

Issues of End of Life Care in Long Term Care Settings in Hong Kong

Dr. Edward MF Leung

President

Hong Kong Association of Gerontology

Hong Kong

(Asia Pacific Regional Conference on End of Life and Palliative Care in Long Term Care Settings 26/9/2013)



**World Health
Organization**

REGIONAL OFFICE FOR **Europe**

PALLIATIVE CARE FOR OLDER PEOPLE: BETTER PRACTICES



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

Principles of Good Death

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

- ❑ 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

When is End of Life

- The Liverpool Care Pathway for the dying – address care in the last few hours/days (Ellershaw & Wilkinson 2003)
- The Gold Standards Framework – supports care delivery over the last few weeks or months of a person's life (Thomas 2003)

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

End of Life and Residential Care

- For an older person moving to a care home to live end of life care could possibly be considered as three stages
 - Concerned with the living and losses experienced in the care home
 - The actual dying and death
 - The bereavement that follows a person's death

(Forggatt K (2004) Palliative Care in Care Homes for Older People)



Guidelines for a Palliative Approach in Residential Aged Care

Enhanced Version — May 2006



THE NATIONAL
PALLIATIVE CARE
PROGRAM

Prepared by Edith Cowan University

Approved by



Australian Government

National Health and Medical Research Council

Comprehensive evidence-based palliative approach in Residential Aged Care – Australia (2010) Anthony Tuckett

- ❑ Implementing evidence based guidelines in residential aged care requires a comprehensive approach which includes education of all staff and the support of management
- ❑ An evidence based palliative approach to residential care improves resident and family outcomes
- ❑ A comprehensive palliative approach education program improves staff confidence to provide a palliative approach for residents and families
- ❑ A systematic approach to advance care planning provides opportunities for residents wishes regarding care decisions including place of care to be respected

Comprehensive evidence-based palliative approach in Residential Aged Care – Australia (2010) Anthony Tuckett

- A palliative care case conference facilitates the identification of residents and family palliative care needs and provides a structure for multidisciplinary care planning
- A palliative care case conference means that all health professionals, the residents and family are “on the same page” with regard to palliative care wishes and needs
- The use of an end of life care pathway improves the terminal care provided to residents and the family
- Training is required for staff to convene palliative care case conferences and the use of end of life care pathways
- Separate education resources are required for staff with differing skills

European Association for Palliative Care

- Report of Palliative Care in Long Term Care Settings for Older People, Jan 2013
- A significant proportion of older people die in long term care settings (20% in UK), residents have complex trajectories of dying: many people live with non-cancer co-morbidities, and there is a high prevalence of dementia. It require a different approach to conventional palliative care

Summary

- Population ageing and rising need of long term care raised the international communities in the concern of end of life care in Long Term Care Settings
- The Need for Regulatory Policies, development on end of life care practice, education and training of generalist and specialist, guidelines and protocol development

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

End of Life Issues in Long Term Care

- ❑ End of life care is crucial for the wellbeing of dying person & family members
- ❑ Rising rate of institutionalization as a result of failing family support system
- ❑ Residents of long term care homes are more likely suffering from chronic and disabling illnesses, sometime terminal conditions
- ❑ Increasingly care homes need to face the issue of death and choice of death

Population Ageing in Hong Kong

<u>Year</u>	<u>65-69</u>	<u>70-74</u>	<u>75-79</u>	<u>80-84</u>	<u>85+</u>	<u>65+</u>
01-02	205,100	210,200	144,100	86,300	62,600	747,052
02-03	251,600	214,700	151,500	91,600	67,700	777,100
03-04	249,400	219,900	157,100	97,100	71,900	795,400
04-05	248,200	227,900	163,100	103,000	76,800	819,000
05-06	246,200	228,300	169,800	107,700	82,700	834,700
06-07	241,800	228,300	178,600	112,700	90,700	852,790
07-08	234,400	234,900	184,700	119,500	97,900	872,200
08-09	224,900	235,200	191,400	123,900	104,200	882,700
09-10	222,100	232,800	199,200	128,000	111,400	893,400
10-11	234,300	230,400	205,200	146,100	125,400	912,100
11-12	263,700	220,700	208,400	151,000	134,100	941,400
12-13	294,900	216,200	210,200	157,500	142,600	977,900

Population Ageing in Hong Kong

<u>Year</u>	<u>65-69</u>	<u>70-74</u>	<u>75-79</u>	<u>80-84</u>	<u>85+</u>	<u>65+</u>
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

High Institutionalization rate in Hong Kong

<u>Year</u>	<u>65+</u>	<u>RCHE</u> <u>Places</u>	<u>% in institutions</u>
01-02	747,052	56,231	7.5%
02-03	777,100	60,821	7.8%
03-04	795,400	62,941	7.9%
04-05	819,000	64,243	7.8%
05-06	834,700	66,371	7.9%
06-07	852,790	69,044	8.0%
07-08	872,200	71,721	8.2%
08-09	882,700	72,827	8.2%
09-10	893,400	73,663	8.2%
10-11	912,100	75,325	8.2%
11-12	941,400	75,228	8.0%
12-13	977,900	75,416	7.7%

Health status of older people in the community and in residential homes in HK (2005)

□ Community

- 71.6% - chronic disease
- 28.3% - 1 disease
- 21.0% - 2 diseases
- 11.6% - 3 diseases
- 10.8% - 4+ diseases

□ Residential Homes

- 95.7% - chronic disease
- 16.7% - 1 disease
- 24.4% - 2 diseases
- 23.1% - 3 diseases
- 31.4% - 4+ diseases

Source: Thematic Household Survey No 21, October 2005, Census and Statistic Department, HK

High Mortality Amongst residents in Long Term Care Settings

- According to statistics from Hospital Authority in 2012
- Amongst all deaths in Medical Specialties of Hospital Authority over age of 60s (24,073) 45% of them are residents from elderly homes (10,800 deaths amongst a total of 70,000 elderly home residents) – 15% amongst old age home residents in one year

High Mortality Amongst residents in Long Term Care Settings

- In another study by my colleagues in Kwun Tong in 4 private homes in the first 6 months of 2013 there were 13.3% deaths amongst their residents
- Death residents have background of:
Advanced Neurodegenerative Conditions (53.8%), End stage malignancy (21.5%), End stage heart and lung condition (10.8%)

Promotion and Development of End of Life Care in Long Term Care institutions

- Hong Kong Association of Gerontology joined as an international partner in International Collaboration for the Care of Elderly (ICCE) and NICE Canada since 2007 on knowledge exchange in elderly care for China
- End of Life Care Project for Hong Kong and Chinese Communities funded by ICCE from 2007-2009

Research

- 5 focus groups
- 30 participants from 5 institutions: including 1 superintendent, 4 supervisors/care managers, 2 medical officers, 6 registered nurses, 3 social workers, 8 care workers, 3 family members, and 3 residents.
- 2 Roundtable discussions
- Elderly people, professionals, policy makers

Findings

- ❑ 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
- ❑ Respondents of different levels of care homes (including senior management, nurses, social workers & health care workers) are very positive about End of Life care; however more concerned about logistic arrangements that require support & planning, and legal & accountability issues
- ❑ Policy makers & professionals are generally positive towards the development of end of life care in RCHE

Main Concerns on End of Life Care Issues in Care Homes

Care homes: Environment, Logistics & administrative arrangement

Legal and policy issues

Staff: Training and support

Issue of Reportable Deaths

- ❑ Rationale for Reportable Death specified in CORONERS ORDINANCE - SECT 16 : main objective is to prevent against abuse, especially if the death occurs in places that should not incur death, e.g. reformatory school / mental hospital
- ❑ In the past: care homes are for more healthy elders, but with continuation of care, residents are becoming increasingly frail & death become more common. Existing legal framework is an obstacle towards a place of death as a choice for residents in RCHEs

Lack of relevant training for care home staff

- ❑ Most of the care home staff are not familiar with end-of-life care. Yet, relevant training and education, including advance care planning, grief and bereavement, and nursing care for dying patients, are not generally available
- ❑ The care home staff may feel uneasy with care of dying residents. This may increase the staff turnover rate.
- ❑ Due to the difficulty in prognostication, it is also difficult for the care home staff to ascertain if the patient's deteriorating conditions is reversible or not, particularly if there is no resident doctor in the institution.

Palliative Care in Residential Care Homes for the Elderly in Hong Kong

- 'Palliative Care in Residential Care Homes for the Elderly in Hong Kong' from April 2010 till September 2013 – A collaborative project between Hong Kong Association of Gerontology and Salvation Army Hong Kong – funded by La Caixa Foundation and Bank of East Asia Foundation
- The project is to pilot palliative care in 6 Residential Care Homes in HK through development of care protocol, care guidelines, training and education, enhancing manpower support to participating RCHes

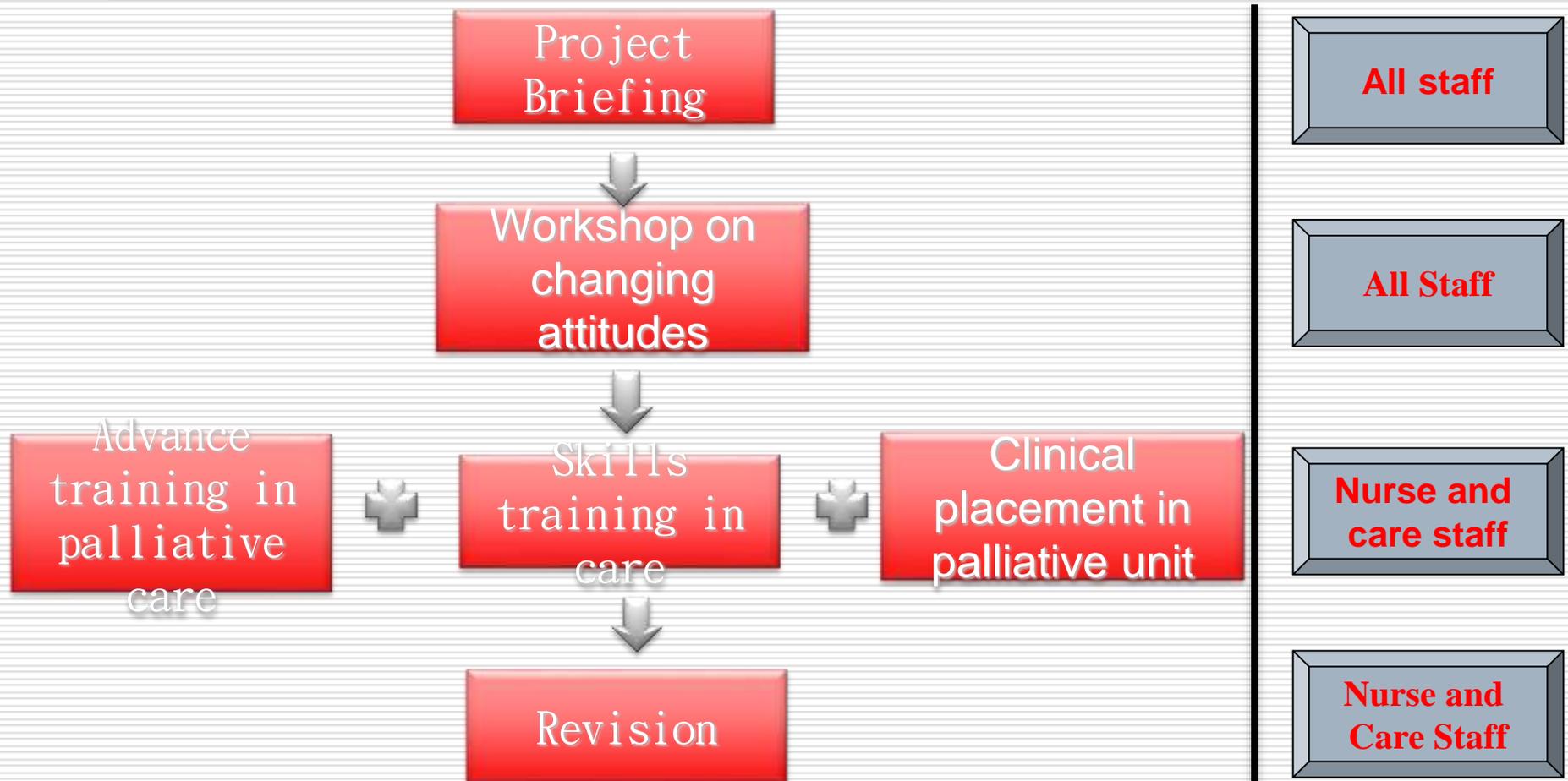
Palliative Care in Residential Care Homes for the Elderly in Hong Kong

- ❑ Commenced in May 2010
- ❑ Palliative Care Team – Nurse Specialist in Palliative Care, Clinical Psychologist and Social Worker in the preparation of the protocols and development of the project
- ❑ Formation of Development Committee – composition of Geriatrician, Nurse Specialist, Social worker, legal profession
- ❑ Completion of the plan for the education, training and workflow of terminal care in care homes

Palliative Care in Residential Care Homes for the Elderly in Hong Kong

- 1. Before Case Screening**
- 2. Case Screening**
- 3. Referral Process**
- 4. Palliative Care Service**
- 5. Terminal Care Pathway**
- 6. Care after death**
- 7. Bereavement Care**

Staff Training for Care Home



Enhanced facilities for terminal care



Individual accommodation renovated within the care home to allow the resident to die in peace with the accompany of their relatives



Case Study of Pilot Project

Madam X, F/78

- Widow with a son and a daughter
- Lived in the RCHE for 15 years
- Multiple Chronic illnesses including Hepatitis B carrier, hypertension, diabetes with retinopathy, old stroke with left hemiparesis, low back pain & sciatica; osteoarthritis of knees and depression
- Diagnosed liver cancer with right hepatectomy done in 2006 and vertebral bone metastasis since May 2011

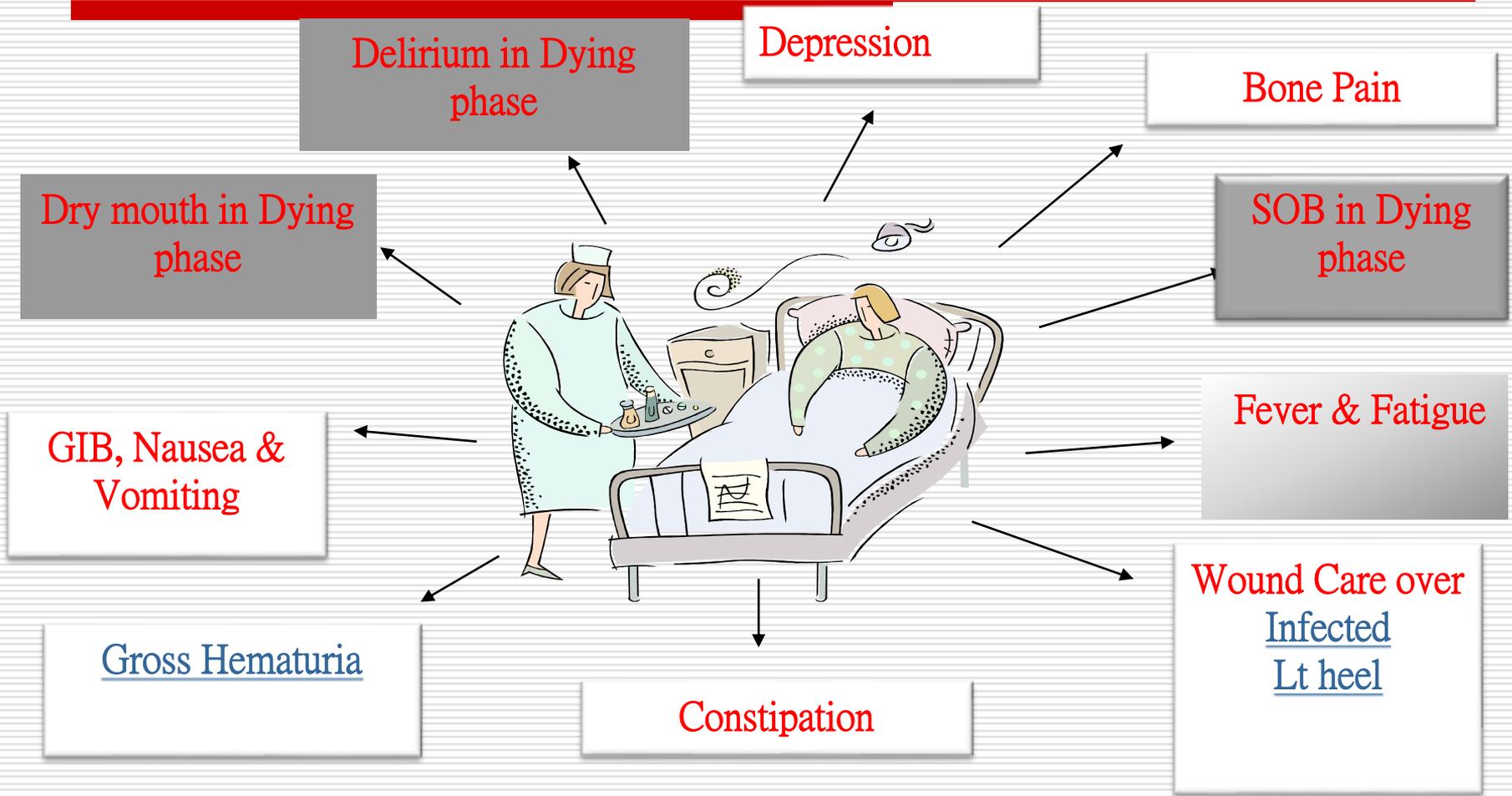
Resident and family's wish

- Accepted her deteriorating health condition and decided to receive conservative treatment and comfort care on left leg ulcer and anaemia
- Strong wish to avoid amputation of leg
- Wish no further hospitalization until end of life
- As a Christian she expressed that she was ready for eternal life in heaven with strong faith to Lord
- Family members fully understand her health condition and agreed to join end of life care project

Progress

- ❑ Advanced Directive was signed on 2/5/2012 with the introduction and explanation of the project
- ❑ PC team and the RCHE care team together formulated the advance care plan according to Madam X physical, psychosocial and spiritual needs; aim of the Advance Care Plan was to enhance her quality of life
- ❑ Regular visit of the Palliative Care team to the resident and emotional support to the family members
- ❑ The Palliative Care pathway has been executed when Madam X found unconscious

Symptoms Control



Progress

- Madam X died peacefully on 22/7/2012 in end of life care room, all relatives stayed at her bed side with praying & worshiping to Lord
- Debriefing session & staff support groups were held
- Bereavement with family members
- Memorial sessions for co-residents, family members and staff of the Home

Outcome

- ❑ No further hospitalization after joining the project, until she passed away
- ❑ She was cared by the Home staff under her wish with symptoms control and comfort care
- ❑ Died peacefully in presence of her family members
- ❑ Quality of life maintained in both physical and psycho-social-spiritual aspects
- ❑ Family members - positive feedback on the advanced care plan and appreciate the support of the Palliative Care team and the Home care team

Reasons for Success

- Close collaboration and support from Hospital Community Geriatric Assessment Team to the Home
- Long term and trustful relationship was well established with the patient and the Home
- Closely working with the care staff of the Home
- Strong medical support by the CGAT including regular and Ad hoc visits during last few weeks of life and also prescription of symptom relieving drugs

Commitment of the Residential Care Home

- Home enthusiastic towards providing end of life care for their residents (Strong religious background and tradition)
- Close observation and monitoring of patient's conditions and reported to CGAT and Palliative Care team members frequently
- The Home has a strong mission and understanding of the concepts behind palliative care
- eagerness to tackle different obstacles and offered immediate support to Madam X and her family

Difficulties and Limitations

- ❑ Staff shortage and manpower strength of RCHEs in Hong Kong
- ❑ Difficulty in gaining the understanding and support of Ambulance Service in fulfilling the the advanced directives of dying patients and carry out unnecessary resuscitation procedures
- ❑ Obstacles in Legal provision – Coroner Ordinance

The Way Forward

- ❑ End of Life Care for Residents in Long Term Care Settings are international directions and reflects the quality of care
- ❑ Policy should be developed to enable the choice of dying in place for residents with the necessary enhancement of manpower in care homes
- ❑ Related Legislation and regulatory framework should be developed
- ❑ Promotion of Advance Care Planning and Advance Directives
- ❑ Training and Education
- ❑ Collaboration between Medical Services and Long Term Care Institutions



Thank you