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Alzheimer's Disease Association in S\$2.6m collaboration with Lien Foundation on Post Diagnostic Support

Programme offers customised care plan for newly diagnosed persons with dementia as well as continuous hand-holding by a dedicated case worker for a year; aims to help more than 2,700 people, including clients and caregivers, over four years

SINGAPORE, 24 September 2020:

1. The **Lien Foundation** has partnered with the **Alzheimer's Disease Association (ADA)** to strengthen support and services for those who are newly diagnosed with dementia. Called **Post Diagnostic Support (PDS)**, the S\$2.6 million programme aims to proactively equip persons with dementia and their caregivers with information, care connections and a customised care plan to ease the confusion and sense of helplessness they face when first told of their impending journey in coping with the condition.
2. The hand-holding, done through one or two initial home visits and regular phone calls by a dedicated case worker, will continue for at least a year. Additional visits, if required, will be made on a case-by-case basis. Before discharge, each client will be equipped with a care plan which takes into account his or her unique needs, wishes and family circumstances.
3. Manned by a multidisciplinary, full-time, five-member team comprising a nurse, psychologist, social worker, occupational therapist and social work associate, as well as a part-time physician with special interest in dementia, PDS will also offer care coordination and counselling, where necessary. Finally, it will create a group of peer caregiver mentors who can provide support to families long after they have been discharged from the programme. Clients are referred by the hospitals where they were diagnosed.
4. The PDS programme was soft launched with a handful of newly diagnosed patients from the **Khoo Teck Puat Hospital (KTPH)** in June 2019 and from **Tan Tock Seng Hospital (TTSH)** in October the same year. However, the pandemic and the ensuing circuit-breaker measures forced a break in home visits from early February to June 2020, though the hand-holding continued via phone calls and online support. Visits have since resumed, though families are given the option of an online consultation, should they prefer to do so.
5. A total of **186** people are on the programme, including 126 from the TTSH Memory Clinic and 60 from the KTPH memory and dementia care service. Referrals are received via the two hospitals. All newly diagnosed patients who consent to the programme are eligible, but

referrals are made based on the discretion of the healthcare professionals. Around 400-450 patients are diagnosed with dementia every year by the KTPH memory and dementia care service. The Memory Clinic at the TTSH Centre for Geriatric Medicine, meanwhile, sees on average 600-700 new cases yearly for evaluation of memory problems, with the substantial majority being diagnosed with dementia.

6. The **National Neuroscience Institute** is the latest healthcare institution to have confirmed participation. Around 600 persons are diagnosed with dementia and other cognitive disorders at NNI every year, which includes about 250 persons who have Young Onset Dementia (YOD)¹.
7. ADA is reaching out to other hospitals to extend the reach of its programme. The programme is expected to benefit around 1,400[1] clients and 1,300 caregivers over four years. Around one in 10 ADA clients are currently on the PDS programme. The service is free for families and will cover all types of dementia.
8. The PDS model of care, while available in parts of the United Kingdom, Canada and Australia, is new to Singapore. In Scotland², for instance, all newly diagnosed persons with dementia are entitled to at least one year of post-diagnostic support.
9. The PDS will complement existing support programmes in Singapore, such as the Agency for Integrated Care's [CREST](#) and [COMIT](#), and Ministry of Health's [Cluster Support](#).

Dementia in Singapore

10. Singapore is one of the fastest ageing countries in the world, with the numbers of seniors expected to soar to close to 25 per cent³ of the resident population by 2030, up from 14 per cent⁴ today. Like many of its East Asian peers, the Republic has already emerged as a node in the global spread of dementia, which was memorably dubbed as the biggest health and social care challenge of the 21st century[2] in a 2017 global report.
11. With a significant increase in the pace of ageing here, the prevalence of dementia for those aged 60 or older is estimated at 10 per cent [3] – or potentially 86,000 people as of June 2019[4]. In those aged 85 or older, prevalence rates could be as high as one in two. The numbers may continue to climb as people live longer – with some estimates suggesting that there could be 130,000 [5] or more Singaporeans living with the condition by 2030.

¹ YOD refers to the onset of dementia between the ages of 35 to 65 years. Persons living with YOD often face challenges accepting their condition and managing it while working, supporting and raising their families.

² <https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support>

³ <https://www.channelnewsasia.com/news/commentary/ageing-issues-ministry-singapore-policy-elderly-seniors-ageing-11782364#:~:text=By%202030%2C%20one%20in%20four,2010%20to%2053.7%20in%202050.>

⁴ <https://www.singstat.gov.sg/-/media/files/publications/population/population2019.pdf> (Table A1.4)

12. Despite a proliferation of new services and more healthcare workers, the dementia care system in Singapore remains stretched, with hospitals bearing a heavy load. A key aim of the PDS programme is to ease the burden on hospitals, where the vast majority of cases are diagnosed, and enable persons with dementia to be looked after in the community. At TTSH, for instance, patients and their caregivers may not feel the need for support services upon diagnosis of dementia if complications of dementia such as challenging behavioral symptoms and caregiver stress have not manifested yet. They are usually advised to contact the Memory Clinic early should they need help with care.
13. The PDS programme focuses on the following key areas:
 - a. Proactively establish contact with newly diagnosed persons with dementia and their caregivers and provide continuous support to them throughout the year
 - b. Draw up collaborative, customised care plans together with persons with dementia and their families to identify early the current and future needs and link them to community support programmes, where necessary.
 - c. Develop caregiver peer support network to provide social and emotional support
 - d. Develop sector capabilities by showcasing a collaborative model of post diagnostic support in the community
 - e. Ultimately help the persons with dementia and their caregivers to live well in the community

Structured Support and Personalised Care Plan

14. The key difference between PDS and existing programmes is that the former offers proactive, comprehensive and tailored education and support from the point of diagnosis, even when there are no major presenting issues. Importantly, unlike the hospital programmes which offer generic information and counselling sessions, a designated PDS case worker will work with each person with dementia and their family to first understand their unique needs and circumstances and, work with them over an extended period, to draw up a personalised care plan that best fits their needs. (See factsheet for a sample care plan)
15. The care plan will take into account family resources first, before recommending professional services, where appropriate. The worker will also help families know the trajectory of the disease – and what to expect not just within the first year of diagnosis, but as the condition progresses. The plan could include but not be limited to current or future living arrangements, care coordination and how to gain access to services, home modification resources and financial schemes (e.g. home caregiving grant, caregiver training grant). This plan can form a blueprint for action, even years down the road, when the person with dementia's condition declines and he or she needs care.
16. The main aim is to maximise quality of life and help the person thrive, despite dementia. The dedicated case worker will also educate the family about dementia, link clients and caregivers to services if necessary, teach the caregivers coping skills and strategies and empower them to make better care decisions when the need arises. Caregivers on the

programme are given a mobile number which they can call for advice and support, should they require it.

17. This gradual, in-depth and unhurried process is bound to be more beneficial for families, compared to the current post-diagnosis support at the hospitals, which is typically provided in one day. At TTSH, for instance, such information and referral sessions are about 30 minutes and some families may not be able to process the new information in such a short period of time.
18. Upon discharge, each family will be given the ADA helpline number which they can follow up with, should they need help. They will also have access to caregiver peers who can provide help and advice to ease the journey. As the condition progresses, virtually all patients lose independence and need to depend on family or formal services for care.

19. **Three broad types of support**

i) Information, Navigation and Planning

- The case worker will make time to understand the family's needs and provide them with tailored information to increase their understanding and awareness on dementia and available resources while being supported through an information kit, mobile applications and relevant websites.
- Caregivers and persons with dementia will be included in the mailing list for dementia-related activities and events and the case worker will follow up with the client/ caregiver through monthly or bimonthly phone calls.
- In the event of new needs being identified or should the caregivers request for more structured follow-up, the case worker would then provide the necessary care coordination and support.

ii) Structured Care Coordination and Counselling

- Where necessary, persons with dementia and caregivers will be linked to suitable services in the community. The case worker will help coordinate care and provide counselling and psychoeducation covering topics such as the impact of dementia, the importance of person-centred care, self-care, respite and so forth. They will also be taught coping strategies and ways to increase resilience. For example, the case worker could help identify ways to help a caregiver cope based on individual preferences – such as going for a walk, talking to a friend or learning deep breathing techniques. Knowledge and skills imparted by the case worker will also enable the caregiver to better understand the perspective of the person with dementia. This, in turn, helps build resilience in the caregiver.
- Families with multiple or complex needs will also be more closely followed up by the multidisciplinary PDS team internally and in consultation with the referring hospitals.

iii) Building Support Networks

- The case worker will also encourage persons with dementia and their caregivers to participate in activities and events organised by ADA and other providers. To reduce

loneliness and stress, it is important to provide platforms that enable caregivers and persons with dementia to form bonds of mutual support with other families with common experiences.

- Beyond forming caregiver support groups, one key focus of the PDS programme is to build and nurture a pool of caregiver peers who can run support groups and befriend families who have recently joined the ranks or those with higher needs, to help them cope with the grim everyday realities of dementia.
- ADA will identify suitable caregivers and ex-caregivers who would like to contribute and be involved further. These caregivers will be trained and supported by ADA with regard to facilitation, communication, counselling and mentoring so that they feel confident to lead and self-organise peer groups. Families can seek guidance and advice from these peer networks even after having been discharged from the programme.

20. Feedback from caregivers and families of persons living with dementia highlighted an urgent need to strengthen client and caregiver support services right after a dementia diagnosis, when certain stresses or feelings of uncertainty may be at their peak, said ADA chief executive officer Jason Foo. "With PDS, we aim to draw up personalised and flexible advanced care plans, offer care coordination and counselling where necessary, and create a group of peer caregiver mentors who can provide support to each other even after clients have been discharged from the programme," said Mr Foo. "This is a key transitional platform for persons living with dementia, their caregivers and family."
21. Dementia is a key pillar of the Lien Foundation's work as the condition is difficult and expensive to manage, exacts a high caregiving toll, and currently has no cure. "Early planning and community support for families living with dementia are essential to lessen the chance of care crises and institutionalisation further down the road," said the Foundation's chief executive, Lee Poh Wah. The programme, he added, also aims to enable clients to harness their residual strengths and abilities and live well in the community. "We hope the case worker can become a friend, facilitator and guide to both clients and caregivers as families take their first steps in the dementia journey."
22. The programme design has benefited from the guidance and steady support from dementia-care doctors at both KTPH and TTSH. Senior Consultant Philip Yap, from KTPH's Geriatric Medicine department, whose patients were the first to try out the programme, said that PDS helps to better meet the needs of people with dementia and their caregivers, and bridges the gaps in existing services. "Extant research has found that caregivers have expressed the need to access information about dementia and the attendant services in a timely and tailored manner. They also appreciate support that is continuous and responsive to ad hoc needs."
23. The best part about the timely and tailored support PDS provides is the constant two-way communication doctors have with the PDS care managers. "We meet the PDS team once a fortnight to exchange notes and discuss plans for the patients we care for," said Associate Professor Yap. "In between these meetings, we are also able to conveniently reach one another should ad hoc issues or contingencies arise."

24. A diagnosis of dementia is not the end-point, but the start of a journey, said Dr Noorhazlina Binte Ali, Senior Consultant in the Department of Geriatric Medicine at TTSH. From the perspective of geriatricians running the hospital's Memory Clinic, one of the gaps in dementia care was the lack of support for patients and caregivers upon diagnosis of dementia. "Diagnosis of an irreversible illness without support can be detrimental for both patients and caregivers. The PDS programme has helped our patients with dementia and their caregivers navigate through the community help available, and facilitated the seamless flow of information between patients or caregivers and specialists in tertiary care."

High satisfaction with PDS: Survey

25. In a preliminary satisfaction survey conducted by ADA on PDS, the vast majority of 23 participating caregivers and 14 persons living with dementia who have been on the programme for more than six months indicated positive or very positive responses to the programme. All caregivers agreed that the programme had helped them learn more about dementia, while close to nine in 10 said they would not be aware of dementia support services without PDS, the programme had helped them gain coping skills and strategies, and they felt more empowered to make care decisions.
26. Caregivers surveyed were the primary caregivers (78%), with about half between the ages of 51 to 70. A majority of the persons with dementia surveyed (79%) are living with mild stage dementia, with 59% diagnosed with Alzheimer's Disease.
27. Of the persons living with dementia surveyed, many had positive feelings about the programme and the home visits. Some shared that the programme helped them to understand more about dementia, while there were also some who felt that the programme helped their family members to understand him/her better. (see Annex B)
28. Dr Chen Shiling, the consulting physician who has been supporting the PDS team, pointed out that just as Covid-19 has brought about a 'new normal' for the world, in many ways, dementia is a 'new normal' as well for the newly diagnosed person and his/her family.
29. "Acceptance, adjustments and modifications are needed, but life can and will go on. Personhood must remain intact and voices must be heard. There can still be desires, dreams and hopes for the future," said Dr Chen. The PDS team hopes to achieve these through a multitude of interventions, and also through the development of individualised care plans. "The goal, simply put, is for the person with dementia and his or her family, to continue to live well."

Annex A - Factsheet: About the Post Diagnostic Programme

Annex B – Real life profiles: Caregivers and persons with dementia

[1] Targets, as of Sep 2020, are subject to review, given pandemic-related uncertainties.

[2] https://discovery.ucl.ac.uk/id/eprint/1567635/1/Livingston_Dementia_prevention_intervention_care.pdf

[3] Data from Well-Being of Singapore Elderly (WiSE study) by the Institute of Mental Health
<https://alz.org.sg/dementia/singapore/>

[4] The figures pertain to resident population only

[5] Calculated based on WiSE 2013 prevalence rate and Duke-NUS study that projected Singapore's elderly population aged 60 and above to be 1.3-1.4 million in 2030. Ansah, J.P., Malhotra, R., Lew, N., Chiu, C.T., Chan, A., Bayer, S. & Matchar, D.B. (2015)

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About 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 its 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/>.

For Lien Foundation

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About Lien Foundation

The Lien Foundation is a private philanthropic organisation that pioneers solutions to improve lives and tackle the root of problems in early childhood development and eldercare in Singapore. It also works to improve access to clean water, sanitation and palliative care among diverse communities in south and southeast Asia. The Foundation's research publications, multimedia advocacy and design projects aim to seed public discourse in the hope that these can lead to better policies and practices in its various fields of work. For more information, visit www.lienfoundation.org

Factsheet

Annex A: About the Post Diagnostic Support Programme

1. Overview

<p>What is the Post Diagnostic Support (PDS) Programme about</p>	<p>The Post Diagnostic Support programme aims to strengthen support services for persons with dementia and caregivers right after a dementia diagnosis.</p> <p>The programme proactively equips persons with dementia and their caregivers with information, support, an individualised care plan and tools to ease the confusion, pain and sense of helplessness persons with dementia and their caregivers often face upon diagnosis of the condition.</p> <p>PDS provides continuous support over 12 months through phone calls and home visits by a dedicated case worker. The customised plan, drawn up in partnership with the client and the caregiver, identifies current and future needs of the person with dementia as well as their caregivers, and links them to community support programmes, where necessary.</p> <p>Caregivers will also be connected to a caregiver peer network to provide them with social and emotional support.</p>
<p>Who is involved</p>	<p>Lien Foundation Alzheimer’s Disease Association</p> <p>Partner Hospitals: Khoo Teck Puat Hospital Geriatric Clinic Tan Tock Seng Hospital Memory Clinic</p> <p>Referrals are received from hospitals. The programme will be extended to the National Neuroscience Institute soon, and ADA is in talks with other hospitals as well.</p>
<p>When did it commence</p>	<p>June 2019 at KTPH and October 2019 at TTSH</p>
<p>Project duration</p>	<p>4 years ¹</p>
<p>Number of persons with dementia currently benefiting from PDS</p>	<p>186</p>
<p>Estimated number of persons with dementia who are likely to benefit from PDS by June 2023</p>	<p>1,400²</p>
<p>Expected number of caregivers who will benefit from PDS by June 2023</p>	<p>1,300 caregivers</p>

¹ The project was soft-launched in June 2019 and will continue for at least four years.

² Targets as of September 2020 are subject to review, given pandemic-related uncertainties.

Total expected number of persons with dementia and caregivers who will benefit by June 2023	More than 2,700
Cost of PDS to clients	Free

2. The PDS Team

The PDS team comprises:

- Nurse
- Occupational Therapist
- Psychologist
- Social Worker
- Social Work Associate
- Part-time Consulting Physician with a special interest in dementia care

Providing quality dementia care requires a holistic care approach. The multidisciplinary nature of the PDS team equips it with a range of capabilities to better assess and manage clients' needs, and facilitate care planning conversations. For instance, the consulting physician advises on programme development as well as the management of clients' care, while the psychologist helps to advise on and address clients' emotional well-being. The social worker helps to address the clients' psychosocial needs and provides the caregivers with links to suitable resources. The nurse helps to address the clients' physical health issues and highlights possible health challenges in the future for consideration in the care plan. The occupational therapist assesses the home environment and recommends suitable mobility aids to prepare the client and family ahead for long-term care needs.

Each PDS client and caregiver will be assigned to one designated PDS caseworker, who will follow up with the client and the caregiver throughout the 12-month duration. The follow-ups will consist of one or two initial home visits and phone calls. The team will also engage in regular case discussions to exchange insights and care recommendations. This allows the team to design holistic individualised care plans and provide robust support to clients and caregivers.

3. Financial Support

\$2.6 million over four years from the Lien Foundation

4. Dementia in Singapore

a. Overview

Resident Population (June 2019)	4,026,209 ³
Estimated Prevalence of Dementia June 2019	86,050 ⁴
Projected (2030)	130,000 -140,000 ⁵

³ <https://www.singstat.gov.sg/find-data/search-by-theme/population/population-and-population-structure/latest-data>

⁴ According to the Well-Being of the Singapore Elderly (WiSE) 2013 study led by the Institute of Mental Health, 1 in 10 Singaporeans aged 60 years old and above have dementia, and according to the Population Trends 2019 report by the Department of Statistics, there are 860,508 Singapore residents aged above 60 years as of June 2019.

⁵ Calculated based on WiSE 2013 study (see footnote 6) and Duke-NUS study that projected Singapore's elderly population aged 60 and above to be 1.3-1.4 million in 2030. Ansah, J.P., Malhotra, R., Lew, N., Chiu, C.T., Chan, A., Bayer, S. & Matchar, D.B. (2015)

b. Caregiving for dementia in Singapore

Economic cost of dementia in Singapore⁶

- Cost of dementia in Singapore was \$532million per year in 2013
- Social care component contributed 76% of the costs, of which unpaid care was 60% of social care costs

Annex B

Individualised Care Plan

The Individualised Care Plan (ICP) is a core component of PDS that is developed after active discussions and inputs from both the person with dementia and his or her caregiver.

The PDS team actively engages the client in discussions on a range of subjects including the client's life history, personal likes and dislikes, as well as detailed care preferences (see illustration below). The ICP will also contain aspects such as financial and long-term care arrangements. If necessary, the team will also facilitate conversations between the client and the caregiver to talk openly about their perspectives and preferences. It offers an opportunity for caregivers to understand what their loved ones prefer and wish for, as very often many families do not usually engage in such conversations in their day-to-day interactions.

At the end of one year, the PDS team aims to equip every PDS client with an ICP. This ICP will also serve as a useful tool to help guide clients and caregivers along their dementia care journey. In addition, it will also enable other service providers to better understand the client as a person, helping them provide more person-centred and holistic care.

Besides health and personal care preferences, the PDS' ICP takes a deep-dive into the details of the client's life. Psychosocial care elements such as the client's biography (e.g childhood experiences, significant life events, past occupations, spiritual beliefs, daily routines, favourite hobbies) and social support systems are captured.

The ICP also strives to cover detailed care preferences such as the client's wishes if he/she is unable to perform his/her favourite pastime, have a favourite food/drink, and records what brings comfort to the client when he/she is feeling moody or sad.

⁶ The Societal Cost of Dementia in Singapore: Results from the WiSE Study, Accepted 11 December 2015

Below is a sample ICP of a fictional Mdm Koh whose main caregiver is her daughter, provided for illustrative purposes.

Sample care plan

Mdm Koh's Beyond One-Year Care Plan

Completed: 08 06 2020

Section A: About Me

- My Biography
- My Personality
- My Social Psychology
- My Legal Arrangements
- My End of Life Arrangements
- My Health
- My Dementia
- My Preferred Plan of Care

Section B: My Caregiving Plan

- Urgent Care Plan
 - Non-Acute
 - Medical Emergencies
- Long-Term Care Plan
- Caregiver's Respite Plan
- Financial Matters

Appendix

- My Complete List of Medical Conditions
- My Current Medications
- Medication Administration
- Mobility
- Activities of Daily Living
- Communicating with Me
- Sensory & Physical Abilities

Section A: About Me

Who Am I: My Biography


- Past occupations: Seamstress (worked at home and customers would come to my house to collect the finished clothes); Housewife after retiring during my 60s. Helped to take care of some of my grandchildren when they were young
- I grew up in Malaysia. Came to Singapore when I was 15 or 16 years old. I stayed at my mother's friend's home and learnt my dress-making skills from her.
- I only studied a few years of primary school because my late father believed that girls do not need to receive too much education. I have 10 other siblings and I am the second oldest in the family, hence opportunities usually go to the younger ones. I also helped to take care of my siblings when they were young, because my parents were busy working in the rubber plantation.
- I met my late husband when I was 22 years old. We were introduced by mutual friends. There was another man who was introduced to me by my mother's friend, but I decided to choose my late husband because he appeared more honest-looking.

My Skills, Hobbies & Interests

- I enjoy making clothes. Now I do not make clothes because of my poor eyesight.
- I will read Chinese newspapers to learn more about what is happening in the world. I enjoy listening to the radio.
- The music also accompanies me during the day when I am alone at home.

My Spiritual Engagement

- I am a Taoist. I usually go to the temple in Bugis during special occasions such as Chinese New Year or when I have worries to confide in Guan Yin.



"I feel that we should treasure the present as much as possible. I do not like to look back at unhappy memories and regret."
- Mdm Koh

Section A: About Me

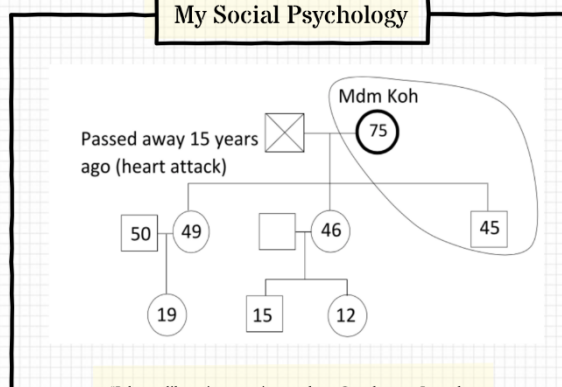
My Personality

- I am an introvert. I have many neighbours and friends because these are people I have known for a long time. I need a lot of time to warm up to people. Maybe because I was too independent in the past, so I take time to accept people's help and friendships.

My Routine

- I will go to the nearby wet market sometimes to buy ingredients to cook. Sometimes my daughters will buy for me when they have time to visit me during the weekdays. I need to cook dinner for my son, if he comes back home from work early.
- If I am not feeling lazy, I will go downstairs for a morning walk. Sometimes I meet my neighbours then we will go to the hawker centre after exercise for coffee.
- I must have a cup of Kopi O every day, otherwise I feel that I have not started my day. I try to make the coffee less sweet if I can.
- My daughters and grandchildren visit me during the weekends. Sometimes they bring food so I do not need to cook.

My Social Psychology



"I do not like to inconvenience others. So, whatever I can do, I will do by myself. I can still go to the market and cook, so I always tell my children to come home to eat."
- Mdm Koh

My Current Living & Care Arrangements

- I live with my son in a 5-room HDB. This flat was bought many years ago, when my children are still young.
- I am not very sure what my son works as, I only know that he works something related to finance. He usually comes home late at night, so I am usually home alone during the day. My daughters are very busy too so I do not call them.

My Relationships with Significant Others

- I am close to my 2nd daughter. Will share my worries with her. I cannot share with my eldest daughter and son because they will keep telling me that I worry too much.
- I will meet my neighbours and friends at the hawker centre for coffee. Usually they will call me to arrange the date or we just bump into each other at the hawker centre.

Section A: About Me

My Legal Arrangements

LPA:

- I have done an LPA
- Have appointed my 2nd daughter as my decision-maker.

Will:

- There is no necessity to do a Will because my children are well-behaved and share good relationships with each other. So I believe that they will not fight over my money.

My End-of-Life Arrangements

ACP:

- Yes, done

AMD:

- I do not see a need to do AMD because my children know what I want.
Funeral arrangements: I have no specific preference, so long as we follow the general Hokkien and Taoist rites.



My Dementia: Mild Alzheimer's Disease

Diagnosed July 2019

My Awareness of My Dementia Condition

- My doctor and family have been telling me that my memory is failing. I feel it myself sometimes when I cannot remember where I placed my house keys. I think that it is natural for me to be forgetful, because I am old.
- I heard about dementia because I remember watching a television show which had someone who was diagnosed with dementia. He could not remember his family members. I believe that my dementia is not serious because I can still remember my family members. I can also cook and go out by myself.

How Has The Diagnosis Made Me Feel About Myself & Others?

- I feel that I can still take care of myself. But my daughters are worried, and they keep telling me to call them anytime if I do not feel well or if I don't feel like cooking. They also took out some of our family photographs and placed them in the living room and bedroom.
- I feel that although I have dementia, I can still function. However, some people think that persons with dementia are "crazy". I have seen elderly people who looked very old and walk around in the hawker centre asking for money. Some give the money, but some are very fierce and ignored them. I feel that it is pitiful.

My Health

- I have cholesterol and need to eat medication every morning.
- Aside from that, I feel that I am physically strong.
- Please refer to Appendix for more details

Section A: About Me How I would like to be Supported



Mobility

- If I have difficulties walking independently, I wish that I can still use a walking stick to move around myself. If I have no energy to walk, I am fine to sit in the wheelchair. However, there is no need to bring me out often because I do not want to trouble anyone to push me around.



Memories

- If I have difficulties remembering my children and grandchildren, I will feel very sad. I would like to have family photographs placed around me so that I can still remember.



Kopi

- If I have difficulties swallowing my Kopi O, I wish that I can still smell the fragrance.



Food

- If I have difficulties eating solid food, I do not want to be on feeding tube because it will feel very uncomfortable. I wish that my food can be cut into very small pieces or I can drink soup.



Toileting

- If I have difficulties controlling my bowels, I am fine to use diapers although I know that it will be very hot. But I do not want to trouble my family to clean up after me. Anyway, I believe that when I grow weaker, I will not be aware of what is going on so most importantly, my family do not feel inconvenient taking care of me.



Future Care

- If my children find it more and more difficult to take care of me, I have already told them that they can send me to a nursing home. I know that they are busy with their own lives so there is no need for them to spend too much money or time on me.



Sweets

- If I am feeling moody, I wish to eat some ice cream or ice kacang because I like sweet things.



Section B: Caregiving Plan



My Urgent Care Plan

- For non-acute situation
 - Mandy Loh (2nd daughter), HP: 9XXX-XXXX
 - Keith Loh (son), HP: 9XXX-XXXX
- For medical emergencies
 - To call either Mandy or Keith (listed above)
 - Mdm Koh has private health insurance that covers B1 wards



My Long-Term Care Plan

- Mdm Koh's children are aware of Mdm Koh's preference to not inconvenience anyone to take care of her. The 3 children have told her that nursing home is a last resort to them because they want to continue to take care of her at home.
- They have discussed with Mdm Koh that if Mdm Koh has growing care needs, they will employ a domestic helper to take care of Mdm Koh. Mdm Koh was initially hesitant because she does not like the idea of having a stranger live-in with her and caring for her. However, she agreed in the end after her children emphasised to her that they would not send her to a nursing home.

Caregiver Respite Plan

- Have applied via AIC's Go Respite just in case the need arises

Financial Matters

- Current & future healthcare financing plans
 - Mdm Koh's children shared that they have sufficient financial resources to be able to take care of Mdm Koh. Mdm Koh also has some savings.
- Existing Resources/Schemes Applied
 - Nil as Mdm Koh does not qualify for any government assistance schemes in view of her well functional status.
 - Can apply for AIC's PGDAS, HCG and FDW Levy in the future



Appendix: My Health as of 08/06/2020



My Medical History

- High cholesterol since a few years ago
- Cataract operation completed last year

Current Medications

- Simvastatin, 5mg in the morning
- Aricept, 5mg in the morning
- No known drug allergies



Medication Administration (i.e. who administers, any special instructions)

- Mandy (2nd daughter) packs Mdm Koh's medications in a weekly pill box.
- Mdm Koh takes her medications on her own.
- Keith will check when he comes home from work.

Food & Fluid Intake (include special requirements, restrictions)

- Able to take solid food
- No problem with swallowing



Mobility (include fall history, outdoor & indoor mobility)

- Independent but requires a wheelchair for very long distances
- Fell at home 2 years ago due to some giddiness. However, has since recovered and no impact on her current walking



Daily Care Needs

- Independent in IADLs
- Independent in ADLs

Communication Abilities

- Speaks in Mandarin; coherent; speaks in full sentences. Occasional word-finding difficulty



Sensory & Physical Abilities

- Intact

POST DIAGNOSTIC SUPPORT PROGRAMME

FOUR REAL-LIFE PROFILES

ANNEX B

1 *Invaluable help from PDS*

Caregiver: Mr Raymond Shong, 51 years, tuition teacher

Person with dementia: Mdm Ng Chong Poy, 74 years, has mild dementia

Mr Raymond Shong was almost at his wits' end with his 74-year-old mother, Mdm Ng Chong Poy. She was often negative and suspicious of people around her, and sometimes even paranoid. For example, if she could not find her things, she may accuse her family members of taking them. It was tough for 51-year-old Raymond, who works as a tuition teacher and is Mdm Ng's eldest son. He is also her main caregiver as she stays with him and his family. Mdm Ng was diagnosed with mild dementia by KTPH last year, and she has been on PDS since late Dec 2019.

In his words, about how PDS helped :

"I have lost count of the many ways that the PDS team has helped my mother and me. They worked hard to win my mum over and had to 'fight' or overcome every single 'test' of will and difficulty she posed to them. For instance, my mum is generally not open to meeting strangers.

When she knew that the PDS team was going to visit, she threatened to leave the house if they came. For the first meeting, I managed to convince her to meet the PDS team in the hospital and from there, they managed to build a good rapport with her and was able to come to our home for their subsequent visits. Since then, she has been very welcoming of their home visits.

Indeed, I am very grateful and elated to have the PDS team come in to help my mother. It was in the nick of time, and as the saying goes – a stitch in time saves nine. Their support has greatly helped and encouraged my mother to think positively, stay happy and live gracefully.

I am lost for words at how the PDS team has in the last six to nine months (especially Bridget & Joyce), tirelessly, diligently and faithfully helped my family in many possible ways and went beyond their call of duty. Now, my mother is willing to give dementia day care a shot.

In addition, the links they have provided to connect me to different organisations and networks are priceless and a real life-saver. I am indebted to the team and wish to thank them a million times for their support, care, help and understanding of my mother's needs and helping us cope with her dementia."

Raymond has created his own description of the PDS acronym to express his thanks and appreciation of the qualities he has found in the PDS team:

Perseverance in understanding the situation
Devoted to their job
Sincere in showing that they care

2 **Someone is looking out for us**

Caregiver: Ms Goh, 49 years, full-time employment

Person with Dementia: Mrs Goh, 78 years, has mild Alzheimer's Disease

Mrs Goh is 78 years old and her husband passed away in 2019. She lives with a domestic helper and her daughter, Ms Goh, visits her regularly. Mrs Goh was diagnosed with mild Alzheimer's Disease by KTPH last year and has been on PDS since September 2019.

Ms Goh appreciates the support PDS provides to caregivers like herself. She also feels that the emotional support provided by the PDS team was invaluable.

In her words, about how PDS helped :

"The support goes beyond the recommendations. The PDS team provided us with crucial emotional support and face-to-face visits during our bereavement when my dad passed on. This kind of support is probably more valuable than anything else. Their home visits were reassuring as the team was able to check on my mum's emotional wellbeing as they chatted with her.

Most of all, the PDS team's support for me as a caregiver is immense. Our caseworker and psychologist, Ms Bridget Goh, advised me in many ways and shared how it was important to allow my mum the time to grieve. She explained to me that persons with dementia needed a longer time to process their thoughts and deal with their grief. She also assured me that it was normal for caregivers to feel guilty about the possible negative feelings we had of our loved ones with dementia. This brought a lot of relief to my mental state and helped me cope with my inner struggles.

It also helps me a lot to know that there is someone looking out for us. For instance, having a telephone number to call anytime when I have a question about my mother or her care needs is a tremendous form of assistance and psychological support especially since my mother is staying apart from me.

The support the PDS programme extends to my mother and me is so precious, especially the emotional strength it gives me."

3

Alone & appreciative of each visit

Person with dementia: Mdm Li, 77 years, widow who lives alone and has mild Alzheimer's Disease

Caregiver: Cousin

Since being diagnosed with mild Alzheimer's Disease by KTPH in August 2019, 77-year-old widow Mdm Li has been on PDS. She lives alone in a three-room flat. Her cousin visits her once every two to three weeks, and calls her each night to check that she has taken her medicine.

One of Mdm Li's daily worries was that she may forget to switch off the stove after cooking. The PDS team helped to address this concern and her financial hardships by successfully referring Mdm Li to a food charity that now delivers cooked food to her every day.

In her words, about how PDS helped :

"I am living alone and am getting more forgetful. So, it is helpful to have someone from the PDS team come to my home to help and talk to me.

They will remind me about what I should or should not do. I do not want to trouble my cousin because he is also caring for his aunt. He is also in poor health because of his asthma.

I appreciate the PDS team for visiting and helping me. Then I do not need to trouble my cousin too much."

4

From chit chats to making handicrafts

Caregiver: Mr Lim Guan Hong, 53 years, married, not working.

Person with Dementia: Mdm Luah, 80 years, has mild Vascular Dementia

When 53 year-old Mr Lim Guan Hong found out from KTPH that his 80-year-old mother, Mdm Luah, has mild vascular dementia last September, he was at a loss. Mr Lim also did not know what to make of his mother's baffling actions and behaviour. For instance, she would buy the same type of vegetables from the wet market for consecutive days. She also tended to cook the same dishes and amount of rice every day, regardless of how many family members were having dinner.

Guan Hong is the main caregiver as his mother stays with him and his family. He is thankful for the PDS team's visits as they managed to reach out to his mother by chatting with her and engaging her with handicraft activities.

In his words, about how PDS helped :

"Eileen (social worker) and her team visited my mum at home, and these visits really helped. They spent time chit chatting with her and engaging her in handicraft activities.

We were also quite keen to attend the [Memories Café](#) activity organised by ADA. The PDS team wanted to link me up with other dementia caregivers for additional support and network.

However, because of Covid-19, I have put off the visits and going to Memories Café. I really hope the situation can get better. Thankfully, we cope better now, with the support from the PDS team."