# End of life care in residential care homes : a local perspective

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# Overview

- Definitions and trends
- Literature review
- Local perspective
- Local experiences
- Summary and way forward

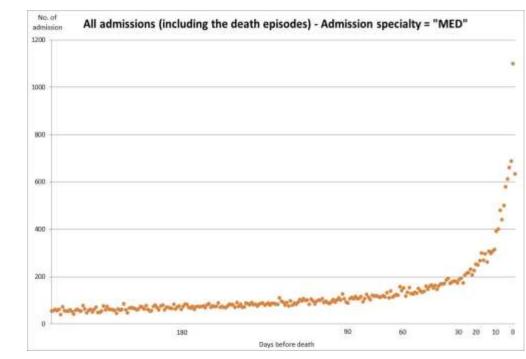
### **Definitions and trends**

# The Gold Standards Framework Prognostic Indicators

4th edition Oct. 2011

- The Surprise Question: "Would you be surprised if this patient was to die in the next few (Six) months ?"
- General indicators of decline—deterioration, increasing need or choice for no further active treatment of disease
- Specific clinical indicators related to certain conditions

#### The Last Year of Life



RCHE residents ~ 8000 deaths per year in medical wards

	Day 365 - Day 181 before the death date	Day 180 to Day 0 before the death date
	Average	Average
No. of A&E attendances	1.29	2.98
No. of Total admissions (MED)	0.98	2.56
Total BDO (MED)	7.89	26.01

Statistics during the last 365 days of life for RCHE deaths (including death episode) Aged 60+ and death in MED of A&E and IP/DP during 2012 (N=10,731), HAHO

#### RCHE Residents are High Volume Users of HA Services

### 7% elderly population in HK

8000 deaths per year in medical wards are RCHE residents

Community

(513 attendances)



A&E 1<sup>st</sup> attendances per 1,000 elderly persons

Hospital Bed Utilisation\* per 1,000 Elderly Persons

**Unplanned readmission** 

(9.4 beds)

(68.8)

(2 281 attendances)

18% : 34%

Note

rate (M&G)

1. \* Include General (acute and convalescent), Infirmary, Mentally III and Mentally Handicapped Beds

2. Elderly Population in OAH and Community, 2011 Population Census Office, Census and Statistics Department

3. OAH residents refer to patients with at least one record coded with LORCHE number in IPAS or AEIS in 2011

#### Literature review

 End-of-life(EOL) care is the support of a person who is approaching death. Their dying experience is often a prolonged process accompanied by a period of functional decline and deterioration

(Lunney, Lynn, Foley, Lipson, & Guralnik, 2003)

 Palliative care which aims at the relief of pain and distressing symptoms, and the provision of psychological, social, and spiritual support

(WHO, 2013)

- Good EOL service should
  - choice and control over where death occurs
  - who is present and shares the end of a life

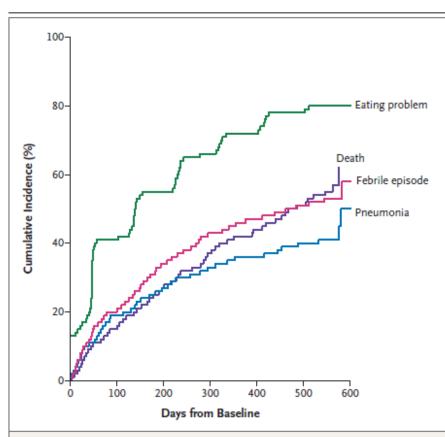
(Smith, 2000)

 EOL care can be achieved in nursing homes, which could enhance quality of life among dying residents

(Nochomovitz et al., 2010; Hendriks, et al., 2013)

#### The clinical course of advanced dementia

Mitchell SL et al. N Engl J Med 2009;361:1529-38



**Figure 1.** Overall Mortality and the Cumulative Incidences of Pneumonia, Febrile Episodes, and Eating Problems among Nursing Home Residents with Advanced Dementia.

Overall mortality for the nursing home residents during the 18-month course of the study is shown. The residents' median age was 86 years, and the median duration of dementia was 6 years; 85.4% of residents were women.

## Advanced dementia is a terminal condition

- Median survival 1.3 years
- Common events requiring hospitalization
  - Pneumonia, febrile episodes, eating problems
- Unnecessary investigations and burdensome interventions
  - i.v. antibiotics, enteral tube feeding
  - Inversely related to carer's knowledge of prognosis , availability of AD/ ACP

### Local studies

- Involved 1,600 cognitively normal residents in 140 nursing homes in Hong Kong
- residents with chronic illnesses in nursing homes preferred to pass away in their own homes or in the care homes they are familiar with

(Chu et al., 2011)

- Involved 50 elderly residents and 51 family members
- 68% of surveyed residents and 80% of surveyed family caregivers preferred death to happen in Care & Attention (C&A) Home

(Lou & Chan, 2011)

### Local perspective

Residential Care Homes for the Elderly (RCHEs) in Hong Kong

- 'Ageing in place' policy
  - 13% aged 60+ (1 Million)
  - Stay in community
  - Stay in RCHE
- As at 31 March 2014
  - 715 RCHEs
  - 70,000 residents (7% elderly)

#### Unique to HK

- Primary care poorly developed
- Older people rely heavily on public healthcare
  - In-patient
  - Specialist out-patient
  - Outreach Community Geriatric Assessment Team (CGAT, 1994)
- RCHE residents
  - No designated primary care physician
  - Death in RCHEs NOT normal practice
  - All deaths reportable to Coroner
  - ~ 8000 die in medical wards each year
- AD / ACP still a novelty
- 93% of deaths occur in hospital
  - Consequences of deaths at other locations
    - Public mortuary
    - Report to Coroner (CAP 504, Coroner Ordinance Section 4, 16)
    - Police investigation
    - Autopsy
    - Taboo to family
    - Drop in price of property

#### "Revolving Door"

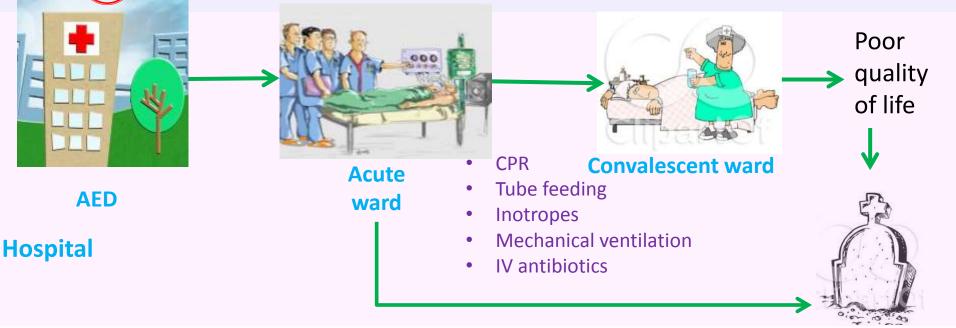
#### **Repeated crisis admissions**

# Patients receive "routine" acute interventions

Recurrent CVA Aspiration penumonia Feeding problems sepsis

Community

**RCHE** 



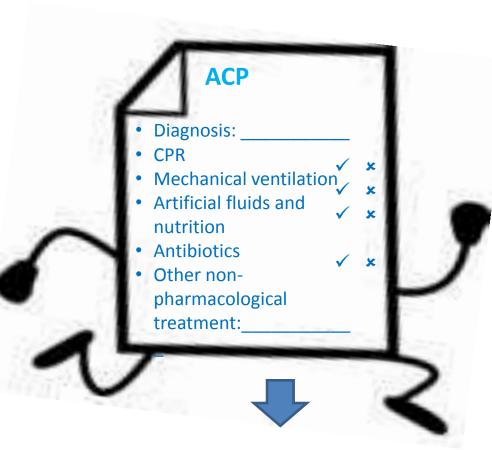
### Local experiences

### EOL program in RCHEs in Shatin district

- Identify patients in RCHEs eligible for EOL care ~ 5% of RCHE population
- 2. Engage patient/family members to formulate Advance Care Plan (ACP)
- 3. Provide symptom control and arrange support services based on the ACP
- 4. Coordinate patient journey, including streamlining admission to designated ward for EOL care

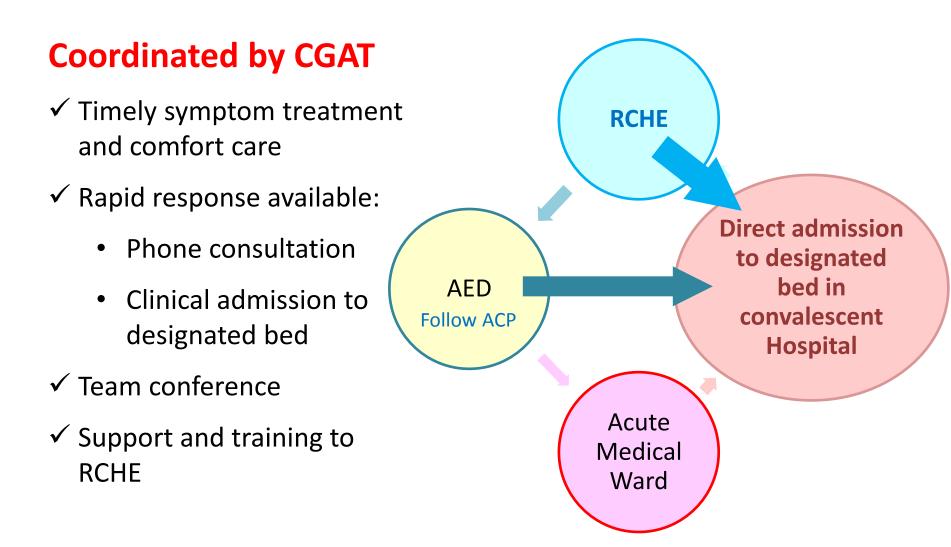
#### **Advance Care Planning**

- Formulate Advance Care Plan (ACP)
  - ✓ Discuss patient's prognosis
  - Identify values, goals & preferences
  - ✓ Review pharmacologic treatment
  - Build up a therapeutic plan and reduce unnecessary therapies
- Delivered by trained CGAT doctor
- Engage patients and family members



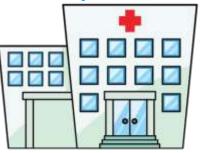
- Provide options to patient/family
- Comfort and dignity
- Reduce unnecessary therapies

#### **Need-based Service Provision**



#### **Last Journey**

#### **Hospital**





- Private corner/farewell room
  - medical wards
  - 🐞 AED in HK West Cluster
- Flexi-visiting hours
- Psychological and spiritual support
- Refer to MSW/PC team/NGO for bereavement support



#### **EOL Care Pathway**

**RCHE** 



Multiple strokes Heart failure Contractures ✓ ACP

- Patient: symptom control and psychosocial support
- ✓ Support and training to RCHE

Resident's conditions deteriorated (e.g. Fever,  $\uparrow\uparrow$ SOB, suspected aspiration pneumonia) RCHE staff unable to provide the care needed



#### CGAT coordination



Direct hospital admission to designated setting ACP adherence

- Symptom control
- Supportive
  treatments
- Psychological and spiritual support

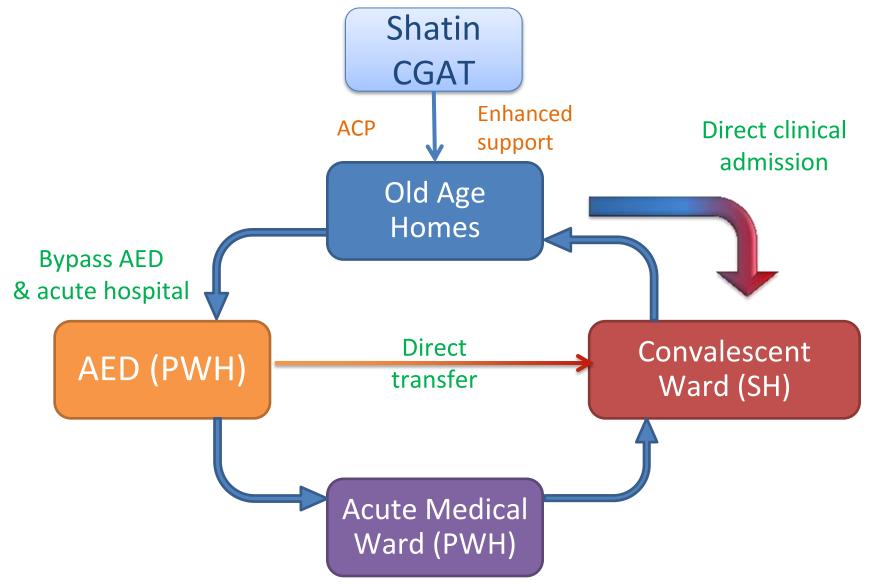
#### Good Death



#### Pilot in Shatin district, winter surge months 2013

- Up to 50% of EOL patients can bypass AED and be directly admitted to convalescent setting
- ACP compliance 97%
- Satisfaction level was high among patients, family and OAH staff
- Limitations
  - service hours of CGAT
  - clinical condition of patient too critical
  - lack of beds in convalescent hospital
- Potentially more patients can be directly admitted

#### A new journey for EOL patients from RCHEs



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#### **Clinical** Experience

#### A New Model for End-of-Life Care in Nursing Homes

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#### ABSTRACT

Reywerds End of Afrik Gare model an sing harnes	Objectives: This study aimed to promote quality end-of-life (801) care for numing home misidents through the establishment of advance care plan (ACP) and instructure of a new care pathway. This pathway bypasied the emergency room (28) and acute medical wards by facilitating direct choics admission to an extended care facility. Design: An audit on a new clinical initiative that encalled the Community Geristrics Outroach Service, ES acute medical wards, and an extended care facility during winter months in Hong Kong. M thoil: The participants were older numing home estifents entrolled in an EOL program. We monitore the ratio of clinical ne emergency admission, ACP compliance rate, average length of stay (ALOS) in both acute hospital and an extended-care facility, either through the liaison of Community Geristrics Durings (ALOS) in the extended-care facility, either through the liaison of Community Geristrics Outroach Service (group A, 10)/A, S23) or transitered from the E8 (group B, 11/26, 143). The remaining 6 patients (group C, 613) were admitted via the E8 to cause medical wards was to ally 1000 in the extended care facility, addition of Compliance fact was nearly 1000 in the extended care unit, groups A and C had unital ALOS of 118 and 111 days, respectively, wherea group 8 had a lower mortality rate of 183. Granchorines Nearly 400 of 201 patients could be managed entirely in an extended-care areing without componenting the quality of Calo, The ALOS of group C in acute medical wards was to skys. The is hospital mortality rate of 183. Granchorines Nearly 400 of 201 patients could be managed entirely in an extended-care setting without compromising the quality of Calo and survival A group C in acute medical wards wards wards wards wards program by inproving the collaboration to between community outnests privates and S2, and extending hours for direct chieled admission to an extended-care facility.
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In Hong Kong, chuonic diseases, such as chunic obstructive pulmonary disease, congestive heart failure, cerebrovascular acident, and dementia-related complications, account for a high level of healthcare utilization, especially during the winter months when patients are more likely to experience acute exacerbations.<sup>1</sup> This phenomenon, known as winter-surge, is associated with an increase in attendances and lengthy waiting times in the emergency room

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(EK) and severe congestion in acute medical wards. Although only 78: of older people in Hong Kong are institutionalized, the "Revolving Door Syndrome," characterized by prepated hospitalizations, is very common among numing home residents." In Hong Kong, the early (<28 days) unplanned madmission rate to acute medical units of public hospitalisis 2-dol higher among institutionalized older people than those living in the community (ie, 36% vs. 1883)." Most of these patients had multiple comorbidities and may have reached their endof-life (ECL) with a life expectancy of less than 12 months.<sup>45</sup>

The Prince of Wales Hospital (PWH) is a 1600-bed acute general hospital, which serves a catchment population of 0.7 million in Shatin, Hong Kong, of which 12% are older people aged over 65. There are 4800 nursing home places in the district, and these institutions

### EOL team at work

# Other models

- TWGH Shuen Wan Die-in-home project
  - In depth psychosocial support
  - Respect patients last wishes
  - Preferred place of care & dying
  - Work closely with local CGAT and hospital
- Salvation Army "Palliative Care in Residential Care Homes for the Elderly"
  - Last 72 hours of life
  - Designated visiting doctor
  - Symptom control

# Summary and way forward

- Services for older patients reaching the end of life are under-developed in Hong Kong
- Some good practices exist but sporadic
- Urgent need for
  - Education & debate
    - Academics, legal profession, government
  - Training of caregivers
    - Healthcare, RCHE, informal carers
  - Adopt practices in healthcare system
    - GP-CGAT-RCHE-AED-hospitals
  - Dying in RCHEs
    - New contract homes with 'dual license'
    - Amend current laws

Thank you huie@ha.org.hk