Why do we need to think about this?

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

We die slower and have time to think about death.
Cultural Consideration in ACP

Filial piety “Xiao”

Family “Jia”

“The son carrying the old”

Filial piety versus letting go: struggles and conflicts

“Pigs under the same roof”

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

Less taboo, more discussion

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

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

- Multiple chronic disease & cumulated morbidities
- Not just single organ-based needs

Multidisciplinary team approach

- Physical, psychosocial, spiritual care

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Advance Care Planning (ACP)
Advance Directive (AD)

- Anticipated functional decline
- Transition to palliative approach

Medical social collaboration

- Empowerment of community caregivers

ACP (AD) as communication and planning tool

Key parts
End of Life care
“Good Death”
(Dying with dignity)

HA Overview
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

Concept ACP (AD/DNACPR as foundation)

<table>
<thead>
<tr>
<th>Year</th>
<th>From inception to completion</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>Under the HA’s ethical framework, ACP concept first inception during development of AD guidance</td>
</tr>
<tr>
<td>2014</td>
<td>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</td>
</tr>
<tr>
<td>2015</td>
<td>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</td>
</tr>
<tr>
<td>2019</td>
<td>ACP guidelines and standardised forms developed allowing flexibility for different clinical departments to modify in view of different operation need (e.g. CGAT)</td>
</tr>
</tbody>
</table>
**Hong Kong Scenario**

- **Consultative Paper (Introduction of AD)**: 2002
- **LRC Report (Substitute Decision-Making & AD)**
  - “Not for legislation” Suggest AD model form
  - Include personal care and health care, excluding LST
- **Public Consultation (CPA)**
- **Public Consultation (AD legislation)**
- **Guidelines on LST**
- **Guidance for AD**
- **Guidelines on DNACPR**
- **Concept ACP (since 2010)**
- **HA set of 4 guidelines**

**Increasing Trend on Number of Patients of Signing Advance Directives (AD) in HA with a Refusal of CPR**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>325</td>
</tr>
<tr>
<td>2014</td>
<td>491</td>
</tr>
<tr>
<td>2015</td>
<td>704</td>
</tr>
<tr>
<td>2016</td>
<td>937</td>
</tr>
<tr>
<td>2017</td>
<td>1398</td>
</tr>
<tr>
<td>2018</td>
<td>1557</td>
</tr>
</tbody>
</table>
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** ... ”

**Vision for HA Palliative Care Services**

All patients facing life threatening and life limiting conditions and their families deserve respect, dignity, compassionate and individual palliative care to address their physical, psychological and spiritual needs, and be given the opportunity to participate in the planning of their care, so as to improve their quality of life till the end of the patient’s journey.

Practical Considerations
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

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
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

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

Guide Appropriate Decision

Consensus Building Process in ACP

Overall treatment goal

Preferred medical care at EOL

Preferred personal care at EOL

Advance Directive
### 4. ACP Vs AD

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

*ACP form 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

• 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
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