



Advance Care Planning in Dementia Context

Caregivers of people with dementia (PwD) often find themselves in a difficult position to make proxy decisions for the care recipients if the care recipients have not expressed their care wishes before their cognitive ability declined.¹ The difficulty and stress may last from the onset of dementia to the end of life and the decision making is even harder when there is family disagreement at times of healthcare crises. To maintain care in accordance with the PwD's wishes, a discussion about future care should be made when the PwD is still in the early stage.

What is ACP?

Advance Care Planning (ACP) is the process of communication among care recipients, caregivers and health providers about future medical or personal care considering aspects such as the disease prognosis, benefits and harms of treatment, values and preferences of the care recipient.² It helps to ensure the wishes of the care recipients would be conveyed, and met when they could not communicate. Care recipients could indicate their preferences and document it by making an advance directive (AD) to refuse life-sustaining treatment (LST) such as cardiopulmonary resuscitation, artificial ventilation, artificial nutrition and hydration (tube feeding), etc. AD is activated when the care recipient is “terminally ill, in a state of irreversible coma or in a persistent vegetative state” and have become mentally incompetent.³

Usage of AD in Hong Kong and worldwide

Some places have passed laws to protect the execution of AD, such as the United States, Canada, Australia, England,⁴ Singapore⁵ and Taiwan.⁶ A study conducted in the US⁷ found that the completion of AD on elderly decedents had increased from 47% to 72% from 2000 to 2010, indicating a more common use of the AD. However, in Hong Kong, AD is still not common. A survey⁸ on 1,067 adults about preference on palliative care showed that the majority of respondents preferred palliative care if they were terminally ill (87%) and agreed that treatment a person receives should be in accordance with one's wishes (86%). Despite this clear preference, the uptake of AD in Hong Kong is low. Among 30 public hospitals, only 3,275 patients made an AD from the period of August 2012 to June 2017, making an average of 22 completed AD per hospital each year in the past 5 years.⁹

Impact of ACP on Caregiver and the Care recipient

A systematic review of 113 articles¹⁰ also presented a similar view on the effects of ACP on increasing compliance of care recipient's wishes and use of hospice and palliative care. In reviews of dementia literature on ACP,^{4,11} it was found that studies regarding the efficacy of



ACP on PwD are currently inadequate, although there is some evidence pointing to the effectiveness of ACP in minimizing inappropriate hospital admissions, death of PwD and increased use of hospice.

Initiating the discussion on EoL matter is difficult, especially in the Chinese society where death remains a taboo¹² and particularly in a dementia context in which people with dementia may be regarded as not competent in making a valid decision.¹³ Therefore, it is crucial for people with cognitive impairment and the families to take the initiative to discuss about ACP as soon as possible so that the care recipients' rights of self-determination could be respected. Jockey Club Centre for Positive Ageing and CUHK Jockey Club Institute of Ageing have respectively produced video and handbooks in a hope to facilitate various parties to start the discussion and planning:

1. Jockey Club Centre for Positive Ageing 《 THE TAIL BEFORE 》 :
<https://www.youtube.com/watch?v=Ftjn2I69eKk>
2. CUHK Jockey Club Institute of Ageing, JCECC Capacity Building and Education Programmes on End-of-Life Care, “Good Death Booklet”:
http://www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Good_Death_Booklet.pdf
3. CUHK Jockey Club Institute of Ageing, JCECC Capacity Building and Education Programmes on End-of-Life Care, Advance Care Planning Handbook:
http://www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Advance_Care_Planning_Handbook.pdf

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13. Wong J, Scully P. A practical guide to capacity assessment and patient consent in Hong Kong. 2003.