#### Role of Community Geriatric Assessment Team in Helping Elders in their Advance Care Planning and End of Life Care

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#### Residential Care Home for the Elderly (RCHE)

o different kinds of RCHEs in Hong Kong

#### RCHEs run by private sectors

different scales

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- variable qualities
- some better equipped are qualified to have places as being 'Bought Place Scheme' [government 'buy' places there by subsidy, equivalent to subvented home beds due to insufficient Government subvented Homes]
- RCHEs subvented by Government/Non-Government
  Organization
  - Care & Attention Home
  - Nursing Home

## Community Geriatric Assessment Team (CGAT)

- outreach service to frail elders living in RCHEs
- providing specialty follow-up
- Win-win situation to patients/RCHEs & hospital/Non Emergency Ambulance Transport Service (NEATS)
  - save transport of different elders of different booked time-slots
  - save waiting area for different elders waiting for consultation
  - save manpower in escorting frail elders during follow-ups
  - increase flexibility in follow-up arrangement
  - seen by designated doctors/nurses: longitudinally follow-up

# Rising demand...

- By 2012, around 40000 elders were living in private Residential Care Home for the Elderly (RCHE)
- 96.9% were aged 60 or over
- Median age 83
- The numbers will be more if included those residing in subvented RCHEs (~ 80000)

#### many of them have chronic illnesses, deteriorating along the disease course: the trajectory

- Neurodegenerative diseases, e.g. cerebrovascular accident, Parkinson's disease
- Chronic organ failure, e.g. chronic heart failure, chronic renal failure, chronic lung failure (chronic obstructive airway disease)
- Dementia & frailty
- malignancies







#### **Conventional practice**

- Patients sent to AED for acute illnesses or exacerbation of chronic illnesses
  - unavoidable sequelae of some chronic illnesses, e.g. recurrent aspiration pneumonia in a patient suffered from major stroke on tube feeding
- 'package curative treatment' offered during hospital stay in acute ward setting
  - stabilizing as soon as possible, using antibiotics (increasing use of 'big gun' antibiotics), inotropes, etc
  - aim shortening acute hospital stay
- Issues of repeated unplanned hospital admissions
  - increasing numbers of AED visits
  - addressing the root problem of the patients
  - Comfort or ?Cure



# Case 1 (i) (fig 3)

- Madam YSY, known cholecystectomy, hysterectomy, Parkinsonism with postural hypotension, cataracts operated, multi-nodular goitre with hemithyroidectomy, anxiety depression
- Institutionalized in private nursing home since 2002 as inadequate home care, falls, increasing anxiety symptoms
- ADL basically supervised/mildly assisted till 2006



- till 2006, progressively decrease in mobility and became chairbound as worsening Parkinsonism features despite titrating medication
- 1/07': admitted once for paroxysmal atrial fibrillation with chest discomfort
- 1/08': symptoms of dysphagia; seek surgical opinion with unremarkable OGD finding

# Case 1 (iii)

- since mid 08': progressive weight loss of 3 kg over ½ year
- 09': dementia features as more dependent in ADL, worsening cognition, irrelevant speech, fluctuating oral intake, more feeding dyspraxia [poor initiation & concentration on feeding, chewing & swallowing] & requiring nutritional supplement use
- blood test ordered: thyroid function normal, serum creatinine & albumin still normal range
- 6/10': Psychiatrist seen: diagnosis of dementia features established; mood neutral, prn hypnotic for disturbed sleep-wake cycle

# Case 1 (iv)

- 6/10': daughter interviewed
  - the deteriorating nature of the chronic illnesses, namely
    Parkinsonism, dementia and functional decline explained
  - anticipated more and more difficulty in feeding, subsequent weight loss & increased susceptibility to infection
    - pros & cons of tube feeding
    - agreed for "comfort feeding"
- 7/10': more feeding dyspraxia, feeding on milk supplement mainly, need patience in feeding
- RCHE dedicated health care workers 'comfort fed' her patiently
- 10/10': psychi FU: bedchairbound, briefly sit-out daily, able greeting, euthymic

### Case 1 (v)

- 1/11': further deteriorated and hardly be fed, still alert
  - ad-hoc seen: Madam Y refused nasogastric tube insertion by gesture/turning head
  - daughter seen again: expressed that "the most important thing is comfort care... she is cared all along by staff here for almost 10 years, this is her home..."
  - understood well the care plan, Madam Y was kept in the aged home for 2 more days till blood pressure dropped and became dull, accompanied to AED
  - passed away peacefully 3 hours after she was admitted to Geriatric ward without any CPR performed



#### Case 2 (i)

- Madam CWYY, staying in the aged home since 96'
- known undifferentiated connective tissue disease, hypothyroidism on replacement, old PTB, fracture Right hip operated 97', cancer of left breast with mastectomy, hypertensive heart disease
- ADL independent till 08' self ambulatory using a frame
- 5/08': noted gradual decline in cognition for ~ 1 year & diagnosed to have dementia after psychiatrist seen

## Case 2 (ii)

- 9/08': completed a course of GDH training for deconditioning: assisted frame walk
- 10/08': psychiatry FU: assisted frame walk, mood well, appetite satisfactory
- 3/10': disturbed sleep-wake, may omit meals
- 7/10': need help in feeding, progressively more disturbed sleep-wake cycle of 2 days of somnolence; still communicable when awake

### Case 2 (iii)

- 1/11, 2/11, 3/11': admitted for decompensation of congestive heart failure
- 4/11': chairbound, occasional confused speech, still able recognize family faces
- 4/11': adm again for CHF decompensation; upon D/C, noted on/off Cheyne-Stokes breathing pattern
- 7/11': few family members seen who came back from U.S.

### Case 2 (iv)

- Diagnosis of and downhill course of
  - advanced heart failure (NYHA IV with frequent admission)
  - dementia & increasing frailty (more disturbed sleep-wake, decreasing oral intake)
- Comfort feeding & Palliative approach agreed & accepted: generally accepted 'Do Not Attempt CPR' if arrest
- 7-12/11': admitted 2 times for decompensated CCF with desaturation, and, sepsis, UTI + retention of urine

## Case 2 (v)

- From 7/12 12/12': decreasing intake, more dependent edema
  - close FU + ad-hoc sessions
  - given O2 in aged home, prn use of diuretic
  - No blood taking
- final days:
  - more edematous, could not be fed, more rattling breathing, kick of fever
  - given suppository panadol, subcutaneous buscopan, haloperidol
    & morphine
- admitted to Virtual Ward of AED & death certified at AED





- Madam YMY, known HT, T2DM combination therapy, old stroke 95', cataracts, hepatitis B carrier, OA spine with low back pain, depression [FU psychiatrist]
- staying in OAH since 99' when her ADL I, unaided
- 7/06': admitted for chest infection, UTI + retention of urine, gastritis (coffee ground vomiting): deconditioned
  - received a course of rehabilitation in Geriatric Day Hospital: stick walk upon D/C

# Case 3 (ii)

#### 8/06': admitted SURG: diagnosed to have hepatocellular carcinoma

- right upper quadrant abdominal pain & fever, 7 cm tumour Right lobe of liver with central necrosis on imaging
- Right partial hepatectomy + cholecystectomy done

#### 10/06': admitted SURG: liver abscess

- upper abdominal pain, fever
- drained, prolonged course of antibiotics
- intervals follow-up CT
- off drain 12/06'
- 07': fall once, frame walk independently, indoor bound, mentally sound, mood neutral
- 4/08': admitted URO: retention of urine again, failed off Foley twice

# Case 3 (iii)

- 10/09': FU SURG: FU imaging/MRI showed biliary cystic tumour
  - planned for conservatively managed after discussed with Madam Y & her daughter
- 8/10': clinically admitted SURG for repair of incisional hernia
- 1/11': O&T seen for progressively increase in Left sciatica
  - XR: OA change, with osteophyte
  - CT done for severe pain: features suggestive of bone metastasis to L4/5
  - referred Oncology & Hospice
- 7/11': accepted grief, naturalistic view towards death expressed
- 9/11': palliative radiation therapy done to pelvis to relieve pain

## Case 3(iv)

- 10/11': generally decrease in mobility & functional status, developed Lt foot ulcer
- IO/11': admitted for catheter related UTI + worsening of Lt foot ulcer
- 10/11': developed sacral sore
- repeated admission for fever, UTI, worsening of Lt foot ulcer, osteomyelitis from 11/11 to 4/12 10 times
  - last 2 admission to O&T & transferred to Hospice: Below +/- Above Knee Amputation offered, Madam Y & daughter refused
  - Madam Y refused blood transfusion, "...leave the blood products for those who really need them..."
- pain satisfactory controlled by regular pain killer, mood neutral upon FU by psychiatrist

# Case 3 (v)

- 5/12': Madam Y & daughter seen at RCHE, she was calm & communicable, understood well her condition, Advance Directive signed, stated not for blood transfusion, artificial tube feeding, Cardiopulmonary resuscitation
- spiritual support by the pastor
- Clinical psychologist follow up patient, relatives, staff of the RCHE
- mood stable, some previously unsettled family issue between Madam
  Y & her son solved
- \* "... we can have choice"



## Case 3 (vi)

#### ♦ from 5/12' – 7/12': staying & cared in RCHE, no AED attendance

- frequent regular + adhoc visits by CGAT doctor& CVMO
  - Pain control
  - Constipation management
  - Catheter related UTI & hematuria: change Foley, flushing by RCHE nurse, regular antipyretic
  - Wound management
  - Patient & relative, and staff support
- RCHE managed to arrange a room for relatives overnight-stay, where they spent the last days of Madam Y in her 'home'
- CGAT doctor informed AED for the potential Virtual ward patient
- She was sent to AED & registered under the Virtual Ward and certified death by AED doctor; death certificate signed by CGAT doctor



#### Case 4 (i)

- Madam LPC, staying in RCHE for years
- singleton, retired teacher; enjoyed independent ADL, stick walker
- Hypertension: followed up in General Out Patient Clinic
- not regularly seen by CGAT

#### Case 4 (ii)

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- 11': admitted SURGICAL for vomiting coffee ground substance, she declined oesophageoduodenoscopy (OGD), given a course of proton pump inhibitor
- 6/13': admitted GERIATRIC for un-witnessed fall, found anemia, peripheral edema; negative fecal occult blood, not iron deficiency, deranged liver function with low blood albumin
  - 6/13': Ultrasound abdomen revealed multiple echogenic liver lesion seen over both lobes of liver with largest 4.6 x 4.9 cm in Right lobe
  - 7/13': Computerized tomography showed numerous bi-lobed hypoenhancing liver masses up to 8 cm compatible with metastasis; apparent focal circumferential mural thickening over ascending colon noted
- Blood test: AFP normal range, sky high level CEA

# Case 4 (iii)

- 5/13': CT findings & provisional diagnosis of Cancer of colon with metastasis to liver explained to Madam L and close friend who accompanied her
  - Madam L was mentally sound, understood the diagnosis
  - Declined further investigation including colonoscopy, subsequent surgery, radiotherapy/chemotherapy
  - She was referred to CGAT for subsequent follow up

#### 27/7/13': seen in CGAT visit, seen with sister who came from China

- chairbound, peripheral edematous, fair oral intake, a bit lethargic, mood neutral
- recapitulated the diagnosis of colon caner with liver metastasis & subsequent deranged liver function with low albumin
- the deteriorating course of the disease explained
- understood & accepted the conservative management & declined any further investigation
- Advance Directive signed: stated NOT for tube feeding, Do Not Attempt CPR





#### Case 4 (iv)

- subsequent regular + ad-hoc CGAT visits during last days
  - § 5/8/13'
    - edematous, tired looking, fair oral intake, increased sense of shortness of breath: oxygen therapy prescribed
    - blood pressure low normal side: antihypertensive drugs discontinued

#### 7/8/13'

- condition static, mood neutral, communicated slowly
- 10/8/13'
  - not much shortness of breath, recalled friends and relatives from China paid visit to her

#### 12/8/13'

 further decrease in oral intake, COMFORT FEEDING using syringe, increasing edema & more tired looking
## Case 4 (v)

#### 19/8/13'

- increasing shortness of breath, desaturation despite oxygen therapy, rattling breath sound, became dull, barely arousable, could not be fed anymore
- became jaundice & more edematous
- nursed in single room in the RCHE, sister from China & best friends accompanied her
- started subcutaneous continuous infusion of morphine, buscopan & haloperidol
- CGAT doctor informed AED the potential Virtual Ward patient

#### 20/8/13'

- found unarousable & unrecordable vitals
- sent to AED & registered under Virtual Ward, death certified by AED doctor
- Death certificate signed by CGAT doctor



# Role of CGAT as interface

- As case manager looking after the frail elders along their disease trajectories and be the 'pilot' throughout the transition of care
- Hospital settings
  - Acute/Convalescent hospitals: facilitate early discharge
  - Geriatric day hospitals: functional maintenance after some acute illnesses
  - Different specialties/subspecialties clinics: case manager of the frail elders, try avoid polypharmacy/follow-up
  - Collaboration among different clinical departments: setting up Virtual Ward with AED & Medical Record Department (MRD)
- Different kinds of RCHEs
  - Government subvented homes
  - NGOs subvented homes
  - Private homes



# CGAT to patients

- longitudinally follow up elders, usually with multiple chronic illnesses
- multi-disciplinary in CGAT
  - Doctor: Geriatric Specialist & Community Visiting Medical Officer
    regular follow up, post-hospital discharge follow-up; ad-hoc consultation
    - Weekly Joint-Grand Round with the hospital team
  - Nurse: designated nurses to look after a few RCHEs
  - Physiotherapist, Occupational therapist, Medical Social Worker
  - Abbreviated Mental Test (AMT), Barthel Index, Norton Rating, Clinical Frailty Scale, Charlson Comorbidity Index

- deal with polypharmacy, disease-disease/disease-drugs/drug-drug interactions
- Care plan implementation, involves relatives/family; regular review according to the trajectory of the chronic illnesses
- Stress symptoms control, not disease cure
- functional maintenance
- Reduce unnecessary follow-ups, investigations, drugs use
- Stress non-pharmacological measures
- Build up rapport

# CGAT to RCHEs

- To private RCHEs
  - guidance, monitoring, support to RCHE's staff (many of them are health care workers, not nurses)
- To subvented RCHEs
  - collaboration, working together with RCHEs' nurses
- Educate about the characteristics of the chronic illnesses trajectory and promote about the care plan aiming from curative to palliative
- Empower them that they are the key persons in taking care of them, especially during the EOL days

- suitable patient, suitable family, suitable timing (disease trajectory), suitable RCHE setting
- preferably not during acute phase/in acute setting
- explain the disease nature & natural course
  - Need to 'titrate' the content dynamically when talk to patient/family (with different background, educational level, culture, insights, etc): tailor-made
  - Treatment aims not curative; stress supportive & palliative: paradigm shift
    - may not follow too strict the target blood pressure, blood sugar level, etc
    - try to reduce/avoid unnecessary investigation
    - explicitly discuss with them that we may actually cut the numbers of medication as the disease progress when the side effects outweigh the benefits
  - "Comfort Feeding Always" concept

- on not single consultation . . ., it needs
  - time for patient/relative to 'digest' the concept
  - time for RCHE staff to follow
  - time for CGAT member to modify the plan accordingly
- always allows patient/family to change their mind
- support & respect their wills
- show concern always, not just during crisis, care for minor symptoms as palliation is becoming more and more important while approaching EOL, especially skin care, excessive oral secretion/sputum, continence care, etc

## **Comfort Feeding Always**

- Eating problems: hallmark of end-stage dementia; ability to eat is generally the last activity of daily living to be lost prior to death
- oral dysphagia: difficulty in chewing; pocketing or spitting
- pharyngeal dysphagia: delayed swallowing initiation, multiple swallows, aspiration
- Ioss of appetite & interest in food, refuse to eat
- inability to sense hunger or thirst

#### Weight loss in advanced dementia

#### decrease in metabolic rate

#### immobility

- atrophic brain
- reset metabolic equilibrium

#### Tube feeding in advanced dementia

#### DO NOT:

- prolong survival
- improve Quality of Life
- reverse effect of malnutrition
- improve healing of pressure sores
- prevent the complication of aspiration

#### • DO:

- have problems of leakage, discomfort, occasional blockage or displacement requiring Emergency Department visit
- usually need restrain the patient (physical or chemical) to prevent them from pulling out the tube
- iatrogenic immobility→pressure sores

# Decision in feeding problem : difficult clinical crossroad in the course of dementia

- decision making for feeding problems: emotional, cultural & moral overlay for both physicians & family members
- eating is a symbolic of caregiving in our society
- apprehension that patient is starving to death!
- even decided not for tube feeding, wrongly interpreted as "do not feed" or "no care"



#### Careful hand-feeding, comfort feeding

- stopping point in feeding: patient will be fed as long as it is not distressing, i.e. stop when bouts of cough/choking
- continued attempts to hand feed, modify meal texture/amount/timing, high-calorie supplement
- assiduous mouth care

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acknowledged risk of aspiration which occurs during end-stage dementia even if *not being fed* (aspiration of oral secretion) or *tube-fed* (reflux aspiration from tube-feeding material)

studies that interviewed terminally ill patient still capable of reporting symptoms, that comfort feeding though not provide adequate nutrition, was able to eliminate any feelings of hunger or thirst

#### Approach

- share some findings on natural history of advanced dementia
- pros & cons of tube feeding
- best conducted when resident's health is stable, not in moments of acute crisis
- rapport; family/relatives' culture/belief
- allows patient to be involved if possible; any Advance Directive
- consider RCHE factor (variable: private/subvented, 'hard/soft wares')
- talk to family again when infection or exacerbation of a comorbidity (usually when new impacts to patient/family)
- provide additional & ongoing support

#### CGAT in Helping frail elders in RCHE for ACP & EOL Care

- Right patient identified at the Right moment
- select, provide training for the Right RCHE
  - Advance Directive; Advance Care Planning
    - Comfort Feeding Always
    - Do Not Attempt CPR

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- Not for antibiotic/artificial feeding/parenteral fluid
- Follow the disease trajectory
- Continuous support to patient, family, RCHE staff
- Liaise with hospital team
  - arrange direct clinical admission during 'crisis' which overwhelm RCHE
  - Joint CGAT Round giving input to the hospital team
    - follow the ACP
    - + facilitate early supported discharge from unfamiliar hospital setting
  - Set up Virtual Ward in AED for the dying patients

### Problems encountered

- awareness of the EOL care
  - Patients, family
  - RCHE, especially front-line health care workers
  - Hospital medical & nursing staff
- underestimate the needs; manpower implication
- Hard & Soft Wares of the RCHEs
- Transport issue between RCHE & Hospital (Virtual Ward in AED) for the *final journey*



