# END-OF-LIFE QUESTIONS

Dr. Abraham C.Y. YAM

Council Member of the HKMA

Chairman of the HKMA International Affairs Committee

MBChB (CUHK), MScPD(Cardiff), MFM (Clin) (Monash), DPD (Wales), PDipCAH (HK), Dip Med (CUHK)

# **PRESENTATION OUTLINE**

The Aging Challenge Local Surveys and Quality of Death Index Hospital Authority Guidelines Challenges of End-of-life care Hospice Care Facilities in HK Pilot Project HKMA's Role

## HONG KONG DEMOGRAPHICS

#### Figure 1 – Number of elderly people aged 65 or above, 2015-2064



Note: (\*) The figures represent the proportions of elderly people in total population. Data source: Census and Statistics Department.

- High institutionalization rate of 5.7% among people aged 65 or above in 2014
  - More than double that of Singapore, South Korea and Japan
  - More than three times of Taiwan
- Around 83 % of some 46,000 deaths every year take place in public hospitals (2016)

http://www.legco.gov.hk/research-publications/english/1516rbo1-challenges-of-population-ageing-20151215-e.pdf http://www.scmp.com/news/hong-kong/health-environment/article/1978199/revealed-why-hospital-chief-wantsgive-hongkongers

### SURVEY CONDUCTED BY THE HONG KONG ASSOCIATION OF GERONTOLOGY

- Conducted in four elderly homes
- 65 residents died within six months of the total number of 488

Residents died within 6 months 13%

In the three months before they died, they were

admitted to hospital

### **2.68** times

• stayed in the hospital

**<u>24.9</u>** days on average

http://salvationarmy.org.hk/en/ media\_centre/media\_detail/138



# 2015 QUALITY OF DEATH INDEX

	Rank/Score / 80 100		Hong Kong —— Average ——— Highest ——— Lowest	
SUPPLY ENVIRONMENT 1) PALLIATIVE AND HEALTHCARE	22	66.6	1) PALLIATIVE AND HEALTHCARE ENVIRONMENT 100 75	
ENVIRONMENT	28	50.4	5) COMMUNITY ENGAGEMENT	
2) HUMAN RESOURCES	20	62.1		
3) AFFORDABILITY OF CARE	18	82.5	4) QUALITY OF CARE OF CARE	
4) QUALITY OF CARE	20	81.3	Economist Intelligence Unit (2015).The Quality or death: Ranking end-of-life care across the world.	
5) COMMUNITY ENGAGEMENT	38	32.5	UK: EIU. http://www.eiuperspectives.economist.com/hea	

hcare/2015-quality-death-index

### LACK OF PALLIATIVE CARE AND END-OF-LIFE SERVICE AMONG THE COMMUNITY ESPECIALLY IN VIEW OF AGEING POPULATION

Dying at home or residential care home for the elderly (RCHE) might be a solution to ease overcrowding in public wards

## **REFERRAL CRITERIA**

Inpatient Palliative Care	<ul> <li>Clinically unstable with moderate to severe symptoms</li> <li>Require day to day medical intervention</li> </ul>
Outpatient Care	<ul> <li>Advanced progressive diseases suffering from symptoms</li> <li>Require specialist opinion for symptom palliation</li> </ul>
Home Care	<ul> <li>Require more intensive monitoring than outpatient</li> <li>Follow up by Home Care Team</li> </ul>
Day Care	<ul> <li>Require daily intervention</li> <li>Clinically stable</li> </ul>

# ADVANCE DIRECTIVE



- 2006 The Law Reform Commission put forward a model form of Advance Directives
- 2010 Concept of Advance Directives was officially introduced in Government papers
- <sup>2012</sup> The Medical Council of Hong Kong (Ethics Committee):
  - Difficulties in drafting the guidelines on advance directives, such as ascertaining the validity of an advance directive
  - A legal framework should be formulated to afford protection to both patients and healthcare professionals

http://www.ha.org.hk/haho/ho/psrm/CEC-GE-1\_en.pdf http://www.info.gov.hk/gia/general/201206/13/P201206130270.htm

## **ADVANCE DIRECTIVE**



### 2012

#### Government :

- Some people still regard it a <u>TABOO</u> to discuss the issue of terminal care and death
- The public at large are not fully familiar with the concept of advance directives
- <u>NOT the appropriate time</u> to implement advance directives at this stage through any form of legislation

#### 2014

#### Food and Health Bureau :

 Have yet to see a substantial change in attitude in the community at large towards promoting advance directives through legal means

## **ADVANCE DIRECTIVES FORM**

		Appendix 1
		Please Use Block Letter or Affix Label SOPD / Hospital No. :
	ADVANCE DIRECTIVE <sup>1</sup>	Name :
I . Per	rsonal details of the maker of this advance direction	(E)
000000341		capital (Line)
Name :	ument No.:	1
	ale / Female	
Ses .		
Date of Birt	(h : (Day) (Month) (Year)	
Home Add	(ress 1	
Tel	No.1	
Home res	L No. :	
Office Te	L No	
Mobile	Tel. No. :	
		W We will the second se
Section	II : Background	minimise distress or indignity which I may suffer or getative state or a state of inveversible coma, or in other ition, and to spare my medical advisers or relatives, or my behalf.
Stetter	tand that the object of this directive is to	minimise distress or indiguity where coma, or in other getative state or a state of irreversible coma, or in other ition, and to spare my medical advisers or relatives, or my behalf.
1.	I understand than terminally ill or in a peating cond	ition, and to spare my
	create when I am terminally incention of the limiting cond specified end-stage irreversable life limiting cond both, the burden of making difficult decisions on r	abarful instructions as to my medical
	both, the builden	ed nor will any
2.	both, the burden of the 1 understand that euthanasia will not be perform treatment be followed in any circumstances, even (please pri-	wy behalf, my behalf, if expressly requested. int name, being over the age of 18 years, revoke all e to my medical care and treatment (if any), and make the
-	treatment be followed in (please pri	int name) being over the age of 18 years, revoke an int name) being over the age of 18 years, revoke an g to my medical eare and treatment (if any), and make the l.
3.	I make by me relating	5
3.	previous advance directive of my own free with	g to it, it is a set of the se
1	following as the ill or if I am in a state o	if irreversible coma or in a pressure way attending doctor and a ting condition as diagnosed by my attending doctor and a lake part in decisions about my medical care and treatment ad treatment are as follows: 
4.	If I become terminally in or	ake part in decisions about my incurcut
	other specificul click, so that I am unable to e	nd treatment are as follows.
1	If I become termination in the second state in the second state of the second state in the second state of	to a start of the second
1	inching the appropriate	
	iote: Complete the following by taking ay part you do not want to apply to you.)	and pray of are as follows: nd treatments are as follows: d writing your initials against that/those box(os), and drawing a line across d writing your initials against that/those box(os).
10	ly have been	
		Anti-abile Burgan Consultation Paper
		stand send bighter second
		August 2006; amended as in Food and in Jun 2014.
	<sup>1</sup> The Form was proposed by the Law Reform Commission on 16 December 2009; modifications made and footnets added by the Commission of the Commission of	August 2006; amended as in Food and in Jun 2014. ie Hospital Authority in May 2010 and in Jun 2014.

- The patient could be the one who raises the issue of making an AD
- Health care workers should be sensitive to
  - i. the psychosocial aspects and personal values of the patient
  - ii. the views of the family members
  - HA AD forms require two witnesses, one of whom must be a medical practitioner

## ADVANCE CARE PLANNING (ACP)

ACP refers to the process of communication regarding the kind of care that will be considered appropriate when the patient can no longer make those decisions

Patient with advanced progressive diseases	Health care providers
Family members	Caregivers

## ADVANCE CARE PLANNING (ACP)

- ACP should be considered in suitable patients in anticipation of progressive deterioration, before death is imminent
- ACP is an integral part of palliative care and should be promoted to a wider scope of patients with advanced progressive diseases
- A Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) decision can be part of ACP

## LOW PUBLIC AWARENESS

- A Population-Based Telephone Survey of 1067 Adults on Knowledge, Attitudes, and Preferences of Advance Decisions, End-of-Life Care, and Place of Care and Death in Hong Kong
- 85.7% had not heard of AD
- 60.9% would prefer to make their own AD if legislated after explanation
- 31.2% of the participants would choose to die at home

# **OBSTACLES IN LEGAL PROVISION**

#### Coroners Ordinance (Cap. 504)

	Report to Coroner	Report to Death Registry
Death at home (attended by doctor within 14 days before death)	×	$\checkmark$
Death at home (not attended by doctor within 14 days before death, but diagnosed with terminal illness before death)	×	$\checkmark$
Death at Residential Care Homes for the Elderly	$\checkmark$	$\checkmark$
Death at Nursing Homes	×	$\checkmark$

http://www.hkag.org/Conference/EOL%20APRC%20conference/ppt/ 07%20Symposium%20III\_Legal%20&%20Ethical%20Issues/Symposiu m%20III\_Mr%20Woody%20Chang\_20130927.pdf

# **OBSTACLES IN LEGAL PROVISION**

- Informants (relatives) must find the right doctor(s) who has attended the patient during his last illness to view the body and sign Form 18
- Doctor to travel to the place of death to view the body
- Time constraint within 24 hours
- Cannot remove the body before obtaining a Certificate of Registration of Death (body must be left at Home or RCHE for some time)
- May need to report to the Coroner (via Police) interview by police and forensic pathologist etc.

## LACK OF PALLIATIVE CARE SPECIALISTS

### Only 19 palliative care specialists



Dr Michael Sham who has worked in palliative care for 30 years "There is no private market ... doctors cannot earn much. Only those with great passion would choose it"

"Home death required doctors to visit patients at home to certify their death, but in reality it was not possible to do so around the clock due to limited manpower"

#### Suggested the use of long-term care homes, which have visiting medical staff and a larger group of caregivers

http://www.scmp.com/news/hong-kong/health-environment/article/1978209/last-wish-hongkong-survey-reveals-most-elderly

# **SHORTAGE IN RCHEs**

- 2015- around 740 RCHEs
- providing approximately 73,000 places
- Equivalent to 6.5 % of the elderly population aged 65 or above
- As at end-April 2015, there were 31,137 elderly persons on the waiting list for subsidised residential care places
- The figure did not include the 8,098 elderly persons who were classified as inactive cases

http://www.hkag.org/Conference/EOL%20APRC%20conference/ppt/ 01%20Keynote%20Speech/Dr%20MF%20Leung\_Issues%200f%20En d%200f%20life%20care%20in%20long%20term%20care%20settings %20in%20Hong%20Kong.pdf http://www.lwb.gov.hk/eng/legc0/17062015.htm

## HOSPICE CARE FACILITIES IN HK



#### Jockey Club Home for Hospice



#### **Bradbury Hospice**

#### Haven of Hope Sister Annie Skau Holistic Care Centre

### PILOT PROJECT PALLIATIVE CARE IN RESIDENTIAL CARE HOMES FOR THE ELDERLY





http://salvationarmy.org.hk/en/ media\_centre/media\_detail/138

- Pioneered by the Salvation Army and the Hong Kong Association of Gerontology launched in year 2010
- Six residential homes for residents who enter to their terminal phase
- 16 residents joined the Project
- Two elders did not enter the hospital until death
- One of them had been admitted to hospital for nearly 20 days per month on average before participating in the Project

# CASE SHARING

- Madam Lam, aged 87
- Severe heart failure and diabetes
- Participated in the "Palliative Care" Project
- Hospitalisation substantially reduced
- Unable to join a family Spring Gathering
- The staff of residential home specially arranged her to meet 25 family members in the residence





## HKMA'S ROLE



HKFMS Foundation Care for Advanced Diseases Consortium

- Member of Care for Advanced Diseases Consortium Goal of the Consortium:
  - Promote end-of-life care among the Hong Kong public
  - Promote public/private/NGO collaboration in palliative care
  - Facilitate availability of aging and dying in place in Hong Kong
  - Advise the Government policy makers and stakeholders on betterment of palliative and end-of-life care for advanced diseases and deaths
- Promote and educate doctors in Hong Kong about palliative and end-of-life care through different medium including Continuous Medical Education lectures

# REFERENCES

Chang, Woody. Legal Issues relating to End-of-life and Palliative Care. Hong Kong Association of Gerontology Conférence, 2013.

http://www.hkag.org/Conference/EOL%20APRC%20conference/ppt/07%20Symposium%20III\_Legal%20&%20Ethica

Cheung, Elizabeth. Last wish: Hong Kong survey reveals most elderly would rather die in hospital than at home. South China Morning Post. 21 June 2016.

http://www.scmp.com/news/hong-kong/health-environment/article/1978209/last-wish-hong-kong-survey-reveals-

Cheung, Kin-chung Matthew. HKSAR Government Press Releases. LCQ19: Residential care services for the elderly. 17 June 2015.

Chung, Roger. Overview of End-of-Life Care in Hong Kong Now and to the Future. Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong. March 2017. http://www.socsc.hku.hk/JCECC/conf2017/wp-content/uploads/2017/03/Roger-Chung\_Overview-of-End-of-Life-Care-in-Hong-Kong-Now\_publicversion2.pdf

Chow, York. HKSAR Government Press Releases. LCO1: Advance directives. 13 June 2012. http://www.info.gov.hk/gia/general/201206/13/P201206130270.htm

Hospital Authority, Referral Criteria for Different Palliative Care Type for Advanced Progressive Disease. Sep 2015. https://www.ha.org.hk/haho/ho/hacp/12158oe\_txt.pdf

Intelligence Unit, the Economist. The 2015 Quality of Death Index Country profiles. http://www.eiuperspectives.economist.com/sites/default/files/images/2015%20Quality%200f%20Death%20Index%2

## REFERENCES

Leung, Edward. Issues of End-of-Life Care in Long Term Care Settings in Hong Kong. Hong Kong Association of Gerontology Conference. September 2013. http://www.hkag.org/Conference/EOL%20APRC%20conference/ppt/01%20Keynote%20Speech/Dr%20MF%

http://www.hkag.org/Conference/EOL%20APRC%20conference/ppt/01%20Keynote%20Speech/Dr%20MF% 20Leung\_Issues%20of%20End%20of%20life%20care%20in%20long%20term%20care%20settings%20in%2 0Hong%20Kong.pdf

Lord, Richard. Advance directives on medical treatments likely to catch on. *South China Morning Post.* 10 June 2014. <u>http://www.scmp.com/lifestyle/health/article/1526817/advance-directives-medical-treatments-likely-catch</u>

Research Office, Legislative Council Secretariat. "Challenges of population ageing". *Research Brief Issue No.* 1 2015 – 2016. <u>http://www.legco.gov.hk/research-publications/english/1516rbo1-challenges-of-population-ageing-20151215-e.pdf</u>

Roger Yat-Nork Chung, Eliza Lai-Yi Wong, Nicole Kiang, Patsy Yuen-Kwan Chau, Janice Lau, Samuel Yeung-Shan Wong, Eng-Kiong Yeoh, Jean Woo. Knowledge, Attitudes, and Preferences of Advance Decisions, End-of-Life Care, and Place of Care and Death in Hong Kong. A Population-Based Telephone Survey of 1067 Adults. JAMDA xxx (2017) 1.e1e1.e9

The Salvation Army. Announcement of the Results and Achievements of the "Palliative Care in Residential Care Homes for the Elderly" Caring for the End-of-life Arrangement of the Residents at Elderly Homes Demonstrating a New Model of Elderly Services. http://salvationarmy.org.hk/en/media\_centre/media\_detail/138

Tsang, Emily. Cheung, Elizabeth. Revealed: why hospital chief wants to give Hongkongers the option to die peacefully in their own homes. *South China Morning Post*. 21 June 2016. <u>http://www.scmp.com/news/hong-kong/health-environment/article/1978199/revealed-why-hospital-chief-wants-give-hongkongers</u>

Working Group on Advance Directives. HA Clinical Ethics Committee. Guidance for HA Clinicians on Advance Directives in Adult. July 2016. http://www.ha.org.hk/haho/ho/psrm/CEC-GE-1\_en.pdf