# Macro Perspectives on the Initiatives and Development of Advance Care Planning (預設照顧計劃) in the Hospital Authority

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HKU/JCECC Symposium on Concerted Efforts in Advance Care Planning:
Regional and Local Experiences
Thursday, October 24, 2019

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## Why do we need to think about this ?

Public

- Era of chronic diseases with cumulative disabilities
- We live longer but we are still mortal


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Public

# Cultural Consideration in ACP

**Filial piety "Xiao"**

*"The son carrying the old"*

Filial piety versus letting go: struggles and conflicts

**Family "Jia"**

*"Pigs under the same roof"*

Patient asks for more autonomy yet respect traditional Chinese culture of family based decision making

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Public

# Less taboo, more discussion

病危醫不醫 六成人想預設指示

調查：八成人未聽過 學者倡探討立法

醫管局「預設醫療指示」表格範本內容

| 指示生效情況 | 醫療指示 | 見證人 |
|---|---|---|
| 說明經主診醫生及最少另一名醫生診斷，證實屬以下3種情況，以致事主無法自行作醫療決定： | 不接受指明的維持生命治療，例如： | • 由兩名見證人簽署作實，其中一人須為註冊醫生，另一人則須年滿18歲 |
| • 病情到了末期，持續惡化且不可逆轉，預期壽命短暫，維持生命的治療只可延遲死亡 | • 心肺復甦法 | • 兩人均不可在指示者的遺產中獲益，例如遺囑或保險單受益人 |
| • 陷入不可逆轉的昏迷或持續處於植物人狀態 | • 心臟起搏器 | |
| • 其他不可逆轉並致生存受限的晚期疾病，例如主要腦功能喪失、晚期胃腸或腦運動神經元疾病 | • 人工輔助呼吸 | |
| | • 甚至把經所有維生治療 | |

資料來源：醫管局「預設醫療指示」表格範本

明報製圖

本港目前未就「預設醫療指示」立法，但在普通法下，被個人意願所作指示具法律效力。在病情持續惡化至不可逆轉時，病人此前設定的「預設醫療指示」會生效，可不接受指明的急救及維生治療，例如心肺復甦法等。（劉焯霖攝）

**Public expectation for HA to facilitate patients making AD**

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HKSAR

## Government aware of the need to promote palliative and EOL care with ACP/AD as key enabler

### 2017 Policy Address

"… Measures will be introduced to provide palliative care and end-of-life care services for an increased number of terminally ill patients … The Government will consider amending the relevant legislation to give patients the choice of "dying in place"……

### 2018 Policy Address

"To allow terminally-ill patients more options of their own treatment and care arrangements, the Government will consult the public in 2019 on arrangements of advance directives and the relevant end-of-life care……"

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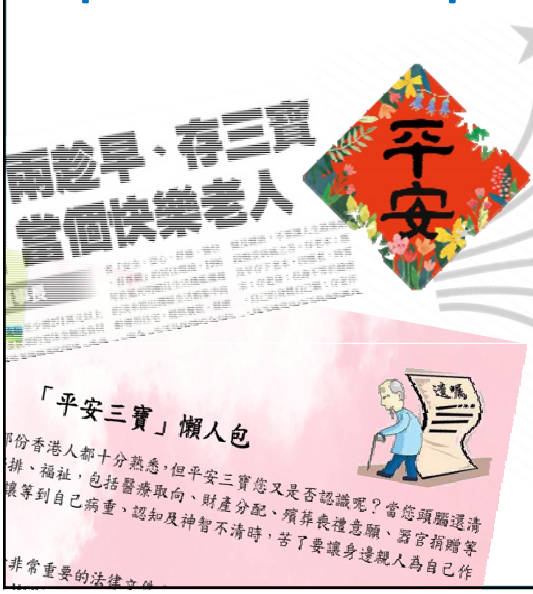
NGO

## Non-governmental Organisations (NGO) are proactive in the promotion of EOL planning




三寶

第一寶 Will
「遺囑」

第二寶 Enduring Powers of Attorney
「持久授權書」

第三寶 Advance Directive
「預設醫療指示」

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## ACP (AD) as key part of good End of Life care

HA

**Multiple chronic disease & cumulated morbidities**

Not just single organ-based needs

**Multidisciplinary team approach**

→ Physical, psychosocial, spiritual care

**Key parts**
**End of Life care**
**"Good Death"**
**(Dying with dignity)**

**Advance Care Planning (ACP)**
**Advance Directive (AD)**

→ Anticipated functional decline
→ Transition to palliative approach

**ACP (AD) as communication and planning tool**

**Medical social collaboration**

→ Empowerment of community caregivers

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醫院管理局
HOSPITAL AUTHORITY

## HA Overview

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# Help patients making difficult decisions

- **Difficult clinical decisions for withhold/withdraw life-sustaining treatment when approaching the end of life**
  - **involve cognitive acceptance of the futility of the life-sustaining treatment**
  - **made in the context of ethical, legal & comply with institutional standards**
- **HA developed various sets of guidelines over the years to facilitate patient's decision-making process**
- **ACP guidelines and standardized forms launched in Jun 2019**

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# Concept ACP (AD/DNACPR as foundation)

| Year | From inception to completion |
|---|---|
| **2010** | Under the HA's ethical framework, ACP concept **first inception** during development of **AD guidance** |
| **2014** | The idea of ACP was highlighted in **guidelines on DNACPR** and the scope was expanded to include discussion with **family members of incompetent patients and minors** |
| **2015** | A new section and appendix on ACP were added into the **HA Guidelines on LST** for the Terminally Ill elaborating an **approach that suits the local context** |
| **2019** | **ACP guidelines** and standardised forms developed **allowing flexibility for different clinical departments** to modify in view of different operation need (e.g. CGAT) |

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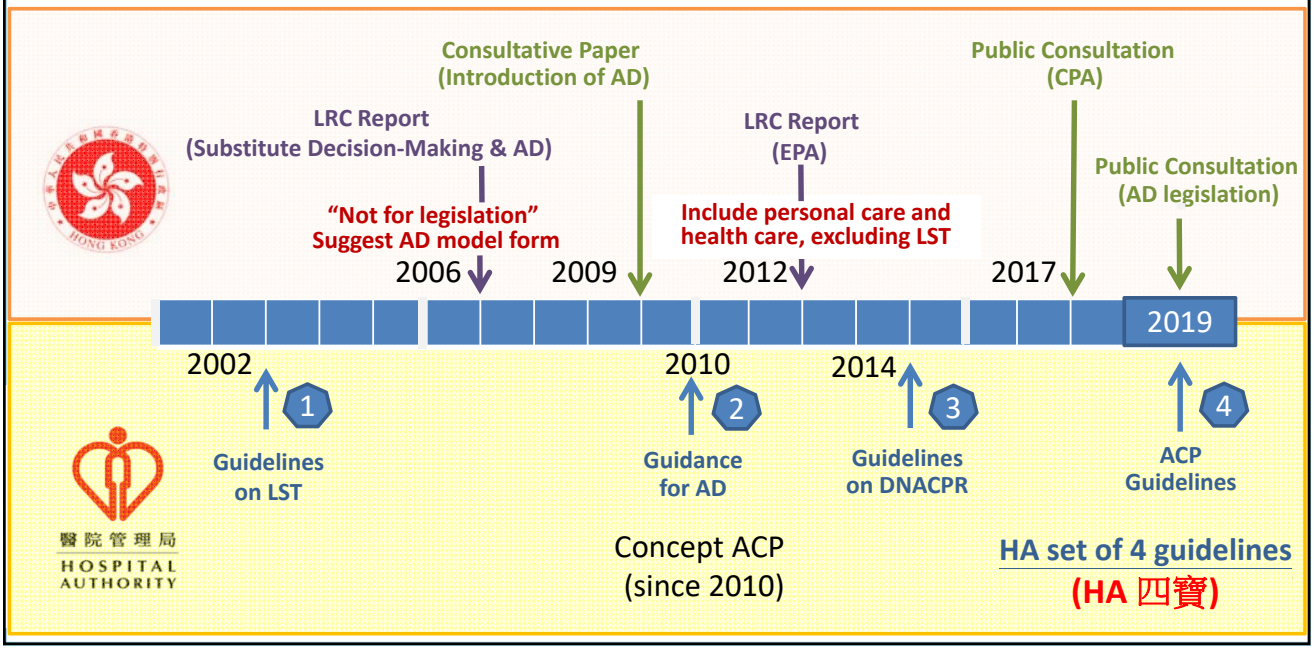
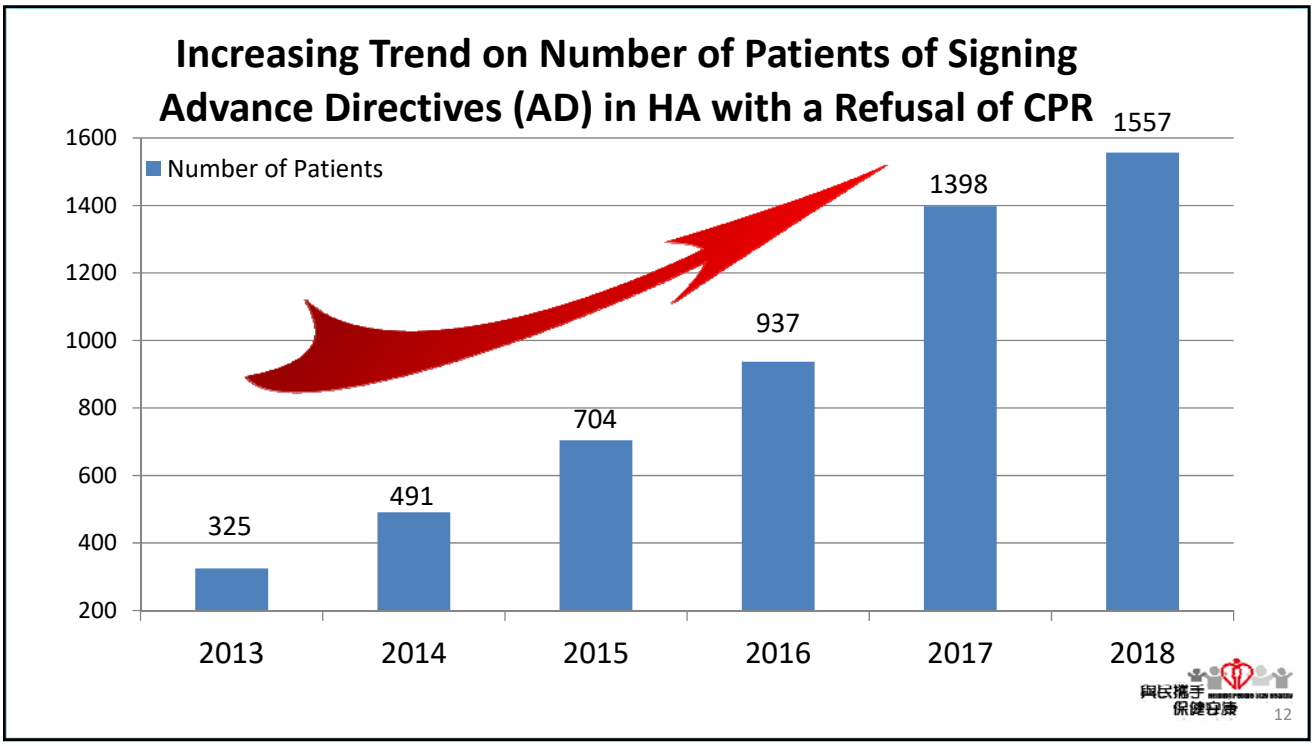
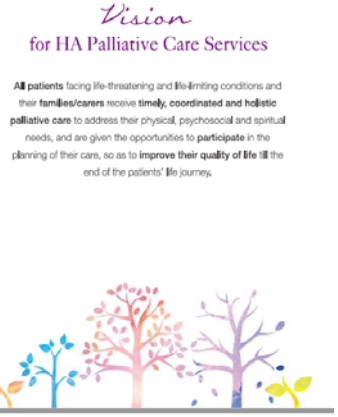
# Hong Kong Scenario



**HA Strategic Plan** "… we are in the process of formulating a Strategic Service Framework for Palliative Care to map out the service models and development for palliative and end-of-life care so as to strengthen the service organisation for more integrated and seamless care … "

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# Practical Considerations

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# 1. Fundamental principles

- **ACP/AD is widely used in HA by clinical specialties such as palliative care, geriatrics, paediatrics, internal medicine for patients with advance irreversible illness**
- **HA promotes ACP as an integral part of clinical care for patients with advanced progressive diseases**
  - A process of communication for patients with advanced progressive disease, their health care providers/ caregivers and family members
  - Consider ahead of time what kind of care is appropriate when the patients can no longer make a decision
  - Reduce conflicts and prepare the patients and family emotionally during future deterioration of patients' condition

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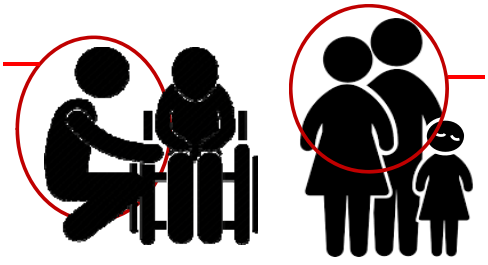
# 2. Extended Scope of ACP in HA

ACP puts emphasis on autonomy of

* mentally competent adult patients *

In HA, the term ACP also includes communication with:

family members of mentally incompetent patients



family members of minors

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# 3. Key considerations

## Do's

- **Appropriate time depends on state of disease & patients' readiness**
- **Staff should have appropriate knowledge of the subject and communication skills (e.g. appropriate time & process)**

## Don'ts

- **ACP should not be initiated simply as routine procedure.**
- **Discussion takes time and effort and is not a simple check list exercise to force patients'/families' decision**

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| Do's | Don'ts |
|---|---|
| • Assess patient's readiness | • Initiate too early or too late |
| • Respecting patient's autonomy | • Taking over to drive patient's decisions |
| • For patient to express their values, wishes & preferences for medical/ personal care | • Attempt without presence of family members, especially for MIPs & Minors<br>(Have not prepare them emotionally in case of future deterioration of patient's condition Assume children /adults with impaired capacity cannot join the discussion) |
| • Consensus building minimizing conflicts among the patient & family | • Assume children /adults with impaired capacity cannot join the discussion |
| • Review may be required as the patient's condition/ preference change | • Handle as one-off checklist exercise |

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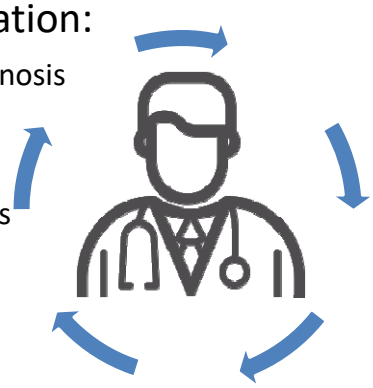
# Information Provider

## Provide

Evidence based information:

- Disease progression & prognosis
- Treatment options: burden, risks, benefits
- To manage expectation gaps e.g. CPR success rate
- To assure that comfort care and palliation is available



## Elicit

From patient:

- expectation from treatments
- preferences for treatment limits
- preferences for personal care
- personal goals to accomplish

From family:

- family values and concerns
- patient's prior wish (for incompetent patients)
- views and preferences of parents (for minors)

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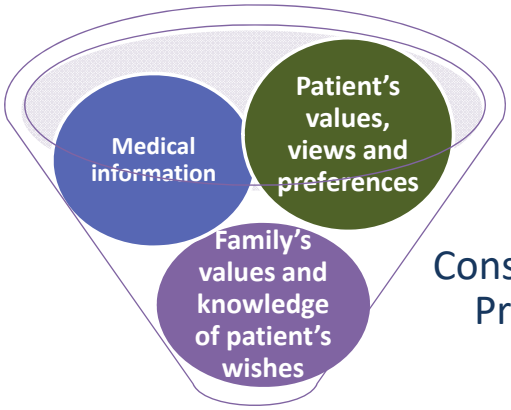
# Guide Appropriate Decision




Consensus Building Process in ACP

Overall treatment goal

Preferred medical care at EOL
Preferred personal care at EOL

+/- Advance Directive

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# 4. ACP Vs AD

| ACP | AD |
|---|---|
| 1. A process of proactive communication | 1. One of the tools during the ACP process |
| 2. ACP form* are not legally binding | 2. AD is legally binding under common law |
| 3. ACP form document patient's wishes, values, and preferences for both medical & personal care | 3. AD specify the medial treatment that patient refuse in case he/she becomes mentally incapacitate |
| 4. During ACP, patient can opt out sign an AD | 4. Sign an AD by itself |

*ACP from serves as reference for healthcare team to make decisions and formulate individualized care plan for best interests of patient.



# 5. Other Considerations

- An individual clinical unit/ specialty may modify ACP form according to needs
- Unlike practices in other countries such as United States, Singapore, etc., in HA ACP/AD is not meant for relatively healthy patient. If such patient's request, HA doctors may ask the patient to seek help from NGO/ private sector
- ACP guidelines should be used with other related guidelines together which stipulate the ethical framework from different aspects of making EOL decisions

# Key Challenges



# Observations

- Two operation challenges - handling of (i) DNACPR between HA & FSD and (ii) AD signed outside the HA
- Public expectation that HA should do more work on ACP(AD)
- Staff sentiment that this may mean additional workload

# Way Forward – HA Perspective



# Key Work Focus (1)

1. **Promote staff awareness**

   (e.g. training, staff forum, a/v materials etc.)

2. **Facilitate integration of ACP (AD) into clinical care**
   - explore new service models, e.g. renal PC services
   - enable more system functions e.g. recognize ACP(AD) signed outside HA

# Key Work Focus (2)

## 3. Support & provide HA views to Government led public consultation underway

Press release to launch public consultation (Sep 2019)


7 public consultation forums (Oct- Nov 2019)



# Thank You

# Q&A