REPORT ON THE

NATIONAL STRATEGY FOR PALLIATIVE CARE

Coordinated by Lien Centre for Palliative Care, Duke-NUS Graduate Medical School

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DUKE NUS GRADUATE MEDICAL SCHOOL SINGAPORE

LIEN Centre for Palliative Care

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Overview of Report and Terms of Reference

Healthcare systems worldwide invariably begin with medical services to look after the sick, then preventive care services to prevent illness and promote health. As society matures, long term and end of life care becomes the next area of focus. Even as Singapore's population ages and prevalence of chronic diseases increase, rising societal expectations with regards to choices and preferences at the end of life create demands for palliative care services that address the needs.

Lien Centre for Palliative Care (LCPC) was commissioned by Ministry of Health (MOH) to formulate a National Strategy for Palliative Care in consultation with key stakeholders in the health care system. A Workgroup was appointed, comprising of health care professionals from restructured hospitals, hospices, home care, Agency for Integrated Care (AIC) and representatives from MOH.

The terms of reference for the Workgroup for the National Strategy for Palliative Care included:

(a) Holistic detailing of the palliative care needs in Singapore including pain relief, symptom control, psycho-social support and addressing bereavement needs.
(b) Systematic review of previous and current palliative care services and an analysis of the strengths and weaknesses of the sector.
(c) Comparison of Singapore's organisation of services with that of top-tier countries such as the United Kingdom and Australia.
(d) Recommendations and the attendant rationale for organisation of palliative care services in the various echelons of healthcare from home to hospital. The recommendations should have special emphasis on sustainability of service offerings and use of non-palliative care specialists and physician substitutes.

Findings and recommendations are summarised in this report. Detailed reviews of the current local and international literature summarising the scientific evidence on actionable strategies relevant to palliative care and analysis of local data done in conjunction with the Health Services Research and Evaluation Division, Ministry of Health were compiled in separate reports.

We acknowledge that this report is not an end-all but just another milestone in the development of palliative care services nation-wide. A new task force will need to delve further into the specific implementation of the recommendations and continuously review and modify strategies with the changing needs of the population.

My appreciation and thanks to all the Workgroup members and secretariat who have contributed much of their time during and after office hours to deliver this report.

A/Prof Pang Weng Sun
Chairman, NSPC Workgroup
Oct 2011

Chapter 1: Executive Summary

1.1 Palliative care aims to relieve the suffering of patients with advanced progressive illness and ensure the best quality of life for the patients and their family members. The provision of palliative care services for patients living with or dying from advanced progressive illness is an essential part of the health care system.

1.2 Palliative care has developed rapidly around the world over the last fifty years to meet the complex and multiple needs of patients with progressive and advanced illnesses. Palliative medicine is now recognized as a specialty in many countries, including Singapore.

1.3 There are trends internationally to extend palliative care from cancer to non-cancer patients, introduce palliative care early in the course of a potentially life-limiting illness, extending the provision of palliative care to all health care professionals, and develop integrated systems to deliver palliative care in a coordinated manner with involvement of doctors in primary care.

1.4 With the ageing of the population, the number of patients in Singapore who require palliative care will increase. It is essential to structure the health care system to deliver such care efficiently to an increasing number of patients facing progressive illness and disability towards the end-of-life.

1.5 Palliative care services in Singapore have developed over the last twenty-five years. It is offered in hospitals, hospices and at home. Palliative care is increasingly becoming a part of mainstream medicine and acknowledged as an essential part of the healthcare system. We have dedicated and passionate health care professionals in the palliative care sector.

1.6 Areas in which improvements can be made include coordination of care, recruitment of manpower, strengthening of capabilities, establishing standards

of care, promoting public awareness on end-of-life issues, and leadership to develop the palliative care sector.

1.7 The goals of the strategy and the key recommendations are summarized in the following table (Table 1):

Table 1: Summary table of goals of strategy and recommendations

Goals of Strategy	**Recommendations**
Goal 1: **All patients with life-limiting illnesses should be identified and their palliative care needs assessed.**	**Ensure that all health care institutions caring for patients with life-limiting illnesses have a system to identify these patients early and assess their needs.** **Palliative care should be extended from cancer patients to include more non-cancer patients with life-limiting illness.** **Chronic disease management programmes, cancer programmes and nursing homes should have guidelines to systematically identify and assess patients who would benefit from palliative care.**
Goal 2: **All patients with life-limiting illnesses should be cared for by health care professionals using a palliative care approach.** **Patients with complex needs should have access to specialised palliative care services.**	**Ensure that all healthcare professionals have a palliative care approach to the care of patients with non-complex end-of-life needs.** **Ensure that all patients with complex needs have access to specialised palliative care services in the appropriate setting, with multidisciplinary team support.**

Goal 3: **Palliative care should be delivered in a coordinated manner that ensures continuity of care across settings and over time.**	**Organize the delivery of palliative care based on the Regional Health System model, with effective collaboration between public, private and VWO sector providers.** **There should be effective coordination of care within each Regional Health System.** **Establish specialised palliative care services with multidisciplinary teams in all restructured hospitals.** **All Regional Health Systems should as a minimum, incorporate home hospice service and inpatient hospice service into the network of care. Inpatient hospices can be part of a community hospital or free-standing.** **Maximise the use of platforms or means for collaboration and communication between service providers, including the use of information technology to facilitate continuity of care for patients.** **Establish well defined roles and criteria for referral to the various palliative care services.** **Encourage the involvement of primary care physicians/GPs in the care of patients with palliative care needs at home and in nursing homes.**
Goal 4: **Palliative Care should be affordable to all who need it and quality care should be provided in a cost-effective manner.**	**Ensure that financing structures support the development and delivery of good quality, appropriate and affordable palliative care in the health care institutions, community and at home.**

Goal 5: **There should be adequate health care professionals with the appropriate training to meet the needs of patients at the end-of-life.**	**Ensure that there is adequate trained staff to deliver quality palliative care.** **Ensure that health care professionals are provided with the necessary training to provide the appropriate level of palliative care for patients.** **Incorporate palliative care training in all undergraduate and diploma courses for doctors, nurses and allied health professionals to ensure that all new health care professionals have basic knowledge in palliative care.** **Develop a framework to review the curricula to match the competencies required for health care professionals at all levels for doctors, nurses and allied health professionals.**
Goal 6: **There should be adequate capacity to meet the palliative care needs of patients.**	**Calibrated increase in inpatient hospice beds to meet the needs of palliative care patients and to function as training resources for all cadres of staff.** **Increase the capabilities of nursing homes to take care of end-of-life patients. Include end-of-life care elements in clinical audit requirements for nursing homes.** **Ensure adequate home hospice care provision to meet the needs of palliative care patients.**
Goal 7: **There should be local standards of care to ensure the delivery of good quality palliative care.**	**Establish local evidence-based standards of care and common outcome indicators.** **Establish minimum dataset for collection of quality (as well as service) indicators to evaluate quality of care and for service planning.** **Establish accreditation system for palliative care service providers.**

Goal 8: **The acceptance and public awareness of palliative care services, advance care planning and bereavement services should be promoted.**	**Ensure a coordinated and concerted effort across the health and community sector to promote awareness of palliative care.** **Promote advance care planning as an opportunity for open communication between healthcare professionals, patients and caregivers.** **Develop clear and consistent messages on advance care planning.** **Ensure all healthcare professionals have basic awareness of advance care planning, including those potentially entering the workforce.** **Develop good community partnerships by engaging relevant groups including key religious and grassroots organisations to promote awareness and acceptance of advance care planning.** **Incorporate grief and bereavement initiatives into the regular activities to promote hospice and palliative care.**
Goal 9: **Palliative care research should be promoted to improve the quality of palliative care and inform policy making.**	**Promote research on palliative care interventions and service delivery to improve the quality of specialist and general palliative care and inform policy making.**
Goal 10: **There should be leadership and governance to guide the development of palliative care services in Singapore.**	**Establish a leadership or governance structure to ensure oversight of the development of palliative care services locally.**

Chapter 2: Introduction

2.1 The provision of palliative care services for patients living with or dying from advanced progressive illness is an essential part of the health care system. With the ageing of the population in Singapore, the number of patients requiring palliative care will increase. It is therefore essential to structure the health care system to deliver health care efficiently to the increasing number of patients facing progressive illness and disability towards the end-of-life.

2.2 The word palliative is derived from the Latin word '*palliare'*, which means 'to clothe' or 'to cloak'. Palliative care aims to relieve the suffering of patients with progressive, advanced illness and ensure the best quality of life for the patients and their family members.

2.3 The World Health Organization defines palliative care as follows[1]:

Palliative care is 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.

Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patient's illness and in their own bereavement;*

[1] WHO Definition of Palliative Care. Available online from: World Health Organisation <http://www.who.int/cancer/palliative/definition/en/> [Last accessed: 4 October 2011].

- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

2.4 The Lien Centre for Palliative Care was commissioned by MOH to formulate the National Strategy for Palliative Care in consultation with key stakeholders in the health care system. A Workgroup was appointed, comprising of health care professionals from restructured hospitals, hospices, home care, Agency for Integrated Care (AIC) and representatives from Ministry of Health (MOH).

2.5 The National Strategy for Palliative Care analyses the national palliative care needs, the current landscape for provision of palliative care services, strengths and weaknesses of the current system, best practices in overseas countries and evidence-based interventions, and makes recommendations for the provision of palliative care services in Singapore.

2.6 It is the hope of the Workgroup that the recommendations in the strategy will be accepted to improve the quality of life and reduce the suffering for people living with and dying from advanced and progressive illnesses.

Chapter 3: International Trends

Origins of modern palliative care

3.1 Dame Cicely Saunders is widely credited as the founder of the modern hospice movement. Through her pioneering work with cancer patients in the 1960s, she discovered that patients with advanced cancer had immense physical, social, psychological and spiritual needs which were often neglected by health professionals[2].

3.2 Dame Cicely Saunders and her colleagues established the first modern day hospice, St Christopher's Hospice, in London in 1967. Since the opening of the St Christopher's Hospice, the palliative movement has come a long way. There has been a rapid expansion and growth of palliative care services and hospices in many countries, such as the UK, US, Australia and Canada. Palliative medicine is today recognised as a specialty in many countries.

Impetus for development of palliative care

3.3 The impetus for development of palliative care worldwide is contributed by several factors which include:

(a) Longer life expectancy and ageing population, with the attendant increase in prevalence of chronic diseases[3];

(b) Shift from acute, sudden and unpredictable deaths in the last century (e.g. due to infections and accidents) to deaths due to cancer and chronic diseases, which are preceded by a period of progressive disability[4];

[2] Clark D. (2007) From margins to centre: a review of the history of palliative care in cancer, *Lancet Oncol.*, May; 8(5):430-8.
[3] Meier D. (2010). The Development, Status and Future of Palliative Care. Available from: http://www.rwjf.org/files/research/4558.pdf [Accessed: 4 October 2011].
[4] Lynn, J., Adamson, D. (2003). Living Well at the End of Life. Rand Health White Paper WP-137. Available online: <http://www.medicaring.org/whitepaper/> [Last accessed: 4 October 2011].

(c) The availability of costly medical technology that may prolong life without improving quality of life;

(d) The recognition that many patients suffer from pain and other distressing symptoms at the end-of-life[5];

(e) The recognition that palliative care can meet the complex and multiple needs (e.g. physical, social, psychological, spiritual) of patients at the end-of-life along the different trajectories of illness[6] (Please see Annexes A and B for more details);

(f) The need to restructure health care systems to deliver good quality care at the end-of-life.

Benefits of palliative care

3.4 A number of scientific studies have demonstrated that palliative care improves pain and symptom management, enhances quality of life and mood of patients, increases patient and family satisfaction and may improve survival of patients[7,8].

International Trends

3.5 Several trends are notable in the development of palliative care internationally:

[5] Field, M.,Cassel, C. (1997). Improving care at the end of life. Committee on care at the end of life. Institute of Medicine. Available from: http://www.nap.edu/openbook.php?record_id=5801 [Last accessed: 4 October 2011].
[6] Murray S et al. (2005). Illness trajectory and palliative care. *BMJ*. 330(7498): 1007–1011.
[7] Report and Recommendations of the Massachusetts Expert Panel on End of Life Care. Patient Centered Care and Human Mortality. (2010)
[8] Temel JS, Greer JA, Muzikansky A et al. Early palliative care for patients with metastatic non-small cell lung cancer. N Engl J Med 3010;363:733-42.

(a) *Extending palliative care from cancer to non-cancer conditions*

Palliative care services, which have traditionally concentrated on cancer patients, have increasingly provided expertise in symptom control for patients with non-cancer conditions[9].

(b) *Extending palliative care to generalists and all health care professionals*

Originally, palliative care developed from the 'grassroots' with committed and concerned individuals coming together. However with time and the increase in knowledge base, specialisation of professionals and organisations took place. Further to this development is the extension of this knowledge base and approach to non-palliative care specialists as well as generalists. Hence, the provision of palliative care is not limited to specialists in palliative care. All health care professionals can play a role in providing palliative care for patients, especially in the community. An example of an initiative to extend palliative care to general practitioners is the Gold Standards Framework in the UK[10] (refer to Annex C for more details).

(c) *Extending and integrating palliative care across all care settings*

Patients with life-limiting illnesses require palliative care in different settings, including at home, during the course of the illness. An integrated system for delivering palliative care allows for continuity of care for the patients. An example is the integrated palliative care system in Edmonton in Canada[11] (refer to Annex D for more details).

(d) *Introducing palliative care early in the course of the disease*

The old concept of switching to palliative mode near the time of death has been replaced by a new paradigm in which palliative care starts early in the course of a progressive disease, often in parallel with disease modifying treatment (see Figure 1). Patients with progressive disease

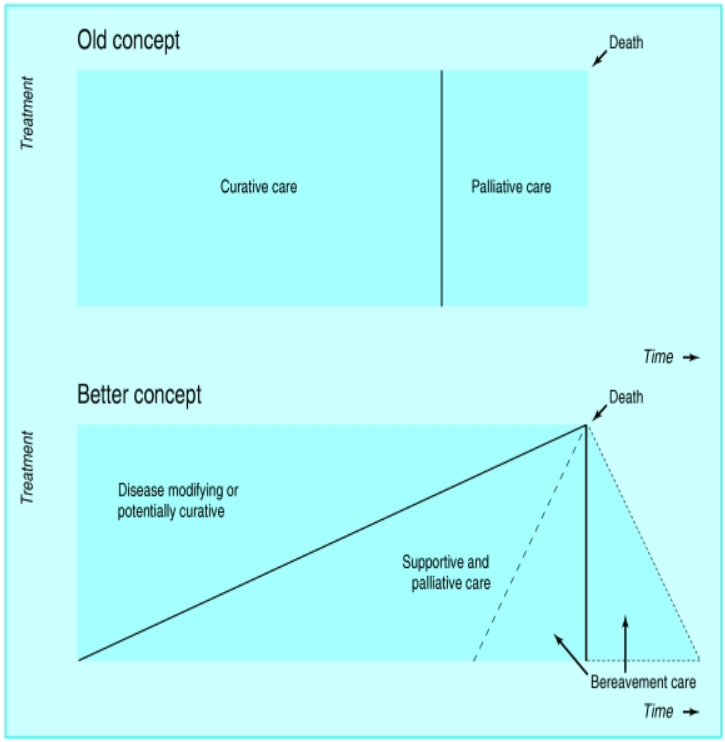
[9] Scott, M. (2008). Care for all at the end of life. *BMJ,* 336:958.

[10] National Gold Standards Framework. Available online: <http://www.goldstandardsframework.org.uk/> [Last accessed: 4 October 2011].

[11] Edmonton Regional Palliative Care Programme. Available online: <http://www.palliative.org/> [Last accessed: 4 October 2011].

often have significant suffering early in the course of the disease and their quality of life can be improved with the introduction and incorporation of palliative care early in the course of the disease[12].

Figure 1: Paradigm shift to introducing palliative care early[12]



(e) *Increasing recognition of the benefits of Advance Care Planning (ACP)*

ACP is a process which enables a patient to express wishes about his or her future health care in consultation with their health care providers and families. ACP helps to ensure that the patient's wishes are respected in the event that the patient becomes incapable of participating in treatment decisions. ACP has been implemented in countries such as the US, UK, Australia and Canada. ACP allows for treatment at the end-of-life to be consistent with the patient's preferences (see Annex E for more details on ACP).

[12] Scott M. et al. (2005). Illness trajectory and palliative care. BMJ, 330(7498):1007–1011.

Quality of Death Index

3.6 The Lien Foundation had commissioned the Economist Intelligence Unit to rank 40 countries on the provision of end-of-life care in the global Quality of Death Index. The Index scored the countries on 24 indicators in four categories: Basic End-of-Life Healthcare Environment; Availability of End-Of-Life Care, Cost of End-of-Life Care; and Quality of End-of-Life Care[13].

3.7 Singapore ranked 2nd among the Asian countries and 18th overall. Singapore was strongest in the category of Quality of End-of-Life Care (11th place) and weakest in the category of Basic End-of-Life Healthcare Environment (30th place).

3.8 While the Quality of Death index gives a measure of the provision of end-of-life in each country, there are some indicators which may not be an accurate reflection of the provision of palliative care, e.g. healthcare spending as a percentage of GDP, number of doctors, hospital beds or nurses per 1,000 non-accidental deaths.

Future development

3.9 Given the demographic trends, the increasing recognition of the needs of patients with life-limiting illness, the benefits of palliative care for cancer and non-cancer patients, and the need to develop effective health care delivery models for patients at the end-of-life, palliative care will continue to develop worldwide to deliver care to patients who need them.

[13] Economist Intelligence Unit. Quality of Life Index. (2005). Available online: The Economist <http://www.economist.com/media/pdf/QUALITY_OF_LIFE.pdf> [Accessed: 4 October 2011].

Chapter 4: Singapore's Landscape

4.1 This chapter begins by examining the demographic and disease trends at the end-of-life in Singapore. This is followed by a description of the development of palliative care in Singapore and the current landscape of service providers and programmes. The chapter ends with an assessment of the strengths and weaknesses of the current system for provision of palliative care in Singapore.

Demographic trends

4.2 With the rapidly ageing population and increase in the number of patients with chronic illnesses who will approach end-of-life as the disease progresses, Singapore's palliative care needs will escalate.

4.3 In 2010, there were a total of 17,610 deaths in Singapore[14]. The number of deaths each year has increased steadily over the last forty years (see Figure 2), due to the population growth, as well as ageing of the population.

4.4 Singapore's population is rapidly ageing due to the longer life expectancy[15] (see Table 2), the post-war baby boomers going into older age groups and the declining birth rates. The Inter-ministerial Committee report on the Ageing Population projected that about 19% or one out of five people will be more than 65 years old in 2030[16]. The population pyramid will transform to a population rectangle as the post-war baby boom generation ages (see Figure 3).

[14] Department of Statistics Singapore. Available online: <http://www.singstat.gov.sg/stats/keyind.html> [Last accessed: 4 October 2011].
[15] Department of Statistics Singapore. Available online: <http://www.singstat.gov.sg/stats/themes/people/demo.html> [Last accessed: 4 October 2011].
[16] Inter-Ministerial Report on the Ageing Population. (1999)Available online: <http://app1.mcys.gov.sg/ResearchRoom/ResearchStatistics/IMCReportontheAgeingPopulation.aspx> [Last accessed: 4 October 2011].

Figure 2: Total number of deaths per year in Singapore[14]

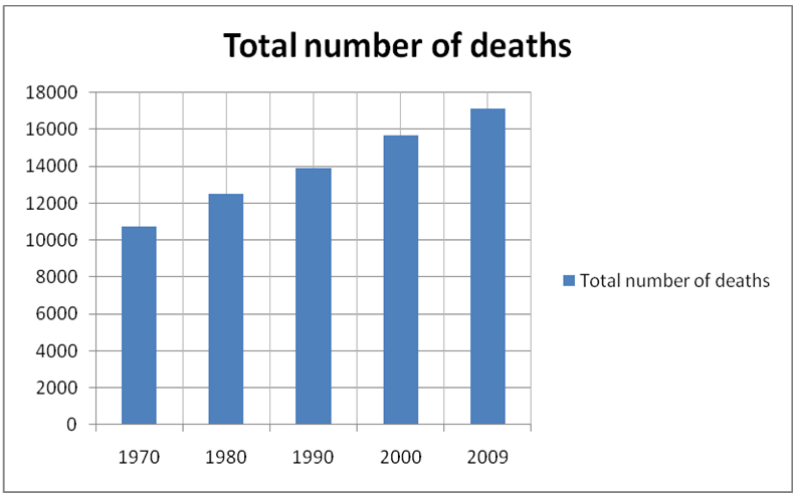
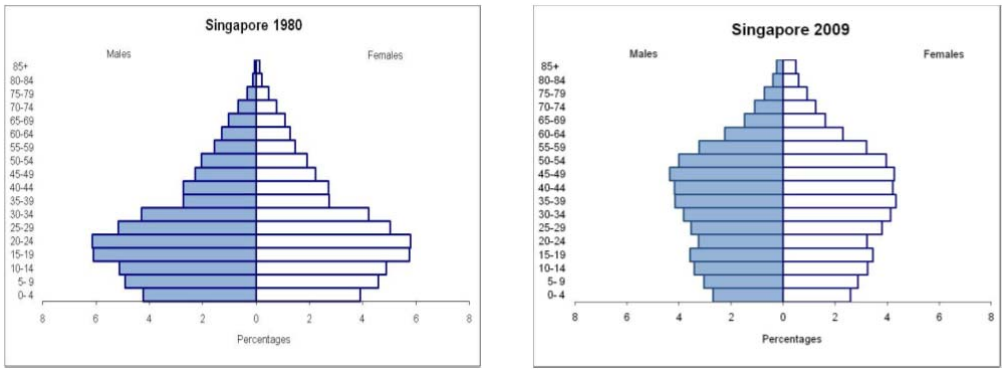


Table 2: Life expectancy at birth in Singapore[15]

Year	1970	1980	1990	2000	2009
Life Expectancy at Birth	65.8	72.1	75.3	78.0	81.4
Males	64.1	69.8	73.1	76.0	79.0
Females	67.8	74.7	77.6	80.0	83.7

Figure 3: Population pyramid for Singapore in 1980 and 2009[17]



[17]State of the Elderly in Singapore 2008/2009. Available online: <http://app1.mcys.gov.sg/Portals/0/Summary/research/State%20of%20the%20Elderly_Release%201.pdf > [Last accessed: 4 October 2011].

Causes of death

4.5 The top ten causes of death in 2007 to 2009 (see Table 3) include cancer, cardiovascular diseases, infections, and end organ failure (e.g. heart, lung and renal failure)[18]. About two out of three deaths were due to non-cancer conditions.

Table 3: Causes of deaths in Singapore (2007-2009)

% of Total Deaths		2007	2008	2009
1	Cancer	27.7	29.3	29.3
2	Ischaemic Heart Disease	19.8	20.1	19.2
3	Pneumonia	13.9	13.9	15.3
4	Cerebrovascular Disease (including stroke)	8.7	8.3	8.0
5	Accidents, Poisoning & Violence	6.0	5.8	5.7
6	Other Heart Diseases	4.3	4.0	4.4
7	Urinary Tract Infections	2.2	2.1	2.5
8	Chronic Obstructive Lung Disease	2.6	2.5	2.4
9	Nephritis, Nephrotic Syndrome & Nephrosis	2.0	2.1	2.3
10	Diabetes Mellitus	3.6	2.7	1.7

4.6 The prevalence of cancer and chronic diseases increases with age and as the disease progresses towards end-of-life, these patients will have increased palliative care needs. The number of people each year who have cancer or chronic diseases at the time of death is expected to increase by about 30% from 8,000 in 2009 to about 10,400 in 2020 (see Table 4).

[18] Principal Causes of Death. Ministry of Heath, Singapore. Available from: http://www.moh.gov.sg/content/moh_web/home/statistics/Health_Facts_Singapore/Principal_Causes_of_Death.html

Table 4: Historical trends and future projections for number of patients with cancer and chronic diseases at the time of death (based on information recorded in death certificate)

Disease Condition	**2007**	**2008**	**2009**	**2020**	**% increase (2020 vs. 2007)**
Cancer	4639	4913	4849	6131	32.20%
Stroke	1783	1675	1592	2461	38.00%
End-stage renal disease	479	691	606	841	75.70%
COPD	468	517	446	489	4.40%
Congestive heart failure	225	240	271	209	-7.00%
Dementia	111	109	80	191	72.40%
Chronic neurological diseases	86	109	114	112	30.10%
Other conditions	8254	7908	8055	9621	16.60%
Total	**16045**	**16162**	**16013**	**20056**	25.00%

Source: Epidemiology & Disease Control Division, MOH

Development of palliative care in Singapore

4.7 The palliative care movement in Singapore had its origins as a grassroots movement in 1985 in response to the unmet needs of patients dying of cancer at home. In 1985, a total of 16 beds were set aside at St Joseph's Hospice for terminally ill patients. In 1987, the Singapore Cancer Society started the Hospice Care Group to provide home palliative care. This was followed by the establishment of Assisi Home and Hospice in 1988, Agape Methodist Hospice Home Care in 1989, Hospice Care Association in 1989, Dover Park Hospice in 1992, Metta Hospice Home Care in 2001 and Bright Vision Hospital in 2002 (see Table 5 for list of palliative care providers).

4.8 Palliative care services in hospitals were developed in the mid-1990s to meet the needs of terminally ill patients who were admitted to hospitals. Over the years, palliative care services have developed in most restructured hospitals (Alexandra/Khoo Teck Puat Hospital, Kandang Kerbau Women's and Children's Hospital, National University Hospital, National Cancer Centre/Singapore General Hospital and Tan Tock Seng Hospital). Changi General Hospital also has staff in training in preparation for formalisation of a palliative care service.

4.9 Some services are looking at expansion. Dover Park Hospice has undergone renovation to increase capacity from 40 to 50 beds. In addition, Assisi Hospice also has intentions to expand beyond its current in-patient capacity of 35 beds. Community Hospitals such as Ang Mo Kio – Thye Hua Kwan Hospital, St Luke's Hospital as well as St Andrew's Community Hospital are all looking at providing in-patient hospice beds.

Agape Methodist Hospice intends to expand their home hospice service and Dover Park Hospice also plans to start a home hospice service. In addition, domiciliary services for the elderly such as Hua Mei Mobile Clinic have started an end-of-life pilot programme extending care for clients under their service to

the terminal phase. They intend to make use of patients' Medisave to support the service.

Table 5: List of palliative care providers in Singapore

Service	Industry/Service Provider
Restructured Hospitals	• Singapore General Hospital/ National Cancer Centre Singapore • Tan Tock Seng Hospital • National University Health System • Khoo Teck Puat Hospital • Changi General Hospital (in planning stages) • KK Women's and Children's Hospital
Inpatient Hospice	• Assisi Hospice • Bright Vision Hospital • Dover Park Hospice • St Joseph's Home
Home Hospice	• Agape Methodist Hospice • Assisi Hospice • Bright Vision Hospital • HCA Hospice Care • Metta Hospice Care • Singapore Cancer Society
Day Hospice	• Assisi Hospice • HCA Hospice Care

HOME Programme

4.10 The AIC-HOME **(**HOlistic care for MEdically advanced patients) Programme (formerly known as National Healthcare Group - Advance Care Programme) is an interdisciplinary programme that provides home palliative care and advance care planning for patients with end-stage organ failure (lung, heart and kidney failure). The programme co-ordinates care with other relevant specialists in the acute hospitals, as well as with other community hospice services, to ensure that patients are cared for optimally and in the most appropriate setting at different stages of their illness. Patients under this programme are at risk of developing acute exacerbations. This home care programme has resulted in improved quality of life and a reduction in

unnecessary hospital admissions (see Figure 4). It has also enabled more patients to be cared at home in the terminal stages, in accordance with their wishes (see Figure 5). The programme is currently available to patients at NUH and TTSH. There are plans to introduce the service to the other restructured hospitals in phases over the next few years.

Figure 4: Re-admissions within six months for patients under AIC-HOME programme vs. historical controls

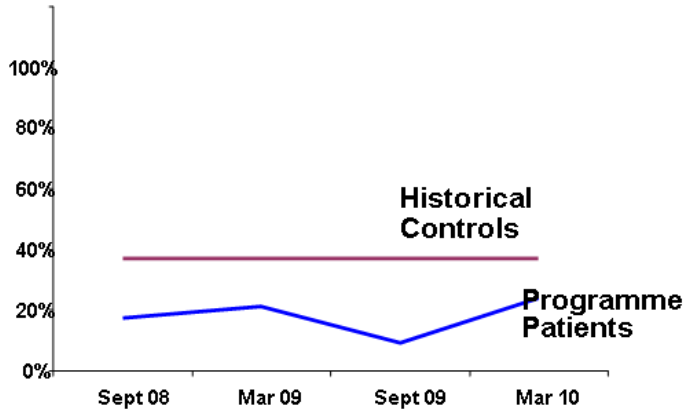
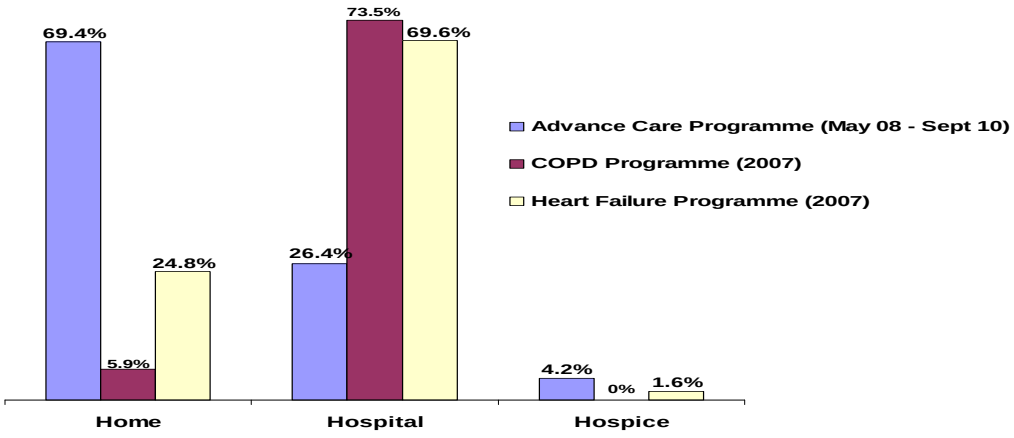


Figure 5: Place of death of patients under AIC-HOME programme vs historical controls

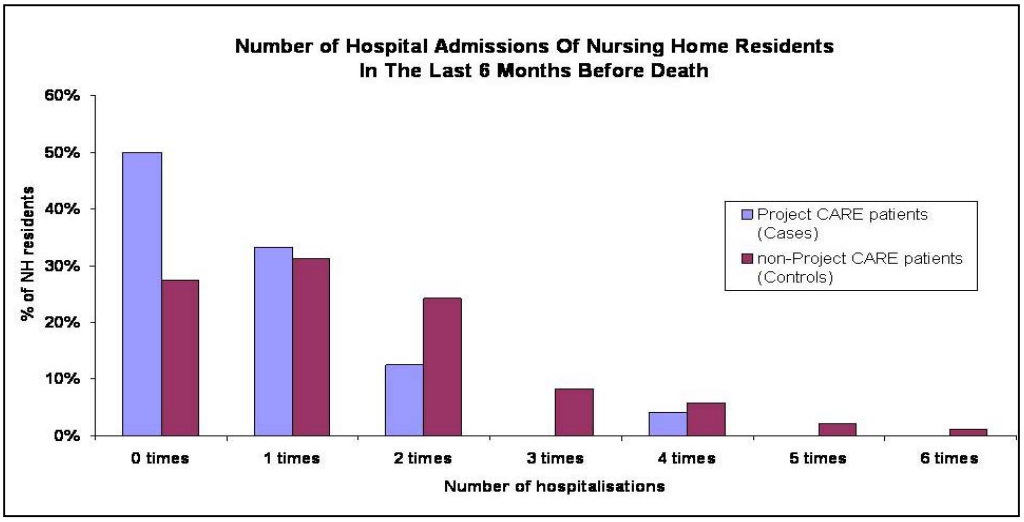


Project CARE

4.11 Project CARE is a pilot program aimed at introducing and implementing palliative care systematically into seven voluntary welfare nursing homes within Tan Tock Seng Hospital's catchment area. It is a collaborative effort of care delivery with the hospital team working with the nursing home team. The key elements of this programme are patient stratification, advance care planning and partnership in terms of provision of end-of-life care. Skill transfer to nursing home staff promotes sustainability and capability building. Preliminary results of this project have been encouraging.

4.12 From the period 1 Sep 2009 to 31 Jul 2011, 1,685 residents had been screened and 65% of eligible residents had advance care planning carried out. Of these, 88.9% died in accordance to the medical preference documented in their Preferred Care Plans. There was less usage of acute care resources as evidenced by hospital admissions in the last six months before death (see Figure 6).

Figure 6: Number of hospital admissions of nursing home residents in the last six months before death



Advance Care Planning (ACP)

4.13 Since the team from Wisconsin, led by Dr Bernard Hammes and Ms Linda Briggs introduced the Respecting Choices® framework to Singapore in 2009, a formalised manner of ACP discussion and documentation has been piloted in a few restructured hospitals, nursing homes and other end-of-life programmes (e.g. AIC-HOME team and Kidney Dialysis Foundation). The National ACP Steering Committee is working closely with AIC and the restructured hospitals to scale up the ACP initiatives. The initiative will increase awareness of ACP and its importance among healthcare workers and members of public; recruit and train more ACP facilitators to assist patients with ACP discussions; and build and strengthen systems, including an IT system to document and honour ACP preferences.

Increasing awareness among healthcare professionals

4.14 Many professional groups have incorporated end-of-life care into their care provision, as well as specialty training. For example, National Neuroscience Institute (NNI) has regular palliative care seminars. The renal teams in various hospitals have been actively referring patients as well as initiating joint projects. Cardiology, Respiratory and Renal teams of TTSH, KTPH and NUH have incorporated end-of-life care into their chronic disease management programme. There is evidence of specialization amongst allied health personnel, social workers and therapists.

Paediatric Palliative Care

4.15 A formal Paediatric Palliative Care Programme has been developed in KKH since 2004. The programme is a collaboration with HCA Hospice Care in order to transit the programme into the community. Assisi Hospice also has a strong tradition of paediatric care with a dedicated family room for children needing palliative care. Asian Women's Welfare Association (AWWA) also

has a Day Care Programme for paediatric patients with chronic life-threatening neurological illnesses.

Bereavement care

4.16 Each palliative care service currently provides its own bereavement support but enlists the help of other organisations (e.g. WiCARE) when necessary. Project Rebuild is a collaboration between Assisi Hospice and the Lien Centre for Palliative Care. It brings together three areas in grief and bereavement care - education, research and clinical services. The project aims to empower the healthcare community with the knowledge and skills in grief and bereavement care, and in understanding the importance of early detection and intervention. A Neonatal Bereavement Volunteer Group operates out of KKH. This is supported by the Children's Bereavement Trust, which is affiliated to a UK group, and is run by bereaved parent volunteers.

Volunteers

4.17 There is a strong volunteer component in care provision by the community hospice groups. They provide both essential as well as value-added services. For example, in FY 2010-2011, HCA Hospice Care, which cares for between 800 and 1000 patients at any one time, had 220 volunteers contributing more than 12,000 hours towards the activities of the organisation. Similarly, Dover Park Hospice, which has a 40-bedded capacity, had volunteers contributing about 16,000 hours in 2010. This is equivalent to $195,000 of manpower cost (Volunteer Investment Value Audit, VIVA ratio of 2.25).

Health financing

4.18 The palliative care services are funded from a combination of government subvention, Medisave, Medifund and out of pocket expenses (see Table 6). There are plans to allow usage of Medisave for home hospice care.

Table 6: Funding of palliative care services

Service	Funding Sources
Hospital-based services	• Government subvention • 3M (Medisave, Medishield, Medifund) • Out of pocket expenses (based on means test)
Inpatient hospice	• Government subvention (based on means-tested rate) • Medisave • Medifund (available at Assisi Hospice and Bright Vision Hospital) • Out of pocket expenses
Home hospice	• Subvention based on blended means-tested rate • Patients are not charged by the various services
Day Hospice	• Funded by National Council of Social Service • Out of pocket expenses

Organisations

4.19 The Singapore Hospice Council (SHC) is the umbrella body of all VWOs providing hospice and palliative care. Hospital-based services are associate members of the SHC. The SHC plays a role in advocacy and coordination of teaching for medical students from the Yong Loo Lin School of Medicine (YLLSoM) NUS.

4.20 Lien Centre for Palliative Care at Duke-NUS Graduate Medical School has taken up some of the education roles previously undertaken by SHC e.g. postgraduate training courses and journal clubs.

4.21 Sub-specialty Training Committee (SSTC) for palliative medicine is responsible for post-graduate sub-specialty training. The Chapter of Palliative Medicine in the Academy of Medicine promotes the professional aspects of palliative medicine. The Singapore Nursing Board accredits the nursing curriculum.

Current Landscape of Palliative Care Education in Singapore

4.22 At present, palliative care education for medical, nursing and allied health professionals is provided by a variety of healthcare and educational institutions.

4.23 Palliative medicine is represented in the undergraduate curriculum of both medical schools, and in some residency programmes e.g. internal medicine, family medicine and anaesthesia (as core or elective). Since 2007, there has been accredited Subspecialty training under the auspices of the JCST (Joint Committee for Specialist Training). The Academy of Medicine, Singapore, also runs an SRS (Staff Registrar Scheme) programme for Palliative Medicine.

4.24 In addition, there are "in-house" training activities, usually in the form of lectures or workshops, for medical officers and residents doing certain postings e.g. Palliative Medicine, Oncology, Geriatrics, in certain healthcare institutions. These are "needs-based" education activities aimed at equipping junior doctors with the requisite knowledge and skills for that particular posting.

4.25 The Singapore Hospice Council (SHC) Postgraduate course in Palliative Medicine has just completed its 26th run and is probably the longest established, regular education activity. This 2.5 to 3-day course is open to all doctors in Singapore. It is now run by the Lien Centre for Palliative Care, and is attended by doctors from a wide range of backgrounds, from house officers, to family physicians and senior specialists.

4.26 The range of palliative education activities for nurses is more diverse, and is offered by a variety of institutions (including the private sector e.g. Parkway College), aimed at the whole range of nursing, from nursing aides to advanced nurse practitioners with Masters degrees. Many of these palliative

education activities are modules within a generalist nursing curriculum, but there are more focused courses e.g. Certificate in Basic Palliative Care Nursing run by Dover Park Hospice, Advanced Diploma in Nursing (Palliative Care) offered by Nanyang Polytechnic and a Specialist Diploma (Palliative Care) to be offered by Ngee Ann Polytechnic.

4.27 There is a dearth of palliative care education opportunities for allied health personnel. A Palliative and End-of-Life Care course has been developed for the Graduate Social Work Programme of NUS (there is no formal component in the undergraduate curriculum). The Medical Social Worker Chapter of the Singapore Association of Social Workers organises “Grief and Bereavement” modules for new Medical Social Workers. The Pharmaceutical Society of Singapore organises a pharmacy course for nurses working in the palliative care setting every two years.

4.28 The only established inter-professional palliative care educational activity in Singapore is the Flinders University Graduate Certificate in Palliative Care, which is run by the Lien Centre for Palliative Care (LCPC) in partnership with the National Cancer Centre, Singapore (NCCS), and Flinders University of South Australia. Now approaching its 6th year in Singapore, the course is a distance-learning one, with two 10-day intensives held at NCCS. Successful graduands may proceed on to the Masters programme of Flinders University. However this course is considered an academic one, and not equivalent to clinical specialist training.

4.29 There is no official central coordinating body for palliative care education except for specialist level training, although within the palliative care community there is often internal consultation. Individual course providers design and deliver the training, while bodies like the Singapore Medical Council and Singapore Nursing Board to accredit the activities. The somewhat *ad hoc* nature of education landscape is partly explained by the history of

development of palliative care itself, which was characterised by passionate and enthusiastic individuals and groups responding to perceived needs.

Strengths

4.30 The strengths of the current system include:

(a) Palliative care is increasingly becoming part of mainstream medicine and acknowledged as an essential part of the healthcare system;
(b) There are many dedicated and passionate health care professionals in the palliative care sector;
(c) There is a strong volunteer corp in the VWOs, consisting of professionals as well as lay volunteers;
(d) Some degree of coordination exists between service providers and palliative care is currently available in almost all settings;
(e) Palliative care education and training have developed to cater to various disciplines and various levels, and have increased in sophistication through the years.

Weaknesses

4.31 The weaknesses of the current system include:

(a) Service providers sometimes work in silos and care provided to the patient is not as well-coordinated as it should be;
(b) Capabilities of service providers are not uniform;
(c) There is a shortage of health care professionals in the palliative care sector;
(d) Palliative care is sometimes regarded as supportive and dispensable in the healthcare system;
(e) Bereavement care and ACP programmes are in early stages of development;
(f) There is no specific accreditation for palliative care providers;

(g) Referral guidelines to the various palliative care services are not clear (e.g. community hospitals, palliative care specialists, inpatient hospices, home hospice, day hospice)

(h) Lack of standardized norms between hospice services in terms of data collection and standards of care;

(i) Overall co-ordination and leadership in sector can be improved;

(j) The role of family practitioners in providing palliative care is currently limited.

Chapter 5: Goals of Strategy and Recommendations

Goal 1:

All patients with life-limiting illnesses should be identified and their palliative care needs assessed.

5.1 All patients with life-limiting illness should have access to palliative care. Life-limiting illness is defined as a progressive and advanced illness with a limited prognosis (although this may be several years) and the focus of care is quality of life.

5.2 The first step is to identify patients with life-limiting illness so that their palliative care needs can be assessed. Patients who are identified late in the course of the illness usually have poorer outcomes of care and unnecessary hospital admissions. Early recognition of people nearing the end-of-life allows for anticipation of potential problems and planning for the care needs.

5.3 Several tools are available to assist with identifying the target population. The Gold Standards Framework Prognostic Criteria was developed to identify patients in primary care with any condition predicted to be in the last 6-12 months of life[19]. Other tools available for determining the prognosis include the NHPCO (National Hospice and Palliative Care Organization) guidelines, disease-specific prognostic tools and the "surprise" questions.

5.4 Beyond identifying patients with life-limiting illness, the Gold Standards Framework (GSF) has a simple assessment tool for comprehensive assessment of palliative care needs. Although the GSF was originally developed in the primary care setting, it has been adapted for use in other healthcare settings such as hospitals and nursing homes.

[19] National Gold Standards Framework [Internet]. National Gold Standards Framework Centre; 2011 Available from : http://www.goldstandardsframework.org.uk/

5.5 Recognising the importance of early identification and assessment of palliative care needs of patients with life-limiting illnesses, all health care institutions caring for patients with life-limiting illnesses should have a system to identify these patients early and assess their needs. Palliative care should be extended from cancer patients to include more non-cancer patients with life-limiting illness. Chronic disease management programmes (which manage patients with progressive organ failure), cancer programmes and nursing homes should have guidelines to systematically identify and assess patients who require palliative care.

Recommendations:

Ensure that all health care institutions caring for patients with life-limiting illnesses have a system to identify these patients early and assess their needs.

Palliative care should be extended from cancer patients to include more non-cancer patients with life-limiting illness.

Chronic disease management programmes, cancer programmes and nursing homes should have guidelines to systematically identify and assess patients who would benefit from palliative care.

Goal 2:

All patients with life-limiting illnesses should be cared for by health care professionals using a palliative care approach.
Patients with complex needs should have access to specialised palliative care services.

6.1 Patients with life-limiting illness will require different levels of care in different settings, depending on their needs and the trajectory of their illness. As stated in the WHO definition, palliative care is an *approach* that improves the quality of life of patients and their families facing the problems associated with the life-threatening illness. Health care professionals at all levels and across all settings should be encouraged to adopt the palliative care approach when treating patients with life-limiting illnesses. Patients should be managed by the appropriate health professionals (including GPs) and in the appropriate setting (including primary care and nursing homes), depending on the complexity of their needs.

6.2 Patients with complex needs should have access to specialised palliative care services. A Specialist Palliative Care (SPC) Professional is a medical, nursing or allied health professional, recognized as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available), who provides primary or consultative care to patients with life-limiting illnesses[20].

6.3 A Specialist Palliative Care (SPC) Service is a service provided by a cohesive interdisciplinary team of specialist palliative care professionals whose main focus of work is the provision of palliative care.

[20] Radbruch, L., Payne, S. and Board of Directors of the EAPC (2009). Standards and Norms for Hospice and Palliative Care in Europe. The EAPC White Paper. European Association of Palliative Care. Available online: <http://www.hospicefriendlyhospitals.net/_assets/_resources/_5-resources-and-courses/EAPC_White_Paper_EU_Norms_Pal_Care_Draft.pdf> [Last accessed: 4 October 2011].

6.4 Due to the complex and interacting needs of patients, palliative care is in many settings optimally delivered through multidisciplinary teams. The multidisciplinary teams may include specialists in palliative care, other specialists, nurses, medical social workers, pharmacists, physiotherapists, occupational therapists and other health care professionals.

6.5 Specialist palliative care service delivery requires a multi-professional team with an interdisciplinary work style. The core palliative care team should consist of nurses, physicians and social workers/counselors with special training, supplemented by psychologists, pharmacists and physiotherapists if possible. Other professionals can be members of the core team, but more frequently will work in liaison with the team. It is desirable for specialist palliative care services to include volunteers or collaborate with volunteer services.

6.6 Complex needs may derive from the patient, carer or health care team and the help required may be intermittent or continuous, depending on the level of need and rate of disease progression. Examples of complex levels of need include[21]:

(a) Physical symptoms - uncontrolled or complicated symptoms, specialized nursing requirements, complex mobility, functioning or self care issues.
(b) Psychological - uncontrolled anxiety or depression, cognitive or behavioural issues.
(c) Social - complex situations involving children, family or carers, finance issues, communication difficulties and patients with special needs.
(d) Spiritual - unresolved issues around self worth, loss of meaning and hope, requests for euthanasia, unresolved religious or cultural issues.
(e) Ethical - conflicting interests involving ethical principles, help facilitate decision making by patient, family or care team.

[21] North Yorkshire and York Palliative Care Group. Eligibility criteria for Specialist Palliative Care Services. 2005.

Recommendations:

Ensure that all healthcare professionals have a palliative care approach to the care of patients with non-complex end-of-life needs.

Ensure that all patients with complex needs have access to specialised palliative care services in the appropriate setting, with multidisciplinary team support.

Goal 3:

Palliative Care should be delivered in a coordinated manner that ensures continuity of care across settings and over time.

7.1 Many patients and families facing life-threatening illness will have palliative care needs, but the level of need will vary between patients, and in the same patient over the course of the illness trajectory. Thus patients are likely to receive palliative care from different providers depending on the location of care, and level of need. Patients may also require care in various settings such as acute hospital, community hospital, nursing home, primary care or at home.

7.2 To ensure seamless, continued care across settings, the health system should be structured to allow for collaboration and coordination between health care providers. The system for the delivery of palliative care should be based on the Regional Health System model, with effective collaboration between public, private and VWO providers.

7.3 Restructured hospitals in all Regional Health Systems should have specialised palliative care services with multidisciplinary teams. All Regional Health Systems should have as a minimum, a home hospice service and inpatient hospice service incorporated into the network of care.

7.4 Inpatient hospices may be free standing or be part of a community hospital. The main role of the inpatient hospice is the management of patients with complex palliative care needs. Hence, the facility must have the capability to handle such patients.

7.5 Platforms for discussion between health care providers from different settings within the Regional Health Systems will allow for joint decision-making, care planning and anticipation of the patient's future needs. Information technology (electronic health records/telemedicine/teleconference) should be used to facilitate collaboration and communication between providers to ensure continuity of care for patients. The ideal situation would be where each

transition by the patient to a different level of care or to a different setting is planned and anticipated as far as possible, in order to avoid the default course of action through an emergency department and admission to an acute hospital.

7.6 There is a need to develop uniform admission and discharge criteria at all levels of care to promote effective coordination and integration of services. In view of the differences in trajectories of dying, it is envisaged that certain settings are more suitable for particular categories of patients who require institutional care, e.g. nursing homes for the very frail with inadequate home support, hospices for cancer patients, and acute hospitals for crisis management of exacerbations of chronic diseases.

7.7 To encourage greater family practitioner involvement in end-of-life care of patients at home, innovative practices may have to be employed. Consideration should be given to provide incentives for setting up group practices with a member of the team taking turns to care of patients at home and at nursing homes. In addition, consideration should be given to incorporate community based home nursing by these groups. One example is the strong GP network in the UK, where district and community nurses work together to support the GP in providing palliative care in the community.

7.8 Such practices can work with specialised home hospice teams or nursing home teams (e.g. Project CARE) to provide specialised palliative care when the complexity of the case exceeds that of the family practitioner's capability.

Recommendations:

Organize the delivery of palliative care based on the Regional Health Systems model, with effective collaboration between public, private and VWO providers.

There should be effective coordination of care within each Regional Health System.

Establish specialised palliative care services with multidisciplinary teams in all restructured hospitals.

All Regional Health Systems should have as a minimum, a home hospice service and inpatient hospice service incorporated into the network of care. Inpatient hospices may be free standing or part of a community hospital.

Ensure suitable platforms for communication between service providers to plan and coordinate care, including maximizing the use of information technology.

Establish well-defined roles and criteria for referral to the various palliative care services.

Encourage the involvement of primary care physicians/GPs in the care of patients with palliative care needs at home and at nursing homes.

Goal 4:

Palliative Care should be affordable to all who need it and quality care should be provided in a cost-effective manner.

8.1 Considering that (i) patients who require palliative care need different levels of care and in different settings; and (ii) affordability is an important factor determining access to palliative care services, it is important to design appropriate financing structures to support the delivery of good quality palliative care services in the health care institutions and at home.

Recommendations:

Ensure that financing structures support the development and delivery of good quality, appropriate and affordable palliative care in the health care institutions, community and at home.

Goal 5:

There should be adequate health care professionals with the appropriate training to meet the needs of patients at the end-of-life.

9.1 An Australian workgroup[22] estimated the population for palliative care as between 50% to 89% of all dying patients, using different approaches in a conceptual framework. Whereas a general palliative care approach will provide adequate care for many of these patients, it has been estimated that 20% of cancer patients and 5% of non-cancer patients will require specialist palliative care in the last year of life. This is a conservative estimate as symptom load and palliative care needs are often not recognised. The projection for Singapore in the year 2020 is approximately 1,200 cancer patients and 700 non-cancer patients who will require support from specialist palliative care services at any one time.

9.2 The above estimates make the assumption that general, non-specialist palliative care is well-developed and readily accessible. In addition, the percentage of non-cancer patients requiring specialist palliative care may rise if the barriers to access are overcome.

Table 7: Proposed service norms of overseas services

FTE Per 100,0000 Population	Australia 23	United Kingdom 24	Singapore (Current)
Consultant	1.5	0.8	0.32
Registrars	1.25	0.9	0.19

9.3 To meet specialist palliative care needs, Palliative Care Australia recommends 1.5 consultants and 1.25 specialist registrars per 100,000 population. The recommendations from the UK are 0.8 and 0.9 respectively. For this, the estimated local numbers are in the parentheses in the table. The current number of SAB accredited specialists in palliative medicine is 33.

[22] McNamara B, Rosenwax LK, Holman CD. (2006). A method for defining and estimating the palliative care population. J Pain Symptom Manage 32:5-12.

However, many are not working as full-time specialist palliative care physicians. It is estimated that only about 16 FTE palliative care physicians are covering specialist services currently and there are 9.5 FTE registrars in training. This is equivalent to 0.32 consultant and 0.19 registrar FTE per 100,000 population. The recommended establishment for medical staff in an in-patient facility is in table 8 below.

9.4 For nursing establishments, the recommended staffing in the table below way exceeds that present in our current in-patient settings as well as that in a 2003 MOH paper, which recommended a nursing staff ratio of 1:1.3 beds. The staffing mix in these countries also do not take into account nursing aides or patient care assistants, which contribute towards manpower count in our ILTC community. In order for hospices to care for the complex needs of patients as detailed in para 6.6, a review of staffing norms is recommended. A staffing ratio of between 0.9 – 1.1 per inpatient bed would be recommended for in-patient facility which is prepared to care for more complex patients.

Table 8: FTE (Full Time Equivalent) per in-patient hospice bed

Healthcare Professionals	**USA[23]**	**Europe[24]**	**Australia[25]**
Doctors	0.08 :1	0.15 : 1	0.04:1*
Nurses	1.5:1	1-1.2:1	1.4:1**

** Refers only to resident medical officers and not to registrars and consultants.*
*** Recommended is 6.5 hours per patient (based on replacement ratio of 1.4, this is equivalent to 1.4).*

9.5 Though Singapore is more akin to Hong Kong, Taiwan and Japan culturally, norms in these countries were not taken into account due to wide variation in

[23] Recommendations from Centre for Advancement of Palliative Care.
[24] Radbruch, L., Payne, S. and Board of Directors of the EAPC (2009). Standards and Norms for Hospice and Palliative Care in Europe. The EAPC White Paper. European Association of Palliative Care.
[25] Currow DC, Nightingale EM (2003). "A planning guide": developing a consensus document for palliative care service provision. *MJA*; 179:S23-S25.

practice in these countries and the lack of easily available source of information. In addition, other than Taiwan, which was ranked above Singapore in the International Quality of Death index, the other countries were all ranked below Singapore.

9.6 To ensure that the training and educational infrastructure is able to meet the anticipated demand in manpower, there should be mandatory training in basic principles of palliative care for all healthcare professionals providing direct patient care. MOH should also ensure that palliative care is part of the curriculum in medical schools, nursing schools, allied health schools, residency programmes, specialty training boards and post-graduate programmes. A framework is essential in this review and would include (but not confined to):

(a) Curriculum review to ensure currency and relevance;
(b) Matching training to learning needs and patient needs;
(c) Review and design of learning materials and platforms;
(d) Development of teaching methods in line with pedagogy principles.

Recommendations:

Ensure that there is adequate trained staff to deliver quality palliative care.

Ensure that health care professionals are provided with the necessary training to provide the appropriate level of palliative care for patients.

Incorporate palliative care training in all undergraduate and diploma courses for doctors, nurses and allied health professionals to ensure that all new health care professionals have basic knowledge in palliative care.

Develop a framework to review the curricula to match the competencies required for health care professionals at all levels for doctors, nurses and allied health professionals.

Goal 6:

There should be adequate capacity to meet the palliative care needs of patients.

10.1 In-patient hospices cater predominantly to cancer patients currently. From FY 2009-2010, only 11% of patients admitted to the hospices have a non-cancer aetiology. The utilization rate for in-patient hospices was around 15% of all cancer deaths. This is at the lower end of estimated requirement (15-25% hospice bed utilization for cancer patients) in countries with more developed hospice and palliative care services. The average length of stay ranged from 24.5 days to 40 days. Most of the patients were admitted from restructured hospitals rather than from home, suggesting that the majority of patients were still admitted to restructured hospitals for symptom control. In Dover Park Hospice, where 90% of patients are admitted from the hospitals, a third of patients die within one week of admission. These factors suggest that hospice bed utilization is not optimised and that more patients are cared for in acute hospitals than necessary.

10.2 The recommendations for palliative beds from Australia and the UK are stated below (see Table 9). With the anticipated increase contributed by the renovation in Dover Park Hospice (bringing the number of available beds from 127 to 137), the number of palliative care bed per 100,000 population is 2.7 locally.

Table 9: Recommended norms for inpatient palliative care beds

	Australia[26]	**UK**[27]
In-patient palliative care beds per 100,000 population	**6.7**	**5.1**

[26] Currow DC, Nightingale EM (2003). "A planning guide": developing a consensus document for palliative care service provision. *MJA*; 179:S23-S25.
[27] Radbruch, L., Payne, S. and Board of Directors of the EAPC (2009). Standards and Norms for Hospice and Palliative Care in Europe. The EAPC White Paper. European Association of Palliative Care.

10.3 This figure cannot necessarily be adopted locally due to the differing demographic make-up, size of country, differences in domiciliary support, availability of other ILTC services as well as public receptiveness. Factors that may ameliorate demand include greater availability of palliative care at home or at nursing homes as well as public perception on hospice care. Nevertheless, with only 127 licensed beds (137 by end September 2011), consideration should be given to a gradual increase in supply of hospice beds. In addition, consideration should also be given to the differing capabilities of the various hospices in planning for more in-patient hospice beds.

10.4 Nursing homes are also more ideally suited to care for patients who are deteriorating according to the frailty trajectory (see Annex B). Specialized home hospice services (such as Project CARE team and other hospice home care providers) can provide coverage for periods when the care needs exceed the capabilities of staff on site. As such, it would be useful in nursing home accreditation to have essential end-of-life care elements incorporated into licensing or accreditation requirements.

10.5 Domiciliary services for the elderly who currently provide home care to the frail elderly should ensure that their services are able to provide round-the-clock service to those with non-complex end-of-life care needs. For patients who have complex needs, there should be consideration for partnership or referral to specialised home hospice services.

10.6 Specialised home hospice services should be adequately resourced to provide support to patients at the end-of-life. Local figures suggest an ideal ratio of 1:25 patients for nurses. This is comparable to home hospice services in other countries (e.g. Silver Chain). Such palliative care nurses also work in partnership with other community-based nurses.

Recommendations:

Calibrated increase in inpatient hospice beds to meet the needs of palliative care patients and to function as training resources for all cadres of staff.

Increase the capabilities of nursing homes to take care of end-of-life patients. Include end-of-life care elements in clinical audit requirements for nursing homes.

Ensure adequate home hospice care provision to meet the needs of palliative care patients.

Goal 7:

There should be local standards of care to ensure the delivery of good quality palliative care.

11.1 Currently, other than acute hospitals who are accreditated by the Joint Commission International (JCI), there are no nationally mandated minimum standards in the care of patients who are near the end-of-life. To this end the committee recommends that local evidence-based standards of care and common outcome indicators be developed.

11.2 With the development of standards, a basic requirement in the review and evaluation of the quality of palliative care delivery is the collection, reporting and analysis of standardized, nationally agreed upon minimum data. This is already present in many of the countries which have well-established hospice and palliative care services.

11.3 In Australia, this is provided at two levels. Firstly, Australia's national agency for health and welfare statistics, the Australian Institute of Health and Welfare, mandates reporting of palliative care performance indicators, as recommended in their national strategy for palliative care[28]. In addition, this framework is further supported by an Australian Government Health and Ageing department-funded voluntary quality initiative – it's Palliative Care Outcomes Collaborative[29]. This national benchmarking exercise resulted from the Australian National Strategy for Palliative Care (2000)[30] and aimed to meet the one of the goals - "to support continuous improvement in the quality and effectiveness of palliative care service delivered across Australia".

[28] National Minimum Data Sets. Available online: <http://www.aihw.gov.au/national-minimum-data-sets/> [Last accessed: 4 October 2011].
[29] Palliative Care Outcomes Collaboration. Available online: <http://ahsri.uow.edu.au/pcoc/index.html> [Last accessed: 4 October 2011].
[30] Palliative Care Australia. (2005). Standards for Providing Quality Palliative Care for all Australians. Deakin West, ACT, Australia.

11.4 In the UK[31], the national minimum dataset for specialist palliative care is administered by the National Council for Palliative Care and has been in existence for more than ten years. A similar dataset is used in Scotland, administered by Scottish Partnership for Palliative Care. This allows for national benchmarking of services, population-based needs assessment and trend analysis.

11.5 In the USA, the National Hospice and Palliative Care Organisation compiles information from the National Data Set[32]. This consists of programme descriptives, patient descriptives, as well as information on care delivery and financing. Similar to our local system, many of the healthcare institutions in the USA also subscribes to accreditation by the Joint Commission International, which requires maintenance of standards of care for patients at the end-of-life.

11.6 Within Singapore, MOH is piloting the interRAI suite of tools, in particular home care and long term care (LTC) suites, in the residential and LTC settings. The objective is to use these tools to assist in the right siting of patients across the transitions and also to raise the clinical quality of care in these settings. Within the numerous interRAI tools, there is a Palliative Care suite which will help the patients to transit from one level of care to another. While it is not designed for the day-to-day monitoring of patients' progression, the common elements across the care suite will "ensure comparability across a wide range of settings and client groups", thus reducing the need for separate assessments and paperwork e.g. pressure sore risk, nutritional assessment, activities of daily living, cognition and mood. It comprises comprehensive multi-dimensional assessment items that will help to trigger and highlight needs, risks and potential for improvement for assessors to act upon through care plans. It is currently used in Canada, Belgium and Finland. This tool has the benefit of being uniformly applicable as the patient crosses

[31] The Minimum Data Set (MDS) for Specialist Palliative Care Services. Available online: <http://www.ncpc.org.uk/page/MDS> [Last accessed: 4 October 2011].
[32] National Hospice and Palliative Care Organization. National Data Set 101. Available online: <http://www.nhpco.org/files/public/Statistics_Research/nds-101.pdf> [Last accessed: 4 October 2011].

settings of care and may also be used for international benchmarking if more countries use it.

11.7 A tool can be selected from any of the above-mentioned, or developed locally, to ensure uniformity in collection and reporting of statistics and performance indicators.

11.8 It is proposed that hospices be classified under a separate category in the PHMC Act. Accreditation of hospices and specialised home hospice services would then, necessarily involve more specific yardsticks pertaining to hospice care rather than nursing home and other non-palliative care specific domiciliary services.

Recommendations:

Establish local evidence-based standards of care and common outcome indicators.

Establish a minimum dataset for collection of quality and service indicators/data to evaluate quality of care and for service planning.

Establish accreditation system for palliative care service providers.

Goal 8:

The acceptance and public awareness of palliative care services, advance care planning and bereavement services should be promoted.

12.1 It is important to promote greater public awareness and understanding about palliative care. Misconceptions or simply lack of awareness about palliative care, as well as how society views death and dying, will affect people's healthcare seeking behaviour. For example, patients and/or family members may carry the misconception that palliative care is meant only for patients at the end-of-life and associate it with giving up hope and treatment, thereby refusing appropriate care.

12.2 The Singapore Hospice Council and the Lien Foundation have been working in partnership to raise public awareness about hospice and palliative care in Singapore. The Singapore Hospice Council publishes a quarterly newsletter (HospiceLink) and organizes Hospice Awareness Week every other year. In 2006, the Council teamed up with the Lien Foundation to launch an inaugural year-long "Life Before Death" campaign to raise public awareness about hospice and palliative care in Singapore. In 2010, a Quality of Death Index ranking end-of-life care across the world was commissioned by the Lien Foundation. This again brought hospice and palliative care into the public consciousness.

12.3 To raise awareness and change attitudes towards palliative care, a concerted effort is needed across the healthcare and community sector, including MOH, the restructured hospitals, community service providers, organisations such as the Lien Foundation, Lien Centre for Palliative Care, Singapore Hospice Council, as well as other relevant groups. Mindsets will not be changed overnight. The Lien Foundation and Singapore Hospice Council's efforts to promote greater public discourse on issues concerning death and dying have been effective in creating greater public awareness about hospice and palliative care. These organizations should continue to champion and lead these public initiatives, with support from the relevant stakeholders.

12.4 Many healthcare professionals have identified the lack of open discussion on death, dying and end-of-life care issues between healthcare staff, patients and their caregivers, as one of the key challenges faced in promoting and providing good palliative care. Advance care planning (ACP) provides the opportunity for such open communication and more should be done to promote awareness and clarity on what it entails.

12.5 It is important that the intentions of ACP do not become misconstrued and misinterpreted as euthanasia or healthcare rationing. Hence, it is important to develop a consistent set of messages with regards to ACP and adopt a multi-pronged approach to engage all relevant stakeholders including healthcare professionals, community and religious leaders, patients and caregivers, as well as the general public.

12.6 Under the guidance of the ACP Steering Committee, AIC should work in partnership with the hospitals, ILTC sector and primary care to reach out to healthcare workers and trainees in the medical, nursing and allied health professions through awareness talks, workshops and courses. The engagement strategy should also include medical, nursing and allied health students entering the workforce through collaborations with the academic institutions. Awareness talks should be conducted at these institutions for graduating medical, nursing and allied health students, with ACP eventually incorporated into the curriculum.

12.7 On the community front, leaders from relevant groups such as grassroots and religious organisations should be engaged. Focus group discussions can be conducted with them to consult and garner feedback on appropriate strategies to promote ACP to the community at large, and to obtain their buy-in and support. As these leaders become better informed about ACP, they can also assist their respective groups in learning more about the relevant issues. Discussions on end-of-life treatment preferences may occur in many settings outside of healthcare organisations, particularly religious organisations.

Developing good working relations with these groups will likely contribute to the success of promoting awareness and acceptance of ACP.

12.8 Capturing attention regarding the importance of ACP and developing effective programmes to educate and motivate people to participate in ACP will be a challenge. In addition to good community partnerships, developing engaging educational materials that deliver consistent and clear messages should be part of the strategy. The materials should be made easily available such as placing them at strategic locations like hospital lobby and waiting areas, and all healthcare staffs, including those at the frontline, should know where to access the materials if asked. Sharing of stories and experiences through the media from healthcare professionals, patients and caregivers who have or would have benefited from ACP is another powerful and effective approach. With guidance from the community engagements, AIC can work with the Lien Foundation and the Health Promotion Board or other appropriate agencies on wider engagement efforts to the general public.

12.9 Bereavement support is another important area in palliative care. The Lien Centre for Palliative Care has been championing efforts to promote greater awareness on issues of grief and loss through Project REBUILD, a community bereavement project funded by the Tote Board and the Lien Centre for Palliative Care. Yearly events including a public and professional forum are organized in conjunction with the World Hospice Day. This initiative, whose forums have been oversubscribed indicating strong interest in the area, should be continued and perhaps, incorporated into the regular activities of the Singapore Hospice Council.

Recommendations:

Ensure a coordinated and concerted effort across the health and community sector to promote awareness of palliative care.

Promote advance care planning as an opportunity for open communication between healthcare professionals, patients and caregivers.

Develop clear and consistent messages on advance care planning.

Ensure all healthcare professionals have basic awareness of advance care planning, including those entering the workforce.

Develop good community partnerships by engaging relevant groups including key religious and grassroots organisations to promote awareness and acceptance of advance care planning.

Incorporate grief and bereavement initiatives into the regular activities to promote hospice and palliative care.

Goal 9:

Palliative care research should be promoted to improve the quality of palliative care and inform policy making.

13.1 While the literature review indicates that palliative care is generally valuable in promoting symptom relief, patient and family quality of life, and access to care, it is not clear what specific strategies are especially effective and in which specific contexts. These questions are of practical importance as some strategies (e.g., round-the-clock access, multidisciplinary teams) involve significant investment in time and resources, which may not be justified based on marginal effectiveness. Conversely, while community-based programs appear to be more effective than no palliative care, it is not clear whether tertiary-care based programs could, for some individuals, be replaced by community-based programs that are relatively inexpensive.

Promising strategies with little evidence

13.2 In our literature review, several strategies appear to be promising but had a dearth of good quality evidence. Examples include:

(a) *Round-the-clock access to palliative care services*: The review found that there is a perceived need by health care professionals for round-the-clock services. However, there is inadequate evidence examining the effectiveness of providing such services in improving patient and family outcomes.

(b) *Use of care pathways and guidelines*: Theoretically, developing and utilizing standards of care based on best evidence should be able to improve care and potentially improve efficiency through streamlining care. Except for a single RCT of the AHCPR guideline on cancer pain management, current evidence is limited to cross-sectional and case-control studies. There is a need to have good quality evidence, such as that provided by randomized control trials, to demonstrate the

effectiveness of using care pathways and guidelines in improving desired outcomes.

(c) *Providing community-based services*: Evidence indicates that providing palliative care in the community is better than providing no palliative care, yet there is little evidence that these services can substitute for palliative care provided through tertiary care hospitals.

(d) *Development of tools for prognosis, triggering referral to palliative care services*: Though there are many prognostic and trigger tools available to identify patients with palliative care needs, the effectiveness of these tools in improving patient outcomes and access to care needs to be evaluated.

(e) *Palliative care strategies specific to children*: Children with advanced cancers or other non-cancer life threatening conditions and their families may have different needs and thus may require specially tailored services. There is currently little evidence of the type of strategies that may be effective in providing care to this group.

(f) *Palliative care for patients with end-stage conditions other than cancer* (end-stage heart failure, end-stage chronic obstructive pulmonary disease, end-stage renal failure, dementia and other life limiting neurological conditions): Patients with these conditions have a different trajectory of illness compared to advanced cancer patients, and thus different palliative care needs.

Strategies of particular relevance to Singapore

13.3 Singapore presents a context that is distinctive in several ways that might affect the impact of specific strategies. These contextual issues include language and culture, health care system and financing, a labour market in

which both spouses are working and a substantial reliance on foreign domestic workers. These strategies that deserve particular attention include:

(a) *Optimal management of pain*: Current reports from Singapore suggest that there may be suboptimal management of pain among cancer patients, resulting from a reluctance to prescribe opioids due to fear of hastening death. More research may be needed to study the attitudes of health care providers towards management of moderate and severe pain as well as the effectiveness of having clinical practice guidelines in achieving optimal pain management.

(b) *Providing support to caregivers of terminally ill patients*: In Singapore there are very strong expectations that families care for older family members. As more Singaporeans die from chronic diseases, the dependence on family for providing care to the terminally ill elderly is likely to grow. There is a need to develop and evaluate strategies to support caregivers in Singapore.

(c) *Use of technology in palliative care*: Singapore is a highly wired and technologically savvy society which nevertheless makes modest use of these capabilities in improving access and quality of care, such as through the use of telehealth based on the new fibre-optic network.

(d) *Organization of palliative care in Singapore*: There is a need to study how this arrangement might be organized in Singapore and whether such model of care would be feasible to develop and sustain (subject to financial, manpower, and other resource constraints) in an effective and cost-effective manner.

(e) *Understanding preferences regarding end-of-life care in Singapore among patients with life limiting illnesses* (e.g. perceived attributes of a good death; preferences for place of care, place of death, life

Recommendations:

Promote research on palliative care interventions that appear promising but for which there is little evidence, especially if they are expensive or may have undesirable consequences.

Research should also be promoted in areas of particular relevance to Singapore or for strategies for which effectiveness, cost, and feasibility are likely to be different in the Singapore context.

Goal 10:

There should be leadership and governance to guide the development of palliative care services in Singapore.

14.1 Experience in overseas countries demonstrates that a co-ordinating body at the national level can facilitate the development of palliative care services. An example is Palliative Care Australia which is the peak national organization in Australia.

14.2 The Committee recommends that a coordinating body at two levels be set up to guide the implementation of the National Strategy for Palliative Care:

(a) Co-ordinating body for funding, accreditation, licensing and oversight of development and delivery of palliative care services in Regional Health Systems.

(b) Co-ordinating body with oversight over development of norms and standards, professional policies, education and promoting public awareness.

Recommendations:

Establish a leadership or governance structure to ensure oversight of the development of palliative care services locally.

Annex A

PALLIATIVE CARE NEEDS

Patients with life-limiting illnesses have physical, psychological, social and spiritual needs. These factors interact with each other in complex ways. Each patient has his or her unique set of needs that should be met through provision of palliative care.

Physical needs

2 More than 70% of patients with cancer will experience pain and about one third will experience breathlessness in the last one to two weeks of life[33]. Patients with cancer may also experience other symptoms such as vomiting, nausea, insomnia, depression and loss of appetite. Patients with non-cancer progressive illness also experience similar symptoms in the last year of life.

Psychosocial needs

3 Psychosocial needs concern the psychological and emotional well being of the patient and their family and carers. Patients with life-limiting illnesses often experience fear of the unknown, fear of dying, loss of role, concerns about coping with the illness and of being a burden to their families, depression, loneliness and other psychological symptoms.

4 Psychosocial care addresses the psychological experiences of loss and facing death for the patient and their impact on those close to them. Psychosocial care includes the practical aspects of care such as caregiver arrangements, finance issues and coping with care at home.

[33] Teunissen SC, Wesker W Kruitwagen C. (2007). Symptom prevalence in patients with incurable cancer: a systematic review. *Journal of Pain and Symptom Management;*34(1):94-104.

Spiritual needs

5 Spiritual needs are important for people at all stages of life and in particular during the terminal and dying phase. Life-threatening illnesses evoke many questions such as the meaning of life, the meaning of suffering and the perception of hope. The individual's beliefs and values help sustain the patient through the illness, and patients should be supported during the course of the illness.

Needs of family and care givers

6 Family members and caregivers play a vital role in caring for the patient with life-limiting illness. Family and caregivers need information and training on how to provide care for the patient, have access to respite care, emotional support and bereavement support.

Bereavement Care

7 Bereavement support should be provided to family members before and after the patient's death. Family members with complicated grief may require counselling or psychiatric services.

Comprehensive assessment of palliative care needs

8 Comprehensive assessment of patient needs and intervention can help relieve symptoms and improve quality of life for patients with life-limiting illnesses. Improvement of symptoms results in enhancement of patient and family satisfaction, functional status and quality of life.

Annex B

ILLNESS TRAJECTORIES

Besides deaths due to infection, acute coronary events or injuries, most people will experience a period of progressive disease and disability before death. More than half will have some form of chronic illness before death. This period may extend from days to months to years before death, based on the trajectory of the illness.

2 Models for illness trajectories have been described to better understand the course of the illness[34]. The trajectories enable health care professionals and patients to understand the course of the illness and make advance decisions for anticipated health care needs. The trajectories provide a broad framework which allows policy makers to understand the care needs along the trajectories and plan and deliver appropriate health services.

3 A caveat is that not all illnesses can be classified based on the three trajectories as some conditions do not conform to these trajectories. The illness of each person is unique and is modified by coexisting illnesses and hence may not conform to the trajectories. Nevertheless, the illness trajectories provide a useful conceptual framework to classify the illness and identify the patient needs.

4 Three illness trajectories have been identified:

(a) *Progressive cancer trajectory*

Patients with progressive cancer have a gradual decline in physical ability over weeks, months or sometimes years. The patient's physical ability declines rapidly during the final days or weeks before death when the disease overwhelms the patient's functional reserves.

[34] Lynn, J., Adamson, D. (2003). Living Well at the End of Life. Rand Health White Paper WP-137. Available online: <http://www.medicaring.org/whitepaper/> [Last accessed: 4 October 2011].

Despite longstanding WHO recommendations (since 1990) to involve palliative care from cancer diagnosis, specialist palliative services traditionally catered to this group of patients only during the last days or weeks of life. However, as mentioned previously, there is a move towards initiating palliative care further upstream in the trajectory to interface with disease-modifying cancer treatment.

(b) *Chronic organ failure trajectory*

Patients with organ failure, especially heart and lung failure, have a gradual decline in physical function over many months or years, with occasional episodes of exacerbation. During these acute exacerbations, the patient experiences worsening of the symptoms and is often admitted to the hospital. Each episode may be severe and may result in death, although the patient often survives many episodes. The timing of death is often unpredictable and sudden.

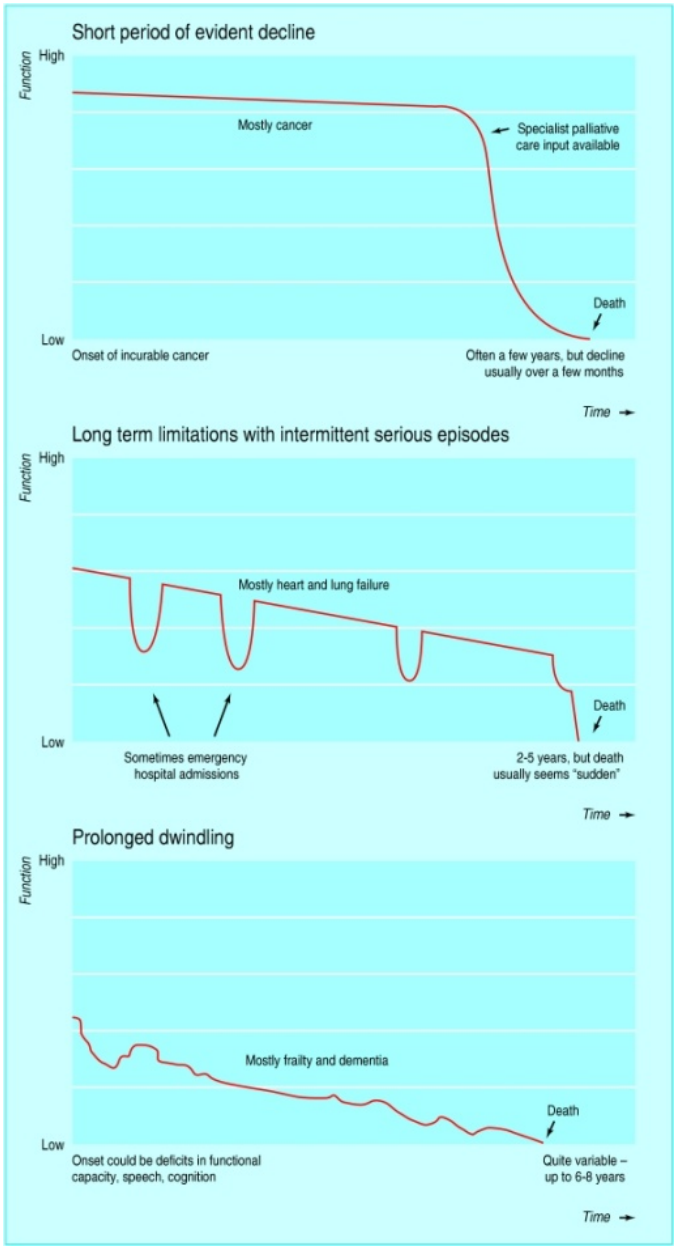
Specific needs for patients in this group include empowering patients and families on how to recognise symptoms and prevent the worsening of symptoms through the effective use of medications. Patients may require home oxygen and appropriate home adaptations. Home care teams can provide treatment at home to reduce the need for hospital admission.

(c) *Dementia and frailty trajectory*

Patients in this group start with a low baseline of cognitive and physical disability due to decreased cognitive ability (such as Alzheimer's disease or other forms of dementia), or frailty as a result of decreased reserves in multiple organ systems. Patients may survive many years and may succumb to an acute event, such as pneumonia.

Patients in this group require the caregivers at home to meet basic needs of patients. In the absence of caregivers, these patients will require quality care in long-term care facilities.

Figure 7: Illness Trajectories[35]



[35] Murray S et al. (2005). Illness trajectory and palliative care. *BMJ*. 330(7498): 1007–1011.

ANNEX C

GOLD STANDARDS FRAMEWORK (UK)

The Gold Standards Framework (GSF) was started by Prof Keri Thomas, a general practitioner in the UK. The GSF was established to provide a standardized system for provision of good quality palliative care by 'generalists' in the primary care setting[36]. The five goals of the GSF are:

(a) Consistent high quality care
(b) Alignment with patients' preferences
(c) Pre-planning and anticipation of needs
(d) Improved staff confidence and teamwork
(e) More home based, less hospital based care

2 The GSF enables health care professionals to systematically identify patients in the last year of life, assess current and future clinical and personal needs and develop an action plan based on the patient's needs and preferences. The GSF is incorporated into the primary care system in the UK in which general practitioners play an important role in the caring for the patient in the community. There is also strong public awareness of the GSF due to the history of its development.

3 The GSF identifies seven key tasks in the provision of palliative care for patients at the end-of-life:

(a) Communication
(b) Coordination
(c) Control of symptoms
(d) Continuity out of hours
(e) Continued Learning

[36] National Gold Standards Framework. Available online: <http://www.goldstandardsframework.org.uk/> [Last accessed: 4 October 2011].

(f) Carer Support

(g) Care in the Dying Phase

4 The GSF is currently considered mainstream policy and practice. The GSF is supported by Royal College of General Practitioners, Department of Health, National Institute of Health and Clinical Excellence (NICE) and other agencies.

5 Elements of GSF are used by 90% of GPs for the Quality Outcome Framework (QOF). The GSF is also adapted for use in 1,000 care homes under the GSF UK Care Homes Training Programme.

ANNEX D

PALLIATIVE CARE PROGRAMME IN EDMONTON

The Canada health care system has a public funding similar to UK NHS-type provision of care. There is a strong public awareness of palliative care and end-of-life issues.

2 Edmonton has an integrated palliative care service which has the following components[37]:

(a) Regional palliative care programme office that co-ordinates care, develop standards, evaluate outcomes and promote education and research;
(b) Family physicians and palliative home care central to the delivery of home care;
(c) Hospice palliative care units;
(d) Tertiary palliative care unit for difficult symptom control and psycho-social issues;
(e) Palliative care consultative services for acute care hospitals, long term care institutions and home care setting

3 The Regional Palliative Care Programme "ensures a co-ordinated, continuous plan of care that minimizes duplication of efforts and is maintained across all settings from referral of patient to support of the bereaved family."

[37] Edmonton Regional Palliative Care Programme. Available online: <http://www.palliative.org/> [Last accessed: 4 October 2011].

ANNEX E

ADVANCE CARE PLANNING

Advance Care Planning (ACP) is a process that enables a patient to express wishes about his or her future health care in consultation with their health care providers and family. ACP helps to ensure that the patient's wishes are respected in the event that the patient becomes incapable of participating in treatment decisions.

2 The components of an ACP programme enable the patient to:

(a) Understand their medical condition and potential future complications;
(b) Understand the options for future medical care as it relates to their current health condition;
(c) Reflect upon their goals, values and personal beliefs;
(d) Consider the benefits and burdens of current and future treatments;
(e) Discuss choices with family members and health providers; and
(f) Document these choices so that they can be honoured by health care providers.

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GLOSSARY OF ABBREVIATIONS

ACP	Advance Care Planning
AHCPR	Agency for Health Care Policy and Research
AIC	Agency for Integrated Care
AWWA	Asian Women's Welfare Association
CARE	Care at the End of Life for Residents in Homes for the Elderly
COPD	Chronic Obstructive Pulmonary Disease
CGH	Changi General Hospital
EAPC	European Association for Palliative Care
FTE	Full-time Equivalent
GDP	Gross Domestic Product
GSF	Gold Standards Framework
HCA	Hospice Care Association
HOME	HOlistic care for MEdically advanced patients
ILTC	Intermediate and Long Term Care
JCST	Joint Committee for Specialist Training
KKH	Kandang Kerbau Women's and Children's Hospital
KTPH	Khoo Teck Puat Hospital
LCPC	Lien Centre for Palliative Care, Duke-NUS Graduate Medical School
MCYS	Ministry of Community Development, Youth and Sports
MDS	Minimum Data Sets
MOH	Ministry of Health
NCCS	National Cancer Centre, Singapore
NHPCO	National Hospice and Palliative Care Organization
NHS	National Health Service
NICE	National Institute of Health and Clinical Excellence
NSPC	National Strategy for Palliative Care
NNI	National Neuroscience Institute
NUH	National University Hospital
NUS	National University of Singapore
PHMC	Private Hospitals and Medical Clinics Act
QOF	Quality Outcome Framework
RCT	Randomised Control Trial
SAB	Specialists Accreditation Board
SGH	Singapore General Hospital
SHC	Singapore Hospice Council
SPC	Specialist Palliative Care
SRS	Staff Registrar Scheme
SSTC	Sub-specialty Training Committee
TOTE	Singapore Totalisator Board
TTSH	Tan Tock Seng Hospital
VIVA	Volunteer Investment Value Audit
VWO	Volunteer Welfare Organizations
WHO	World Health Organization
YLLSoM	Yong Loo Lin School of Medicine