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# LEAVING WELL: END-OF-LIFE POLICIES IN SINGAPORE

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## **IPS Exchange Series**

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# **LEAVING WELL: END-OF- LIFE POLICIES IN SINGAPORE**

**YVONNE ARIVALAGAN  
CHRISTOPHER GEE**

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# Executive Summary

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## **EXECUTIVE SUMMARY**

Seventy-seven per cent of Singaporeans wish to die at home, according to a survey by the Lien Foundation in 2014. However, the reality is far from the ideal, with just 24 per cent of deaths occurring at home and close to 70 per cent taking place in hospitals, nursing homes and charitable institutions as of 2017. With over 200,000 Singapore residents currently aged 75 and above and hundreds of thousands of family members having to soon contend with the complex issue that is the end of life, this gap between preferences and reality must be addressed. In addition, as health literacy and awareness regarding care options increase with future generations, Singaporeans' expectations on what constitutes a "good" death will rise and evolve. It is important that Singapore's overall care infrastructure adapts to these changing expectations, so that more people feel supported in their care needs and preferences.

In this report, we consider what is needed to help Singaporeans die well and in accordance to their preferences. We look at ways in which end-of-life care can be better integrated with long-term and primary care services so that patients' needs and preferences are more consistently met throughout their interactions with the healthcare system. We also question the under-resourcing of the palliative care sector in comparison to hospitals and tertiary institutions, and emphasise the need to further support and build the capacities of this sector.



At the same time, we also consider what is needed to help Singaporeans live well, particularly in old age and in the absence of close kin, social and financial resources. Thus, while this report addresses planning for and care at the end of a person's life, it also addresses issues that emerge much earlier in a person's life which can have a downstream impact on the quality of death. Some key issues we consider include the tension between patient autonomy laws and the dynamics of joint decision-making in families in healthcare settings. We also consider ways to strengthen community support for individuals, families, and older persons in particular, as the components of end-of-life and even long-term care are social as much as they are medical in nature. We also identify some features of the healthcare system that may prevent individuals from taking a more proactive approach in their own care plans and consider ways to address this.

This report also identifies what the government, healthcare providers, communities, families and individuals can do to improve the quality of death in Singapore.

**Government agencies** such as the Agency for Integrated Care and the Office of the Public Guardian could work more closely on a number of fronts. They could merge the documentation processes required for services like Advance Care Planning (ACP) and appointing a Lasting Power of Attorney to simply matters for individuals and families. The Agency for Integrated Care and the Office of the Public Guardian



could also train professional deputies under the new Professional Deputies and Donees Scheme to conduct ACP facilitations, particularly for those without close kin. Silver Generation Ambassadors could also be equipped with the skills to introduce the Professional Deputies and Donees scheme to older adults living alone.

**Members of the community and community-centred initiatives** such as the Community Network for Seniors (CNS) could include support for those facing a terminal illness or for families experiencing bereavement. Arts practitioners could be further supported to conduct community events encouraging members of the public to reflect and talk about death. Human resource departments could raise awareness about end-of-life planning in workplaces through talks or workshops and even provide bereavement support for staff members.

Given the importance of culture and spirituality at the end of life, religious organisations should work closely with palliative care providers to raise awareness about ACP and end-of-life planning, and also provide spiritual care at the end of life. Similarly, religious and cultural community leaders could organise discussions with members of their respective communities to draw important cultural concerns about the end-of-life experience and design culturally relevant care programmes.

Schools and universities serve as an important platform to raise awareness among the young about the importance of early ACP, and

prepare future generations for the often complex decision-making processes that arise at the end of life.

**Players in the healthcare system** could trial outcome-driven funding models in long-term care settings so as to better align financial incentives with improved care quality for older persons. The capabilities of the palliative care sector, particularly home and community-based providers must also be enhanced through improving training, remuneration, and working conditions as well as exploring new models of delivering care. A greater pool of healthcare providers, mainly general practitioners, allied health professionals and emergency medical specialists must be trained in palliative care so that more Singaporeans can have access to palliative care should they desire it.

Some initiatives call upon multiple sectors to work together to encourage more Singaporeans to consider early end-of-life planning. Key milestones in a person's life, such as attaining adulthood at age 21, marriage, childbirth, retirement, purchasing life insurance and making funeral preparations for a late loved one serve as opportunities to initiate conversations on end-of-life planning. Institutions such as the Registry of Marriages, the CPF Board, and even industry players like life insurance providers could provide platforms for individuals and family members to begin thinking about their future care plans in non-clinical settings.



Perhaps most importantly, **individuals and families** must recognise the importance of planning early for unplanned future events, such as the diagnosis of terminal illness. This report identifies some institutional and cultural barriers that may make it difficult for individuals and families in making choices and decisions on such emotionally charged matters. It recommends solutions to better prepare and support families in their advance care and end-of-life planning. Critically, laws such as Section 13(8) of the Mental Capacity Act forbid family members from making decisions concerning the life-sustaining treatment of an incapacitated individual. Given the close dynamics of healthcare decision-making among families in Singapore, it is vital that more families are made aware of this restriction so that important conversations are not put off until it is too late.



# Chapter 1

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## Introduction



## INTRODUCTION

With an increase in the number of care options at the end of life and the moral complexities surrounding such healthcare decisions, the time is ripe for us to talk openly about how we wish to live as we grow frailer until death occurs. To this end, this report asks: what are the barriers - social, cultural, psychological, and systemic - that might prevent individuals and their families from having these much-needed conversations? What are the major policy levers that can be used to enhance the current system to support end-of-life preferences with the concomitant trade-offs and create more enabling frameworks and environments for families and society to have open, non-threatening conversations about dying?

**Chapter 2** of this report lays out the major medical, financial and emotional complexities that arise at the end of life. Advancements in medical technology coupled with prolonged, often unpredictable trajectories for prevalent chronic conditions create uncertainties over when the end of life truly begins. The costs of aggressive, potentially life-sustaining treatments can also be substantial for individuals and their families. Disagreements over financial matters and the course of a loved one's treatment are often a source of conflict within families.

These complexities underscore the importance of early advance care planning, where individuals can have open, realistic conversations with their families about their preferred treatment options in the event of a terminal diagnosis. Yet, many families still avoid having these

conversations for a number of reasons including denial, superstition, disagreements over financial matters and the course of treatment, and a desire not to upset a loved one who may be dying.

**Chapter 3** emphasises that the dignity and autonomy of the dying must not be neglected in the midst of these rising complexities. Too often, the wishes and preferences of patients are marginal in their own care plans, which is perhaps a broader reflection of the value that is placed on personhood in complex care settings, particularly of those who are older, frailer and no longer economically productive.

The following sections identify three broad areas where existing ideologies, frameworks, laws and practices could be re-evaluated or improved to better support end-of-life preferences. They also consider ways to better enable families, healthcare providers and society to have meaningful and realistic conversations about death and dying.

**Chapters 4, 5 and 6** identify opportunities for further action at the societal and community level. **Chapter 4** emphasises the importance of building the social capital of older people to ensure their well-being at the end of life. **Chapter 5** considers how Singaporeans can be encouraged and incentivised to adopt a more proactive approach in making decisions about their own healthcare plans. **Chapter 6** considers how culture, religion and spirituality can be better integrated into end-of-life services.



**Chapter 7** looks at the dynamics of joint decision-making in Singaporean families, particularly in medical settings, and considers how patient autonomy can be better preserved in healthcare decision-making.

**Chapter 8** examines how end-of-life care and other healthcare services including primary and long-term care can be better integrated to cater more holistically to a person's needs throughout life and old age in particular.

Important initiatives which have already been undertaken in the key areas outlined above are summarised in **Annexe 1**. Key initiatives include the government's plan to ramp up the capacity of the palliative care sector to 360 beds and 6,000 home palliative care places by 2020, up from 180 beds and 5,150 places respectively in 2015. There has also been an increase in research and training on the application of palliative care to non-cancer illnesses such as end-stage organ failure and dementia. Singapore also has a National Strategy for Palliative Care as well as national guidelines for palliative care which establish local, evidence-based standards for care in this sector. A working group has been established with support from the Singapore Hospice Council and funding from the Health Ministry to ensure the adoption and implementation of the guidelines.

Key initiatives from religious organisations, the arts, social service and philanthropic sectors are also outlined in Annexe 1.



## METHODOLOGY

In August and September 2016, IPS brought together around 100 experts from different sectors for Action Plan Singapore, a series of a scenario-planning workshops to discuss Singapore's future in the year 2026. One of the themes discussed during the workshops was longevity, and the changes needed to devise a whole-of-society approach for successful ageing. Participants identified end-of-life care as an important area that must be planned for as Singapore's population ages rapidly. In particular, participants proposed that a taskforce be appointed with the goal of producing a White Paper to highlight the scale and number of issues to be addressed in the area of end-of-life care and planning.

Following Action Plan, IPS convened a working group of experts to put together a report and series of recommendations on this issue. The working group comprised experts from the healthcare, legal, social work, research and policy planning fields. The working group met three times over a period of 16 months, from August 2017 to April 2019. The authors of this report also sought individual consultations with some members of the working group during this period. The content of this report derives largely from discussions and consultations with working group members.

The insights of the working group were supplemented with secondary research on existing information and data pertaining to end-of-life care in Singapore and around the world.



## Chapter 2

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### Setting the scene



## **SETTING THE SCENE: MEDICAL, FINANCIAL AND EMOTIONAL COMPLEXITIES AT THE END OF LIFE**

### **Medical complexities: Varying illness trajectories**

While life expectancy in Singapore has been rising, data shows that a rising proportion of these added years is being spent in poor health. While a male Singaporean resident is likely to spend the last eight years of his life in ill health, female Singaporeans are expected to spend the last decade of their lives in poor health. This is because the prevalence of age-related illnesses in the population rises in tandem with longer life expectancies. While a minority of the population may age healthily due to a combination of genetic, socio-economic and environmental factors, many others are likely to be increasingly unable to meet their basic needs due to disability, physical and mental illness as they grow older. Principal causes of death in Singapore in 2017 were cancer, pneumonia, ischaemic heart diseases and cerebrovascular diseases including stroke. Most common chronic diseases were diabetes, hypertension and lipid disorders such as high blood cholesterol. About 3 in 4 Singapore residents aged 65 and above are affected by diabetes, high cholesterol or hypertension, or a combination of three (Choo, 2018).

For many afflicted with chronic diseases, death is more likely to follow a long period of deterioration than occur suddenly. To help clinicians plan and deliver appropriate care and give patients and their carers a better understanding of their situation, scholars have categorised



disease trajectories based on timeframe and patterns of probable needs and interactions with health and social services.

Illnesses like cancer involve steady progression over a period of weeks, months or in some cases years, and have a clear terminal phase. Most of the patient's deterioration and impairment of function occurs in their last few months. However, the disease trajectory for other types of patients is typically longer and less predictable. Patients with conditions like heart failure or chronic obstructive pulmonary disease are usually ill for many months or years with occasional acute, often severe exacerbations, with the timing of death remaining uncertain. Those with conditions like Alzheimer's, other dementia, or general frailty are more likely to lose weight and functional capacity over time and then succumb to minor physical events which could prove fatal (Murray et al., 2005).

These varying illness trajectories underscore the importance of curating appropriate care services for patients with chronic health conditions who are surviving longer, but with poor quality of life. They demonstrate that progressive deterioration and death are inevitable, and that the axiom to "cure more than care" may be misdirected in some instances. A more realistic outlook on death could thus reduce unnecessary hospital admissions and aggressive treatments and instead help families and healthcare professionals practically plan for a "good death," with greater focus on quality of life and symptom control.



Family conflict could arise when family members disagree about the rationale and goals of care for a loved one, in particular, if care should be aggressive and life-sustaining, or conservative and palliative. The rising complexity of care needs and services as highlighted in these different illness trajectories hence emphasises the importance of early advance care planning, where individuals are informed about and can note their preferred treatment options in the event of a terminal illness.

### **Financial complexities: Singapore's healthcare financing philosophy and cost considerations at the end of life**

Self-reliance, efficiency and fiscal conservatism are the main philosophies that underpin healthcare delivery and financing in Singapore. While these principles ensure that national healthcare spending is financially sustainable, entrenched anxieties persist among some over rising healthcare costs, especially for aggressive medical treatments for the terminally ill. Those who decline additional medical treatments commonly express the desire not to burden their family members, a sentiment that alludes to the financial and emotional complexities of decision-making at the end of life and again reinforces the value of early advance care planning.

#### ***Healthcare financing philosophy***

Singapore's healthcare system has been lauded internationally for achieving strong outcomes at relatively low cost. Such outcomes are



comparable to or even exceed those of other developed nations, especially considering that total healthcare expenditure in Singapore based on 2016 data was only 4.55 per cent of GDP, versus around 17 per cent in the United States and 10 per cent in the United Kingdom (World Bank, 2019).

This has largely been achieved through a mixed health financing system that emphasises individual and familial responsibility so as to avoid the moral hazards of single-payer healthcare schemes seen elsewhere. Seven out of eight Singaporean residents have medical savings accounts (MediSave) with balances totalling \$88.6 billion in 2017, which may be used to pay for hospitalisation, day surgery and outpatient expenses as well as healthcare needs in old age (Ministry of Health, 2019). Claim limits on services covered under MediShield Life and other cost-sharing measures like co-payments and deductibles help to keep overall healthcare spending low by preventing overconsumption. Government subsidies are also capped at a monthly household income of \$2,600 per capita.

At the same time, to ensure that no Singaporean is denied access to basic healthcare because of affordability issues, public hospitals, polyclinics, and nursing homes are directly subsidised by the government, which foots up to 80 per cent of the total bill in acute public hospital wards. Medifund, an endowment fund to help in-need Singaporeans pay for their medical bills, acts as a safety net for patients who face financial difficulties with their remaining bills after



receiving government subsidies and drawing on other means of payments.

### ***Long-term, palliative and end-of-life care financing system***

Whilst services in the healthcare sector are well-established and supported by financing programmes and schemes as described above, the financing of care in the long-term, palliative and end-of-life care continuum is less well developed. Most of the provision of services at this end of the continuum is informal, provided by families and the community (Gusamo, 2017). Home- and community-based services are provided by a small group of voluntary or charitable organisations that are funded either on an ad hoc, project basis (Phua et al, 2019), or by Ministry of Social and Family Development recurrent and capital funding grants (Ministry of Social and Family Development, 2019).

End-of-life care and dying in a hospital can sometimes be cheaper from an individual's perspective than doing so at home. This is due to perverse financial incentives that push people to seek hospitalisation for their long-term care needs, particularly for middle-income families who are ineligible for government subsidies for long-term care provided to lower-income families (Phua et al., 2019).

### ***Perception of unaffordability***



There thus remains a perception of unaffordability over the costs of care especially towards the end-of-life, best expressed in the view held by some that “it is cheaper to die than fall sick in Singapore.” The elderly poor and an unsubsidised “sandwiched” class of middle-income caregivers of the elderly are among those who may face the most difficulty and anxiety over meeting healthcare costs.

High medical costs, which come in the form of out-of-pocket payments, co-insurance and deductibles, remain prohibitive for some individuals, especially for treating terminal illness in expensive tertiary care settings. An increase in chronic illnesses such as diabetes and high cholesterol, paired with advances in medical technology also mean that there are now more treatments available to prolong life, albeit even for a short period time, at significant cost (Koh, 2015; Soin, 2018). Elderly persons are among those facing the greatest financial burden, as evidenced by estimates from IPS’ National Transfer Accounts study which show that healthcare costs for an 85-year-old are around 10 times that of a 35-year-old.

Due in part to high costs, an estimated one in five patients might decline treatment when they first see an oncologist (Gan, 2018). Some kidney patients have also been found to refuse dialysis treatment, with many citing the costs of treatment, consultations, medication and even transport (Khalik, 2014; Seah et al., 2015).

This is because the risk of catastrophic illnesses is borne by individuals and their families due to limits on government expenditure.





Even with a substantial 90 per cent of a \$100,000 medical bill covered by MediShield Life, the remaining 10 per cent co-payment may still be significant for an elderly person with no income. Furthermore, due to caps on government subsidies, a family of three with a total household income of \$7,803, for instance, would just miss the cut-off for government subsidies and thus represent a sandwiched class of middle-income families who may face financial difficulties in meeting healthcare costs (Ho & Huang, 2018).

Medical costs are a common source of conflict within families, especially when individuals choose to decline treatment to not burden his or her family and family members. Families often put off having conversations about ACP due to this reason. The complexities that arise due to the realities of Singapore's healthcare system and financing philosophies all the more reinforce the necessity of early advance care planning.

### **Emotional Complexities: Some common family scenarios**

End-of-life planning and care can be emotionally challenging as individuals and families find themselves in new and different circumstances. The following are common scenarios experienced by Singapore families dealing with a loved one's terminal diagnosis. Families may not wish to inform a loved one about an advanced diagnosis and may avoid having necessary conversations with them about dying. This scenario can be complicated by several factors. For example, a patient could be ambivalent about the course of care and



leave decision-making to his or her children. On the other hand, a patient may want more control in the decision-making process and is left feeling frustrated when excluded from the conversation. It may also be possible that a patient recognises the severity of his or her condition but says nothing to avoid upsetting family members.

Families may also put off having conversations about ACP because they are too busy to spend time with a loved one until an acute medical event occurs. The often distressing and depressing nature of the event may further delay necessary conversations between family members. Family members' existing belief systems may also complicate this scenario. Some may be superstitious of talking about death or wish not to dampen their loved one's hope or will to live.

As discussed in **Chapter 7** of this report, this culture of silence around end-of-life issues within families can often confound the intent of laws and processes in Singapore that encourage and help individuals make their own decisions on their preferred course of treatment. Section 13(8) of the Mental Capacity Act forbids family members from making decisions concerning the life-sustaining treatment of an incapacitated individual. These restrictions act to avoid possible conflict between a physician's recommendation and family members' wishes that can put the welfare of the patient at risk. Individuals are thus strongly encouraged to state their wishes in an ACP and communicate their wishes to their family members while they still retain decision-making capacity so that physicians can make informed decisions concerning the individual's best interests. The cultural and emotional barriers that

may prevent families from doing so will need to be addressed in future end-of-life policies and programmes.



## **Chapter 3**

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# The value of a life: Care for those no longer economically productive



## **THE VALUE OF A LIFE: CARE FOR THOSE NO LONGER ECONOMICALLY PRODUCTIVE**

The time near the end-of-life can be distressing for families, given the rising medical, technological and financial complexities of caring for a loved one with a terminal diagnosis. As a result, many families put off having these difficult conversations until it is too late. The dignity of the individual, especially a frail older person, can thus often be neglected amidst rushed hospital visits, discussions with healthcare providers out of earshot, and care plans that do not adequately account for their wishes and preferences.

The marginality of older persons' wishes in their own care plans is perhaps a broader reflection of the value that is placed on personhood in complex care settings, particularly of those who are older, frailer and no longer economically productive. Jeremy Lim likened the philosophy underlying Singapore's healthcare system to a regime where the social rights of individuals, including access to high quality care, are linked to productive economic activity (Lim, 2013). The ethos of self-reliance in safeguarding one's own health demonstrates this, with an emphasis on paying for one's healthcare needs through personal savings and contributions accrued from participation in the labour force. This could partly explain why the charitable sector was among the first to provide hospice and palliative care services in the 1980s, with government recognition and funding support only coming in later. Experts have also described the eldercare sector as over-medicalised, with more attention paid to efficiency and safety than seniors' dignity and quality of life.



Can and should this paradigm, which has served Singapore extremely well in the last 50 years, continue to do so for the next 50, in the context of rapid population ageing? As care needs in the population grow more complex while familial support diminishes, access to good care must not depend on a person's financial ability alone, but rather include vital social dimensions of well-being. Greater emphasis must be placed on the unmet social needs of frail older adults, which broadly encompass elements like social connections, emotional and psychological health, and having a sense of control and autonomy over their own lives.

End-of-life care represents an important juncture in re-evaluating the direction Singapore can take regarding the nature of its healthcare system. The road to person-centred, dignified and high quality end-of-life care — and indeed, care in general — requires further reflection on the social aspects of Singapore's care infrastructure, including the relationships that are built and sustained between members of a community and the value accorded to lives that are no longer economically “productive”.



## **Chapter 4**

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# Social and community initiatives



## **DEVELOPING SINGAPORE'S SOCIAL CAPITAL TOWARDS ENSURING WELL-BEING AT THE END OF LIFE**

As Singapore's population ages, it is increasingly important that a person's well-being, dignity and value in the eyes of society are not dependent on their financial ability alone. Where financial capital may be insufficient as a means for some to access the care they need, it is necessary to strengthen alternative levers of support found in the community and wider society. After all, many of the challenges facing Singapore's ageing population today are social, rather than purely economic or medical in nature. Shrinking family sizes and the growing prevalence of loneliness and depression among elderly persons also call for stronger and more innovative solutions for social support structures for the population.

Care for the elderly, including those with a terminal illness, is one area where the social components of care are just as important as the medical. Numerous studies worldwide have demonstrated the impact of strong social networks on a range of health outcomes, including survival and reduced admissions to tertiary care. Many of the social afflictions facing older persons in Singapore, such as isolation, loneliness and bereavement, cannot be addressed in increasing the number of services and professionals, but rather in strengthening community support.

As broadly defined by scholars, social capital consists of two interlinked components: community participation and social cohesion.





Participation, in the form of activities like interacting with friends and neighbours, civic engagement and volunteering, can add positively to feelings of social cohesion, which include factors such as trust, a sense of belonging and norms of reciprocity within a community (Isbel & Berry, 2016). Examples around the world of initiatives to strengthen the social capital of older people in the context of end-of-life care include mobilising community resources, either through naturally occurring social networks or externally facilitated ones, or through the direct support of trained community volunteers. Some projects involve efforts to influence society's perception of and reaction to death and dying, such as through work with schools, businesses or professionals, or offering seed grants to communities to develop work themselves. Others focus on awareness, education and training of community members in topics such as writing a will and advance care planning, or efforts to explore society's perception of the issues through local or national conversations (Sallnow et al., 2016).

## **Recommendations:**

### **4.1. Develop a multi-level database of social network mapping**

Introduced in 2016, the Community Network for Seniors (CNS) programme comprises a large network of VWOs, grassroots and community groups, and government agencies. The CNS connects these groups to seniors who may need a combination of different healthcare and social services. Community volunteers like neighbours and Silver Generation Ambassadors (known as Pioneer Generation



Ambassadors, or PGAs, before the Pioneer Generation Office became part of the Agency for Integrated Care) promote active ageing among healthy seniors, provide emotional support for the seniors who live alone, and refer relevant care providers to frail seniors.

The value of such services could be strengthened through regular social network mapping, whereby all of an individual's major points of contact are recorded at regular intervals, either by PGAs, other volunteers, or by their primary care physicians. By obtaining a snapshot of the people an individual interacts with on any given day, be it neighbours, hawkers or shopkeepers, support networks and services can be more effectively tailored to the individual's daily lived experiences and naturally occurring social ties.

#### **4.2. Include end-of-life support in the CNS programme**

An added service that could be provided through the CNS programme is support for those facing a terminal illness or families experiencing bereavement. Volunteers could be trained to provide basic counselling and guidance to their neighbours on available and relevant end-of-life services. Neighbours and members of a community could be tapped to provide respite support for families caring for a loved one, share practical tips and knowledge to make the caring process easier, and even offer support for basic needs such as helping a stressed or bereaved caregiver with purchasing groceries.



### **4.3. Equip Silver Generation Ambassadors and other volunteers with skills to introduce Professional Deputies and Donees Scheme for those without close kin**

As family sizes continue to shrink, more support will be needed for those without close kin to help them make decisions concerning end-of-life matters. The steps to making a Lasting Power of Attorney, for example, can be arduous for those unaccustomed to legal processes. The Office of the Public Guardian works towards protecting the dignity and interests of individuals who lack mental capacity and are vulnerable as well as encouraging proactive planning for an eventuality of losing one's mental capacity. The Professional Deputies and Donees scheme, launched in September 2018 and administered by the Office of the Public Guardian, allows professional deputies to act for persons who lose mental capacity, in particular elderly singles or childless elderly couples, who may not have family members or close friends to rely on to be their proxy decision-makers. The Public Guardian allows individuals with mental capacity to make a Lasting Power of Attorney to appoint a professional deputy as part of their pre-planning for future contingencies.

However, it is unlikely that many people are aware of this service. To ensure that fewer in-need individuals fall through the cracks, Silver Generation Ambassadors could carry out personalised outreach to seniors and caregivers to introduce the Professional Deputies and Donees scheme and point them to relevant support schemes depending on their needs. With the merging of processes such as the



ACP, Lasting Power of Attorney and Professional Deputies and Donees as outlined in recommendation **5.2**, Silver Generation Ambassadors could play a vital role in connecting people with the appropriate services.

#### **4.4. Support more community-centred options for families and individuals to have end-of-life discussions and advanced care plans**

- ***Arts-based approaches***

The arts is a useful tool to encourage people to think and talk about complex matters such as death and dying. Arts-based community engagement initiatives such as “Both Sides, Now” have been effective in inviting members of the public to express their thoughts about death, both directly and through the medium of art, in safe, non-threatening environments. Increased funding and support to arts organisations and initiatives could be vital in raising awareness about end-of-life issues among larger segments of Singapore’s population and encouraging more people to begin considering the importance and positive impact of early end-of-life planning.

Arts-based communication techniques could also be adopted by professionals and volunteers in both medical settings and within the wider community to conduct conversations on end-of-life matters. Some key techniques include deep listening to better understand a



person's concerns and using relational aesthetics to replicate social circumstances within which an individual can participate and express their thoughts. Artists could even be hired to provide arts-based therapy or communication sessions on end-of-life issues in various sites such as hospitals and hospices, but possibly also in schools, workplaces, religious organisations and community hubs.

- ***Engage human resource departments in providing end-of-life, bereavement support***

Human resource professionals, particularly in large companies, are already well placed to provide support to their colleagues on matters regarding end-of-life care. Policies and practices on employee welfare could be extended to raising awareness about end-of-life planning through talks or other programmes organised in collaboration with relevant care providers. As a first point of contact with the working population, such programmes could create valuable opportunities for working adults to talk about end-of-life care and planning with their own family members. Human resource departments could also provide bereavement support to staff members. This could include allowing temporarily flexible work hours and locations for bereaved employees, offering specific help on selecting care facilities, filling out medical claims or life insurance policies, identifying appropriate support services, and more generally creating an environment where employees feel supported during difficult times.



Healthcare institutions could take the lead on implementing such HR policies and practices, as many healthcare workers deal regularly with common end-of-life concerns, death and bereavement. Studies have shown that a lack of support for staff grief and bereavement can reduce the ability of staff to deliver compassionate and quality care for patients, particularly those in high-mortality settings like hospices, long-term care facilities and intensive care units (ICUs). This could in turn have an adverse impact on staff turnover and morale, the continuity and consistency of care, and client and family satisfaction ([Schulz, 2016](#)).

- ***Other community-centred approaches***

Sections 4 and 5 of this report will delve into other community-centred approaches that can help raise awareness of and support individuals' preferences with regard to end-of-life care.

#### **4.5. Expanding measures for the end-of-life experience**

What we measure is what we value, so the saying goes. Better valuing processes, human relationships and emotions can inform the creation of new tools and methods to improve the end-of-life experience for many people. Studies in the United States have found that measures of outcomes in end-of-life care mostly addressed the domains of quality of life, quality of care and satisfaction, and pain and physical symptoms. Gaps in measuring important domains of end-of-life care included include continuity of care, advance care planning, spirituality,



and caregiver well-being. Examples of measures that have been used in the latter set of domains include the Decision Conflict Scale (DCS), an instrument used for evaluating decision-making processes; a questionnaire assessing families' attitudes, perceptions, and patterns of choice in the management of terminal cancer patients; the Life Closure Scale, developed to measure psychological adaptation in the dying; the Hogan Grief Reaction Checklist (HGRC), a 61-item measure across six constructs (despair, panic behaviour, blame and anger, disorganization, detachment, and personal growth); and the General Functioning Scale of the Family Assessment Device (FAD), a 12-item scale assessing family functioning (Mularski et al., 2007).

Further research into what matters for the dying and their loved ones in the Singapore context, including familial relations and decision-making at the end-of-life, spiritual and other psycho-social needs of the dying, and experiences of grief and bereavement could aid in the development of more appropriate measures to improve the quality of death.

#### **4.6. Support more behavioural, social research into end-of-life care, attitudes in the Singapore context**

Following on from recommendation **3.4**, disciplines such as behavioural psychology, social anthropology and sociology should be used to examine human relations, institutions and, behaviour, particularly in the context of healthcare and end-of-life care. Supporting research in these fields could improve understanding of



the social norms, values and attitudes towards healthcare, including how health, medicine and care systems are perceived by different groups of people, the reasons for these perceptions and even how people define and understand illnesses. Which forms of care do seniors most value? What are the barriers in people's minds with regard to end-of-life planning? How do people perceive death and dying? How can awareness of end-of-life planning be promoted in workplaces, religious sites, schools, and other community settings? Projects to develop Singapore's social capital and improve models of community-centred care could benefit from such knowledge, particularly in designing community care programmes that are relevant to the existing social and cultural environment.

More partnerships could be built between medical, humanities and social science departments in Singapore's universities to equip students with the knowledge of how these disciplines can be brought together to improve the quality of end-of-life care in Singapore. For example, Yale-NUS College and Duke-NUS Medical School currently offer the Yale-NUS and Duke-NUS Liberal Arts and Medicine Pathway for liberal arts students who are planning to pursue a career in medicine. The Pathway was established with the aim of shaping future clinicians who appreciate the interconnectedness of the sciences, social sciences and humanities in medical practice. Similar programmes could be established to prepare for Singapore's future end-of-life care needs.





## **Chapter 5**

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# Proactive public engagement in healthcare



## PROACTIVE PUBLIC ENGAGEMENT IN HEALTHCARE

The approach to healthcare in Singapore today has been described as overly reactive, which poses challenges for encouraging families to be proactive in making advance care plans. Care is usually provided at the later stages of illness, and often in the Accident and Emergency (A&E) units of hospitals. Preventive health screening rates for common ailments such as colorectal cancer and breast cancer are low according to data from [Ministry of Health \(2018\)](#) National Health surveys. Based on the 2016 Health Behaviour Surveillance of Singapore, 78 per cent of Singaporeans aged 40 to 69 years had gone for basic health screening in the past three years for high blood pressure, high blood lipids and diabetes. However, among those who had abnormal screening results, only half followed up to see a doctor. The Ministry of Health further estimates that about a third of diabetics may be unaware that they have the disease ([Khalik, 2017](#)).

This is brought about by several factors, including the prevailing fee-for-service model on which a majority of private general practitioners operate, the skewing of incentives towards the provision of acute, episodic care in expensive tertiary settings, and a relatively weak primary care sector. Fewer than 40 per cent of Singaporeans have a regular family physician (Ministry of Health, 2011), which contributes to underdeveloped long-term doctor-patient relationships. According to Lee et al, (2007), who have identified choice of doctor as one of the key determinants of trust, “doctor-hopping”, which is a common occurrence in Singapore, may undermine the trust that individuals



have in their primary care doctors. The fee-for-service payment model accounts for this in large part, as it does not incentivise physicians to provide health promotion services such as advice and counselling, instead compensating them on patient volume, procedures and prescriptions. This is significant, given that 80 per cent of primary care in Singapore is provided by private medical clinics. In addition, just 55 per cent of chronically ill patients are managed by private general practitioners, with polyclinics tending to the remaining 45 per cent (Khoo et al., 2014). Continuity of care is often lower in a polyclinic setting, as patients are assigned to any doctor available from a common pool of physicians on duty. Yet, the availability of subsidised care in polyclinics make them an affordable option to many Singaporeans, particularly those from lower-income groups (Khoo et al., 2014).

Singaporeans' largely reactive relationship with the healthcare system could also be tied to the degree of choice that some, particularly lower-income groups, the elderly, or those with reduced mental capacity, can exercise in seeking care options. A lack of infrastructure to support a wide range of needs and preferences could further compound the problem of over-reliance, with many leaving important healthcare decisions to their families or care providers.

A study by Chow et al. on the factors influencing choice of seeking treatment found that many patients chose to receive care at polyclinics, which were established by the government to provide affordable, heavily subsidised primary healthcare to the lower-income group,



rather than from a private general practitioner (2012). This was despite the longer waiting times and the availability of financing schemes to subsidise private primary care treatment. Many of these patients were elderly adults, the unemployed, retirees and homemakers who were seeking treatment for chronic diseases. Strict eligibility criteria and means-testing for admission to nursing homes and other care facilities may further restrict the extent to which people feel they can choose their desired healthcare services and thus more heavily rely on the recommendations and directions of their care providers.

The system's success in leading to positive health outcomes for the population may also contribute to the notion that healthcare professionals are in the best position to advise individuals on the most appropriate care options. A paternalistic approach to doctor-patient relationships, where open and amiable discussions about seeking a second opinion or exploring other care options are limited, could erode individual agency in healthcare decision-making.

What are the perhaps unintended consequences of the above factors on patient autonomy, especially in end-of-life planning? Advance Care Planning, for example, often requires that individuals take the first step in initiating a conversation on their future health and personal care desires, be it with their loved ones or healthcare professionals. The same goes for writing wills, appointing a Lasting Power of Attorney and signing an Advance Medical Directive. Despite an uptake in recent years, the numbers of people initiating these processes still



remains low. About 5,100 ACPs were completed between 2011 and 2015. Since its introduction in 1997 to 2015, 24,682 Advance Medical Directives were made, with about half being signed between 2010 and 2015 (National Archives of Singapore, 2016).

As end-of-life planning is in large part a matter of personal responsibility and ownership over one's healthcare needs and preferences, the presently reactive nature of healthcare-seeking in Singapore poses a challenge to efforts promoting early end-of-life conversations. Indeed, advance care planning only makes sense if people feel like they have viable options and the ability to exercise their choices.

## **Recommendations:**

### **5.1. Initiate conversations about end-of-life planning during life's milestone events**

Adopting a whole-of-society approach in promoting awareness about early end-of-life planning could help make more Singaporeans aware of and proactive about making future healthcare plans. In *Living With the End in Mind*, Koh Buck Song suggests that for a national conversation on end-of-life planning to be sustained, it would help to enlist as many individuals, industry players and interest groups as possible to conduct such conversations in their respective circles on a smaller scale (Koh, 2011). One way to do this is by identifying occasions or milestones in a person's life that are conducive to



initiating such conversations. These include attaining adulthood at age 21, marriage, childbirth, retirement, purchasing life insurance, and making funeral preparations for a late loved one. Marriage, for example, symbolises a commitment to another person that encompasses caregiving, providing emotional support, and planning for the future. Many caregivers of the aged are in fact, spouses, and this trend is set to rise if Singapore's fertility rate remains low or dips further. Registering a marriage could hence serve as a natural opportunity to discuss matters like appointing a Lasting Power of Attorney. Institutions such as the Registry of Marriages, and others such as life insurance providers and the CPF Board could provide platforms for individuals and family members to begin thinking about their future care plans in non-clinical settings.

## **5.2. Merge end-of-life support services under single or joint administrative body**

Dismantling possible institutional barriers to starting the end-of-life planning process could encourage more families to initiate this first step. As this process can be complicated, particularly for families who may be unaware of the different schemes and documentation required, it may be beneficial to merge essential services under a single or joint administrative body. Integrating processes such as the ACP and the Lasting Power of Attorney, for example, is a natural way forward given the interconnected nature of both conversations. As the respective administrators of each service, the Agency for Integrated Care (AIC) and the Office of the Public Guardian could link the documentation

processes required for both services. The Professional Deputies and Donees scheme, which was launched in September 2018 under the Office of the Public Guardian and allows professional deputies to act for persons who lose mental capacity, could also be linked to the ACP process for individuals without close kin. Professional deputies could also be trained and empowered to conduct ACP facilitations.

In line with recommendation **5.1**, integrated end-of-life planning services could be offered in a wider variety of sites within the community, and during key milestones of an individual's life.

### **5.3. Provide end-of-life education in schools at post-secondary levels**

Educating students about death is one way to raise awareness among and prepare future generations for the often complex decision-making processes that arise at the end of life. Taiwan's Life Education curriculum could serve as a model for Singapore. It introduces students at the Primary 5 and 6 levels to concepts relating to life and death using illustrated books and discussions in small-group settings. Relatable life experiences involving nature, pets, puberty and grandparents are discussed to instil in students an understanding of the life cycle, birth, growth, ageing and death. High school electives and interdisciplinary courses conducted by universities then delve deeper into issues relating to ethics and spiritual development.



Singapore too can consider life and death education, perhaps at post-secondary levels to encourage greater awareness of the value of life and end-of-life care. As in Taiwan, experiential learning could be included through field trips to hospices, interviews with relatives, and small-group discussions with classmates, so that students gain deeper insights about death beyond the textbook. Interviews with grandparents or other older relatives about their experiences with death or coping strategies, for example, could serve as an opportunity to introduce the subject in families within the context of care and empathy. Such methods further help to normalise death as natural, rather than a failure of modern medicine. This helps to shape perceptions of a “good death”, calling to question the pursuit of life-sustaining medical treatments at the expense of comfort care. Community organisations could also get involved as part of a whole-of-society approach to raising awareness about end-of-life planning, by providing course materials or sites for field visits.





## Chapter 6

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# Multi-culturalism and religious, spiritual care



## **MULTI-CULTURALISM AND RELIGIOUS, SPIRITUAL CARE**

Multi-culturalism has been espoused as a cornerstone of Singapore's identity and founding values since the 1950s and 1960s. Held in equal standing with the principles of meritocracy and secularism, Singapore's multi-cultural ideology celebrates cultural diversity while at the same time opposing any affirmative or discriminatory action against a person on the basis of ethnicity. Care is taken to ensure that no Singaporean receives partial treatment because of their background. Some public leaders have even expressed the hope that Singapore may one day be a "race-blind" society.

Providers of end-of-life care in Singapore are similarly committed to this equality. There is no hospice in Singapore that caters exclusively to any particular ethnic group. While this is undoubtedly an admirable and important principle to abide by, striving towards an absence of ethnic discrimination could also mean neglecting to recognise nuanced cultural traits and differences that may actually be salient to an individual's identity and needs in care settings. Perhaps the solution, as has also been recommended by some expert sociologists and policymakers is not to be a "race-blind", but rather a "race-conscious" society (Ng, 2017).

Numerous studies have demonstrated that culture and religion do in some part affect an individual's perceptions of death, palliative care and decision-making at the end of life (Mazanec & Panke, 2015; Gysels et al., 2012; Steinberg, 2011; Searight and Gafford, 2005).



Research also shows that sensitivity and attentiveness to an individual's cultural background could improve the care that they receive and enhance their quality of life. Care for an individual's spiritual well-being, for example, is gaining recognition as a crucial aspect of the holistic and person-centred care. Providing care that is culturally appropriate and sensitive to the spiritual and religious needs of patients is increasingly being seen as an important part of the work of hospice and palliative care professionals. In fact, maintenance of sensitivity to religious and spiritual beliefs was one of the eight components of good end-of-life care identified among middle-aged and older Singaporeans by Malhotra et al (2012). Doctors in Singapore also acknowledge that the end of life is more than just a medical issue, but a deeply spiritual and religious one as well, as seen in a study by Jacinta Tan and Jacqueline Chin (2011).

In their study on what matters most for end-of-life care across 14 specialised palliative care teams in Ontario, Canada, Mistry et al. (2015) discovered that being free of emotional burden, which included the fear of dying, were considered critical in ensuring a patient's final days were pain-free. Studies have also found that spirituality can enhance the end-of-life experience and even increase resilience to adverse events that may otherwise hasten death (Reid, 2012). These findings echo Dame Cicely Saunders' concept of "total pain", which encompasses the physical, emotional, social, and spiritual dimensions of distress (Richmond, 2005). Physical pain in an individual with terminal illness could conflate with spiritual distress, which could include feelings of severe grief, depression, fear and



meaninglessness (Low, 2017). Medical treatments alone are therefore insufficient in helping patients cope with such feelings. Yet, in Singapore, spiritual care remains an underdeveloped feature of holistic care.

Singapore's multicultural makeup should thus be an important consideration in the development of spiritual care frameworks, given a diversity of religious and spiritual beliefs in the population.

## **Recommendations:**

### **6.1. Involve religious leaders and communities in end-of-life conversations**

Despite the strong religious and spiritual connotations to end-of-life care, there still exists a divide between faith-based organisations and providers of services related to end-of-life planning and care. There is certainly scope for religious leaders and institutions to do more in this space, such as raise awareness among their communities about the importance of early end-of-life planning and provide pastoral care or chaplain services to individuals who may want them. There is also potential for closer collaboration between the two spheres, with religious institutions helping to design relevant spiritual care programmes for patients in hospices, for example. This could go some way towards ensuring that fewer communities are underserved with regard to spiritual care at the end of life.



## **6.2. Develop culturally relevant end-of-life care programmes, designed by communities**

As seen above, culturally relevant care programmes, particularly at the end of life, can improve patient experience and welfare. It is also important that culturally relevant care programmes are not based on and do not reinforce stereotypes about different ethnic groups. Categorical approaches to culture-appropriate care often focus on broad ethnic or religious groups and list traits that characterise each group. However, such approaches could risk dealing in stereotypes, according to Daniel Epner and Walter Baile, who instead propose a newer, cross cultural approach to culturally competent care that focuses on foundational communication skills, awareness of cross-cutting cultural and social issues, and health beliefs that are present in all cultures (Epner & Baile, 2012). Rather than making assumptions of people based on their background, the new approach is premised on patient-centred care and uses communication skills such as empathy and exploration to understand patients' needs, values and preferences. This approach also discourages care providers from using their own cultural norms and lenses to understand or advise a patient. Patients' preferences regarding language used by care providers, physical contact and strategies they employed to cope with their situation were found to be culturally rooted to some extent. At the same time, certain preferences expressed by patients may not necessarily be cultural, but rather practical in view of their circumstances.



Religious and community leaders could organise research and consultations with members of their respective communities to draw out unique or salient cultural concerns about the end-of-life experience. Insights from these consultations could then be shared with palliative care providers through toolkits or discussion forums to better inform the design of culturally relevant care programmes.



## **Chapter 7**

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# Individuals and their families



## **STRIKING A BALANCE BETWEEN PATIENT AUTONOMY AND THE DYNAMICS OF JOINT DECISION-MAKING IN SINGAPOREAN FAMILIES**

As the first line of support in society, the role of families in end-of-life decision-making cannot be overlooked. Government policies actively promote familial ties, with housing grants offered to those who purchase a flat close to their parents and tax reliefs granted to individuals who top-up their parents' CPF accounts. The 1996 Maintenance of Parents Act enforces this principle by holding adult children to account for not financially supporting their aged parents despite having the means to do so. In determining if Medical Endowment Fund subsidies will be granted, an assessment is made of whether a patient and his or her family members have difficulty in meeting healthcare costs. These laws and policies point to the primacy of the family, and the foundational role that family members are expected to have in caring for and supporting the elderly.

The dynamics of joint decision-making in Singaporean families become especially apparent in medical settings, with many families playing a central and often dominant role in the healthcare decisions and plans of their elderly relatives. Studies show that older persons tend to defer healthcare decisions to their relatives, particularly those they depend on for financial support. Relatives have also been found to withhold diagnoses or terminal prognoses from the elderly patients, with healthcare professionals often being asked to facilitate this non-disclosure. Local research on non-disclosure and collusion in





healthcare settings over the last 30 years suggests that this is a prevalent occurrence in Singapore (Krishna & Menon, 2014). The underlying reasons behind acts of non-disclosure and collusion are largely rooted in cultural values and social expectations of an individual's responsibility to care for his or her parents in their old age. Families may do this to protect patients from the responsibility of making hard decisions and losing hope in the face of bad news as well as to maintain their filial obligations to care for their relatives (Tan et al., 2011).

While certainly well-intentioned, such practices are at odds with the Western principles of patient autonomy and self-determination that strongly underpin medical ethics in Singapore. Adult patients have the right to be informed about their medical condition and then make informed treatment decisions with their doctor, including decisions about how much they allow the doctor to tell their family members and how much they wish to involve them in decisions about their care. Besides impeding on the rights of the patient to determine their own care and treatment options, acts of non-disclosure and collusion also put healthcare professionals in a difficult position, both legally and ethically.

Menon et al (2018) posited that this seeming incompatibility between Western-centric principles around patient autonomy and local cultural attitudes towards familial involvement in healthcare decisions may be a reason for mixed perceptions on the value of Advance Care Planning. Many respondents in their study were confused or anxious



about ACP and expected it to be of limited value as family members, rather than patients themselves, were usually the main decision-makers.

A review of the literature as well as our discussions with working group experts including physicians, medical social workers and legal professionals revealed that there are differing views on this matter. Some experts believe that families should be more involved in end-of-life decision-making. However, others are of the view that familial involvement should be kept to a minimum to safeguard the patient's welfare in instances of medical futility or to ensure there is no under-provision of care where a moderate improvement to the patient's condition is possible. These tensions can be a significant barrier to promoting and implementing further end-of-life planning initiatives and hence call for stronger consensus on this matter.

Over time, however, it is likely that prevailing patterns of healthcare decision-making in families will shift and evolve with future generations. Higher educational attainment, knowledge of available care options, together with greater exposure to decision-making in modern medical settings mean that incidents of collusion and non-disclosure may decline among families in the future. The intergenerational differences that play out in today's care environment, largely between the Pioneer Generation and the Baby Boomers, will likely change and make way for new familial dynamics in the coming decades, and bears consideration by healthcare professionals, researchers and policymakers.



## **Recommendations:**

### **7.1. ACP facilitators should emphasise to families the restrictions under Section 13(8) of the Mental Capacity Act**

Reasonably, current laws pertaining to familial involvement in healthcare decision-making tend to err on the side of caution and seek to prevent abuse. Section 13(8) of the 2008 Mental Capacity Act (MCA) forbids an LPA-appointed donee from making decisions concerning life-sustaining treatment or any other treatment to prevent serious deterioration in the health of a mentally incapacitated individual. The doctor must then make these decisions based on the patient's best interests, that is, by weighing all relevant factors and circumstances to arrive at an outcome that maximally promotes the welfare of the patient (Chan, 2011).

Given that many older patients defer healthcare decision-making to their family members, it is vital that ACP facilitators discuss the restrictions under Section 13(8) of the MCA during the ACP process and seek clarification from individuals regarding their preferences on this matter. This point could serve as a strong impetus for individuals to more clearly recognise and exercise their right to decide on their own course of treatment, and thereby become a critical reason to make an ACP to begin with. As long as individuals state their preferences in their ACP, even if it is for family members to ultimately make decisions on their behalf, this could at least provide physicians with greater assurance that they are acting according to the patient's



best interests. However, further consensus must be built among experts on this issue.



## Chapter 8

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# Shared responsibilities



## **SHARED RESPONSIBILITY ACROSS CARE SYSTEM TO INTEGRATE END-OF-LIFE, LONG-TERM CARE AND OTHER CRITICAL HEALTH SERVICES**

Experts have recommended that holistic care and person-centeredness, which are strongly advocated in end-of-life care, should also be applied throughout an individual's interactions with the healthcare system and not just at the final phase of his or her life. For this to work, however, there must be a greater alignment of responsibilities and goals between the different stakeholders at each stage of an individual's life journey.

As noted by Koh Buck Song in *Living With the End in Mind*, when the dominant medical culture is to “cure more than care,” particularly in situations where cure may no longer be possible, futile treatments begin to take precedence over patients' comfort (Koh, 2011). Advances in and the availability of new medical technologies may be also contributing to the rise of a death-denying culture, which could alter patients' perceptions of the value of palliative care. Curing and caring could appear incompatible, especially in an environment where healthcare professionals are under constant pressure to meet treatment targets.

At present, doctors in Singapore are required to refer patients to palliative care providers in order for them to receive this form of care. Doctors and nurses surveyed in the Lien Foundation's “Life Before Death” report identified late referrals as one of the weaknesses in the



current healthcare system's ability to support the terminally ill or dying (Lien Foundation, 2015). In 2017, 63 per cent of deaths took place in hospitals, 24 per cent occurred at home, and a further 6 per cent in nursing homes and charitable institutions ([Registry of Births and Deaths, 2017](#)). Besides patients' or family members' preferences for continued treatment, these statistics could also point to a certain reluctance, hesitation, or even feelings of inadequacy and clinical incapability among healthcare professionals to acknowledge when a patient is dying.

An arbitrary and unhelpful distinction between general healthcare and end-of-life care thus emerges. Studies have found that what patients value most at the end of life are physical comfort, pain management, having their wishes honoured and respected, maintaining control over their care decisions and being cared for by a trustworthy doctor, among others (Mistry et al., 2015; Malhotra et al., 2012). Should these needs not be valued and met throughout a person's interaction with the healthcare system over the course of his or her life? Such preferences require care that is person-centred rather than disease- or symptom-specific. They call for a greater, multifactorial focus on the social, emotional, psychological and spiritual aspects of care in addition to the medical. At the moment, such an interdisciplinary and holistic approach to care is lacking, emerging as a priority only towards the end of a person's life.

Shared responsibility across the care system is hence needed to bridging the gap between palliative and other forms of care and in



creating the conditions for good end-of-life care and planning. A holistic model of care that emphasises health promotion and disease prevention and caters to an individual's total health needs is expected to be more cost-effective and lead to improved clinical outcomes. These benefits also extend to care at the end of life, ideally when a dedicated family physician is able to counsel individuals on the best treatment options available that are suited to their needs, while also considering their financial, personal and other circumstances.

## **Recommendations:**

### **8.1. Shift to an outcome-driven approach for long-term care financing by trialling capitation payment model**

How can financial incentives be better aligned with the goal of increased quality of care? One solution that has been mooted by a number of experts is revamping the financing model used for managing patients with chronic diseases, by shifting from the current fee-for-service model towards a capitation model. The latter is a system where doctors are paid a guaranteed sum per patient for a defined total population. Dr Jeremy Lim of global consultancy Oliver Wyman, and author of *Myth Or Magic: The Singapore Healthcare System*, recommends this model for three reasons (Lim, 2015). First, the assured income could enable doctors to invest time and resources to proactively care for patients and enable patients to understand their conditions better, which could result in overall better care and lower costs. Second, the perverse incentive to pursue more patients with





shorter consultation periods under the fee-for-service model is removed, and patients can receive the level of care they need. Third, capitation systems create new incentives for doctors, through targets such as good blood pressure control and reduced hospital visits.

Long-term care facilities could serve as ideal sites to trial capitated financing systems. As many of the illnesses facing older people today are chronic and often follow long and unpredictable trajectories, capitated financing models are better suited for tending to the variety and changes in patient's needs as their conditions progress. Capitated financing allows for greater continuity of care, stronger doctor-patient relationships, and adjustments in services and care plans to accommodate increasing disability, multiple co-morbidities and recurring complications (Lynn et al., 1998). Adverse selection problems could also be better managed in long-term care settings as care recipients represent sub-groups of the population with better-known risk characteristics than the general population. Better attention to long-term care needs could also reduce the need for acute care services.

The benefit package to long-term care recipients could also be expanded to include end-of-life care services, such as quality of life and symptom management, and provision of family counselling and support. By enabling the provision of palliative care alongside curative treatment, capitated financing models could further dispel the notion that palliative care is relevant only to the last week of a person's life.



## **8.2. Enhance palliative care training for general practitioners, allied health professionals and emergency medical specialists**

Furthermore, close to two-thirds of deaths in Singapore take place in hospitals, which suggests that the majority of medical professionals dealing with end-of-life care are not palliative specialists. As A&E services are often the first ports of call for many frail and socially isolated seniors, emergency medical specialists are an important target group for palliative care training.

General practitioners, family physicians and allied health professionals that are able to care for patients in their homes or in the community are another key target group for palliative care training. This is in line with the government's objective of promoting ageing-in-place and community-centred care. It is also an important step towards re-orienting the "cure more than care" approach and prioritising patient preference and comfort over futile, aggressive hospital treatments.

While recent years have seen a greater emphasis on research and training in this area (see Annexe 1), more can still be done to equip a wider pool of healthcare professionals with the skills needed to provide patients with a comfortable end-of-life experience.

Training more healthcare professionals in palliative care could also ensure that patients with long-term chronic conditions and less predictable prognoses have access to palliative care too. Palliative



care has historically been focused on individuals with incurable cancer, a factor that strongly associates the service with the terminally ill and dying. However, rising numbers of people with other chronic conditions demand that palliative services be appropriately tailored to a growing diversity of care needs, and furthermore, that patients with less predictable prognoses are not neglected by palliative care providers. Some scholars have even argued that access to palliative care should be on the basis of need rather than diagnosis (Whitehouse, 1995; Addington-Hall et al., 1998; Traue & Ross, 2005).

Dementia, for instance, is a progressive, lifelong illness that is accompanied by widespread impairment of mental function which may include memory loss, language impairment, disorientation, personality change, difficulties with activities of daily living, self-neglect and psychiatric syndromes. Patients with dementia may also experience greater difficulties in, and are therefore less likely to make advance care plans (Harris, 2007). With one in 10 Singaporeans over the age of 60 diagnosed with dementia, tailoring advance care plans and palliative care programmes for those with this lifelong condition must be a priority for the healthcare system.

### **8.3 Strengthen palliative care capabilities in community, broaden networks of home nurses and other allied health professionals to deliver palliative care in the community**



Data shows that most people prefer to die at home and that there is a need to boost the palliative care capabilities of the community care sector to reduce pressures on acute care facilities in hospitals. However, home and community-based providers of palliative care services, including community hospitals, nursing homes and home care services, face severe manpower shortages that limit their ability to provide the services required and preferred by a growing portion of the population. More needs to be done to improve training, remuneration, and working conditions in home and community care as well as explore new models of delivering care.

In addition, many allied health professionals including medical social workers, clinical psychologists and therapists are attached to hospitals and major healthcare centres as their primary location. Locating them and enabling them to form teams in the community could more firmly secure their roles as focal points for care needs in the community. Due to round-the-clock obligations common in the home and community care sector, the supporting infrastructure around allied health professionals in the community could be further boosted through partnerships with general practitioners and volunteers to ensure manageable workloads and access to respite. It is important to lift the resourcing levels of the long-term and palliative care sectors to achieve parity with the rest of the care continuum.



#### **8.4. Widen use of electronic health records to include Advance Care Plans, and link different electronic record systems so that all involved in care can access care information.**

Electronic health records potentially serve as a useful tool for establishing links between different care needs and providers. Swift access to a record of an individual's advance care plan, for example, could enhance the care they receive and ensure it is consistent with their personal care goals and preferences. It also stands to be improve coordination between different care providers across the continuum of care, strengthen the capabilities of community-and home-based care providers and allow the public to readily access the information they need to make sound healthcare decisions. Seniors who live alone or who lack close social networks could be better reached and cared for appropriately, and not just when emergency strikes. Healthcare providers would be able to access a more comprehensive picture of the patient's medical history and bring about the best outcomes for patients in a more efficient and holistic manner. Physicians could be better equipped to tailor their treatments with information on patients' past conditions and histories. This also makes it easier to outline future care plans, without having to go through the primary care coordinator on every occasion.

Uploading one's Advanced Care Plan onto an electronic health record system also requires some comfort with data sharing. What are Singaporeans' attitudes on sharing their medical records, not just with family members, but with the public? While there are clear benefits to



data sharing, particularly as care needs grow in complexity, it is also important to generate more public feedback and policy discourse on issues of data privacy, security, ownership and liability.



# Chapter 9

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## Next steps



## **NEXT STEPS**

We recommend further research and discussion on several issues identified in this report.

First, the funding models around palliative care need to be re-evaluated, particularly as care in the home and community is emphasised over hospital care. Currently, home and community-centred palliative care services are largely provided by voluntary and charitable organisations, which are mainly funded through donations and government subventions. To keep the costs of inpatient and day hospice care affordable, subsidies are made available via means-testing and patients can use their MediSave funds. Home palliative care is provided by voluntary work organisations for free, and financed ultimately via a combination of donations and government grants.

As demand for palliative care services rises in the coming years, it will become increasingly important to ensure that palliative care providers in the community are better resourced, particularly in terms of manpower and training. Further discussion is needed on possible tensions regarding the funding of palliative care services, particularly if they should continue to be provided by charities or operate based on a bundled payment or group funding model. Can and should some palliative care services be provided for free or is society prepared to introduce co-payments for the service as with other healthcare services?



Second, further discussion needs to take place regarding the viability of the restrictions under Section 13(8) of the Mental Capacity Act, which presently do not allow family members to make decisions concerning the life-sustaining treatment of a patient. Given many older persons' preferences to defer to their family members to make healthcare decisions on their behalf, is there scope to liberalise this law and create provisions to include family members in critical healthcare decisions, especially if this is what the patient wants?

Third, in order for Advance Care Plans to be uploaded onto a national electronic health record system, Singaporeans must first accept the notion of sharing their personal data. The recent SingHealth cyber-attack as well as the passing of the Personal Data Protection Act (PDPA) in 2017 have reasonably raised concerns about the safety of a national e-records system. Medical professionals have said they want greater reassurances of the steps that will be taken to avert security breaches in the future. Some doctors have suggested the patients be given the choice to opt out of sharing any information they deem too sensitive or private (Wong, 2018). Further discussion and consensus-building among members of the public, the government and healthcare professionals regarding Singapore's preparedness to shift to an e-records system is therefore an important next step.

Lastly, we believe there is scope to develop some of the recommendations outlined in this report into actionable programmes or pilots. Recommendation **4.2**, for example, calls for the inclusion of end-of-life support services into the already existing and operational



CNS programme. Recommendation **4.3** identifies key professionals — human resource professionals and arts practitioners — who can carry out work in their respective fields to enhance awareness and support around end-of-life issues. Recommendation **5.3** calls for educators at the post-secondary levels to incorporate end-of-life issues into their lesson plans using Taiwan’s death education programme as a guiding blueprint. Recommendations **6.1** and **6.2** encourage cultural and religious leaders to generate discussions around what matters to the different ethnic communities in Singapore with regard to end-of-life care so as to improve the quality of care for different communities.



## **Annex 1**

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### **End-of-life care in Singapore**



## **END-OF-LIFE CARE IN SINGAPORE**

In this section, we highlight some of the major initiatives that are already in place to better support and facilitate end-of-life planning and care in Singapore.

### **Palliative and Hospice Care**

The modern hospice movement began in Singapore in the mid-1980s, when a group of Catholic nuns at the St Joseph's Home set aside 16 beds to take care of dying patients. Prior to this time, hospice and palliative care in Singapore was still associated with "death houses" or funeral homes in Chinatown that came into existence in the late 1800s, where people nearing death were left to die (Wright et al., 2010). The island's first team of home hospice care volunteers was set up under the Hospice Care Group in 1987, which later formed the Hospice Care Association in 1989 as an independent charity. The late 1980s and early 1990s saw a rise in the number of charities providing end-of-life care services, with hospital-based palliative care entering the mix in 1996, in the Geriatric Medicine Department of Tan Tock Seng Hospital. Today, palliative care is available in all government acute care hospitals and community hospitals in Singapore and is also provided by a number of VWOs.

In 2015, there were about 180 inpatient palliative care beds and 5,150 home palliative care places in Singapore. MOH has said it will ramp up capacity to 360 beds and 6,000 home palliative care places by

2020. Out of more than 5,000 medical specialists in Singapore in 2016, 28 were palliative care specialists (Singapore Medical Council, 2016). Estimated charges for inpatients hospice care before means-testing are around \$7,000 a month (Healthhub, n.d.) Home hospice care is available for free, made possible through grants from the Health Ministry, the National Council of Social Services (NCSS) and through donations from foundations, corporate sponsors, and members of the public.

### ***Palliative care for non-cancer illnesses***

Recent years have seen an increase in research and training on the application of palliative care to non-cancer illnesses such as end-stage organ failure and dementia. In October 2017, [Dover Park Hospice](#), [Nanyang Technological University \(NTU\) Lee Kong Chian School of Medicine](#) and the [National Healthcare Group \(NHG\)](#) set up The Palliative Care Centre for Excellence in Research and Education, or PaIC. PaIC aims to develop and provide quality, evidence-based training and education programmes to build capabilities and networks among healthcare professionals and volunteers, so they may competently support patients at the end-of-life. PaIC offers courses and talks to care providers and supports research on end-of-life issues.

Hospices in Singapore have also begun to provide palliative care services for patients with conditions such as dementia and end-stage organ failure. Programme DIGNITY, for example, is a collaboration



between Dover Park Hospice and Tan Tock Seng Hospital to provide palliative home care for patients with advanced dementia.

### ***Advance care planning***

Advance Care Planning, a documented process that enables patients to discuss future healthcare plans with family members, healthcare professionals and trained facilitators, was piloted in Tan Tock Seng Hospital in 2009. Two years later, the Ministry of Health appointed the Agency for Integrated Care (AIC) to oversee and coordinate the implementation of a national ACP programme with public hospitals and community care providers. This national ACP programme, Living Matters, is adapted from the Respecting Choices programme at the Gunderson Health System in Wisconsin, USA. Respecting Choices is an internationally recognised, person-centred model of ACP, which is also used as a guiding framework to train care workers in Singapore.

Through ACP, individuals are able share their personal values and beliefs with their loved ones and healthcare providers and explore how these values and beliefs may influence their healthcare preferences during difficult medical situations. ACP facilitation is offered by multiple hospitals, nursing homes, hospices, community hospitals, home medical care teams and designated ACP clinics throughout Singapore. Appointments must be made in advance. Charges of around \$30 to \$50 apply for some clinics while others provide ACP facilitation for free. About 5,100 ACP plans were completed between 2011 and 2015 (National Archives of Singapore, 2016). Offering free

or subsidised ACP facilitation services in non-medical settings in the community could further improve the public's accessibility to such services.

One of the key legal matters discussed during ACP facilitation is the Lasting Power of Attorney. The latter legally designates a healthcare proxy who would make decisions on the healthcare of the individual in the event the individual is unable to do so. As of March 2018, 43,000 people have submitted their Lasting Power of Attorney applications to the Office of the Public Guardian (Tan, 2018). To encourage more Singaporeans to initiate this process, the Office of the Public Guardian has waived the application fee of \$75 until 31 August 2020.

### ***Mental Capacity Act***

The Mental Capacity Act, enacted in 2008, provides important clarifications and institutions in respect of individuals who lose decision-making capacity and experience a decline in physical and mental functions. The MCA enables a donee to make decisions on behalf of an individual who lacks mental capacity, further stressing that the donee must account for the incapacitated patient's past and present wishes and feelings as well as their values and beliefs according to the "best interests" standard (Singapore Statutes Online, 2019).

In March 2016, the Mental Capacity (Amendment) Bill was passed in Parliament to better protect those who lack mental capacity. One of



the key amendments was the introduction of professional deputies to serve individuals, in particular elderly singles or childless elderly couples, with modest to significant assets, and who may not have family members or close friends to rely on to be their proxy decision-makers. This is in support of an emerging trend seen in Singapore that is characterised by rising rates of singlehood and childlessness and shrinking family sizes.

In September 2018, the Mental Capacity (Registration of Professional Deputies) Regulations came into effect. Under this scheme, professionals from selected professional groups (i.e., lawyers, doctors, accountants, allied health professionals, nurses and social workers) who are registered with the Public Guardian can be appointed by the Court to act for individuals who have lost mental capacity. Individuals with mental capacity can choose to make a Lasting Power of Attorney to appoint a professional deputy acting as donee, as part of their pre-planning for future contingencies.

### ***National Strategy and Guidelines for Palliative Care***

In 2011, the Lien Centre for Palliative Care and Duke-NUS Graduate Medical School published the Report on the National Strategy for Palliative Care. In recognition of the growing number of people in Singapore who will require palliative care, the report outlines 10 goals, each with a set of recommendations. These include better identifying and assessing the needs of patients with terminal illness or complex needs who may need palliative care; delivering palliative care in a



coordinated manner that ensures continuity of care across settings and over time; ensuring that palliative care is affordable to all who need it; ensuring that there is adequate capacity and trained staff to meet the palliative care needs of patients; and establishing local evidence-based standards of care.

In 2015, the Standards Development Subgroup of the National Strategy for Palliative Care Implementation Taskforce published the National Guidelines for Palliative Care. The guidelines were developed in fulfilment of one of the goals of the National Strategy for Palliative Care, which was to establish local, evidence-based standards for palliative care. Included in the report are thirteen guidelines, each accompanied by a set of specific, measurable indicators and tools, methods or resources useful in implementing the guideline. Examples include conducting holistic assessments of patients approaching the end-of-life through symptom and spiritual assessment tools, and supporting caregivers of patients with terminal illnesses by equipping them with strategies for self-care outlined in caregivers' handbooks and online resources (National Strategy for Palliative Care Implementation Taskforce, 2015).

A working group was established in 2017 with support from the Singapore Hospice Council and funding from the Health Ministry to ensure the adoption and implementation of the guidelines. The two agencies have embarked on a quality improvement project to plug existing gaps and seek to upskill providers to meet the national guidelines.



## **Efforts From Religious Organisations**

### ***Palliative care: An Islamic perspective***

In June 2017, the Safinah Institute, a Singapore-based Islamic educational institute organised a talk on the common hurdles faced by families in palliative care, including elements of psychological and spiritual insights (Safinah, n.d.).

### ***Combined meeting with Professor John Wyatt and the Christian Medical and Dental Fellowship***

This meeting was held in October 2016 at the Clinical Research Centre in the National University of Singapore and was attended by more than a hundred healthcare workers, doctors, nurses and church members. Professor John Wyatt, Emeritus Professor of Neonatal Paediatrics at University College London, was invited to discuss the issue of ethical dilemmas in end-of-life issues and care. Some topics discussed included assisted suicide, palliative care, and dying in a technological healthcare system.

### ***End-of-life forum***

Hosted by the Catholic Medical Guild of Singapore in 2016, this forum was intended for participants to seek answers to end-of-life issues from a Catholic perspective, as well as to encourage general

discussion about end-of-life care in an informed manner. The speakers invited were Catholic Theologian Rev. Father David Garcia and Palliative physician Dr Ong Yew Jin.

### ***Death and dying: Some medical and ethical aspects***

Death and Dying: Some Medical and Ethical Aspects is a statement given by Dr Chew Chin Hen at the Family Life Ministry Forum on “The Christian’s Perspective on Dying” held in October 2005. It aimed to reconcile the Christian view of the sanctity of life with the concept of death with dignity, particularly in a time when medical technology is able to sustain essential functions in the final stages of terminal illness (Chew, 2005).

### **Efforts from the Arts/Creative Sector**

Since 2013, ArtsWok Collaborative and Drama Box, co-presenters with the Lien Foundation and the Ang Chin Moh Foundation, have been running “Both Sides, Now”, a community engagement project about what it means to live and die well. The project employs short films, puppetry shows, forum theatre, installations and participatory artworks to encourage visitors to reflect on their hopes and fears about living and dying, to have such conversations with loved ones and to take practical steps to make advance care plans. “Both Sides, Now” has reached communities in neighbourhoods like Chong Pang, Khatib, Toa Payoh and Telok Blangah. They have more recently embarked on a multi-year presence in Chong Pang and Telok Blangah to engage



the communities there on a deeper level over a longer time frame. The goal is to strengthen social ties and motivate sustainable involvement among community members to support one another in making informed decisions about end-of-life plans.

A 2016 impact evaluation study of “Both Sides, Now” identified the community engagement event’s successes in Khatib and Toa Payoh in 2014 as well as areas for improvement (Wales & Rajendran, 2016). The study found that the event was able to attract a diverse audience in terms of both age and culture and create a safe space for audience members to confront difficult issues and share their thoughts. The art styles used also made the art highly accessible and relevant to members of the public. The event further demonstrated the value of the arts as a form of communication that invited people to reflect and express themselves in real and abstract ways about complex topics like death. Participants were also able to choose the kinds of knowledge they wished to acquire, avoid, or pass on to others. The event’s role as a site of informal learning was hence found to generate valuable pedagogical resources.

The study noted that skilled artists are integral to the continuation of arts events such as “Both Sides, Now”, and highlighted the need for a larger budget to employ and train more artists. As the languages used during the event were predominantly English and Mandarin, there was a concern that audience members who did not speak these languages were disadvantaged. The organisers and audience members also emphasised the importance of follow-up activities, particularly for

seniors who are fairly isolated, to keep discussions on death and dying sustained after the event and to help participants manage the emotional nature of its content. Some recommended training staff members at senior centres to handle end-of-life issues.

### **Efforts From the Social Service and Philanthropic Sector**

In addition to “Both Sides, Now” the Lien Foundation has commissioned and organised numerous community initiatives and studies on death and dying in Singapore. Their “Life before Death” campaign, rolled out in 2006, has sought to break the culture of silence surrounding death in Singapore through documentaries, live performances, art installations, photo exhibitions and creative design competitions.

The Lien Foundation has also commissioned several studies on end-of-life care. *Living With the End in Mind* is a study on how to increase the quality of death in Singapore based on the perspectives of 30 leaders in the local end-of-life space.

The Quality of Death Index, a report by the Economist Intelligence Unit, ranked 80 countries based on the affordability and quality of care, community engagement, human resources and the palliative and healthcare environment. Singapore was ranked 12th in the Quality of Death Index.

### ***Good Death Project***



The Good Death Project began as a social work initiative under Montfort Care, a community-based social service provider. The project was piloted in 2016 and promotes early end-of-life planning. Good Death aims to abolish the taboo surrounding death and envisions a death-friendly community that is open to holding conversations about living and dying well. Montfort Care also conducts Death Education workshops that encourage participants to speak freely about death and dying and is working with community stakeholders to promote early end-of-life planning.



## **Annexe 2**

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Leaving Well: End-of-Life Policies in Singapore

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## **Annexe 3**

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# List of contributors and acknowledgements



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