# Advance care planning for older people with dementia

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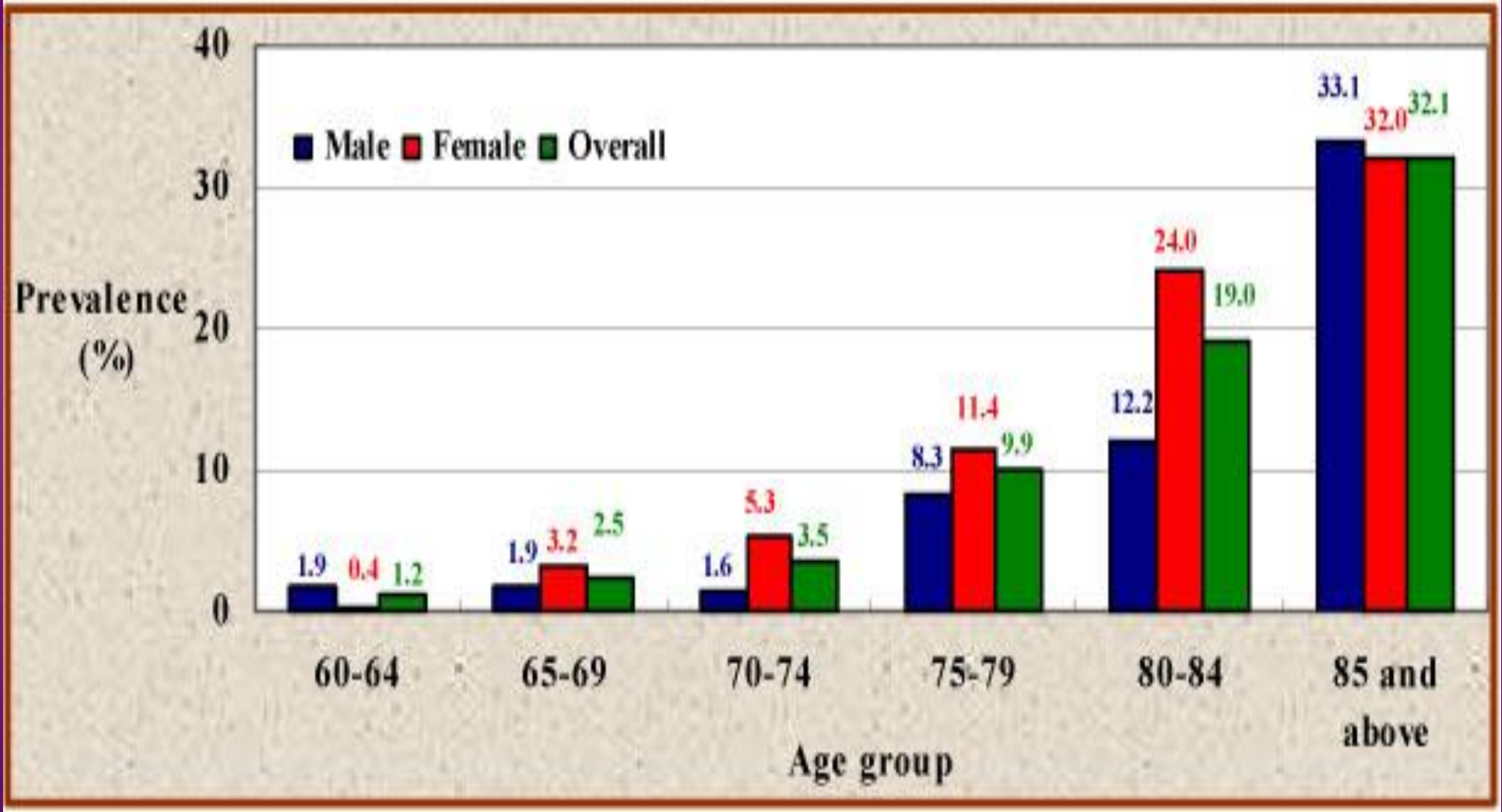
# Prevalence of dementia in community dwelling old people






Centre for Health Protection (2006). Aware (Newsletter). Volume 3, Issue 12

# Health Trends

- Longer life
- More chronic diseases
- More dementia
- Better access to health care
- More technology to sustain life

# Advanced dementia

- Dependent
- Mentally incapable
- Poor eating
- Limited but uncertain life expectancy
- Quality of life difficult to assess

# Symptoms in Advanced Dementia

- Pain
  - Contracture, sores, constipation, retention, other diseases
- Dysphagia
- Confusion
- Depression
- Isolation

# Causes of death

- Pneumonia
  - Aspiration (saliva, food)
  - Immobility
  - Malnutrition
- Intercurrent illness
  - Tend to be under-treated
- Difficulty in diagnosing end of life

# Views of old age home residents

- 140 care and attention homes
- 1600 residents（average age 82 years）
- When terminally ill，
  88 %chose palliative care
- 61 %do not wish life sustaining measures
- 74% do not wish tube feeding
- 35 %prefer to die in old age home

Chu LW et al., 2011

# Feeding problems in advanced stage

- Loss of appetite
- Loss of weight
- Refusal to eat
- Tube fed
- Physically restrained

# Chinese family caregivers' attitudes towards Tube Feeding

% agreed to withhold tube feeding from demented elders in scenario of

| » | Before | After |
|---|---|---|
| – Critical illness | 20% | 28% |
| – Irreversible Coma | 41% | 55% |

Kwok T et al 2007

# Myths of tube feeding in dementia

1. Tube feeding prevents pneumonia
2. Starving to death is uncomfortable
3. Tube feeding is not harmful

# Myth 4 No alternative

Comfort feeding

- frequent small meals
- family
- food preferences
- take off diet restriction
- food consistency

# No tube feeding is euthanasia?

- Tube feeding is a medical intervention, not basic life support
- Care professionals are not obliged to provide futile medical intervention
- Futility is a medical judgment
- Hand Feeding a disabled person is regarded basic nursing care, unless it causes great distress to patients

# Who can decide ?

- Family
- Advance directive
- Advance care planning
- Guardianship board
- Enduring power of attorney
- Law court

# Family as surrogate

Most people want family to decide

Family knows wishes of patient

Family can be trusted

Family is the key provider of care

# Families as surrogate decision makers

- End of life decision is burdensome
- Family may not know
- Family impose own value
- Conflict of interest
  - Psychological
  - Financial
- Family cannot agree among themselves

# Advance directive

Legal document made by patient before he/she becomes ill

Patient's wishes in specified clinical situations

Legally binding in some countries

Law reform committee in HK recommended a standardized but informal form of advance directive

| | | |
|---|---|---|
| 醫院管理局 HOSPITAL AUTHORITY | # 預設醫療指示 [1] | 請以正楷書寫或貼上病人標籤<br>入院／門診號碼：.............................<br>姓名(英文)：.............. ..(中文)............<br>身份證號碼：.........性別：.....年齡：.....<br>部門:........組別:......病房／床號:...../...... |

**第 I 部：此預設醫療指示作出者的詳細個人資料**

**姓名**：...................................................................（請以正楷書寫）
**身份證號碼**：...................................................
**性別**：**男性／女性**
**出生日期**：____／____／___
(日) (月) (年)

**住址**：....................................................................................................

....................................................................................................................

**住宅電話號碼**：...................................................
**辦事處電話號碼**：...................................................
**手提電話號碼**：...................................................

**第 II 部：背景**

1. 本人明白此指示的目的，是當本人病情到了末期，或處於持續植物人狀況或不可逆轉的昏迷，或有其他特定的晚期不可逆轉的生存受限疾病時，將本人所可能身受或造成的痛苦或尊嚴損害減至最低，並免卻本人的醫療顧問或親屬或兩者同時肩負代本人作出困難決定的重擔。

2. 本人明白無論在任何情況下醫生／院方都不會執行安樂死，亦不會依循本人在治療方面的任何非法指示，即使本人明文要求這樣做亦然。

3. 本人____________（請清楚填上姓名）年滿 18 歲，現撤銷本人以前曾就自己的醫護及治療作出的所有預設醫療指示（如有的話），並自願作出下述預設醫療指示。

4. 如經本人的主診醫生及最少另一名醫生診斷，證實本人是病情到了末期，或陷入不可逆轉的昏迷或處於持續植物人狀況，或有其他特定的晚期不可逆轉的生存受限疾病，以致無法參與作出關於自己的醫護及治療的決定，則本人對自己的醫護及治療的指示如下：

(註：填寫以下部分時請在適用的方格內加上剔號，在方格旁邊簡簽，並在任何不希望適用於自己的部分劃上橫線。)

[1] 表格由法律改革委員會(法改會)於 2006 年 8 月 16 日建議，根據食物及衛生局於 2009 年 12 月 23 日發表的諮詢文件更改，醫院管理局於 2010 年 5 月及 2014 年 6 月作出修訂及加上附註。

預設醫療指示 HA 9611/MR

# Problem with advance directive in dementia

- Long time gap between early and late dementia
- People may change their mind
- Can't cover all scenario
- Should it be Legally binding ?
  - What if it contradicts clinical judgement

# Advance care planning

- Detailed discussion with family about care plan
- Consensus
- Keep record of agreed care plan

# Shatin Hospital 沙田醫院
# End of Life Care Program 晚期護理計劃

## Advance Care Planning Checklist 預立醫療照顧計劃清單

**Diagnosis 診斷**

Gum Label

- ☐ Dementia 晚期認知障礙症
- ☐ Frailty 晚期衰弱
- ☐ Dense Stroke with limited recovery 嚴重中風
- ☐ CKD 晚期腎衰竭
- ☐ COPD 晚期慢性阻塞性肺病
- ☐ Liver cirrhosis 晚期肝硬化
- ☐ CHF 晚期心臟衰竭
- ☐ Marrow failure 晚期骨髓衰竭
- ☐ Malignancy 末期癌症____________________

**ACP Items 預立醫療照顧項目**

CPR when breathing and/or pulse stops 當心跳及/或呼吸停頓時進行心肺復甦急救的安排
- ☐ *Do not attempt CPR (allow natural death) 不進行心肺復甦急救，只協助自然呼吸*
- ☐ *Attempt CPR 進行心肺復甦急救*

NIPPV 非入侵性正壓通氣: BIPAP 型呼吸器
- ☐ *No 不同意使用*
- ☐ *Trial period 嘗試使用一段時期*
- ☐ *Not yet discussed 未作討論 / Not yet compromise a decision 未有決定*

Transfer to acute bed (for SH patients) 情況轉變時移送急症醫院 (適用於沙田醫院住院病人)
- ☐ *No 不同意*
- ☐ *Yes 同意*
- ☐ *Not yet discussed 未作討論 / Not yet compromise a decision 未有決定*

Artificial Fluids and Nutrition 輸液和管飼

Feeding tube: 胃管餵飼
- ☐ *No 不同意*
- ☐ *Trial period 嘗試使用一段時期 remove if causes discomfort 如有不適則停止*
- ☐ *Accept long term use 接受長期胃管餵食*

Fluids: 輸液
- ☐ *Refuse SC/IV 不同意輸液*
- ☐ *Accept SC only 只作皮下輸液*
- ☐ *Accept IV or SC fluids 可作輸液*

Antibiotics 抗生素
- ☐ *No further antibiotics, use other comfort measures 不再使用抗生素，但會繼續其他舒緩治療*
- ☐ *Oral only 只用口服抗生素*
- ☐ *Accept IV 可接受靜脈注射抗生素*

Others 其他: ____________________________________________

Dr (Name & signature) 醫生姓名及簽署____________________Date 日期____________________

☐ Discussed with patient 已與病人商討

☐ Discussed with family (name/ relationship) 已與家屬商討(姓名/關係)

見證人姓名____________________________ 與病人關係____________________

**** Patient / relatives should inform nurse/doctor ASAP if they change their decision ****

**** 如改變主意，請盡早聯絡醫護人員 ****



醫院管理局 新界東醫院聯網 Hospital Authority New Territories East Cluster

# End of life care programme at Shatin Hospital

- Target older geriatric patients with less than one year of life expectancy
- Combine advance care planning with palliative care
- Continuity of care

# How to build a consensus with family

- Build TRUST
- Communicate diagnosis of end of life
- Listen
- Explain pros and cons
- Encourage respect for patient's view

# How to build a consensus with family

- Recognize the diversity of views
- Express opinion
- Team approach
- Patience

# Case for early advance care planning

- Family may be less emotionally stressed
- More time to reach consensus
- Involvement of people with dementia

# Challenges of early advance care planning

- Family may be less motivated to be involved
- Family cannot conceive hypothetical situation
- Family may change their mind when circumstances change

# Conclusion

- Quality of life in advanced dementia is poor
- Life sustaining measures e.g. tube feeding make their QOL even poorer
- Protective measures
  - Advance care planning
  - Palliative care
  - Advance directive

# 愿您们的工作更文明！