

3 in 4 Persons with Dementia feel ashamed and rejected, Singapore's first national survey on dementia finds

- More than 5,600 across Singapore including persons with dementia, caregivers and general public participated in this survey
- Persons with Dementia: 72% of persons with dementia feel rejection and loneliness while 50% of them feel that they cannot be open with others regarding their condition. More than 56% of them say that people treat them as less competent.
- General Public: 56% of the general public rate themselves low in dementia knowledge, and more than 54% feel uncomfortable interacting with persons with dementia
- Almost 80% of all respondents (or 8 in 10) say that they want to do more to improve the lives of people living with dementia
- 70% of all respondents (or 7 in 10) agree that persons living with dementia should live "with family in their home" and agree that Singapore needs to provide more dementia-friendly amenities.

Singapore, 29 April 2019 – Persons with dementia and their caregivers experience rejection, loneliness, shame, and feel less competent, the first national survey on dementia in Singapore has found.

This survey by the Singapore Management University ("SMU") and Alzheimer's Disease Association ("ADA") reveals that nearly 3 in 4 persons with dementia feel rejection and loneliness, and more than 1 in 2 feels that others act as though they are less competent due to their condition. Nearly 30% of caregivers feel embarrassed while caring for their loved ones with dementia in public and more than 1 in 10 feels that others around them seem awkward.

Said Mr Jason Foo, Chief Executive Officer of Alzheimer's Disease Association, "Stigma affects more than just the quality of life for persons with dementia and their families. It really emphasises that we should use the right type of language; show more empathy for persons with dementia and their caregivers and aim to integrate persons with dementia into the society by building dementia-friendly communities to support them."

In measuring stigma levels towards Alzheimer's disease and other related dementias, findings show that unsurprisingly, those who hold no connection to dementia have the highest stigmatic attitude. However, this is followed closely by the persons with dementia themselves, with 1 in 2 feeling ashamed of their condition, citing stigma as the main reason.

Based on the findings, amongst the general public, males are significantly more stigmatic than females, while baby-boomers (age 70 and above) are the most stigmatic, followed by millennials (age 21 to 39) and Generation X (age 40 to 69).

While almost 60% of the general public and persons with dementia said “Yes” to incompetency in persons with dementia, 90% of caregivers disagreed that loved ones with dementia are incompetent.

More needs to be done to raise dementia awareness

Reinforcing the need for more dementia education and awareness, more than half (57%) of the general public rate themselves low in dementia knowledge and feel uncomfortable interacting with persons with dementia, with almost 44% feeling frustrated with not knowing how to help people with dementia.

It is however encouraging to note that nearly 8 in 10 of all respondents want to do more to improve the lives of persons with dementia. In fact, 73% think that persons with dementia can still enjoy life and that more can be done to improve their quality of life.

“We need to strive towards changing the mindset of society and break stereotypes. All of us should not focus on their (persons with dementia) deficits, but on what they can still do with their remaining abilities. It’s important to recognise that they can still lead purposeful and meaningful lives,” added Mr Foo.

Working closely with ADA to develop a tailored survey, Senior Lecturer of Statistics at SMU, Ms Rosie Ching, and her 99 undergraduates collated 5,679 responses across Singapore. The study formed the bedrock of a SMU-X Statistics module undertaken by students. Code-named *Remember.For.Me.* by Ms Ching, this is a first-of-its-kind and Singapore-wide study that draws a picture of Singapore’s attitudes and awareness towards Alzheimer’s disease and dementia. The survey results are available at <http://www.screeningstatistics.com/alzheimers/>

Prof Lim Kian Guan, Vice Provost (Undergraduate Matters) and OUB Chair Professor of Finance, said creating greater awareness among students about society’s perceptions of dementia, is one of the first steps towards nurturing citizens who can make meaningful impact to society. “Forging an inclusive society is by no means an easy task. *Remember.For.Me.* gave SMU students enormous exposure to a societal challenge and contributed to the ongoing national discussion on Singapore’s steep greying gradient. Through this project, students gained a deep, immersive and practical hands-on experience of applying statistical methods to analyse the realities of Alzheimer’s disease and dementia beyond the classroom. We hope our statistical findings will spur Singaporeans to learn more about what can be done to improve the lives of those living with dementia, as well as that of caregivers.”

Takes a Society to Make a Difference

One in 10 people aged above 60 in Singapore has dementia, according to the Institute of Mental Health, with the condition affecting half of those above 85. This translated to an estimated 82,000 cases locally in 2018. The number is expected to go beyond 100,000 by 2030 and it is impossible to rely on one sole organisation to make a difference.

“ADA believes that proactive steps should be taken to educate people to be aware of dementia, be mindful of any preconceived thoughts of dementia as a debilitating condition. In building inclusive dementia friendly communities – anyone and any organisation can be part of this movement,” emphasised Mr Foo. “We can look at what we do and explore ways to see how we can include persons with dementia in our everyday life and reduce the stigma.”

To combat this stigma, ADA will be launching a nationwide dementia awareness campaign in June, starting with a set of Dementia-Language guidelines followed by roadshows, events, talks, videos and culminating in a public event on the 21 September on World Alzheimer's Day in commemoration of World Alzheimer's Month in September 2019.

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Background Information on *Remember.For.Me.*

In January 2019, SMU students in a unique Statistics module created by Rosie Ching, Senior Lecturer of Statistics at SMU's School of Economics, collaborated with Alzheimer's Disease Association (ADA) on *Remember.For.Me.* The study formed the bedrock of a SMU-X module undertaken by students.

Survey Methodology:

Prior to the study, Ms Ching invited ADA to SMU to speak to her students at length about the state of people's attitudes towards dementia and stigma involved. All 99 students then organised themselves in groups of 6 to 7 each and invested more than 3 months of intense work in the study, survey and analysis, gathering a total of 5,679 respondents in 5 weeks.

Students collected data via more than 133 survey questions, evaluating variables covering the relationships between the Dementia Stigma Index (DSI) and gender, education, race. The thousands of data lines subsequently underwent rigorous analysis over a 4-week period by Ms Ching and her students. The DSI measures an individual's level of openness, on a scale from 0 to 100, with 0: holding the least stigma and 100: having the worst stigma.

Quotes and Testimonials:

Rosie Ching, Senior Lecturer of Statistics at SMU's School of Economics, said: "I approached ADA to ask if they wanted to work with me in exploring Singapore's dementia landscape, recognising dementia as a rapidly burgeoning problem of worrying proportions in greying Singapore, with this disease already a worldwide epidemic. I've had my students sharing of their grandparents and relatives with dementia. My own beloved great-grandmother died of this when I was an undergraduate and her suffering during the 90's is something I'll never forget. I am deeply grateful to my students for toiling alongside me in seeing this massive *Remember.For.Me.* project through. It has exposed us all to a problem largely not openly discussed nor well understood but which exerts one of the most onerous burdens in society. My students and I are privileged to have worked with ADA in generating statistics which will spark greater understanding, change and improvement."

Daryl Loy, a 23-year-old undergraduate from SMU's School of Law, said: "It's never a dull day in my statistics classes where lessons are filled with real-life examples from every aspect of life. *Remember.For.Me.* was a perfect complement in allowing us to bring what we had learnt in class to practice. It provided us a thorough understanding of how Singaporeans felt about dementia and placed an otherwise theoretical subject of statistics, into its larger societal context. Data collection was a particularly meaningful experience, as each survey response brought about also genuine conversations about the state of dementia in Singapore. It was a good opportunity for us not only to hone our skills in data analysis, but also grounded our critical thinking abilities as we sought to make sense of the numbers in identifying policy gaps for ADA, our SMU-X partner organisation."

Claudia Si Tho, a 20-year-old undergraduate from SMU's School of Social Sciences commented:
“*Remember.For.Me.* has been the most interesting and fulfilling project I have ever worked on. Prior to this, statistics just been like any other subject that I had to complete, but this project opened my eyes to a whole new world. I saw how statistics can come alive and impact our society positively. Through *Remember.For.Me.*, I have hope for Singapore to progress towards being a dementia-inclusive society. I look forward to the changes in attitude and action that our project findings can hopefully help to bring about.”



Photo Caption: Remember.For.Me. Alzheimer's Disease & Dementia Project by SMU Senior Lecturer of Statistics, Rosie Ching (in red long-sleeved jacket) and her Statistics students. Photo includes Mr Jason Foo, CEO of ADA (in white long-sleeved shirt). – Photos by SMU

About Singapore Management University

Established in 2000, Singapore Management University (“SMU”) is recognised for its high-impact multi-disciplinary research that addresses Asian issues of global relevance, and for its innovations in experiential learning. With over 10,000 students, SMU offers bachelors, masters and PhD degree programmes in Accountancy, Business, Economics, Information Systems, Law and Social Sciences, and executive development programmes. Through its city campus, SMU enjoys strategic linkages with business, government and the wider community in Singapore and beyond. For more information, visit www.smu.edu.sg

About SMU-X

SMU-X is an experiential learning framework where students tackle real-world challenges by taking on projects from corporate, non-profit and government-sector organisations. Pioneered at SMU in 2015, the SMU-X curriculum combines academic with experiential learning through the heavy use of projects from partner organisations.

SMU-X courses challenge students to use their knowledge and skills to recommend solutions through interdisciplinary approaches. Partner organisations and faculty are involved in active mentoring so that students benefit most out of this deep relationship. The result is a tripartite learning loop – students get a better understanding of what it means to use theory learnt outside the classroom; our faculty learn how real-world adapts theories; and our partners deepen their own learning through the findings and recommendations by SMU faculty and students. This inculcates in all parties the value of continuous learning which is imperative given today’s rapidly changing economic conditions.

To date, SMU has conducted 48 unique SMU-X modules (equivalent to 180 course-runs) together with more than 300 partners since the pedagogy was introduced in 2015. More than 6,000 students have benefitted from the SMU-X pedagogy and delivered about 900 projects with partners from the public sector (12%), private companies (73%) and NGO (15%). In the current Academic Year 2018-2019, at least 30 SMU-X modules will be offered and another 2,500 students are expected to partner with organisations across all sectors. SMU-X has been lauded by global accreditation body Association to Advance Collegiate Schools of Business (AACSB) as an ‘innovation that inspires’. For more information, visit <https://x.smu.edu.sg/>

About Alzheimer’s Disease Association

Alzheimer’s Disease Association (ADA) was formed in 1990 because of a growing concern for the needs of persons living with dementia and their caregivers. The Association hopes to reduce stigma by increasing awareness and understanding of dementia; enabling and involving persons living with dementia to be integrated and accepted in the community; and leading in the quality of dementia care services for persons living with dementia and their families.

Striving towards a dementia inclusive society through our four strategic service pillars; Centre-Based Care, Caregiver Support, Academy and Community Enabling, ADA aims to advocate and inspire the society to regard and respect persons living with dementia as individuals who can still lead purposeful and meaningful lives. For more information, visit <http://alz.org.sg/>

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