





Media Release

Dementia Patients in Pilot Palliative Home Care Programme Enjoyed Better Quality of Life and Less Distress

Patients in Temasek Foundation Cares – Programme Dignity exhibited less behavioural challenges and had their pain symptoms managed more effectively

21 September 2017 – Findings from a three-year pilot palliative home care programme for advanced dementia patients showed all-round improvements in their quality of life, coupled with a lower utilisation of acute healthcare services. Temasek Foundation Cares – Programme Dignity is the first-of-its-kind programme in Singapore catered specifically for end stage dementia patients. This programme is a collaboration between Temasek Foundation Cares, Dover Park Hospice and Tan Tock Seng Hospital. It was funded by Temasek Foundation Cares on a grant of \$1.5 million. Results of care for 331¹ patients were tracked from 2014 to 2017.

2. Prompted by the need for dedicated palliative care for patients with advanced dementia, Programme Dignity was piloted in 2014 with the objectives of:

- i) Providing integrated, person-centred care for patients at their final stage of life;
- ii) Supporting their caregivers; as well as
- iii) Establishing a suitable and effective care model for end-of-life palliative home and community care for advanced dementia patients.

¹ A total of 372 patients participated in the Temasek Foundation Cares – Programme Dignity, of which 331 patients consented to the study.

3. A multi-disciplinary Palliative Home Care Team comprising of doctors, nurses, medical social workers and allied health professionals from Dover Park Hospice and Tan Tock Seng Hospital cared for a total of 372 advanced dementia patients and their caregivers at their homes.

4. Mr Richard Magnus, Chairman of Temasek Foundation Cares said, "Persons with advanced dementia need a patient-centric specialised, medical, social and sensitive support. Caregivers are often at a loss on how to care for them. Palliative and a continuum of social care individualised to the specific patient help to alleviate significant distress at their final stage of life. Programme Dignity provides an integrated model of care to patients, caregivers, healthcare professionals and health institutions which enable patients to live out their remaining days with a relatively better quality of life in the familiarity and comfort of home."

5. Programme Dignity's care model is person-centred and dementia-specific. Through regular home care visits and 24 by 7 support even after office hours, the home care team works with caregivers to alleviate physical symptoms such as breathlessness and pain, manage medical complications and address distressing behaviours. These distressing symptoms, common in advanced dementia patients, are often psycho-social and emotional in nature and are stressful not only to the patients but to the caregivers too. As patients typically could not articulate their needs, many convey their fears and anxieties through behaviours such as eating less, apathy, disrupted sleep patterns and agitation.

Better quality of life and less distress for patients and caregivers

6. Results from programme validated the viability of an integrated model of community care for improving the quality of life in advanced dementia patients and support for caregivers. With the programme, 90% of patients were able to live out their remaining days in the comfort of their own homes, according to their wishes.

7. Patients registered a 16.7% improvement in Quality of Life² after they were cared for in the programme. The study also found that pain and behavioral challenges are positively correlated with the Quality of Life score i.e. patients' quality of life improved significantly when these symptoms were addressed. More importantly, there was an 18.3% reduction in pain³ severity experienced by patients after being in the programme.

8. Behavioural challenges such as eating less, apathy, disrupted sleep cycle and agitation were reduced in one-third of the patients⁴, from 80% to 53%. The severity of these problems also improved by 52.8%.

9. A feature of Programme Dignity is that caregivers⁵ are also provided the necessary support so that they do not suffer from caregiving burnout. 53% of caregivers were at risk of anxiety and/or depression prior to receiving support from Programme Dignity. 146 caregivers interviewed two months after the demise of their loved ones with advanced dementia expressed 90% level of satisfaction with the care and support given by the home palliative care team.

Sharp drop in hospital re-admission, length of stay and emergency room visits

10. Programme Dignity showed positive impact on patients' utilisation of acute healthcare services. Significant reductions in hospital re-admissions, length of hospital stay and emergency room visits were observed. These indicators also contributed to patients and caregivers experiencing fewer distress, with less resources spent in hospital and more quality time spent with the family member at home.

² Measured by the Quality of Life in Late-Stage Dementia (QUALID) Scale. QUALID is an 11-item tool administered to caregivers of persons with late-stage Alzheimer's disease and other types of dementia. ³ Measured by the Pain Assessment in Advanced Dementia (PAINAD) Scale. PAINAD is a five-item tool

to assess pain in patients with cognitive impairment. ⁴ Measured by the Neuropsychiatric Inventory Questionnaire (NPI-Q), a clinical instrument for assessing behavioural and psychological symptoms in dementia.

⁵ Measured by the Zarit Burden Interview and administered to caregivers to assess caregiver burden.

11. Hospital re-admissions and emergency room visits fell by 71.4% and 72.7% respectively because medical complications and distressing symptoms which usually lead to hospital visits were well-managed by the Programme Dignity team in the patients' homes. Before enrolling in the programme, patients were admitted more than 2.5 times per year. This fell to an average of 0.7 times after they joined the programme. When patients had to be admitted to hospital, the length of stay for patients in Programme Dignity also reduced by 50.5% compared to before their enrollment.

12. Elaborating on why this new model of care works for advanced dementia patients, Dr Allyn Hum, Programme Director and Senior Consultant, Palliative Medicine, Tan Tock Seng Hospital and Dover Park Hospice, said: "Programme Dignity works because we believe caring for advanced dementia patients is more than just about dispensing drugs. It is about honouring the person for who the patient is, and caring for the caregiver."

13. She explained, "Our team works with the caregivers to identify the cause for the patient's distress and offer solutions to resolve the suffering. Some of these distressing symptoms may be due to their emotional state, such as anxiety and fear which is often not addressed. For example, using touch and loving gestures can help to calm an agitated patient. Understanding the patient and placing his favourite items around him can provide assurance and reduce his distress."

Programme Dignity model of care to be replicated to the wider community

14. With the success of Programme Dignity pilot, this new model of care will be funded as part of National Healthcare Group's (NHG) expanded pilot integrated home palliative care programme moving forward. NHG will be working with DPH and other community partners, such as home personal care providers, to offer more holistic care for clients with advanced dementia and other non-cancer conditions.

15. Professor Lionel Lee, Chairman of Dover Park Hospice said, "As a charity hospice, we are always mindful that as we expand the programme, we need to ensure

its long-term sustainability through charity dollars and government subvention. Therefore we are grateful to Temasek Foundation Cares for working with us to bring this new model of care to its maturity; and now to the Ministry of Health for their support to continue with this programme. Together, we will expand home palliative care to other non-cancer terminal conditions and make home palliative care a viable choice for more patients."

16. Mr Richard Magnus added, "Historically, palliative care has been for patients who have cancer. Programme Dignity expands the boundary of palliative care to advanced dementia patients. This pilot initiative shows advanced dementia patients are better and effectively cared in their own homes, rather than in health institutions but with access to medical care. This integrated model of care for advanced dementia patientia patients will now be implemented nationally."

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About Temasek Foundation Cares

Temasek Foundation Cares is a Temasek funded non-profit philanthropic organisation that aims to help improve the lives of underprivileged individuals, families and communities in Singapore; and to build the capability and capacity of all people in Singapore to be prepared for emergencies.

Set up in 2009 as an Institution of a Public Character, it works in partnership with various voluntary welfare organisations, non-profit organisations, government agencies, Ministries and other institutions to support programmes that contribute to the well-being, dignity, livelihood, and emergency preparedness of its beneficiaries.

For more information, please visit http://www.temasekfoundation-cares.org.sg/

About Dover Park Hospice

Dover Park Hospice was founded in 1992 as a secular, non-profit organisation to meet the growing need in Singapore for hospice care for terminally-ill patients. It is Singapore's first purpose-built hospice, designed to provide a serene environment close to nature.

Dover Park Hospice was started by volunteers, and today volunteers continue to play an integral role in all aspects of hospice work, from patient care to social activities and administrative support. They are an important complement to the permanent staff, working together for patients and their families.

Open to everyone regardless of age, race, religion or income level, Dover Park Hospice is dedicated to meeting the unique physical, emotional and spiritual needs of those who are nearing the end of life's journey. The goal is to enhance the living, comfort the dying and support the grieving with compassion and dignity.

At Dover Park Hospice, Every Moment Matters. Since 1992, we have brought care and comfort to more than 11,000 terminally-ill patients and their families through a programme of active and compassionate service.

About Tan Tock Seng Hospital

Tan Tock Seng Hospital (TTSH) is one of Singapore's largest multi-disciplinary hospitals with 173 years of pioneering medical care and development. The hospital has 45 clinical, allied health and pharmacy departments as well as 16 specialist centres. It also has three institutes that are spearheading care, research and innovations in geriatric medicine, infectious diseases and ophthalmology. Powered by more than

8,000 healthcare staff, TTSH sees over 2,500 patients at its specialist clinics and some 460 patients at its emergency department every day. TTSH is part of the National Healthcare Group, providing holistic and integrated patient care.

With a strong quality culture steeped in patient safety, TTSH constantly challenges itself to provide faster, better, cheaper and safer care for patients. To achieve this, the hospital keeps abreast and believes in investing in its staff, facilities, medical technology and system improvements. In recognition of its commitment to excellent patient care and its comprehensive range of quality healthcare services, TTSH has been awarded the ISO 14001 and OHSAS 18001 certification as well as the prestigious Joint Commission International (JCI) accreditation.