DIGNITY IN DEMENTIA

by Agency for Integrated Care (AIC)

Singapore has one of the fastest aging populations in the Asia Pacific region. By 2030, it is expected that 15-20% of the population will be made up of individuals aged 65 years and above.

Local epidemiological studies show that the prevalence of dementia ranges between 2-14%, and is expected to increase from the 28000 reported in 2012, to 80000 in 2030. The prevalence of cognitive impairment also increases with age – from 0.8% in individuals aged between 60-64 years, to 32.2% in those aged 85 years and older.

With a rapidly greying demographic and longer life expectancy, we will be caring for an increasingly frail population, many of whom may suffer from dementia.

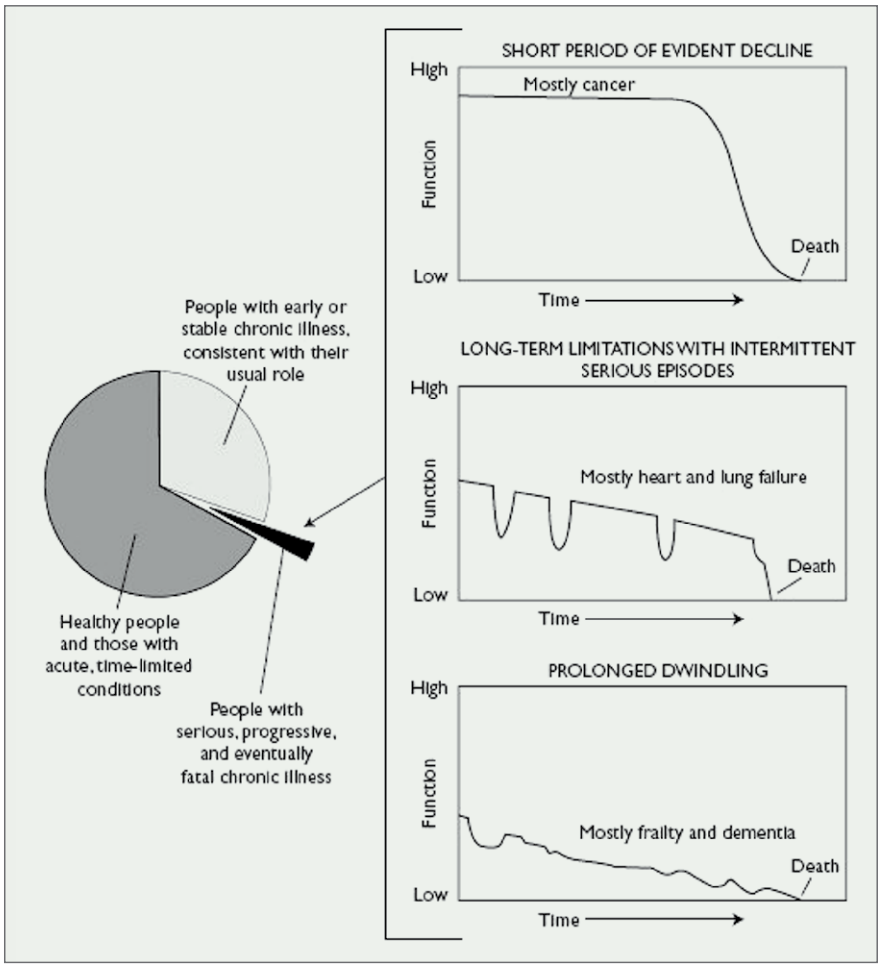

Figure 1: Trajectory of End Stage Illnesses. Lynn and Abramson. 2003

Dementia as a Terminal Illness

The disease trajectory for dementia is progressive (Figure 1). Patients inevitably move from the mild phase where one can be forgetful, through the moderate stages where one may require more help with basic care, and eventually, to the advanced stages where speech and mobility becomes severely diminished. While dementia per se is not lethal, patients do die from complications related to advanced dementia as a result of increased mental and physical disability.

Despite this knowledge, dementia is not traditionally viewed as a life threatening illness. In the United States, where dementia is the 6th leading cause of death, it remains under-recognised as a terminal illness. In Singapore, the situation is similar.

Unique Challenges Faced by Dementia Patients

The unfortunate outcome of such under-recognition is that many advanced dementia patients do not receive care that dignifies the last days of their lives. They may not receive the support that allows them to live their final days comfortably with their loved ones. Their families, many of whom have cared for them unreservedly for years, suffer significant psychological morbidity with burn-out, depression, demoralisation and anxiety.

Dementia patients face many unique challenges. They suffer losses which may be more prolonged compared with patients suffering from advanced cancer or other end organ diseases. Many dementia patients also have poor pain management as they may be less able to articulate their pain, leading to it being under-treated. Other challenges that arise as their disease progresses include diminishing mental capacity, sun downing, behavioural and nutritional issues, overuse of psychotropic medications and restraints, as well as recurrent infections and hospitalisations.

The need to support caregivers of dementia patients cannot be over emphasised. Due to the disease trajectory of dementia, there is a prolonged period of adjustment where the loss of patients' personal attributes leads to a "social death", and loss of cherished interactions which add to the sense of grief for loved ones long before death approaches. Coupled with the demanding needs of caregiving, it is no wonder that many caregivers of dementia patients face severe stress and burnout.

Palliative Support for Dementia Patients

What can the medical community do to better care for dementia patients and their caregivers? The answer lies in palliative care.

The World Health Organisation (WHO) defines palliative care as "an approach which improves quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain

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and other problems, physical, psychosocial and spiritual".
Not only is the palliative approach well placed to provide person-centric dementia care, the provision of specialist palliative care will alleviate suffering experienced by patients and their caregivers at the final stage of life. Such support should be integrated into the care of patients with advanced dementia, to achieve the best possible quality of life for both patients and their caregivers.

In addition, advance care planning (ACP) discussions are also important in helping families and caregivers of dementia patients cope with and prepare for the uncertainties ahead. ACP plays an important role in helping medical providers and patients' loved ones formulate decisions that support patients' preferences, goals and values. Understanding the patient's disease trajectory and prognosis helps medical providers hold such discussions at appropriate timings.

Developmental Opportunities

Currently, such support is not readily available for dementia patients and their caregivers in their homes. The Agency for Integrated Care (AIC) is working with palliative care providers in the community to develop programmes catered to this group of patients and their caregivers. More updates will be available by next year.

CM

A TIMELY CONSULT

by Dr Nicholas Foo Siang Sern, Editorial Board Member

"Doctor, my wife is not well," frowned Mr Raj, "she has been unable to take her meals over the last three days."

The GP listened as the patient's husband continued talking, noting that the patient herself did not utter a single word.

Mr Raj concluded in a whisper," Doctor, I think my wife has been 'hexed'..."

"Why do you say that she has been 'hexed'?" enquired the GP.

"To tell you the truth, my wife was warded in the hospital about two months ago. She had suddenly become confused one day. They did all sorts of tests on her including a CT scan of her head but they could not find anything wrong with her. Eventually a psychiatrist came to see her and he concluded that she was fine and discharged her! All that money wasted! "said Mr Raj, sounding most exasperated.

He continued, "So I then concluded that she must have been hexed. I had a dispute with someone over some business matters before that and I believe that person must have placed a curse on my wife. I decided to bring my wife to see a priest and she was back to her usual self after he said some prayers for her. I thought that everything was settled but it seems that she has taken ill again."

"Maybe you could prescribe her some medication to make her feel more comfortable for now," he replied, "I will probably have to bring her to the priest again but he has gone away for a while and will only be back next week. I am a little worried that she is not eating and behaves strangely."

Mr Raj had been the GP's patient for several years. He was about fifteen years older than his wife and they had been married for ten years. Both of them ran a small but profitable business together and seemed to be happily married with no domestic issues. They had an 8-year-old daughter, whom they doted on dearly. The GP had known Mrs Raj to be a level-headed person and this current problem was most puzzling to him. Something was not quite right.

The GP turned to face Mrs Raj and asked her if she had anything to say. The previously stoic lady suddenly burst into tears, as if relieved that she had been granted permission to break her silence.

"It's that boy who is causing all the trouble!" she cried out.

And then the whole truth came gushing out. For the first time, the GP found out that Mr Raj had previously been married to another woman with whom he had a son. His son was now

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