

A close-up, artistic photograph of an hourglass. The top bulb is filled with a vibrant teal liquid, which is dripping into the narrow neck. The bottom bulb is partially filled with a lighter, clear liquid. The lighting creates sharp reflections and highlights on the glass surfaces.

LIVING WITH THE
END IN MIND

A STUDY OF HOW TO INCREASE THE
QUALITY OF DEATH IN SINGAPORE

PERSPECTIVES OF 30 LEADERS

by Koh Buck Song

*“Show me the manner in which a nation cares for its dead
and I will measure with mathematical exactness
the tender mercies of its people,
their respect for the laws of the land
and their loyalty to high ideals.”*

Sir William Gladstone
(1809-1898)

Four times Liberal Prime Minister of Britain

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A NEW BEGINNING:

BETTER QUALITY OF DEATH, HIGHER QUALITY OF LIFE

WHY SINGAPORE MUST DO MORE FOR END-OF-LIFE CARE

As a nation, Singapore is at times seemingly relentless in striving to improve its quality of life. Now, it must do more to enhance its quality of death. As the country advances further to First World status, in some areas, serious deficiencies have opened up, fresh fissures stretched further by driving forces such as a rapidly silver-haired population, fewer babies, and smaller nuclear families downsizing to the limit: individuals living out the rest of their days alone. How to raise the quality of end-of-life care—so as to raise the quality of life itself—is more urgent a question than ever.

This study, commissioned by the Lien Foundation in Singapore, places the spotlight squarely on a subject whose importance can only expand. The project's ultimate end in mind is to achieve greater widespread public and professional awareness, and to garner support for all relevant ways to enhance the environment for quality palliative and end-of-life care, from the home to hospice and hospital

A GREYING SINGAPORE: BY 2030:

- Singapore's resident population aged 65 and above is projected to triple from 300,000 today to 900,000
- Coupled with a declining birth rate, one in five residents will be aged 65 and above, compared to one in 11 today.

Sources: Committee on Ageing Issues: Report on the Ageing Population, Ministry of Community Development, Youth and Sports 2006, and Population Trends 2009, Department of Statistics

systems, and everything else in between, that can help facilitate a good death, for a better life.

To get there, some major proposals are surfaced in this report. Everyone in Singapore should start talking, and thinking, about the quality of death. Policy-makers need to see the value of end-of-life care (as opposed

to expensive acute medical care) and work together on a new national strategy. A revamp of the incentive scheme, that currently discourages doctors' attention on the palliative aspects of healthcare, is long overdue. Doctors, nurses and all healthcare practitioners must be trained differently. Cultural attitudes towards death must be better understood and addressed. Hospices can be helped to become more sustainable both for inpatient and home care. More support can be given to community care facilities to enhance care in the neighbourhood, and to families to provide better end-of-life care at home. Individuals can be encouraged to readjust their outlook and priorities, and live life anew.

In July 2010, a global Quality of Death Index was released, the result of commissioned research by the Lien Foundation and conducted internationally by the Economist Intelligence Unit (EIU)¹. Out of 40 countries surveyed, Singapore ranks mid-table at 18th on overall score. The tiny, modern city-state, with its sleek infrastructure and industrious focus on hardware and credentials, fares best at 11th place on quality of end-of-life care, a factor

with 40 per cent weightage. It ranks 16th on availability of care (25 per cent weightage), and on cost of care (15 per cent weightage) the ideologically anti-welfarist Republic drops to 20th position. But on basic end-of-life healthcare environment (20 per cent weightage), it falls even further to 30th place, just above the bottom 10 nations.

This study complements the earlier EIU international ranking with an in-depth examination of deeper key issues in Singapore and what can be done. Here is a synthesis of the perspectives of 30 doers and thinkers in the space of end-of-life care in Singapore. Their views are aggregated into the main text of this report in "Chatham House"² style, without specific viewpoints being attributed. Strengths and weaknesses, opportunities and threats of the landscape and total environment for end-of-life care are examined in all its facets—national strategy, public policy, health budget, medical education and practice, nursing, civil society, law, relevant industry sectors, community, social norms, philosophy, psychology, culture, religion and spirituality, ageing and ageism, family relationships,

emotional well-being and outlook on life. Required paradigm shifts are outlined. A wish list for the future is collated. Options for deeper analysis, appreciation, adjustment and advancement are surfaced, as much to aim to elevate policy as to empathise with psychology, enhance practice and eradicate prejudice. It is hoped that, in fostering a fuller, more integrated consideration of life's end, this study will mark very much a new beginning.

A NOTE ON DEFINITIONS:

"Palliative care" is defined by the World Health Organisation as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."³ "End-of-life care" includes palliative care but also covers social, legal and spiritual aspects of care. "Hospice care" refers to care in specialist institutions.

1 See the Lien Foundation-Economist Intelligence Unit survey website at www.qualityofdeath.org

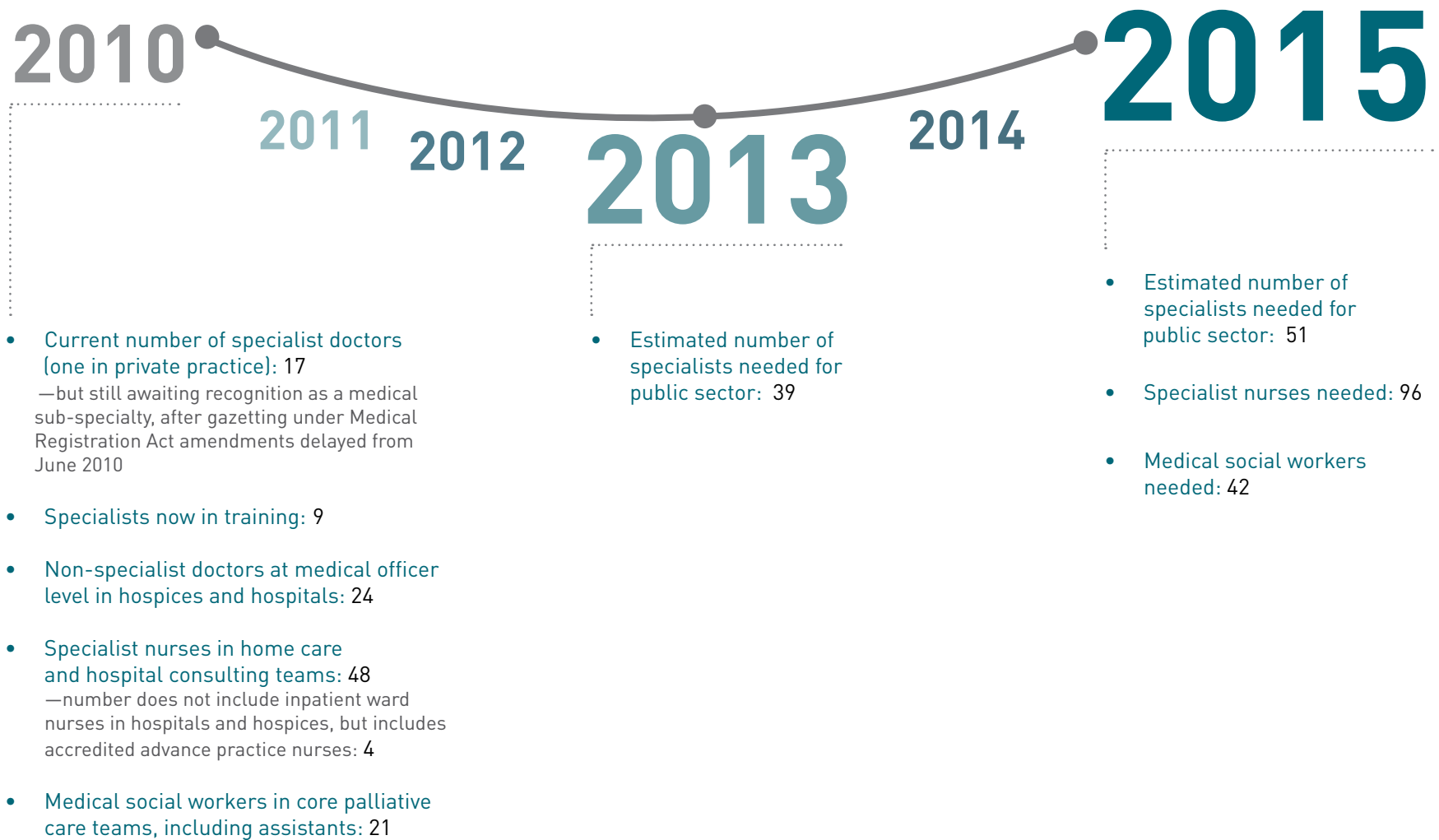
2 "Chatham House rules" allow individual speakers to express their most candid views in their own capacity rather than as official representatives of their organisations.

3 See the World Health Organisation website at www.who.int/cancer/palliative/definition/en/

PALLIATIVE CARE SNAPSHOT

POPULATION	4.839M	HOSPICE DAY CARE SERVICES	2
TOTAL DEATHS	17, 222	NEW ADMISSIONS FOR DAY CARE PER YEAR	211
TOP CAUSES OF DEATH:		AVERAGE PATIENTS ATTENDING DAY CARE PER DAY	52
CANCER	29.3%	% NON-CANCER HOSPICE DAY CARE PATIENTS	10.4%
ISCHAEMIC HEART DISEASE	20.1%		
CHARITIES PROVIDING COMMUNITY HOSPICE SERVICES	8	RESTRUCTURED HOSPITALS WITH PALLIATIVE CARE SERVICES	5
HOSPICE HOME CARE SERVICES	6	NEW REFERRALS FOR HOSPITAL INPATIENT PALLIATIVE CARE	3,758
NEW HOME CARE REFERRALS	3, 595	HOSPITAL ADMISSIONS INVOLVING PALLIATIVE CARE	5,834
PATIENTS UNDER HOME CARE AT ANY TIME	1, 030	% NON-CANCER HOSPITAL PALLIATIVE CARE CASES	23.4%
% NON-CANCER HOSPICE HOME CARE PATIENTS	13.5%		
IN-PATIENT HOSPICES	4	ESTIMATED COVERAGE BY COMMUNITY HOSPICE SERVICES:	
COMMUNITY HOSPICE BEDS	127	CANCER DEATHS	60-70%
HOSPICE ADMISSIONS PER YEAR	1,104	TOTAL DEATHS	20%
NEW PATIENTS PER YEAR	1,035		
% PATIENTS DISCHARGED ALIVE FROM HOSPICE	22.2%		
AVERAGE LENGTH OF STAY IN HOSPICE	24.5 TO 40 DAYS		
% NON-CANCER HOSPICE IN-PATIENTS	10.7%		

PALLIATIVE SPECIALISTS SHORTAGE



Source: Lien Centre for Palliative Care, Duke-NUS Graduate Medical School 2010

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HEALTHCARE GROUP HEADS

Dr Jennifer Lee

- Chairman, Agency for Integrated Care
- Senior Consultant, Ministry of Health

Mr Liak Teng Lit

- Chief Executive Officer, Khoo Teck Puat Hospital

Dr Lim Cheok Peng

- Executive Vice Chairman, Managing Director, Group President and CEO, Parkway Holdings
- Member, Singapore Medical Council
- Cardiologist, Mount Elizabeth Hospital

Dr Lim Suet Wun

- CEO, National Healthcare Group
- CEO, Tan Tock Seng Hospital

Assoc Prof Benjamin Ong

- CEO, National University Health System (NUHS)
- Member, Singapore Medical Council

Prof Tan Ser Kiat

- Group CEO, Singhealth Group
- Member, Singapore Medical Council

MEDICAL ACADEMIC HEADS

Prof Ranga Krishnan

- Dean, Duke-NUS Graduate Medical School

Assoc Prof Tan Kok Chai

- Master, Academy of Medicine
- Senior Consultant, Singapore General Hospital

Prof John Wong

- Dean, Yong Loo Lin School of Medicine, National University of Singapore (NUS)
- Member, Singapore Medical Council
- Deputy CEO, NUHS
- Director, National University Cancer Institute

MEDICAL EXPERTS

Assoc Prof Roy Joseph

- Dept of Neonatology, NUHS

Prof Kua Ee Heok

- Professor and Senior Consultant Psychiatrist, Dept of Psychological Medicine, NUHS
- President, Gerontological Society

Prof Low Cheng Hock

- President, National Healthcare Group College
- Emeritus Consultant, Tan Tock Seng Hospital

Assoc Prof Pang Weng Sun

- Chairman, Medical Board, and Senior Consultant, Geriatric Medicine, Khoo Teck Puat Hospital

The titles and designation of the experts are correct as at time of interview in 2010.

HOSPICE AND PALLIATIVE CARE

Dr Noreen Chan

- Senior Consultant, Palliative Care, Ministry of Health
- Visiting Consultant, Dover Park Hospice
- Senior Consultant, Dept of Haematology-Oncology, NUHS

Assoc Prof Cynthia Goh

- Centre Director, Lien Centre for Palliative Care
- Head, Dept of Palliative Medicine, National Cancer Centre Singapore

Dr Seet Ai Mee

- President, HCA Hospice Care

Sister Geraldine Tan

- Administrator, St Joseph's Home

Dr Tan Yew Seng

- Medical Director, Assisi Hospice

COMMUNITY LEADERS AND EXPERTS IN OTHER FIELDS

Prof Alastair Campbell

- Chen Su Lan Centennial Professor of Medical Ethics, NUS
- Director, Centre for Biomedical Ethics, NUS
- Member, Bioethics Advisory Committee

Assoc Prof Angelique Chan

- Dept of Sociology, NUS
- Dept of Health Sciences and Systems Research, Duke-NUS Graduate Medical School
- Director, Tsao Foundation Ageing Research Initiative, NUS

Mr Jeffrey Chancellor

- Managing Partner, TransLifeCare death care consultancy

Mr Gerard Ee

- Chairman, Council for Third Age
- Chairman, National Kidney Foundation
- Chairman, Changi General Hospital

Assoc Prof Terry Kaan

- Faculty of Law, NUS

Mdm Low Mui Lang

- Executive Director, The Salvation Army Peacehaven Nursing Home

Dr Kalyani Mehta

- President, Singapore Association of Social Workers
- Associate Professorial Fellow, Department of Social Work, NUS
- Associate Faculty, UniSIM

Mr Ng Kok Song

- Chairman, Lien Centre for Palliative Care, Duke-NUS Graduate Medical School
- Group Chief Investment Officer, Government of Singapore Investment Corporation

Mr Samuel Ng

- CEO, Marine Parade Family Service Centre
- Principal, YAH! Community College

Assoc Prof Phua Kai Hong

- Associate Professor of Health Policy and Management, Lee Kuan Yew School of Public Policy, NUS
- Chair, Asia-Pacific Health Economics Network

Bishop Dr Robert Solomon

- President, National Council of Churches of Singapore
- Bishop of The Methodist Church in Singapore
- Medical doctor by training

Mrs Ann Wee

- Associate Professorial Fellow, Department of Social Work, NUS

THE END IN MIND

AN EXECUTIVE SUMMARY OF WHAT POLICY-MAKERS, PRACTITIONERS AND PEOPLE CAN DO

Some destinations and directions in enhancing Singapore's end-of-life care

A WISH LIST FOR QUALITY OF DEATH

The next chapter of this study is about “beginning with the end in mind”, arguing for a whole new outlook on life’s end. To walk that talk in this study itself, here is the key end-product of this study right up front—a summary of the vision and aspirations of the 30 experts interviewed for this Lien Foundation project.

The ultimate wish is to empower the personal wish of each individual, at the end of his or her life, to be cared for in the way they would like. They should have access to help to make informed decisions and enjoy the assurance that their wishes will be respected even as they receive professional and dignified treatment and assistance.

At the policy level, this calls for responsive and effective statutory provisions and comprehensive and empathetic public education. Government should support bottom-

up initiatives by putting together a national strategy, facilitating measures proposed through legislation and policy decisions and lending its resources. The value of a national strategy was also a key finding of the Quality of Death global index released in 2010.

At the community level, quality care at the end of life is most desired, where the most glaring need is for sufficient and well-equipped hospice facilities that are adequately staffed by caring staff trained in palliative care.

How to get there drew a plethora of ideas, ranging from big visions to small suggestions. The varied perspectives shed light on the many fronts of the movement towards a better quality of death. Along the way, immediate, practical steps are highlighted. These can be grouped into three main aspects:

1. GET THE NATION TALKING

Because a higher quality of death involves practically every aspect of life, the whole community must get involved. The public has to become much more aware of the real issues and start to change attitudes, beginning with the convention to avoid talk of death. Then it has to act to both demand and deliver higher standards of care.

The first task is to spark a “national conversation”. Academics can contribute with insights, research and surveys to inform, educate and generate talking points, while the media acts as a multiplier to reach all segments of society.

A national conversation would include many smaller conversations between different groups, for example, financial advisors, the medical profession, the family as caregiver—each with a different intent and social setting but ultimately converging on a consensus of what constitutes a good death.

It is impossible to predict exactly how and where the conversation will lead, but our experts envisage the following happening:

- a) Families openly planning for the end of life well before a loved one’s death.
- b) Employers providing “family care” leave, not just child care leave.
- c) Retirees volunteering in a network of community-based services for those nearing life’s end.
- d) Insurance companies offering healthcare policies that cover hospice inpatient and home care.
- e) Funeral service providers treating the dead with due dignity and refined sensitivity.

2. REVAMP THE MEDICAL SECTOR

One particular group needs special attention: the medical profession. Currently, the dominant culture and incentive structure in medicine is to cure more than to care, to push for expensive and elaborate treatments rather than ministering more holistically to patients’ other needs.

A major built-in systemic disincentive in specialist training is that palliative medicine is a sub-specialty that can be studied only after a person has been trained in the much more lucrative fields of internal medicine, paediatrics, medical oncology or family medicine.

Not surprisingly, there are now fewer than 20 palliative care specialists in Singapore, with not many more in the pipeline. Remedying this deficiency is not just a question of increasing the supply of specialists. The root problem has to be tackled by instilling a more balanced mindset throughout the profession:

- a) The whole medical system needs to widen its focus from high-tech acute care to include other “softer” end-of-life needs, including the emotional and psychological well-being of patients.

- b) Palliative and end-of-life care should be expanded, integrated, recognised and promoted in medical school and continuing education.
- c) Instead of trying to be healers intent on saving life at all costs, doctors should also play the role of “lifestyle counsellors” who give holistic advice that factors in financial, personal and other circumstances. General practitioners, for example, should be equipped with information such as end-of-life care amenities in the neighbourhood.

3. MAKE PALLIATIVE CARE VIABLE

Currently, there are no commercial hospices in Singapore, only a few commercial providers of hospice palliative care in acute care hospitals to supplement hospice care by welfare organisations.

Thus, there is scope to make end-of-life care more sustainable by reducing the dependence on charity, building more commercially-run hospices, enhancing their business model and injecting private sector practices and approaches.

More extensive home care can be promoted as a paid service, at the same time as efforts are made to encourage home care to be recognised and valued by society.

A private sector mindset could also be applied to help with providing training as well as complementary services in palliative care. Most family home care givers have the best intentions but just lack the knowhow and confidence to provide end-of-life care.

A NATIONAL CONVERSATION BEGIN WITH THE END IN MIND

There is a need to get the whole country to take a new approach to life's end.

GETTING EVERYONE THINKING ABOUT THE QUALITY OF DEATH

Just as the well-known management maxim “begin with the end in mind” tells business people to focus first on their final objective, the same phrase can be applied, with a twist, to the end-of-life phase of a person’s last days, from the time one knows with some certainty that death is imminent. The key to a better quality of death is to live one’s life with the end in mind.

“There’s so little being done that anything you do is a lot.”

Prof Ranga Krishnan

Dean, Duke-NUS Graduate Medical School, on the gulf in public and professional awareness

Beginning with the end in mind, for an individual, would mean being more realistic about death as early in life as possible. With such a focused mental outlook, one can then begin to plan for the end of one’s life, to prepare for “a good death”, generally thought to be one that is free of pain,

fear, anxiety and other distress, in physical, emotional and psychological comfort and familiar surroundings, preferably at home, with family and friends at hand. With the end in mind, the rest of one’s life gains a more structured, settled direction and scope. This proactive alignment can begin as early in life as one is comfortable. Even a teenager invited to ponder the destiny of his personal blog, say, 100 years into the future would have taken a first step towards a refocus on life with the end in mind.

For a society, beginning with the end in mind means being aware of the need to address death and embrace it, think of it, talk about it, prepare for it. A good start is to foster a national conversation, together with smaller conversations among policy-makers, in the medical sector and other spheres of life. A national conversation on end-of-life care would be an extension of other ongoing national conversations on “active ageing” and “successful ageing”, just as the notion of “dying in place” would extend the ongoing conversation on “ageing in place.”

Britain is a good example of a country with an active conversation going, mainly spurred by Dying Matters, a 12,000 member-strong coalition set up in 2009 by the National Council for Palliative Care⁴. In Singapore, conversations would need to be started in schools as much as among professionals. The medical system needs a

“An individual could make regular contributions to book a place in a nursing home or hospice while he is still a fit and healthy working adult.”

Prof Tan Ser Kiat

Group CEO, Singhealth, on investing in a good death

paradigm shift away from an over-emphasis on curing to a more balanced approach to caring, to reform its most basic reward schemes. Surveying doctors and nurses on end-of-life scenarios could be one way to promote awareness. The hospice movement is beset with obstacles of public ignorance, misperception and outright prejudice. The development of law is held back by too much caution, too little public discussion. And people everywhere still live out life's end

without the quality they deserve and could so easily acquire a little more of.

What is the immediate end in mind for this study? To help spark a national conversation about the end of life, to spur everyone to stop and scrutinise what they would want for themselves, for their loved ones and best friends, to surface pervasive mindsets, prevalent concerns, blind spots and vital issues, to suggest options for anyone involved in policy, practice and perception-shaping, and to support and partner with other efforts to work towards enhancing the total environment of care at the close of this mortal existence. This would take to a new level the “die-logue” conversations promoted by the Lien Foundation’s Life Before Death initiative since 2006. Hopefully, it would reduce the proportion of people reluctant to discuss death with those who are terminally ill (60 per cent, in a Lien Foundation street poll released in April 2009).

Conversation needs talking points. To surface these, more research is needed on what people really want, think and feel about the end of life, on a few levels as follows:

- Values about what is a good life and a good death, including self-sufficiency and mutual

help, medical compassion, dignity in death, the role of medicine. Personal values need to be set against society’s values, including what has been called the excessive “worship of the young” and a version of “meritocracy” that values only those who are economically useful.

- Attitudes including pragmatism (keeping options open in the near-, medium- and long-term), idealism, individualism or social consciousness.
- Issues, for example, whether a strain on economic resources warrants ending life voluntarily, whether doctors are best-placed to administer end-of-life choices, whether people have a right of control over their own lives, and a right to others’ assistance even in ending life, whether manipulation of life and death is an inevitable aspect of the future of medicine.

To get the conversation going, the medical system has a big role. That movement has already started with the promotion of “advance care planning”, a new approach to patient care which includes end-of-life conversations with patients much earlier than practised now. This is being adapted from the “respecting choices” movement from the United States. In the US, the conversations

⁴ See the Dying Matters website at www.dyingmatters.org for more information.

with patients lead up to a legal document called Physician Orders for Life Sustaining Treatment (POLST), which is filled in upon hospital admission. In Singapore, the form is part of a less definitive “preferred care plan” instead.

The few who are currently involved in advance care planning would like to see other entities join in the effort. For instance, they advocate more nursing homes sending their staff for training in advance care planning so that everyone in healthcare can work on the same framework. A large measure of national coordination could be undertaken by the

“A lot of care need not be provided in a hospital.”

Dr Lim Suet Wun
CEO, National Healthcare Group

Agency for Integrated Care, a national body set up to integrate primary (acute) care and “step-down” (or long-term) care including in community hospitals. Observers see the Agency being at its “fetal stages” of formation and think that “the fetus needs to grow up very quickly” given the growing need for more societal attention to end-of-life care.

To sustain the needed mindset shifts, the mainstream media, especially influential editors, feature writers and commentators, play key roles in helping to shape the national agenda, even as more discussion happens online. More conversation could even bring international benefits. Singapore could act as a test-bed for quality end-of-life care in a multicultural society, surfacing useful lessons for other societies.

CASE IN POINT THE UNITED STATES

LET’S ALL TALK ABOUT DEATH

The United States has a National Healthcare Decisions Day, a day in the year set aside to encourage people to get the information and opportunity to communicate and document their healthcare decisions, including promoting advance directives. In two years since 2008, 34 states have come onboard involving 700 state and local organizations and 80 national bodies. Some 730,000 people have participated and 10,000 advance directives have been filed.

For more information, see the campaign website at www.nationalhealthcaredecisionsday.org.

EXTENDING THE CONVERSATION: GO FORTH WITH MULTIPLIERS

In the 2000 book, *The Tipping Point: How Little Things Can Make A Big Difference*, writer Malcolm Gladwell describes how social movements can reach critical mass with the help of people who can connect a cause to wide social networks, especially those who are very good at persuading others and on whom people rely for information. A national conversation on how to enhance end-of-life care in Singapore must be sustained to really make an impact. To reach a tipping point, it would help to enlist as many conversation “multipliers” as possible, individuals and industry and interest groups who can start and sustain smaller conversations around related aspects of life in many different circles.

One way to do this is first to identify occasions in a person’s life which are conducive to initiating and prompting such conversations. An obvious one: buying life insurance. Here, the life insurance industry could play a bigger role. There is a direct business benefit in a new area of insurance covering hospice inpatient and home care, which is currently not widely available. Insurance companies and agents could fulfill their corporate social responsibility (CSR) at the same time—helping to build up society in counselling their

clients on end-of-life, or at least referring them to further counsel. There is some concern that overall costs might rise once insurance comes into the picture, but this should be outweighed by the overall benefits to society of greater protection and peace of mind.

“We need to signal to the population that dying is something you can have your say about.”

Dr Kalyani Mehta
President, Singapore Association of Social Workers

Another life occasion: when a will or other similar legal document is made. Law firms and lawyers could meet their business objectives while also doing some CSR. Other groups could also play a part, such as those involved with helping people make donations and leave a legacy, say, to a university, or those involved in administering human organ donations. Even the increasingly popular pastime of blogging among the young

could be an occasion to initiate a conversation about the end of life.

The whole society could have a mass conversation about end-of-life matters. One idea is to have a “life half-time” national event marked every year with a festival of activities. Each year, a figure is announced officially as the current “half-time” adjusted annually, based on the current life expectancy for men and women divided by half. These figures are currently on the uptrend (see pg 17). The latest number for 2009 is 79 years for men, up from 78.4 in 2008, and 83.7 for women, up from 83.2 in 2008. So this year, for example, those at “life half-time”— all men aged 39.5 years (79 divided by half) and women aged 42 (83.7 divided by half) would be treated to special seminars and other activities relating to end-of-life, while everyone else is encouraged to reflect and plan for themselves too.

With such a national “life half-time” event, more people over time would think about their own end-of-life plans. Other multipliers would come in, including financial advisors and life coaches or even “death coaches”.

TOWARDS A NATIONAL STRATEGY

In the EIU Quality of Death Index, a handful of countries, including Britain and Australia, were singled out for having a national end-of-life strategy, thereby achieving better global rankings. Singapore was not among them. A national conversation on the subject would move people, perceptions and priorities towards a coherent country plan.

The experts interviewed in this study universally praised the role played thus far by voluntary welfare organisations, who stepped in to fill the vacuum that exists in the space between a hospital system that is costly and sometimes out of reach, and the home, where care is often inadequate and sometimes not an option. There are five restructured hospitals that offer palliative care

services, but there is much room for expansion, as community hospice services cover only 20 per cent of deaths or about 3,500 of the 17,300 patients who die each year.

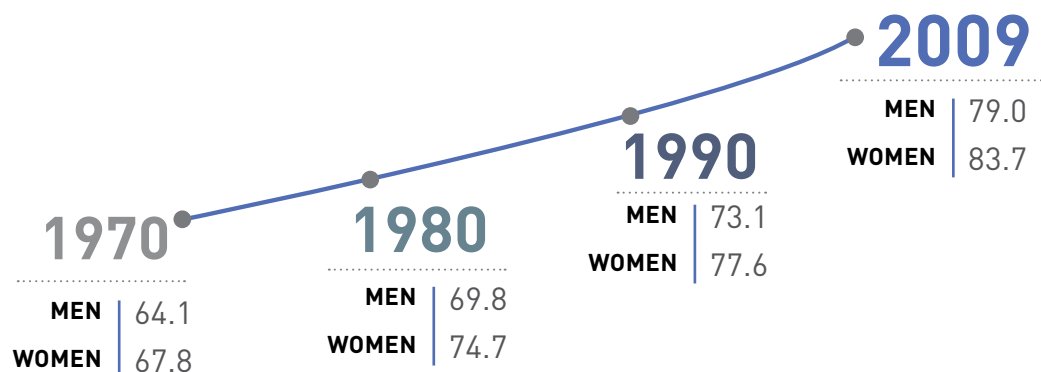
“The Singapore public generally... has no concept that they are entitled to certain ‘rights’ in determining the quality of their deaths.”

Dr Lim Cheok Peng

Executive Vice Chairman, Parkway Holdings, on the need for more public engagement

LONGER LIVES

RISING LIFE EXPECTANCY:



Source: Population Trends 2010, Department of Statistics, Singapore

The existing landscape has a few “uniquely Singapore” characteristics. Singapore is a young nation—many Singaporeans have no direct personal experience of being a caregiver to a dying person, including those currently middle-aged, who might have parents aged 70 or 80 still alive, and did not have to look after their grandparents. Without direct experience, many are said to be “amazingly short-sighted” about the end of life—they do not plan what to do with retirement savings, and tend to be conditioned to assume the

government or someone else will take care of things.

To address such an audience, the need for more integrated national coordination applies also to many other facets of life. Take, for example, the need for more community information about end-of-life care facilities in housing estate precincts—this should come under the purview of the Ministry of Community Development, Youth and Sports or even the Ministry of National Development, and not the Ministry of Health. The Law Ministry has to lead in strengthening the laws relevant to the end of life. The Ministries of Finance and Education also need to play bigger roles, in funding and public awareness. For infrastructure adjustments, the Ministry of Transport could come onboard to support initiatives such as the South East Community Development Council and Singapore Mass Rapid Transit's new collaboration in September 2010 to provide free taxi services for elderly residents in an area stretching from Potong Pasir to Marine Parade. Such services should also cover patients in hospice day care.

Even agencies involved in enhancing overall quality of life could take a closer look at the quality of death, and this would cover the Ministries of Trade

and Industry, and Information, Communications and the Arts. Singapore's compactness is a plus point for piloting end-of-life care initiatives, just as it has been a "living lab" in other contexts such as in new technology. To support this development, the government could consider more concrete support such as incentives to spur the growth of an industry sector providing services for end-of-life care, in the manner of industry cluster development deployed by agencies such as the Economic Development Board, which already looks into three new growth areas relevant to the end of life: urban solutions; health, wellness and ageing; and lifestyle products and services⁵. If ever there was a "whole-of-government" project, this is it.

Clearly, not having a national strategy is unsustainable. Because of the current fragmented system, there is no "ownership" of the patient (since there was never a strong family doctor culture), leading to "medical homelessness" or "patient nomadism"—patients going from specialist to specialist (assuming they can afford it) with no one to coordinate their care in a way that respects their preferences.

What is needed is to have palliative care embedded in an overall framework of integrated

care that works across all settings and is seen as an important aspect of patient-centred care, rather than an optional extra.

General practitioners can, for example, be better regulated and encouraged to play a bigger role in a few ways, including counselling on end-of-life and directing patients to end-of-life care amenities in the neighbourhood.

CASE IN POINT

SWEDEN

TIME HEALS ALL WOUNDS

Sweden is a country with a longstanding holistic approach to palliative care, the subject being on the national agenda since 1979. But even then, it was only in 2010 that the first national conference on palliative care was held and there are still remaining issues to coordinate activities across the nation's 20 counties. In most cases, beginning with the end in mind is going to take time, since it is quite a paradigm shift, almost like turning one's life priorities upside down.

Source: European Journal of Palliative Care 2010

⁵ See the Singapore Economic Development Board website at www.sedb.com for more information.

Yet, many issues remain. Current hospices have challenges with staffing, have a waiting list and some are not easily accessible to people who use public transport and cannot easily afford taxi-rides. More hospices are needed, with an

“People will see it’s good business over time.”

Mr Ng Kok Song

Chairman, Lien Centre for Palliative Care, on the prospects of economically viable end-of-life care

emphasis on providing real respite rather than subsistence level care. Cancer is very well-served but not other chronic ailments. It is famously difficult to keep good staff; many succumb to burnout. Salary benchmark reviews are overdue. Some are optimistic that the private sector should be involved in operating hospices for a fee, and that this will build up to a viable business over time, given the latent demand. Most terminal cases that cannot be managed at home end up in acute hospitals, which are not geared to treat such cases well.

Hospice and palliative care providers have secured enough funds from fund-raising so far, but for how long more? Charity can only stretch so far.

Planners doing cost-benefit analysis will have to grapple with technical aspects such as “norm costs” and “household income cap”, and get these levels right, otherwise there will be a demand and supply mismatch and the non-profit sector would once again have to come in to fill the gap.

With more care sited at home, it will be timely to set the wheels in motion towards formalising family care leave, as an extension of childcare leave which has already become a norm in Singapore. In the US, employees can take a number of days’ paid leave, and a number unpaid. As for training, the medical curriculum needs a revamp to “mainstream” palliative care. Even polyclinics can help train nurses, while hospices train maids. In the community, more touchpoints are needed, from having web portals for community services to friendly neighbourhood general practitioners becoming advisors knowledgeable about end-of-life care amenities in their precincts.

CASE IN POINT

PUBLIC IGNORANCE

HOSPICE CARE: 22 YEARS, STILL INVISIBLE

A Lien Foundation street poll in 2009 found that eight in 10 people had heard of hospices. But ignorance is still widespread, sometimes among those one would expect should know. A former Member of Parliament who recently benefited from hospice care expressed deep gratitude to the head of the hospice. He had not known previously that hospices even existed at all—this, despite the hospice movement in Singapore having launched home care as long ago as 1988.

The hospice head’s lament: “22 years, and the general public still do not know of us.”

PERSONAL CHOICE DIVERSITY IN DEATH

Respecting individual choice at the end of life and enhancing the supporting laws will help people to die well.

LETTING PEOPLE CHOOSE HOW THEY WANT TO DIE

The expression “different strokes for different folks” contains an unfortunate pun in the context of health, but it does sum up the fact that better end-of-life care must start with acknowledging the diversity of personal choice in the manner of one’s dying. This may be harder to cater to in a more communitarian society like Singapore, in spite of its status as one of the most westernised and globalised countries in Asia.

“We need to give people options... we can’t railroad everyone onto one track.”

Assoc Prof Cynthia Goh

Director, Lien Centre for Palliative Care, on respecting diversity of choice in end-of-life care

Often, there is not enough awareness that there are choices at the end of life, as at any other stage in life. Sometimes, family members, asked what they would want for their relatives at life’s end, come to a “cathartic realisation,” saying: “We never knew we could make these choices.” In truth, death is not the great leveler, in that there is no “one size fits all” end of life for everyone. For example, a typical grandmother may have a

different stance on extraordinary life-sustaining interventions from a “never-say-die” entrepreneur who might protest: “If I stop fighting, I’ll die.”

First, some hurdles of prejudice and misperception must be overcome. Many families ask that disease prognosis and imminence of death are not made known to their loved ones. Openly discussing a dignified death without pain and undue discomfort is still awkward at best, alien at worst. Sending patients to a hospice for terminal care is regarded by many as “abandonment.” In the same way, the hospice programme has been largely more successful with the English-educated, but the spread in its popularity to the Chinese-speaking heartlanders, or to the Malay and Indian communities more steeped in their own cultures and traditions, could be more limited. Again, there is an insufficient grasp of what people really want.

But first, even before anyone tries to ask people what they want, the people themselves must have real options—from readily available caregiver training to hospice services—that they can freely choose. Safeguarding the right to choose in spite of incapacity is enshrined in the Advance Medical Directive Act.⁶

⁶ An Advance Medical Directive is a legal document that you sign in advance to inform the doctor treating you (in the event you become terminally ill and unconscious) that you do not want any extraordinary life-sustaining treatment to be used to prolong your life (definition from Ministry of Health, Singapore).

THE LAW SO FAR – TOO SQUEAMISH AND SKELETAL?

“If funerals can be framed as the carrying out of the deceased’s last wishes, much of the grief can be reduced and made more meaningful.”

Mr Gerard Ee

Chairman, Council for Third Age, on seeing death in a new way

“Society needs to press the ‘pause’ button and ask: Are we on the right track?”

Mr Liak Teng Lit

CEO, Khoo Teck Puat Hospital, on society’s obsession with materialism at the expense of the human touch

As far as legislative backing for a national consensus on end-of-life issues goes, Singapore is already seen to be remarkable as an Asian country for what it has put in place. For example, it was the first country in Asia to come up with a definition of brain-death in the 1990s but it took sections of the public, such as the Muslim community, 10 years more to become comfortable with it. Nonetheless, Singapore’s laws are, at best, seen as “skeletal,” with too high a threshold and framed so conservatively that they “fall far short of what people might like.” More can be done to bring the laws closer to what they are in other places such as Korea and Hong Kong, where public debate has been more extensive in more open political cultures. The main concern thus far: a few minority religious groups have dominated public feedback, leaving a lack of knowledge of the values of the largely silent majority.

The unanimous view is that the legislation and practice of the Advance Medical Directive (AMD), in use since 1997 and with fewer than 10,000 filed to date, needs updating. In the US, information about AMDs is required upon hospital admission. But in Singapore, concerns over possible abuse

has meant that law-making so far has been “too cautious and unduly squeamish”⁷, designed too legalistically and so water-tight that it only applies to those who are “nine-toes-in-the-grave” dying. Misperceptions still prevail, such as that the AMD is geared to help the system cut medical costs. Currently, the AMD needs to be signed when one is still healthy and lucid and requires two witnesses (one of whom must be a doctor).

“Currently, the laws provide only walkways where it is not clearly swampy.”

Assoc Prof Terry Kaan

NUS Faculty of Law, on the need for more extensive laws

Some think it should be legal for patients to sign the AMD with just a lawyer or Commissioner of Oaths present, and to discuss AMDs much earlier. What were “extraordinary life-sustaining measures” to be rejected in the original Act may not be so extraordinary today. The process required of doctors to check the AMD Registry is also cumbersome.

⁷ Health Minister Khaw Boon Wan, in his speech at the official opening of the Lien Centre for Palliative Care at the Duke-NUS Graduate Medical School, 14 October 2008.

“There is nothing more comforting than a peaceful death.”

Prof John Wong

Dean, Yong Loo Lin School of Medicine, NUS

Meanwhile, new laws are in force, also without enough meat. The Mental Capacity Act came into effect in March 2010, taking just a few months to be crafted, when in Britain it took over a decade—this speed has partly been due, again, to lack of public debate. It applies mainly to parents of children with intellectual disability, those suffering from dementia, singles and childless couples. The law includes the granting of lasting power of attorney to persons who can help look after the financial and other personal matters of someone who is incapable of handling them personally. Certificates can be issued by psychiatrists, practising lawyers or accredited doctors. Currently, only 80 doctors are on the list of the Office of Public Guardian, physicians who have attended the required training. Certainly the list is too short.

As advance care planning is further promoted and put into practice, the supporting legislative environment will need to be adjusted to facilitate

a process that can reflect better a patient’s expression of general values and beliefs regarding the end of life. These laws will need regular review, just as advance care planning itself is about regular updates of a patient’s values history—covering the physical, functional, financial, psychological, spiritual and moral domains. Like life itself, law should be a process, not an event.

“John Wesley’s observation of early Methodists was to note how well they died. In medieval days, pastoral care was primarily conceived of in terms of ars moriendi (the art of dying)... helping people to die well, so that they can live well.”

Bishop Dr Robert Solomon

President, National Council of Churches of Singapore, on helping people die well

A NEW “WELLNESS” MINDSET FOR DOCTORS AND PATIENTS

To contribute more to better end-of-life care, the medical school curriculum needs to be changed. Palliative care as a subject—from technical expertise all the way to bedside manner—needs much more attention and focus than the current couple of days’ worth of curriculum time. Doctors and nurses need a new mindset, to see and feel that psychological comfort is as important as physical well-being.

One suggestion to help in the culture change is to build more hospices as annexes to hospitals, so that it is easier for healthcare professionals to spend more time observing best practices “next door”, and so, “imbibe” more of the culture of palliative care. The beginnings of such a framework already exist, for example, having the Ren Ci Community Hospital within the Tan Tock Seng Hospital complex. This model should be studied further to see how it can be extended or adapted. Here, the presumed benefits include sharing of resources and expertise, as well as some peace of mind from the fact that if ever there is a need for emergency acute care, this would be available “just next door”. However, the counter-view to this is that situating next door may not be entirely a good thing if a hospice is still seen as a “second-grade replica” of a hospital.

Benefits such as economies of scale from bulk purchases, it is argued, can be derived without the two institutions needing to be co-located. Instead, what hospices need most is to upgrade their facilities and upskill their staff, given that the main care issue is comfort.

“The pain of the mind is worse than the pain of the body.”

Prof Kua Ee Heok

Senior Consultant Psychiatrist, National University Health System

By focusing on high-tech acute care, doctors may have missed an opportunity to assert control over the field called “wellness”, for want of a better term. This space has long been taken over by others who have filled a space with obvious market demand, coming from other non-medical interests such as aromatherapy. There may be much underestimated value in the concept of yin and yang in traditional Chinese medicine, to minister to the whole body and being. It might just be a matter of time before western doctors become more like their eastern colleagues. Some believe the line has already been crossed, and doctors will no longer be warriors defeating disease and become

instead “midwives of death”. As the population gains from good preventive medicine and nutrition, and with better infrastructure, most people will live relatively long and healthy lives free of disease. Hence, the medical profession faces a paradigm shift—the need for doctors to switch emphasis from chasing after cures to learning to care.

Only attention to psychological and softer physical aspects will help ease towards a gentler trajectory to death. As the American cultural anthropologist Ernest Becker said in his 1973 book *The Denial Of Death*, much of modern society tends to be “a death-denying civilisation”. Denial of death surfaces in the focus on youth in popular culture, or the incessant pursuit of materialism.

Instead of this, it is important to make death truly a part of life, and to develop healthier attitudes towards it. To those of religious persuasion, because most Singaporeans belong to one religious community or another, there may be much potential to bring this about, both as an educational and therapeutic strategy within those communities and tapping the energies therein. But even here, there is more work to be done. In churches that have a ministry to seniors,

activities often involve a nostalgic return to youthful days, or enjoying outings and holidays. These can remain superficial and fail to address what one needs to do to come to terms with real concerns at the end of life. So, this would involve not just prayer and yearning for the afterlife, but also physical comfort and addressing secular anxieties. Just as the physical would benefit from becoming more spiritual, sometimes even the spiritual must become more physical.

CASE IN POINT FUTILE ACUTE CARE

DEATH’S NEEDLESS STING

Dr Ong Kian Chung, a respiratory physician at Mount Elizabeth Medical Centre, has seen over 100 patients die painfully, often in the intensive care unit, over his 22-year career. “In many such cases, the pain was unnecessary,” he says, but was suffered because the families of the patients insisted on the treatments, which can cost up to \$8,000 a day.

Source: The Straits Times 4 April 2009

MEDICAL SYSTEM REVAMP

“DON’T JUST DO SOMETHING,
STAND THERE...”

Why doctors need not always rush to give acute care, how medical resources can be realigned, and how the dead deserve more dignity

DOCTORS DON’T ALWAYS NEED TO
“PLAY HERO”

The dominant culture in medicine is to cure more than to care. Doctors are put on a pedestal as heroes; some even say, “superheroes”. They see their purpose in life as doing their utmost to save lives. To speak of death is to admit defeat, to accept failure. But in reality, there is no need to always “do their darndest” to prolong life. Sometimes, near the hour of death, what is needed is not “don’t just stand there, do something” but the opposite: “Don’t just do something, stand there...”

Under the current medical system, market forces work in one direction only. The whole incentive structure is geared towards procedural work and acute care. Instead of this, a different norm could be one in which more doctors play more of the role of “lifestyle counsellors” who can advise patients better because they are more familiar with their medical and personal histories. Employers can move away from the current common system of having a panel of company doctors based on ad hoc acute care and health screenings without follow up support, motivated by underlying distrust. Instead, healthcare should be about total well-being and preventive care in

preparation for the end of life. Employees can be encouraged to see their doctors even when they are healthy. Doctors need to give patients a very clear idea of healthcare costs in every sense, including emotional and physical. With both doctor and patient taking a more holistic approach to health, when it comes to the end-of-life, both parties would also be better-prepared and more focused on the right priorities.

“The ‘fightback’ on acute care has to come from the public.”

Assoc Prof Angelique Chan

Dept of Sociology, National University of Singapore and Duke-NUS Graduate Medical School, on overcoming the over-emphasis on acute care intervention in the medical system

Expertise in palliative care is known to be woefully scarce and under-valued compared to more glamorous medical disciplines that pay much better. The specialist training system has an in-built disincentive mechanism in that palliative medicine is a sub-specialty that can be studied only after a person has been trained as a specialist

in internal medicine, paediatrics, medical oncology or family medicine⁸. Currently, there are only a handful of palliative specialists (fewer than 20) trained in Singapore, with not many more in the pipeline of receiving the three years of training needed. The grossly overworked palliative care specialists are known to be suffering burnout. This gap must be filled soon or there will be even fewer experts in the near future, even as demand for their clinical skills increases.

“There is a happy medium between heroic, high-tech medicine and doing nothing.”

Assoc Prof Phua Kai Hong

Lee Kuan Yew School of Public Policy, on the optimal care that palliative care can offer

The hurdles will have to be overcome against a backdrop of some political sensitivity. Mention of giving people options to decline “medically futile” treatment at the end of life can be misinterpreted as being motivated by the government’s hidden intent to cut costs and subsidies by treating fewer people with terminal illnesses. Meanwhile, prevailing conditions leave

some room for improvement. One particularly sharp observation describes the worst nursing home situation thus: “In the name of protection, we imprison our frail elderly.” This may have come about because the system has “over-professionalised” care and “substituted the human touch with machines.” There are too many rules about where residents can go and what they can and cannot do. Vaccination for all is sometimes enforced, when it is unnecessary, as pneumonia is “nature’s way to go”. A candid assessment of where acute care stands in all this has it that, although people always say that those working in healthcare are not supposed to play God, in reality every day those in charge of acute care *are* playing God, applying the latest medical knowledge and, unwittingly perhaps, allowing technical capability to run ahead of the intellectual ability and judgment to make the best decisions. Instead, more often, it might be best to truly let nature take its course.

The key may be just to help people get ready for the final journey in a well-settled state. People who have fulfilled their dreams are probably less afraid to die. In place of hasty acute care can be a kind of “slow medicine” customised for the elderly, an approach to healthcare that includes

practices such as applying low doses of medication and building up gradually, and also, paying more attention to other “well-being” aspects such as physiotherapy. As for long-term care, one option may be to “go back to kampong days,” a Singaporean version of what other countries such as Japan and Scandinavia have created, with neighbours helping to look after the frail elderly. This need will definitely increase with the move towards dying in place in one’s own home, neighbourhood and community.

“We don’t want people to run to hospital to die.”

Assoc Prof Roy Joseph

Department of Neonatology, National University Health System

To bring about this shift, palliative care must be incorporated into the medical school curriculum. It must be embedded into the very thought processes of doctors and nurses in their daily work, and become part of their continuing education throughout their careers. The big move needed is from a hospital-centric system to one that is much more patient-centric. To make this happen, it will be necessary to address the “hidden curriculum” of healthcare professionals—not what

8 See the August 2010 Singapore Medical Association article The Hobbit’s Guide To Dying online at <http://news.sma.org.sg/4208/Hobbit.pdf>

ADDRESSING MISALIGNED MEDICAL RESOURCES

they learn in training, but the unspoken values that underpin their whole purpose in work. In short, a whole new outlook on the end of life.

CASE IN POINT

DOUBLE STANDARDS FOR ACUTE CARE

NOT IN MY BACKYARD...

The scene was a learning session to discuss the ethics of informed consent, at a pathological conference attended by over 200 hospital staff. A case study was presented of a 78-year-old man living alone in a hospice. Stricken with dementia, he was incapable of making any decisions himself about his own healthcare. He had already had one leg amputated; now his other foot was gangrenous. The question: To operate or not to operate? Asked to vote, two-thirds of the room said, "Operate."

Then the scenario was modified and they were asked the same question, but this time, they were the patient. Only two people raised their hands. In real life, the man was operated on (predictably, perhaps) and died a few days later. The moral of the story: Sometimes, the best care is to do nothing.

"The economics of it are perverse."

Assoc Prof Benjamin Ong

CEO, National University Health System, on the misallocation of resources away from palliative care

In arguing for greater priority for end-of-life care, the key question arises: Are resources for healthcare being allocated in the best way? "No" is the most common answer. Misallocation of resources comes across starkly: in a typical hospital intensive care unit, a patient pays about 10 per cent of costs after subsidy, whereas in in-patient hospice care the proportion a patient pays is usually about double. The hidden factor is the subsidy.

"Hospitalisation seems cheaper only because it is heavily subsidised."

Assoc Prof Pang Weng Sun

Chairman of the Medical Board, Khoo Teck Puat Hospital

Europe and the US are into rationing resources, after years of welfarism. Singapore is not in that situation but there is no less need to correct misalignment of incentives. If there is a market failure, the state must come in. Healthcare spending, currently at 3 to 5 per cent of gross

domestic product (GDP), should rise to 8 to 9 percent sooner and more effectively, some argue. By contrast, in the US, the figure is closer to 15 to 18 per cent. Most developed countries, without the worst excesses seen in the US, have it at around 10 per cent of GDP. With palliative care, more people can be cared for, for much less money in total because there would be less spent on expensive acute care, and this could be what many want in the first place, if they only knew it was available. A 2006 study in Spain showed that more palliative home care and lower use of emergency rooms reduced overall healthcare costs by 61 per cent compared with costs in 1992⁹. Studies have also shown that palliative care produces better intrinsic results for patients. For example, the New England Journal of Medicine reported in August 2010 a case in which 151 lung cancer patients were split into two groups and, compared with those who had acute care, those who had palliative care reported higher quality of life scores, had less depressive symptoms and lived longer—11.6 versus 8.9 months' median survival rates¹⁰.

On their part, voluntary welfare organisations need funds to get more manpower and to meet higher recurrent costs. Currently, they have to contend with issues such as unbalanced competition

⁹ The Quality of Death, a global ranking and study by the Economist Intelligence Unit for the Lien Foundation, 2010

¹⁰ See <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678#>, *The New England Journal of Medicine*, August 2010

THE NEED FOR MORE DIGNITY IN DEATH CARE

for manpower from restructured hospitals and restrictions on hiring staff. Hospices try to match the reward schemes of hospitals and hope that staff will gravitate towards them for intangible factors such as job satisfaction and better work-life balance. Even while allowing for more commercially-run hospices, more hospices need to be built using government funds, in the way that other hospitals are built and financed, so that no one is denied a hospice bed because of lack of beds or personal funds. Also needed are more resources and funding for home care and day care, training of caregivers, palliative care professionals and allied health workers, and public education.

“Our grossly overworked palliative care specialists are suffering burnout... something must be done to remedy this situation quickly.”

Prof Alastair V. Campbell
Director, Centre for Biomedical Ethics, NUS

“We need to make the Eiffel Tower look like a regular pyramid.”

Dr Seet Ai Mee

President, HCA Hospice Care, on building up the structure of palliative care, adding to what hospices provide by enhancing the upper levels, by strengthening it as a medical specialty and training more nurses

Good end-of-life care means seeing everything right through. The notion of “death care” is about how the very end of life—the dead body itself—is treated, even after the very last breath has been exhaled. There should be a deep, abiding sense of respect, of a person being transferred “from my care into your care”. Quality, hygiene, professionalism, consideration and a human touch are paramount. This “bedside manner” shown to the deceased extends beyond doctors and includes not only nurses and other ancillary staff in hospitals and hospices, but also law enforcement officers in situations such as certifying deaths and the conduct of funeral services industry staff.

“We need someone in each hospital to champion palliative care.”

Dr Jennifer Lee

Chairman, Agency for Integrated Care

During this time, very often, in hospitals, family members are not allowed enough time to grieve and just be present. Instead, once death has visited, different teams of total strangers march in to perform their tasks in a seemingly cold and callous, sometimes careless, manner. Deeper

issues need further examination, such as working conditions in a largely unregulated funeral services industry, licensing, standards, transparency, accountability, spot checks and enforcement. The benchmark would be a country like Canada, considered to have the “gold standard” in death care by industry players. Valued at over US\$1 billion, the industry is sophisticated in aspects such as memorialisation of the dead, and is working on innovations such as eco-burials (burials in new, environmentally-friendly ways), and there is even certification given by a Green Burial Council.

“The end-of-life journey should encompass facilities with rooms for loved ones of the dying to stay with them.”

Mdm Low Mui Lang

Executive Director, The Salvation Army Peacehaven Nursing Home

In the new Khoo Teck Puat hospital in Yishun, there is a “no one dies alone” programme that has volunteers sitting with patients until they take their last breath. A sound-proof room called “the last office” provides a place for the family to be with the patient at life’s end. This is a healing

space, for grief, solace, the resolution of emotional issues. To manage such a space, doctors and nurses with a special touch are needed, and they must go into action long before the palliative stage. For hospitals, the billing system should recognise the time doctors spend not rushing around to execute acute care, but just “being there” for the patient’s family. This kind of “pastoral role” for doctors should be seen as an integral part of medical care. Hospital administrators might have to accept some measure of redundancy in personnel or manpower hours.

Japan has been held up as a role model in showing respect at life’s end, with the family truly involved in this facet of life. The missing piece is having someone with authority to declare, at the right time, that the goal of care has changed to palliative mode. Hospitals are sometimes not structured to deal well with death, and may make too quick decisions and so, unwittingly, deprive the patient’s next-of-kin from being present at the most precious moments of the end of life of a loved one.

Extending care into the community, there is a need for a hospice in every town, some argue, to stay well clear of any feeling that any family is “sending

a relative to Siberia”. If death were to occur within the community, among familiar faces and with care easily accessible to all, this would help take the “sting” out of death. Thus, death is not “the enemy who ends phase one of life”, but—along with its favoured companion, dignity—becomes “almost a friend” accompanying a person to the next stage of existence.

“The dead patient is not just a body but Mum or Dad.”

Mr Jeffrey Chancellor

Managing Partner, TransLifeCare death care consultancy

FAMILY CARE

A NEW “SANDWICH GENERATION” BURDEN

The three-tier family in Singapore faces a much bigger task to provide palliative home care for their folks, as filial piety is redefined and dying in place becomes more commonplace.

SHRINKING FAMILIES, MUCH OLDER ELDERLY, NEW END-OF-LIFE CHALLENGES

Old age, for some in Singapore, is no longer golden. The worst manifestation of this is the commonly heard Singaporean expression: “No fear of death, only of falling sick,” capturing the concern over imposing high costs of acute medical care on one’s family. As nuclear families get smaller with a declining birth rate, and more people are single or childless, a new item is on the demographic menu—a new type of “sandwich generation” family, with the weight of two pieces of “bread” on top and one below: the parents and grandparents who need to be cared for, in addition to children.

The “sandwich generation” was previously thought of as a typical working couple who must look after not only the next generation below (their children) but also the one above (their parents). With longer lifespans, more will have to look after not only their parents who may be aged over 60 but also their grandparents who may be over 80.

Helping to resize the sandwich even further are other trends such as the growing number of “empty-nest” homes in which an older couple have children who have “flown away” to distant

“SANDWICH” UPSIZING BETWEEN 1999 AND 2009:

- Residents aged 65 and above increased from 7% to 8.8%
- Single citizens aged 30-34 rose from 33.2% to 41.9% for men and from 21.7% to 29.8% for women
- Ever-married female citizens who are childless increased from 14.4% to 20.6% for those aged 30-39 and from 7.2% to 8.9% for those aged 40-49
- Total fertility rate (TFR) hit an all-time historic low of 1.22 in 2009, the Chinese having the lowest TFR and Malays the sharpest decline

Source: Population in Brief 2010, National Population Secretariat, Prime Minister’s Office

lands to work or have emigrated for good, adding to the 180,700 overseas Singaporeans¹¹. With the “silver tsunami” of rapid ageing also well on the way, smaller families will add to the challenges of enhancing end-of-life care.

“The whole of Singapore is going to become one big nursing home.”

Sister Geraldine Tan

Administrator, St Joseph's Home

To help facilitate family togetherness, every small adjustment might help. One suggestion is that nursing homes could all have a playground, to make it more conducive for families with young children to stay longer when they visit their elderly relatives and spend quality time together. More senior activity centres run by the Ministry of Community Development, Youth and Sports (MCYS) could be set up in the void decks of public housing blocks, so there would be no need to go to a doctor or hospital to get advice on very basic aspects of end-of-life care. Just as professional care can be brought into the home, more homeliness can be brought into caring institutions.

THE FUTURE OF FILIAL PIETY

Singapore's westernisation is only skin-deep; you only have to scratch a bit to find Asian values underneath. But something is going on in the state of family life, if there even has to be an “Eat With Your Family” Day in May each year, a national campaign to encourage people to leave work earlier to do what should be the most natural thing—have dinner with their families at home. The rat race may be getting so hectic that many have no time to break “cheese” together. It takes two hands to clap. Most of the blame has been directed at the young, but on the part of the elderly, it is not uncommon for mothers to swear off cooking altogether, given easy access to cheap food and their children's default habit of eating out due to long working hours in any case. Some grandmothers decline to help with the grandchildren, opting for a retirement of almost complete leisure—which does not help the situation either.

The overall impact on society is as various as it is visible. Some have observed further declines in respect for the seniority of age, for example, authority issues crop up in the workplace. To counter this, there are suggestions that the Community Involvement Programme in schools—which gets students to do a number of hours

of community service to earn requisite points—should last for a whole week instead of just a perfunctory few hours each time. Longer stretches could be made available for those who are really interested, rather than foisted on

“The family needs a great deal of support... especially as we move towards the era when four-generation families become the norm—they are with us already, but not nearly so common as they will become as longevity extends.”

Mrs Ann Wee

Associate Professorial Fellow, Department of Social Work, NUS, envisaging the family of the future

everyone. Hospices have expressed keenness to host such immersion sessions. To fit better into “rat race” schedules, elderly day care centres in the community should close at 10pm rather than 6:30 p.m. to make it easier for family members to pick up their elderly relatives. The legal framework could be strengthened to facilitate

children to set aside some of their earnings towards their parents' end-of-life care. Whatever it is, filial piety must be reframed.

CASE IN POINT

SINGAPORE DREAMS

LOOK MA, NO HANDS

A banner with the statement "My dream is to live near my children" was displayed at the National Day Parade in August 2010 at the Padang, as part of the year's "Live Our Dreams" theme. That it even has to be a "dream" to live near one's children in such a small country sums up one aspect of the situation for families today.



PHOTO BY KOH BUCK SONG

A typical case: An elderly widow lives alone in Redhill estate, one of Singapore's oldest public housing areas, known for its relatively higher proportion of elderly residents. Her son lives with his wife and children in Sengkang on the north eastern coast, one of the newest estates. The young couple have their hands full coping with work and bringing up children. They cannot afford to buy an apartment closer to the central parts of the island, while Mum is steadfast in not wanting to "burden" them by moving to live with them.

The result: A filial son leaves his mother by herself most of the time. So near, yet so far.

HELPING PEOPLE TO “DIE IN PLACE” AT HOME

Another challenge to filial piety will come from the growing desire to die in place. For some people, sending their ailing family members to a nursing home and leaving instructions for them to be sent to a hospital when their conditions get worse counts as “having done something for them.” But what really happens is that such cases end up with multiple medical investigations and active treatment without much real benefit and instead prolonging discomfort and the process of dying unnecessarily. This is where filial piety acts against the interests of the frail elderly.

“I hope more people will be able to say goodbye at home and not in the coldness of the hospital.”

Prof Low Cheng Hock
President, National Healthcare Group College

On the other extreme are family members who do not want any further hospital care for their relatives and tell nursing home staff not to send them to hospital at all, despite professional opinion that the resident may improve with treatment. Avoiding healthcare costs is usually the main reason for this. This sometimes poses a difficult ethical dilemma for staff.

What families need is more support to equip them to handle end-of-life care matters themselves, rather than think there is no option other than outsourcing. Funds must be made available—whether from the state or other sources—to train people and empower them to feel confident that they can look after a sick elderly person at home, to make end-of-life care as simple and natural as first aid. Singaporeans are observed to be “particularly frail” in this area, due to cultural factors including an over-reliance on foreign domestic help. This reality is unlikely to alter any time soon, so long as double-income families remain the norm.

But something more can be done to help more people realise their wish to die at home, including expanding hospice home care and promoting public awareness of the value of such care. Maids can be sent for training. Granny flats can be built in the same building but not next door. Hurdles—preferences for privacy and perceptions that looking after the physical needs of loved ones is somehow “beneath us”—must be overcome. The state and other parties can only help so much. The key is to keep families close to each other. Ultimately, better end-of-life care, like charity, must begin at home.

“Doctors are trained in the western system but must operate in an eastern society, so they have to adjust.”

Assoc Prof Tan Kok Chai
Master, Academy of Medicine

COMMUNITY CARE THE BEST THINGS IN LIFE ARE FREE?

Better end-of-life care need not mean costly solutions, but reshaping cultural mindsets, sustaining free home care and promoting altruistic neighborhood volunteerism.

HOW TO REALLY REST IN PEACE

Death is about letting go, and there are as many ways of coming to terms with that as there are human beings. For some, it is about “settling old scores” and resolving conflicts. For others, the arts can play a vital role in enabling people to process their memories as they prepare for the last journey. How do people really feel about how they want to depart?

“Where your treasure is, there your heart will be also.”

Mr Samuel Ng

CEO, Marine Parade Family Service Centre, quoting a Bible verse to advocate higher societal priority on caring for the dying

In Singapore, one area of intense academic research interest and speculation is the psyche of the majority group in the population—non-Christian older Chinese. Taoism, Buddhism and ancestor worship are their common spiritual affiliations. It has been suggested that the way this group thinks of death is with a mixture of stoic resignation and going with the flow. This is alluded to in a saying of the ancient sage Confucius: “If we

don’t really know about living, how can we know about dying?”

There has been “deafening silence” from this group, as they have not made their views heard in earlier debates such as over the Human Organ Transplant Act. However, academics suspect that this group may be more relaxed about death than some people imagine, and quite a proportion might prefer to let nature take its course rather than undergo expensive and painful treatment. For this group, their greatest wish about the end of life is captured in a phrase roughly translated as “to die happy”, or “onn lok sei” in the Cantonese dialect, where it is used most commonly—that is, to die at home, with family all around, free from pain and distress, and ideally after a certain major milestone has been reached in life, completing a duty such as seeing a child getting married and so finally clearing the “finishing line” in bringing up children.

If this is indeed a prevailing worldview, then some current medical approaches might be barking up the wrong tree. For instance, the treatment of disease is spoken of usually with

the terminology of war—but this, some argue, is wrong especially in more developed countries, and Singapore “crossed that line” of development in 2004 when the top killer became cancer, which is incurable and hence, not something you can defeat. Hence, the medical profession would do better to shift its focus from combating disease to enhancing well-being at the end of life—in other words, helping to bring about “onn lok”.

RELYING ON THE COMFORT OF STRANGERS

It looks like Singaporeans will need to keep looking to strangers to provide palliative care. Some 180,000 foreign women work in Singapore as domestic workers, and an estimated 50 per cent engage in some form of home care-giving. Since the practice of engaging foreign domestic help is not likely to decline any time soon, one aspect of enhancing end-of-life will have to involve institutions such as hospices providing training for maids, and this would need to expand further in future.

But there are other obstacles. Many families go to hospital first before they try a hospice, so by then, they would have exhausted most of their funds. There are still deep negative connotations of the term “step-down care”, when in fact, the care intensity may be higher in a hospice or with home care than in a hospital.

“It’s a calling; that’s why we’re here.”

Dr Tan Yew Seng

Medical Director, Assisi Hospice, on why hospices do what they do

Hospices will have to adjust as well. Now, they are under-charging for inpatient care and definitely for home care. Home care is available without charge even to the rich, although some may make a donation and help even out the cost. Home care continues to be free due to the concern that people will opt to forgo care if they cannot afford, or do not want, to incur the expense, and society as a whole will then be impacted. In a Lien Foundation street poll released in April 2009, the top end-of-life concern was not wanting to be a healthcare burden to one’s family. Whereas in the US, a 10 to 20-bed hospice is the norm, in Singapore, hospices have 35 to 40 beds, and the waiting list can fluctuate, sometimes up to 20. Such a long waiting list is considered less than ideal, an indication of latent demand out there. Perhaps hospices could charge for the first month and then work out a package later, for a start.

CASE IN POINT

SOFTLY, INTO THE NIGHT

“JUST LET ME GO...”

In the absence of more extensive empirical data, rare snapshots give a glimpse into prevailing attitudes towards the manner of the end of life.

In September 2010, at a focus group of several Chinese non-Christian elderly persons, as part of a university study project, the consensus was to “go the natural way”, “without using extraordinary life-sustaining measures”, but in any case, to avoid unnecessary medical interventions towards the end. As one respondent said: “When the time comes, just let me go, don’t let me hang with all the machines.”

And as for being remembered, the favoured way cited was “sea burial”, to have one’s ashes cast into the sea. Fussing about death was thought to be futile. “Once it’s gone, it’s gone.”

IT TAKES A VILLAGE...

If it takes a village to raise a child, so the ancient African saying goes, so too, will it take a village to take end-of-life care up to where it should be. Adjustments will be needed in a few areas of life, and everyone must chip in. Community amenities such as family service centres are experimenting with new end-of-life “services” such as bereavement support and counselling. Dedicated taxi services would be a godsend for the elderly, to overcome the mobility issues that now keep many of them at home and indoors much more than they might want, or is good for them.

“It’s very difficult to die well if you haven’t lived well.”

Dr Noreen Chan

Visiting Consultant, Dover Park Hospice

As a parallel, legal aid as a service to the community is more successful pro bono than with discounted fees, which are perceived to devalue legal skills. People generally feel good doing a noble service for society, more than they would giving away discounts. This might hold lessons for evolving a community system that will enhance the

living environment in a housing estate for the frail elderly, many more of whom will be living alone and needing support from the community.

Paying neighbourhood “aunties” to do this service is one option, for them to also earn income to add to their retirement finances. But this may turn out to be a disincentive instead, just as with lawyers. This is especially so in Singapore society, where any kind of domestic work has been commoditised and devalued. Instead, what might fare better is to appeal to the spirit of altruism. Whether this will work is an intriguing poser, which can only be settled with experimentation. Meanwhile, the question remains—could the best things be free in death, as in life?

ABOUT THE AUTHOR

Koh Buck Song is the Principal Analyst of this study commissioned by the Lien Foundation.

He is the CEO of Integrative CSR Consulting Pte Ltd, a consultancy that helps organisations fulfill their corporate social responsibility. A master's graduate in public administration from Harvard University's Kennedy School of Government, he has been an Adjunct Associate Professor of leadership at the Lee Kuan Yew School of Public Policy, National University of Singapore, as well as Adjunct Faculty in the humanities at the School of Social Sciences, Singapore Management University.

He is the author and editor of 17 books on subjects including nation branding, corporate governance, housing policy, national economic strategy, and culture and heritage. He was a columnist, writer and editor at The Straits Times from 1988-99.

ABOUT THE LIEN FOUNDATION

The Lien Foundation is a Singapore philanthropic house noted for its model of radical philanthropy. It invests in innovative solutions, convenes strategic partnerships and catalyses action on social and environmental challenges. The Foundation drives institutional capacity building to address crucial community needs, and empowers individuals to reach their full potential. It seeks to enhance educational opportunities for the disadvantaged, excellence in eldercare and environmental sustainability in water and sanitation.

The Foundation advocates better care of the dying as part of its mission to advance eldercare. It first conceived and spearheaded the "Life Before Death" initiative in 2006 to create greater public awareness about end-of-life issues in Singapore. Since then, the Foundation has continued its drive to highlight the urgent need for improved care for the dying. It also sought to de-stigmatise death and dying by spurring 'die-logues' amongst the public. In 2010, the Foundation commissioned the Economist Intelligence Unit to conduct the first-ever global Quality of Death index ranking 40 countries on their provision of end-of-life care.

www.lienfoundation.org