

# Report urges better end-of-life planning

It highlights gaps in care and suggests ways to improve in areas like costs, family support

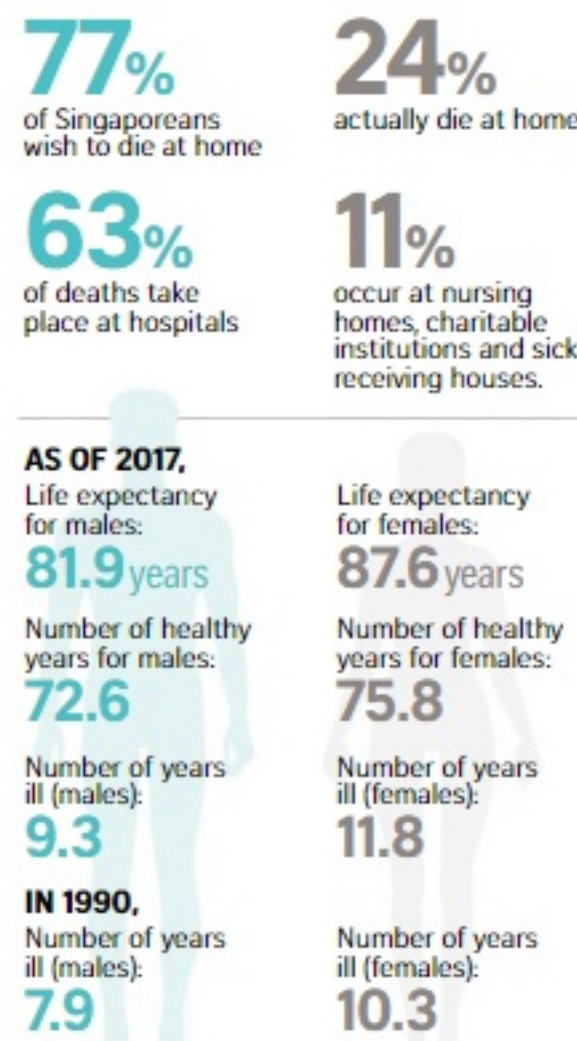
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When it comes to talking about death and dying, Singaporeans uncharacteristically leave things to the last minute. But this has to change as the country ages, with a robust national plan needed to prepare people for their final days, the Institute of Policy Studies (IPS) recommended in a comprehensive new report yesterday. "As Singaporeans, we plan for almost everything, from the first house that we purchase to a child's first school," said IPS research associate Yvonne Arivalagan, one of the study's authors. "But this is a really important aspect of life that very few people actually plan for." The 97-page report highlighted aspects of end-of-life care where gaps remain and recommended improvements, including in the areas of

costs, family support, and the ease of planning and communicating one's final wishes. It is based on the findings of a group of experts from various fields, who studied the issue over a two-year period. "We find that one of the most common scenarios is that people just don't talk about this until it's too late," Ms Arivalagan added. "At that moment, it's very distressing and there are a lot of financial considerations to think about... The idea is to talk about this issue much earlier." A Lien Foundation survey in 2014 found that 77 per cent of people preferred to die at home. But data from last year's Singapore Demographic Bulletins showed that only 24 per cent achieved this, with 63 per cent dying in hospitals. And although Singapore tops the world in life expectancy, with the average Singaporean enjoying the longest span of living in good

health, there has also been a rise in the number of unhealthy years lived by people here. When it came to costs, the report's authors noted that people may find it cheaper to die in a hospital than at home, simply because of how government subsidies are structured. Financing programmes for end-of-life care services are also less developed than in the rest of the healthcare system, since most care is informal and provided by families and the community. In fact, healthcare costs can be the source of familial rifts, especially when patients decline treatment so that their loved ones will not have to shoulder the burden of their medical bills. IPS senior research fellow Christopher Gee, who co-authored the study, noted that Singapore has traditionally invested heavily in acute hospitals and less in long-term care. Although this is changing, subsidies are still skewed towards the old model, he said. "It's not easy to level this up. But going forward, we will need to think about how we can incentivise peo-

## A matter of life and death



The number of people writing a will, doing advance care planning, signing an advance medical directive and appointing a Lasting Power of Attorney remains low.

- Between 2011 and 2015, 5,100 advance care plans were completed.
- From 1997 to 2015, 24,682 advance medical directives were made, with about half being signed between 2010 and 2015.
- As of March 2018, 43,000 people have submitted their Lasting Power of Attorney applications.

Source: SINGAPORE DEMOGRAPHIC BULLETINS 2018, IPS, THE BURDEN OF DISEASE IN SINGAPORE, 1990 - 2017 STRAITS TIMES GRAPHICS

ple to seek care at home or in the community, rather than in the hospital, because that's a big reason why so many of us end up dying there." At the same time, the authors noted that families often have a "culture of silence" when it comes to end-of-life issues, making it difficult for the tough conversations about a person's care preferences to take place. For instance, a critically ill person may not want to inform family members of a poor diagnosis in order to avoid upsetting them, or vice versa. Others may have a superstitious aversion to talking about death, or may be reluctant to dampen a loved one's will to live. These cultural and emotional barriers must be tackled in any programme dealing with end-of-life issues, the study's authors said. They also pointed out that there needs to be more awareness of advance care plans and the Lasting Power of Attorney (LPA) scheme, which help a person's family make decisions according to their wishes if they are no longer able to do so. While advance care plans serve as guides to a person's treatment preferences, LPAs are legally binding documents through which one can appoint someone to make decisions for them, should they lose mental capacity. Documentation processes for these and other related services could be merged under a single administrative body, simplifying matters for families, the authors suggested. On a national level, schools, workplaces and even religious organisations can encourage people to start conversations on these issues and normalise them as part of life, they added.

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Madam Tsang Sow Kuen (in red) and Madam Tan Lu See having a game of Rummikub at the Wellness Kampung Senior Activity Centre on Thursday. For the two seniors, making their last wishes known - so their children know what to do when the time comes - is not a topic to shy away from. ST PHOTO: GIN TAY



## Kick-starting talk on death and dying early

Linette Lai and Shabana Begum

Although Madam Tsang Sow Kuen is active, independent and in good shape for her age, the sprightly 80-year-old has already made her final wishes known to her children. "They just need to follow my instructions. It's less complicated that way," said Madam Tsang. Added her friend, 64-year-old Tan Lu See: "Our mothers never talked to us about these things. We had to learn it all ourselves. Now, we tell our children so that they will know what to do." Both took part in a workshop on living and dying well organised by local charity Both Sides, Now, which uses art and drama to kick-start conversations on death and dying. Yesterday, the Institute of Policy Studies (IPS) released a comprehensive report on the end-of-life care policy in Singapore, highlighting

common issues and making recommendations for improvement. These included tackling the problems of costs, family support and the ease of planning and communicating one's last wishes. Dr Ng Wai Chong, chief of clinical affairs at the Tsao Foundation, emphasised that more palliative care funding needs to go towards end-of-life care for frail seniors. At present, most of such funding goes towards conditions with a clear prognosis, such as cancer and organ failure, he said. Frailty in this context refers to a condition in which seniors may experience symptoms such as significant unintended weight loss or have difficulty climbing stairs or walking. "While Tsao Foundation is committed to providing quality end-of-life care to our home-bound frail seniors through our Hua Mei Mobile Clinic, the lack of a sufficient financial incentive may deter other aspir-

ing service providers from starting, or sustaining, their home-based primary care, especially as part of vital long-term care until the very last breath," Dr Ng said. Mr Timothy Liu, chief executive of the Dover Park Hospice, also highlighted the importance of starting the conversation on palliative care earlier - for example, when a person is first diagnosed with a terminal illness rather than when they are referred to a hospice for such care. "It will be a bit late to start the conversation on palliative care when a patient is referred to us, as the patients are quite advanced in their illnesses," he said. In the IPS report, researchers pointed out that families are often averse to bringing up the topic of death and dying for fear of upsetting their loved ones or for superstitious reasons. That might have been the case for her mother's generation, but not for herself, Madam Tan said. "We are not so pantang (Malay for 'superstitious') these days," she said. Madam Tsang was matter-of-fact: "When it's time for you to go, it's time."

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## Key recommendations

**The restrictions under Section 13(8) of the Mental Capacity Act must be emphasised to families.** The law forbids Lasting Power of Attorney-appointed donees, who are most likely the family members, from making decisions about the life-sustaining treatment of a mentally incapacitated loved one. If the patient has not stated his wishes in advance through advance care planning (ACP), for instance, the decision to preserve his life or take him off life support lies with the doctor. ACP facilitators should discuss the Act's restrictions with family members and ask the elderly about their preferences.

**Palliative care providers should involve religious leaders in end-of-life conversations.** Culture and religion influence

each patient's perceptions of death and his final days. Religious institutions could help to design relevant spiritual care programmes for patients in hospices.

**Start the difficult conversations on death and dying.** The Institute of Policy Studies researchers said it is time to normalise end-of-life topics and not shy away from them. These topics can be raised at milestone events such as attaining adulthood, marriage, childbirth and retirement, or while getting life insurance.

**Develop the palliative care sector further, in terms of providing financial incentives and manpower.** The researchers said government medical subsidies are skewed to-

wards treating medical conditions and covering healthcare services, while long-term care services are financed by a small group of voluntary or charitable organisations. Hence, patients choose to die in hospitals rather than at home, since subsidies push people to seek hospitalisation for their long-term care needs. The researchers also said more doctors, allied health professionals and medical specialists should be trained in palliative care.

**Simplify paperwork for family members when they make end-of-life plans.** For instance, the Agency for Integrated Care and the Office of the Public Guardian could work more closely together by merging the documentation processes for ACP and appointing a Lasting Power of Attorney.