financially.
3. Educate families on legal policies and processes to safeguard their money.
4. Develop and extend insurance policies to adequately cover dementia.
5. Develop self-sustaining business models to provide dementia care support.
6. Use common set of control guidelines for the private and public sectors.
7. Collaborate with existing community players.
8. Tap on technology.
9. Conduct research and development on dementia care, for example, apps and services, e-nurses, emergency helpline, etc.

FGD7 Faith-based Organisation

1. Use personal faith to teach values and respect for PWDs – internalize the values of the faith.
2. Conduct community outreach and enable PWDs to continue to participate in faith-based activities.
3. Tweak existing programmes to suit members with dementia.
4. Train individual members to become befrienders.
5. Review the current groups' physical environment for suitability, safety and security for members with dementia.
6. Create sub-communities and collaborate with the secular groups and agencies, to promote awareness and support.
7. When in contact with a PWD in the community, to check if they are associated with any of the faith groups.
8. Provide integrated help, services and financial support from the community.
9. Provide assistance and support for member caregivers.
10. Help in the early detection and referral for relevant services.
11. Religious leaders to be pro-active.
12. Advocate for members with dementia.

FGD8 Public

1. Share knowledge and any experiences, personally or through social networks.
2. Help as a volunteer.
3. Share openly with others if a family member has dementia.
4. Normalize the subject – it could help create acceptance in the long run.
5. Get to know your neighbours and be able to identify someone with dementia.

Topic 3. What Are The Issues And Challenges You Foresee In Supporting A Dementia-Friendly Community?

1. General lack of awareness and understanding about dementia:
 - a. By families (due partly to denial and the myth that it is part of normal ageing) – hence leading to the person missing early diagnosis.
 - b. By the various sectors and the community – leading to apathy, stigma and stereotyping of PWDs.
 - c. By society at large – leading to social stigma.
 - d. By some professionals in dementia care – leading to inconsistency in care standards and delivery.
 - e. Insufficient and inaccurate televised media coverage.
 - f. General lack of interest and attention on dementia issues.
 - g. Low visibility of PWDs in the community – general lack of communication and interaction with PWDs.
 - h. Current focus on academic achievement amongst the young.
2. Sustainable funding for dementia-related programmes, services and publicity:
 - a. lack of understanding by funders from the various sectors.
 - b. Multi-stakeholders with different priorities in the industries.
 - c. Competition with other illnesses for government budget and funding.
 - d. Lack of awareness of avenues for funding and subsidies.
3. Community resources:
 - a. Insufficient community resources, such as daycare centres due to the NIMBY (not-in-my-backyard) syndrome.
 - b. Not easily accessible - stringent eligibility criteria and the existing zoning perimeters makes it restrictive.
 - c. Lack of collaboration between ministries, resources and research.
 - d. Limited venues for diagnosis.
 - e. Lack of “one-stop” agency for different resources needed.
 - f. Possible service gaps in organizations.
4. Training:
 - a. Limited avenues for training in dementia care.
 - b. Who to bear the costs of training.
5. High medical and non-medical costs, for example, costs of respite care, affecting especially middle-income families (the “sandwiched” groups) who do not qualify for financial assistance.
6. Global manpower shortage in medical staff (for example nurses), Social Workers and care staff – over-reliance on foreign helpers and care staff, giving rise to cultural and language issues.

7. Stringent government policies, for example, policies governing the employment of foreign domestic helpers.
8. Changing demographic and household structures resulting in smaller nuclear families – increasing numbers of seniors without family support.
9. Constant changes in landscape and an overstimulated environment.
10. Over-reliance on technology and IT-automated systems, causing some PWDs to be confused, fearful and further isolated.
11. Lack of a champion for dementia cause in the community and an umbrella campaign to push dementia projects forward.
12. Lack of awareness and education on the psychosocial aspects of dementia.
13. Challenges in identifying persons with mental capacity issues and helping them make decisions.
14. Practicality issue – how much is each sector able to help?
15. Caregiver issues
 - a. Main caregivers working fulltime struggle to meet demands from both parties.
 - b. Reluctant to be identified and to receive assistance and training.
16. Insufficient help for persons with dementia to deal with legal issues.
17. Personal Data Protection Act – preventing information sharing.

Topic 4. What Suggestions Do You Have To Address These Issues And Challenges?

Social Structures

1. Rekindle the Kampong Spirit in the neighbourhood.
2. Provide widespread training to enhance understanding of dementia and ability to support PWDs.
3. Set up a structured, coordinated and integrated system of care – linking healthcare, community and social services.
4. Organisations to collaborate (including providing a one-stop service delivery).
5. Create a social support network to encourage PWDs to continue to socialize in the community.

Infrastructure

Encourage socialising, build cohesive neighbourhoods, enhance community bonding and kampong spirit, by putting in place

1. Key familiar infrastructure, such as traditional coffee shops, and age-friendly orientation points, such as landmarks, familiar nodes and activities.
2. Easily accessible public amenities, such as buildings, transportation and interfaces.
3. Dementia-friendly, barrier-free physical environment.
4. More public spaces within housing estates and neighbourhood parks.
5. Strategic public housing arrangements to increase the visibility of seniors in the neighbourhood.
6. Safer home designs to enhance the independence of PWDs at home.
7. Planners, architects, developers and designers to design and build based on user-centric needs (universal design):
 - To educate the public (end-users) on Universal Design and introduce BCA's Universal Design mark for buildings which comply with the codes and guidelines.
 - To accommodate current demands and to incorporate the flexibility for changes in the future as people's attitudes and expectations change.
 - To introduce universal design/user centric design philosophy in schools.
 - BCA to continue to educate and raise awareness amongst architects, designers and developers on new legislative measures, codes and guidelines for a barrier-free and ageing-friendly design.

Technology

1. Create social platforms (website, online support groups, etc) for PWDs to chitchat and for caregivers and organisations to share and exchange ideas.

2. A monitoring device – integrate IT-enabled connections into building/environment designs.
3. A tracking device (GPS) that is not easily removed, as well as an identification so that people can identify and assist PWDs if need be.

Policies/Government Initiatives

1. Ministry of Education
 - a. To introduce topics on understanding and care of the elderly and PWDs in the school curriculum, starting from pre-primary, to prepare children from young for the silver tsunami.
 - b. To reinstate Civics and Moral Education – to inculcate values of respect and patience for elderly and PWDs.
2. Tertiary Institutions (NUS, NTU, Unisim, polytechnics, etc.) – to incorporate topics on dementia in the curriculum of certain professional courses, such as Social Work and Nursing, to enhance their knowledge and service delivery.
3. MOM
 - a. To review policies on the number of foreign domestic workers (FDWs) allowed per family – some families require and can afford to hire more than one FDW.
 - b. To review policies on the eligibility for male FDWs – some families need male FDWs to handle their male PWDs at home.
 - c. To review the 2-year contract for FDWs – some families have difficulties looking for and training a suitable replacement. Nursing Homes become a “no choice” option for them.
4. Relevant ministries (MOH, MSF):
 - a. To review the remuneration package (salary and benefits) of professional staff and care staff, such as Social Workers and Nurses, to attract students into these fields and to retain them in the sector. Currently, we are very short of these workers, especially local ones.
 - b. To take steps to enhance their social status.
5. NCSS – to review the publicity and application process for Safe Return Card and enhance its attractiveness. Currently, it is not known to many people. Those who are aware are also not motivated to apply for them or carry them (due to stigma).
6. MOH to adopt “City for all Ages” policy – to look into policies that can also help the middle-income group who do not qualify for MOH subsidies. Also, to provide better healthcare funding, specifically for PWDs.
7. Singapore Kindness Movement to initiate a Kindness Campaign on dementia.