Pathway to Dying at Home: Facilitating Choices for People with Advanced Terminal Illnesses - A Practitioner Perspective

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Presentation Outline

- Ageing Population and Mortality Trends
- End of Life Needs in An Ageing Population
- End of Life Decision Making
- Dying in Place and Choice of Place of Death
- Future Development and Challenges

Population Ageing in Hong Kong

Year	65-69	70-74	75-79	80-84	85+	65+
13-14	326,600	212,100	209,900	164,400	150,600	1,063,600
14-15	364,600	214,900	209,900	166,000	160,000	1,115,400
15-16	397,500	222,900	206,900	167,300	170,200	1,164,800
16-17	414,800	251,800	198,900	170,600	178,500	1,214,600
17-18	429,900	282,200	193,000	172,700	187,700	1,265,500
18-19	447,500	313,000	192,900	173,200	196,800	1,323,400
19-20	461,900	349,800	196,200	173,700	203,000	1,384,600
20-21	483,300	381,400	204,500	171,900	209,700	1,450,800
21-22	507,600	398,800	232,000	165,600	216,400	1,520,400
22-23	535,500	413,800	260,800	161,400	223,000	1,594,500
23-24	556,500	430,900	290,200	162,200	228,300	1,668,100
24-25	576,100	445,100	324,500	166,000	231,400	1,743,100

Leading causes of death in US for those above age of 65

- 1. Heart Diseases
- 2. Cancer
- 3. Stroke
- 4. COPD
- 5. Pneumonia

Alzheimer disease ranked number 10

Leading causes of death in Hong Kong (Age >65) 2014

Cancer	9267
Pneumonia	7072
Heart Diseases	5347
Cerebrovascular	2793
Chronic Lower RD	1622
Renal	1516
Dementia	1095
Septicemia	793

Age Specific Mortality Rate in 2013 Per 1000 population in HK

Age groups	Male	Female
40-44	1.2	0.7
45-49	2.0	1.1
50-54	3.1	1.7
55-59	5.2	2.8
60-64	8.4	3.9
65-69	12.6	5.8
70-74	22.5	10.5
75-79	36.0	18.4
80-84	61.4	36.6
85+	128.9	90.0
All Ages	7.2	5.0

Deaths in Hong Kong

- In 2014,
- a total of 46,000 deaths, 90% happened in Hospital Authority
- By 2035, number of death to increase to 69,000
- By 2046, number of death to increase to 92,000

Principles of Good Death

(The Future of health care of Older People, Age Concern, UK 1999)

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensures wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

Definition of End of Life Care

(General Medical Council, UK 2010)

- For those people who are likely to die within the next 12 months
- Include those people whose death is imminent (expected within a few hours or days) and
- Those with
  - Advanced, progressive incurable conditions
  - General frailty and co-existing conditions that mean they are expected to die within 12 months
  - Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
  - Life-threatening acute conditions caused by sudden catastrophic events

End of Life Care

(National Institute for Clinical Excellence NICE, UK)

- Treat the patients as individual
- Show patients respect and preserve their dignity
- Help with control of symptoms particularly pain
- Offer psychological, social and spiritual support
- Reassure patients that their families and carers will receive support during their illnesses

UK NHS End of Life Care Program commenced 2004

- Greater choice for patients of place of care and place of death
- Fewer emergency admissions of patients who wish to die at home
- Fewer patients transferred from a care home to hospital in the last week of life
- Improved skills among generalist staff in the provision of end of life care

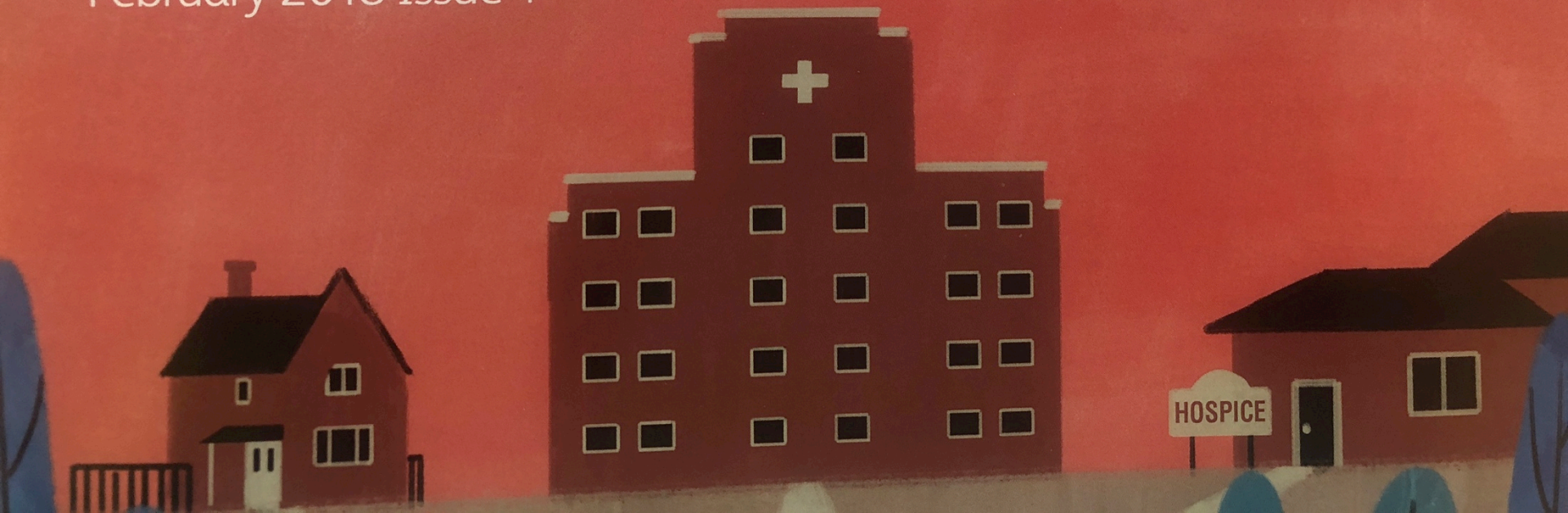
Commentary

Membership magazine of the Royal College of Physicians

Decisions about end-of-life care

Can the NHS continue to meet the needs of its patients?

February 2018 Issue 1



End of Life Issues in Chinese Communities

- Death and Dying – a subject often avoided in many Chinese societies
- Institutionalization of death – most people will be sent to hospital when they are dying at home or in residential homes
- Admission to acute hospitals causes unnecessary interventions to terminally ill patients

End of Life Issues in Chinese Communities

- Breaking bad news in chinese patients and their family members
- Older patients' wishes in end of life decision making
- Advance Care Planning / Advance Directives
- Need for more public education on life and death issues and professional training

The Economist Intelligence Unit

The 2015 Quality of Death Index

Ranking palliative care across the world

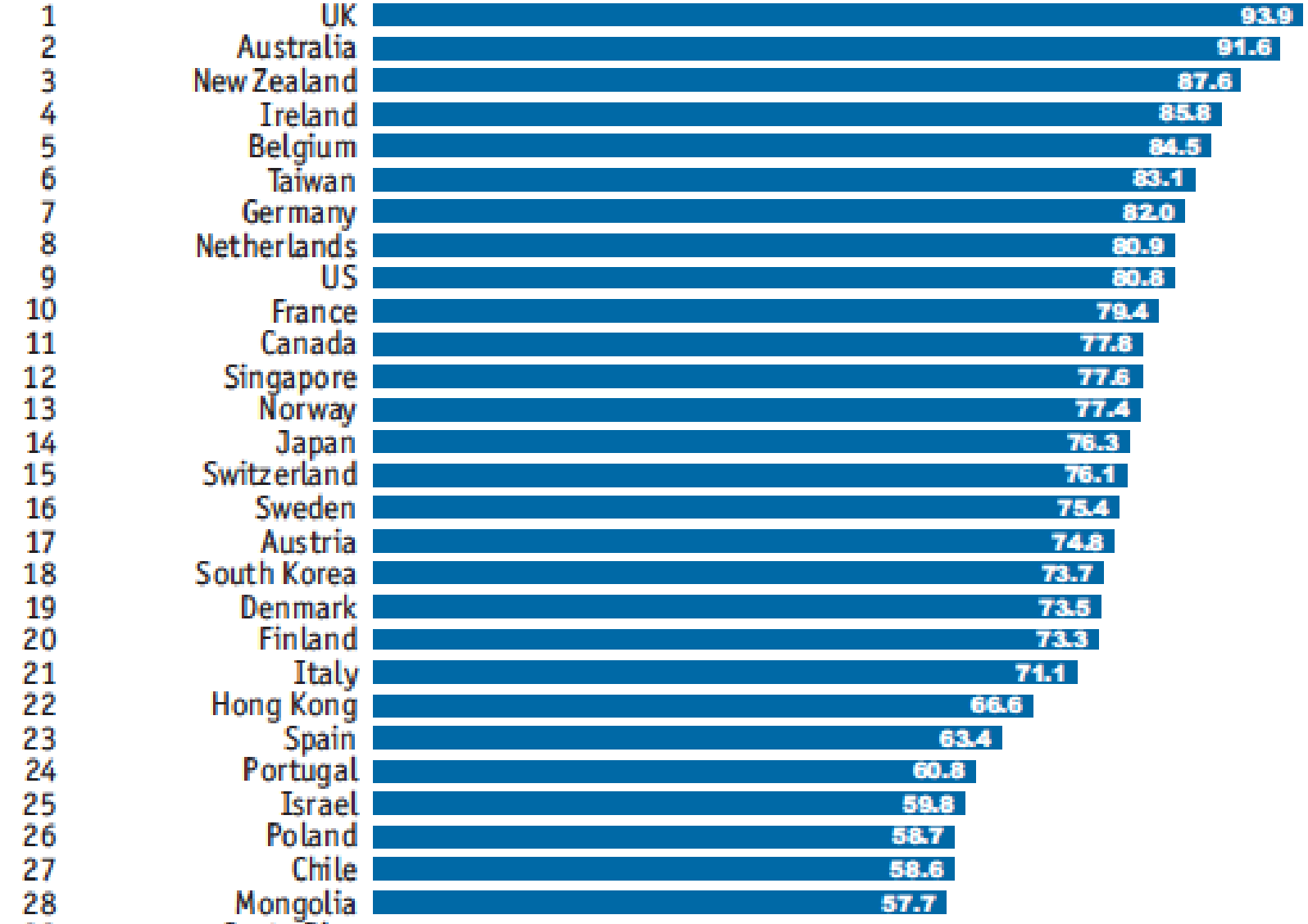
A report by The Economist Intelligence Unit

Commissioned by

LIEN foundation

Figure 1.2

2015 Quality of Death Index—Overall scores



Across the world, large numbers of people die in hospital each year, yet many would rather spend their final days at home or in a hospice. In the UK, this is something the palliative care community is working to change—not only to increase the quality of care people receive but also to help the country's National Health Service cut costs.

Recent research by Age UK, a charity, found that the average number of patients kept in hospital unnecessarily while waiting for community or social care rose by 19% between 2013/14 and 2014/15. An NHS bed costs on average £1,925 (US$2,980) per week, Age UK estimates, compared to about £558 for a week in residential care or £357 for home care.[42]

ing Post

day, June 21, 2016 / See live updates at www.scmp.com

HEALTH

Allowing patients to die at home 'will ease hospital strain'

Former health minister heads study into ways for Hongkongers to spend final days at home

End of Life in Chinese Older People interviewed

- Older people and their family members support the idea of End of Life care
- Most older people are not afraid or anxious about death, it is not a taboo to them

Preparation for Promoting End of Life Care in Older People with Terminal Illness

- Patient and Family Communication
- The use of Advanced Directives and Advance Care Planning
- The application of DNACPR order
- Agreement of Care Plan between the Medical Practitioner with Patient and Family members
- Issues of Futility Treatment Vs Quality of Life

Goal of Care in the Terminally Ill Patient

- Appropriate palliative care
- Improve quality of life
- Support to family
- Right to a good death
- Die with dignity
  - Protecting physical and psycho-spiritual integrity
  - Avoid distress, pain and suffering
  - Respecting the choice of the person
  - Treasuring the terminal phase of life

Dying at Home as a Choice

- Case Studies

Case I

- 88 years old lady
- Enjoy good physical health
- Developed progressive abdominal distension for 1 month
- CT Abdomen - Ca Tail of Pancreas with Liver and Peritoneal Metastasis
- Admitted to St Paul's Hospital for Ultrasound guided drainage
- Family opted for palliative care

- First consultation on 5/10/2015
- Come with 2 daughters and granddaughter
- Sound Mental state, Mobility and ADL independent
- Examination showed Ankle edema and Ascites
- Wished to have out patient management
- Daughters expressed that patient did not aware of abdominal tumor yet

- Noted progressive abdominal distension and shortness of breath in the following days by relatives
- Agreed to be admitted for further drainage of ascites
- Admitted on 10/10/15 with ultrasound guided insertion of pigtail catheter
- Also noted pneumonia in CXR
- Patient strong wish to be discharged back home instead to stay in hospital
- Discharged with pigtail catheter for continuing drainage of ascites at home same day evening
- FU next Wednesday in clinic

- Further followed up on 14/10/15 morning
- A total of 1.5 litres of blood stained ascites fluid drained
- Examination showed large mass over left side of abdomen
- Diagnosis of abdominal tumor disclosed to patient in presence of relatives
- Patient requested to be cared at home as far as possible

- Further discussion with daughters and son
- Expressed the wish to have their mother to be cared at home and die at home if possible
- Explained to family that not much monitoring and intervention could be performed at home and patient may die much earlier
- Family understand and accept the management at home
- Since patient is already very weak so will be arranged for Home Medical Follow up

Management Plan

- Continue with Pigtail Drainage at home to relieve abdominal discomfort
- Continue Oral Antibiotics for Chest Infection
- Adequate Pain Relief
- For Arrangement of Dying At Home
- Advise given to contact Funeral Agency for prior arrangement of dead body handling upon death

15/10/15

Pain relieved with oral morphine

Further Home Visit in the evening of 15/10/15 to review progress and support the family

All family members understand that she will be dying soon

Agreed to continue to be cared at home until death

Advised to call when patient further deteriorated in BP and pulse

Plan for review next day

16/10/15

- Informed by Daughter at 1:30 pm that it seems that her mom has passed away because her BP is not recordable and not arousable
- Arrived her home at 3:00 pm, still pupil response to light, no respiration, very weak femoral pulse palpated
- Pupil fix and dilated at 3:54 pm and certified death at home with Form 18 and Form 2
- Patient son able to arrive Death Registry before closing hour and obtained the Official Certificate of Death
- Funeral Parlour pick up body at 7:50 pm

Summary

- Patient with a Terminal Illness with limited life expectancy
- Family and Patient strong wish to be managed at home
- With provision of Home Medical Care patient's family is able to fulfill the wish of their mother
- Family members were gathering together with the patient in the last 2 days of life and Grace her in her religion
- All family members have a fulfilling experience during the death of their parent

Reason for success

- Experience on End of Life Decision making important
- Adequate communication with patient and family
- Appropriate use of Advance Decision Making with family – Advance Care Planning
- Educated and Supportive Family
- Appropriate arrangement for funeral handling before death

Case 2

- 54 year old gentleman with history of Ca Colon for two years, received operation but with recurrence, treated with chemotherapy, multiple abdominal metastasis and pleural effusion
- Repeated admission to hospital for pleural effusion and abdominal pain
- Referred by Oncologist for requesting not for further hospitalization and wish to be cared at home instead

- Interviewed patient and wife at home
- Patient stated clearly that he did not enjoy the stay in hospital (even in the private hospital) frequent disturbance by normal nursing observation and procedures and cannot have adequate rest
- Patient's wife respect his wishes, other family members including sister and son provide support to patient also
- Family agree not for any blood tests and interventions including blood transfusions and opt for natural death at home

On Dying at Home

- Patient's wife do have worry on whether able to look after him when he is in a terminal condition
- Need to provide counselling and support on possible symptoms on dying and possible drugs to relieve symptoms
- Detailed explanation to family on the handling of death and post death arrangement
- Information on funeral parlour arrangement provided

Home Care during terminal stage

- Provided by Wife, Sister and Son
- Medical Home Visit regularly and on demand
- Symptoms relieve with analgesics and morphine
- Patient passed away peacefully within 2 days when his condition further deteriorated
- Visited by close friends in the last 2 days of life
- Family not hurry on death certification when he died at home

Case 3

- Elderly Lady with Advance Dementia
- Referred from Neurologist for management of her Advance Dementia
- Patient look after well at home by son, daughter in law and Domestic Helper
- Family found the experience of her admission into hospital horrible, restrained in bed and not enough attention to bowel and urinary needs during hospitalization

- Counselled family on the progression of Advance Dementia including possible feeding problem
- Family understand the issue of feeding problems in Advance Dementia and opt for Comfort Feeding instead of Enteral Feeding as it is likely that she will pull out any tube put into her
- Opt for Home Care and avoid hospitalization

- Developed reduced feeding about 4 months later
- Progressive decreased intake
- Family requested for Home Visit as patient too weak to attend clinic
- On Home Visit, patient well cared by Son, Daughter in law and Domestic Helper at home
- Request for Dying at Home

- Counselled family on the issues of Dying at Home
- Understand the challenges and agree to care her till her final stage
- Increased agitation 2 days later, given Morphine and Haloperidol to calm her down
- Passed away peacefully at home 3 days later
- Family grateful able to have the patient died under their own care

Case 4

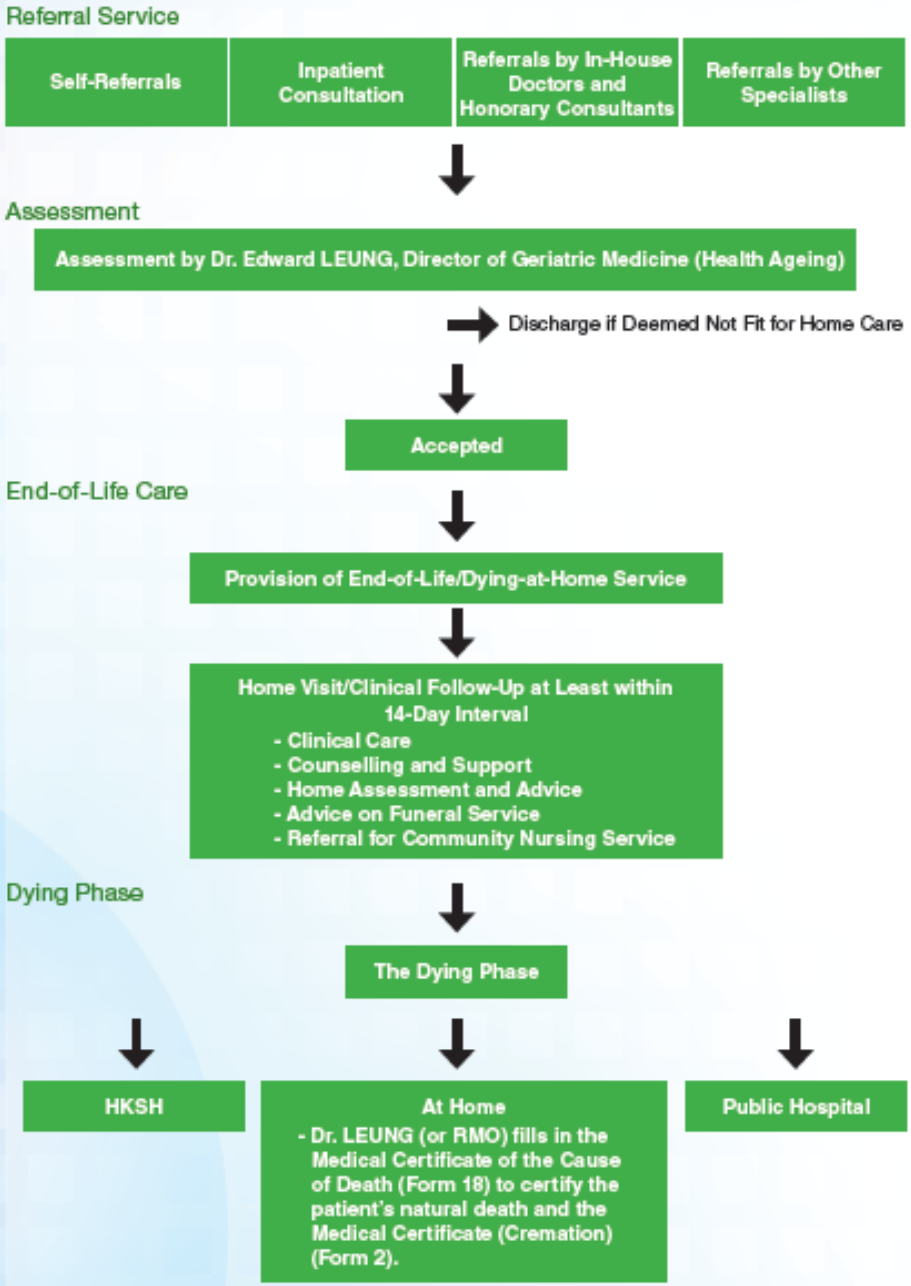
- 91 year old lady with history of Parkinson Disease
- Found Carcinoma of Esophagus 1 year ago with RT done and not opt for operation
- Referred from Oncologist for tumour recurrence and request for Home Care
- Well cared by Son, Daughter in law, Domestic Helper and other sons at home
- Main problem is swallowing problem require NG Tube feeding and mobility problem at home
- Required regular admission for change of NG tube and blood transfusion every three months
- Family wish patient to stay at home and die at home instead of admitted to hospital for her final days

- She was followed up in clinic and hospital for about one year for her anemia and mobility problem
- One year later developed increasing swallowing difficulty and family request to care at home till her final days
- Installed Oxygen Concentrator and Portable suction at home to relieve her discomfort
- Finally died peacefully at home in early morning and was certified death at home

Hong Kong Sanatorium and Hospital

End-of-Life Home Care Programme

HKSH End-of-Life/Dying-at-Home Programme



Enabling Dying at Home in Hong Kong

- Public awareness and patient education on choice of Dying in Place as possibility
- Advance Directive or Advance Care Planning
- Professional education and training
- Adequate Communication with family and advise on aspects of terminal care at home
- At least able to see the patient within 14 days
- Adequate symptom relief
- Certifying death with Form 18 and Form 2 available and ready
- Funeral Parlour Arrangement

The Way Forward

- More public education and promote awareness of End of Life Decision Making
- Promotion of Advance Care Planning and Advance Directives
- Training and Education for Health Care Professionals
- Extend Palliative Care Training to Disciplines outside Palliative Care – Medicine, Surgery
- Early Communication with patients and family on Advanced Chronic Conditions to facilitate patient and family choice and respect patient wishes
- Home Medical Care – Extension of Public Private Interface in End of Life Care
- Home Palliative Nursing Support
- Community Support Program for Patients and Families with Terminally Ill Patients
- Dying at Home Friendly environment - Body Movement, ? Mortuary

Thank you

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