Living with Dementia; Dying with DIGNITY

80,000 SINGAPOREANS ARE EXPECTED TO HAVE THE DISEASE BY 2030. MANY SUFFER IN SILENCE AMID POOR QUALITY OF LIFE. PALLIATIVE CARE IN ADVANCED DEMENTIA CAN HELP.

BY **DR ALLYN HUM**
SENIOR CONSULTANT // CENTRE FOR GERIATRIC MEDICINE, PALLIATIVE CARE CLINIC // TAN TOCK SENG HOSPITAL

ONE OF THE DIFFICULTIES I face as a geriatrician is the sense of helplessness in addressing the challenges experienced by my patients living with dementia. Contrary to popular belief, dementia is not part of the normal ageing process. It is an incurable neurodegenerative disease which causes sufferers to lose their autonomy and identity.

Dementia, of which the commonest form is Alzheimer's, has no regard for social class, education or affluence, afflicting people from all walks of life. Memory and basic functional loss erode individual independence and dignity. In its advanced stages, patients eventually require care for basic needs and are often bedbound.

In 2012, about 28,000 people in Singapore aged 60 and older had dementia. The number is expected to soar to 80,000 by 2030. The number will increase with Singapore's ageing population, as the odds of developing dementia increase as one grows older. Singapore's economic, social and healthcare burden from dementia is estimated at $1.4 billion annually.

Patients with advanced dementia have poor life expectancy. In an effort to prolong life, many are tube-fed or placed on intravenous drips. Some are restrained to prevent self-harm. Unfortunately, these well-meaning treatments rarely improve survival, while severely impacting the quality of life. It is therefore imperative that we put in place interventions which focus on helping patients live and die with dignity.

An approach that deserves more attention is palliative care. Widely used in managing serious conditions like cancer and end-stage organ illnesses, it focuses on improving the quality of life for patients and their families by alleviating pain and suffering at any stage of a life-threatening illness. Palliative care can be administered alongside existing care plans, ensuring that patients continue to live comfortably, even with advanced illnesses.

But palliative care in dementia treatment is undersubscribed. One reason is that advanced dementia is not traditionally viewed as a life-threatening illness. Neither is dementia a certified cause of death in Singapore. This is in contrast to places like England and the United States, where dementia is

the second and sixth leading cause of death, respectively. Another reason is that dementia progression is notoriously hard to predict, making it difficult for healthcare professionals to pinpoint an appropriate time to recommend palliative care, if at all.

For example, advanced dementia patients are incapacitated by severely diminished mental faculties and their world becomes progressively silent as they lose the ability to express themselves. In the last year of life, 83 per cent of patients experience confusion, 72 per cent are incontinent, while more than half suffer constipation and reduced food intake. Some 64 per cent of patients also experience significant amounts of pain — akin to late-stage cancer sufferers.

These symptoms are often not recognised or addressed. This, coupled with frequent hospital visits from recurrent infections, leads to poor quality of life in the final days. Caregivers undergo considerable emotional and physical stress having to watch their loved ones suffer, while struggling to cope themselves. There needs to be greater awareness and education of the suffering of advanced dementia patients and caregivers among the healthcare community and public, and the eventual upscaling of resources to support patients and families in the community.

More innovative strategies can help provide cost-effective care across different healthcare settings. One such method is home-based palliative care. Dover Park Hospice and Tan Tock Seng Hospital jointly developed a pilot programme funded by Temasek Cares, one of the philanthropic organisations under Temasek Holdings, to address the needs of advanced dementia patients and their caregivers at home.

Temasek Cares-Project Dignity builds on existing home care models and tailors palliative care protocols to dementia sufferers. Disease-based, but needs-specific, the programme evaluates patient comfort and caregiver well-being through internationally validated dementia-specific measures. As patients are not able to clearly articulate distress, discomfort is evaluated through non-verbal cues such as facial expression, body posturing, vocalisation, breathing pattern and response to comfort and care.

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DR ALLYN HUM, SENIOR CONSULTANT, CENTRE FOR GERIATRIC MEDICINE, PALLIATIVE CARE, TAN TOCK SENG HOSPITAL

Challenging behaviours may also be a surrogate expression of physical or emotional distress. Caregiver awareness and environmental and medication changes can be adapted to respond to these cues, to relieve distress and improve quality of life. Teams comprising nursing, social work, geriatric and palliative specialists make regular home visits, where they use dementia- specific measures to gauge pain and suffering in patients.

The team also supports families by helping them anticipate changes in care, and advising caregivers on coping with adjustments in physical and emotional well-being along the way. In addition, the team acts as an intermediary, liaising with hospital, hospice and home, and simplifying the administrative process for caregivers. After-hours support is provided through an emergency hotline.

Since October 2014, the programme has helped over 200 patients with advanced dementia. Patients are referred to the home care team by their physicians in Tan Tock Seng Hospital, in consultation with their families. With this support, patients can remain at home, in a familiar, non-threatening environment, surrounded by loved ones. Caregivers, whose physical and emotional needs are often overlooked, are, in turn, supported by the home care team.

However, the challenges of providing such services within the community are all too real. Dementia care is complex, requiring specialised training. In addition, a comparative lack of resources and funding in the community makes home care work extremely demanding. The current pilot shows the benefits of a collaborative care model involving tertiary hospital, home care team and hospice. Such a model of care can potentially be replicated in the other regional healthcare systems in Singapore.

As our population ages, palliative care has to be expanded to match disease-specific needs. Healthcare providers have to be skilled in managing multiple complex end-stage conditions across various healthcare settings, including in the home. We need to develop and expand disease-specific palliative home care teams, equipped with the necessary medical and allied health expertise to support caregiving at home throughout Singapore. Members of the community can also do their part to provide emotional and social support to families in need. In caring for our vulnerable elderly, Singapore must and can do better. LW

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