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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 Social and Family Development'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/>.

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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