INTRODUCTION

1. Singapore population is rapidly aging. It is estimated that one in five (18.7%) Singapore residents would be elderly by 2030. With 60% of the elderly residents aged 65 years and older known to be suffering from at least one chronic condition (diabetes, hypertension, high blood cholesterol), health care is an important factor in the overall care plan for the elderly. With more educated elderly residents, technological advances in healthcare, and the growing acceptance of the concept of patient autonomy, advance care planning (ACP) becomes increasingly important, and would better prepare Singaporean residents for their future healthcare needs and decisions.

TERMS OF REFERENCE

2. The Subcommittee of the National Medical Ethics Committee (NMEC) on Advance Care Planning (ACP) was tasked by the main committee, in Apr 2009, to propose an ethical framework for Advance Care Planning that is relevant to the Singapore context.

BACKGROUND

3. Modern technology and treatment modalities have allowed doctors to influence the course of illness. However, this may not be the individual’s preferred course of treatment, for example at the end of life, when priorities of quality of life and comfort could take precedence over longevity.

4. The emphasis in other countries has shifted from making advance directives, which are limited to medical decisions, to ACP, which has a broader goal of care in general. ACP need not be limited to ill individuals, and can be used by anyone in the community. A short write-up on overseas practices related to ACP and the factors affecting the making of advance care plans are found in Annexes A & B.

LOCAL SITUATION

5. Slightly more than half (56 – 58%) of all deaths that occurred between 2002 – 2005 among Singaporean residents aged 65 and older occurred in acute hospitals, a figure that is comparable to that in England (58%). Another 21% died in care homes and hospices, while around 18% died in their own residence.

6. A recent 2008-2009 local street-poll survey conducted by Lien Foundation on 800 respondents aged 25 – 59 years old revealed that about 60% of respondents said they were comfortable with talking about their own death or dying. However, when asked about talking to someone who is terminally ill, more than half of them said they were not comfortable. Of those surveyed who knew a terminally ill person, about half
had not spoken to them about issues relating to death. The most common reasons for not being comfortable talking about death were fear and a lack of knowledge in this topic.

7 The respondents who were more comfortable talking about their own death or dying were more likely to be younger, single, educated, had a good perception of the level of end-of-life care, and belonged to a minority race group, e.g. Caucasian. Religion did not seem to have a significant influence, as free thinkers were not less comfortable about talking about death, compared to those with a religion.

8 Communication about issues related to death or dying is not yet commonly practiced in Singapore. This may be a challenge for ACP, where communication is integral, and the subcommittee has chosen to focus on this area of ethical handling of communication during ACP in this document.

SCOPE OF DOCUMENT

9 Communication during ACP is one of the important elements for useful and valid advance care plans, apart from issues such as the timely identification of advance care plans or statement of wishes at time of its potential use.

10 This document serves as a guide for healthcare professionals on the ethical handling of communication in ACP. It highlights the key ethical principles in the communication process between the healthcare professional and adult patients in the healthcare setting. Detailed step-by-step processes on how ACP should be done will not be covered in this document.

TERMINOLOGY

Advance Care Planning
11 The term "advance care planning" or ACP in this document will be adapted from the definition used in the UK National Health Service. ACP will refer to a voluntary process of discussion about future care between an individual, their care providers (irrespective of discipline) and often those close to the individual, should the individual become seriously ill in the future and be unable to make decisions, and/or communicate their wishes to others\(^6\). Even if the individual is still able to make his wishes clear at the point when he requires the care, ACP would facilitate the decision to be made. ACP may include clarifications on the individual’s wishes and concerns, important values and personal goals of care.

Advance directive
12 Advance directives are a part of ACP, and refer to oral and/or written instructions that convey treatment preferences in the event of a loss of decision-making capacity\(^7\). Advance directives could include living wills, which are written, legal document that spells out the preferred types of medical treatments and life-sustaining measures under specific circumstances. In Singapore, the Advance Medical Directive (AMD) Act allows patients to indicate their wish not to have any extraordinary life-sustaining treatment\(^a\) to be administered should they become unconscious or incapable of decision-making and are suffering from terminally illness.

\(^a\) “Extraordinary life-sustaining treatment” is defined in the Act as “any medical procedure or measure which, when administered to a terminally ill patient, will only prolong the process of dying when death is imminent, but excludes palliative care”.\(^*\)
**Durable power of attorney**

13 A durable power of attorney for healthcare, which legally designates a healthcare proxy, who would make decisions on healthcare of the individual in the event the individual is unable to do so. The Singapore Mental Capacity Act (MCA), enacted in 2008 and implemented on 1 March 2010, allows a person to make a lasting power of attorney (LPA) to appoint a proxy, called the “donee” to make medical decisions (consent to carrying out or continuation of treatment) on the person’s behalf, should he eventually become mentally incompetent. However, a donee may not make any decision concerning life-sustaining treatment or treatment which is reasonably believed to be necessary to prevent a serious deterioration of the patient’s condition.

**SCOPE OF ACP**

14 ACP is not limited to end-of-life scenarios, but extends to long-term care situations as well. ACP is intended to put the best interests of the individual into practice in the event. It could involve all well adult individuals living in the community, who may or may not be patients, but would be especially useful for the individual who becomes mentally incapacitated and is unable to make decisions or communicate his wishes.

15 ACP is a process of assisting the individual to:
- (i) understand their medical condition and potential future complications;
- (ii) understand the options for future medical care as it relates to their current health condition;
- (iii) reflect upon their goals, values and personal beliefs;
- (iv) consider the benefits and burdens of current and future treatments;
- (v) discuss choices with family/important others and health providers, and document these choices.

16 The intended outcome of ACP discussions is a statement of wishes, which can be in either the written or oral form. This statement is not legally binding, but would be of importance when a judgment is to be made in the person’s best interests. This statement of wishes does not mark the end of ACP. There should be an ongoing update and clarification of concerns, values and preferences over time, whether or not a statement of wishes is made.

17 Some patients may also subsequently decide in advance their preferred treatment and care option for a predefined future medical situation, such as the refusal of certain treatment or procedures. ACP may thus lead to, but should not be reduced to, the writing of an advance directive, or the making of a lasting power of attorney to appoint a donee to make medical decisions on their behalf should they become mentally incompetent.

18 While communication on ACP is an integral and important component to achieve the intended objectives of ACP, it must be emphasized that it is only one part of the overall framework for ACP, which starts with the conversation, leading to the expression(s) of wishes/priorities, the recording of these preferred wishes, its storage and eventual retrieval and honouring.
ROLE OF HEALTHCARE PROFESSIONALS

19 Notwithstanding that ACP is a deeply personal issue for the individual, and that ACP should be done with the individual’s family members and loved ones, the healthcare professional also has a role to play in the ACP process.

20 Individuals might not understand the clinical implications of their care and treatment preferences, and healthcare professionals are well-positioned to clarify issues and provide adequate and sufficient medical or healthcare information. The healthcare professional should play a supportive and sufficiently participatory role. He/she should take time to discuss the individual’s goals, fears, beliefs and wishes. ACP is just like most quality clinical encounters in medicine; the healthcare worker has a key but not all-encompassing role.

MAIN ETHICAL PRINCIPLE IN ACP

21 The primary ethical principle in ACP is respect of the individual’s autonomy. ACP allows the individual to achieve some sense of control over his future care through prior discussion on care and treatment preferences. There is also growing societal expectation that if one’s decision-making capacity is taken away in future, one’s wishes for medical treatment should still be respected.

GUIDING PRINCIPLES FOR THE HEALTHCARE PROFESSIONAL ON COMMUNICATION DURING ACP

22 The following guiding principles should be upheld in the communication during ACP between the healthcare professional and the individual.

A. Who should facilitate ACP?

(i) Appropriate staff selected based on their qualities. All health and social care staff should be open to any discussion initiated by the individual, and know how to respond to basic questions about ACP. However, staff selected for training on communication during ACP should have the right qualities such as empathy, sensitivity to the needs of others, patience, maturity, truthfulness,
and flexibility in managing the discussions. The professional should have rapport with the individual before initiating any ACP discussion\textsuperscript{12}.

(ii) \textit{Knowledgeable in the individual and the options available}. Trained healthcare professionals should be knowledgeable in the benefits, harms and risks of the various treatment, procedures, support, services available in general. They also should have adequate knowledge of the specific health and social situation of the individual. They should be aware when they have reached the limits of their knowledge and competence and know when and from whom to seek advice. These trained staff should be supported by a professional with relevant specialist knowledge, where necessary.

\textbf{B. With whom should the healthcare professional be considering ACP?}

(iii) \textit{Voluntary participation}. ACP should be voluntary, and initiated by the individual even though ACP discussions could be and should be offered at primary healthcare settings. The individual should not be pressured or forced to participate in ACP, whether it is by family members, loved ones or the healthcare professionals.

(iv) \textit{Sensitive and appropriate initiation of ACP}. Trained healthcare professionals should initiate ACP in the healthcare setting only if, in their professional judgement, it could benefit the individual. This could depend on the prognosis and pattern of disease progression and on the patient’s willingness to engage in discussion\textsuperscript{12}.

(v) \textit{Choice to decline or defer discussion}. The individual should be informed that he can decline or defer discussion, at any time. His wish not to confront or discuss future issues must be respected at all times.

(vi) \textit{Involvement of loved ones}. Individuals should be encouraged to involve loved ones in ACP so that they understand the individual’s wishes. Individuals should decide on who should be involved. Reflective discussions in a non-crisis situation would prepare all involved and might minimize their guilt and concerns in future, for instance, if the individual choose to refuse life-support treatment\textsuperscript{11}.

\textbf{C. When and where should the discussion be held?}

(vii) \textit{Comfortable, unhurried settings}. Discussions should preferably be carried out in comfortable, unhurried surroundings. Ideally, ACP should be offered in the community, e.g. as part of routine health care in primary care and outpatient settings, before individuals become acutely unwell\textsuperscript{12}. This helps individuals make sound decisions in a calm state of mind and less stressful environment, and allows sufficient time for reflection and thorough evaluation.

(viii) \textit{Readiness of the individual}. Discussions should be carried out when the individual is ready and settled. For instance, if a discussion is to be initiated or held, healthcare professionals should avoid initiating it immediately after move to a care home\textsuperscript{12}. 

D. The discussion

(ix) **Acknowledgement of pre-existing plans.** Pre-existing statements of wishes should be acknowledged and reviewed, if relevant \(^\text{12}\).

(x) **A process, instead of a single event.** ACP is an on-going process rather than a single event or a tick box exercise. This allows sufficient time for comprehensive information sharing, clarification, reflections and decision making by the individual.

(xi) **Provide flexibility on treatment decisions.** There should be periodic review of the advanced care plans to align them with the individual’s wishes and preferences which might change with time due to new treatment or diagnosis, disease progression or the occurrence of any other life changing events \(^\text{12, 13}\).

(xii) **Stopping a discussion.** The healthcare professional should look out for cues that the individual wishes to end the discussion. The discussion should not be continued if it is causing the individual excessive distress or anxiety.

(xiii) **Confidentiality.** Confidentiality of the individual’s plans should be respected in line with current good professional practice.

E. Good attitudes to be adopted by the healthcare professional

(xiv) **Focus on the individual.** Discussions should be focused on the individual’s comfort level, views, values, goals and preferences. Information given should be tailored to the individual, such that he understands it. Healthcare professionals should clarify any ambiguous terms used by the individual, e.g. “Could you explain what you mean by not wanting any heroics?” \(^\text{12}\) Summarizing, checking and reflecting in this way ensures that healthcare professionals fully understand the individual’s wishes.

(xv) **Avoid stereotyping.** Although the individual’s culture, religion & beliefs should be properly acknowledged, respected and addressed during the ACP discussion, these must be interpreted in the context of a patient’s unique history, family background and socioeconomic status. Healthcare workers should not use gender, racial or ethnic, religious or cultural background as simplistic, straightforward predictors of the individual’s beliefs or values which will lead to harmful stereotyping of the individual \(^\text{14, 15}\). Healthcare workers should build trust necessary for the individual to confide in him or her.

(xvi) **Avoid imposing one’s values.** Healthcare professionals should take account of his / her personal experiences and beliefs and ensure that they do not act as barriers to communication. For example, if the professional has strong views on end-of-life care, influenced by their own religious beliefs, they should ensure that they do not impose their views on the individual. If there is a conflict of interest, a different professional opinion could be sought.

**GUIDE FOR HEALTHCARE PROFESSIONALS ON COMMUNICATION IN ACP**

23 A flow chart, which is intended as a practical guide for healthcare professionals in the communication process during ACP and is based on the guiding principles above, is shown here:
ACP is a voluntary process of discussion between an individual and their care providers and persons close to them and the purpose is to clarify a person's wishes and care preferences for future care should they become seriously ill in the future and are unable to make decisions and/or communicate their wishes to others.

**Has an intent to initiate ACP been expressed?**
(by the individual, or the healthcare professional, as deemed necessary)

- Yes

**Are you the right person to facilitate the discussion?**

Ensure that you:
- have been trained on communication during ACP
- have rapport with the individual;
- have adequate knowledge of the individual and care/treatment options available;
- are supported by a professional with relevant specialist knowledge, if necessary;

- Yes

- If you are uncertain or are not suitable, do not proceed.
- Ask a colleague who is suitable to facilitate the discussion.

**Are you discussing with the right person(s)?**

Conduct the discussion with the individual who initiated the discussion and is ready to discuss

- You may initiate a discussion if you think that it could benefit the individual and is appropriate and sensitive.
- Encourage and allow the individual to choose who they wish to include in the discussions (e.g. their family or any loved ones).

- Yes

- If the individual defers or declines one aspect of or the whole discussion, or shows excessive anxiety, do not proceed.
- Ask a colleague who is suitable to facilitate the discussion.

**Are you discussing at the right time and place?**

Check that the individual is ready and settled, and is open to discussion on ACP

- Discuss in comfortable and unhurried surroundings.
- Ideally, conduct discussions in the community (e.g. primary and outpatient care settings).

- Yes

**Are you discussing in an appropriate manner?**

- Acknowledge and review any pre-existing plans.
- Ensure that the discussion is not a single event or tick-box exercise.
- Respect the confidentiality of the individual’s plans.
- Focus on the individual’s comfort level, views, values, goals and preferences.
- Give information such that the individual understands it.
- Clarify any ambiguous terms used by the individual. Summarize and check that you understand the individual.
- Acknowledge and respect the individual’s culture, religion & beliefs. Avoid using gender, racial or ethnic, religious or cultural background to predict the individual’s beliefs or values.
- Avoid imposing your views on the individual.
- If there is a conflict of interest, get a different opinion from your colleague.
RECOMMENDATIONS / CONCLUSION

24 The basis of ACP is respect of the individual’s autonomy in deciding his future care. With ACP, individuals can make some decisions prospectively should they lose their capabilities to make decisions or communicate in future. Effective communication, handled in an ethically acceptable manner, is critical in ACP. While ACP is ultimately patient-centric, the discussions can involve loved ones and the healthcare professional involved in his care.

25 Where healthcare professionals are involved, it is recommended that, in the communication during ACP:

(i) Healthcare professionals facilitating ACP discussions should be trained, have the appropriate qualities, skills, have rapport with the patient. Trained healthcare professionals must know of the various treatment procedures and have adequate knowledge of the individual’s situation and the care/treatment needed.
options available for the individual’s care. They must also have access to professional staff with relevant specialist knowledge.

(ii) Although ACP should be voluntary and initiated by the individual, ACP discussion could be offered in primary care and outpatient settings, before individuals become acutely unwell. The healthcare professional may also initiate ACP if deemed beneficial to the patient.

(iii) Healthcare professionals should encourage and allow the individuals to include their loved ones in the discussion.

(iv) ACP is an on-going process rather than a single event or exercise, with periodic reviews and updates where appropriate.

(v) The individual has the final say on whether to carry on, decline, defer or stop the discussion. Discussions should be conducted only when the individual is ready.

(vi) Discussions should be conducted in comfortable and unhurried settings and should be discontinued if the patient exhibits excessive distress or anxiety.

(vii) Discussions should be focused on the individual’s comfort level, views, values, goals and preferences. Both the healthcare professional and the individual must put in efforts to ensure that they understand each other.

(viii) Healthcare professionals should respect the individual, including keeping confidentiality, and avoiding stereotyping or imposing of one’s values.
ADVANCE CARE PLANNING OVERSEAS

United States

1 In USA, the concept of ACP can be said to be initiated in the 1960’s to honour the wishes of the terminally ill. The concept of advance directives originated from the ‘right to die’ movement. The first living will was devised by the Euthanasia Society of America and attorney Luis Kutner in 1967 to advocate the right of individuals to make their own decisions about medical care at the end of life.

2 Until recently, the emphasis has been on the completion of advance directives to enhance autonomy, rather than ACP per se. This trend has been driven in the USA by the implementation of the Patient Self Determination Act during the 1990s.

United Kingdom

3 In some jurisdictions like the UK and some states in the US, the law has since legally provided for individuals to make legally binding advance directives; the naming of surrogate decision makers; notification of these aforementioned rights and detailed provisions for ACP.

4 Lately, emphasis has shifted from using an advance directive for medical care to the potential for ACP to help patients and their families prepare for the last stage of life, review their immediate goals and hopes and strengthen relationships. ACP is not just about autonomy and the exercise of control, but also on personal relationships and relieving burdens placed on others.

5 In the UK, ACP has been emphasised in the End of Life Strategy for England and the associated National End of Life Care Programme as having the potential to contribute to better end-of-life care outcomes. The first step of the care pathway set out in the End of Life Strategy is ‘discussion as the end of life approaches’ involving ‘open and honest communication’ and ‘identifying triggers for discussion’. Other end-of-life initiatives are the ‘Gold Standards Framework’ (GSF) which provides a whole systems approach to improving end-of-life care in community settings, and ‘Preferred Priorities of Care’ (PPC) a tool for recording ACP discussions and any resultant decisions.

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b The law mandates that, in healthcare institutions that receive Medicare or Medicaid funding, patients must be informed of (1) their right to accept or refuse treatment, (2) their rights under existing state laws regarding advance directives, and (3) any policies the institution has regarding the withholding or withdrawing of life-sustaining treatments. The institutions are also required to engage in ongoing education activities for both their employees and the general public regarding the right to accept or refuse treatment and the opportunity for drafting or signing advance directives.

c The End of Life Strategy promotes high quality care for all adults at the end of life. It is the first for the UK and covers adults in England.

d The Gold Standards Framework (GSF) is extensively used across the UK, embedded as mainstream within primary care and endorsed by all major policy groups, including The National Institute of Clinical Excellence, the Royal College of General Practitioners and Royal College of Nursing.

e The Preferred Priorities of Care (PPC) is a patient held document designed to facilitate patient choice in relation to end of life issues; it has been identified within the NHS End of Life Care programme as an example of an advance care plan.
Australia

6 In Victoria, Australia, Respecting Patient Choices (RPC) Program\(^1\) considers advance care planning as a series of steps an individual can take to help him make plans for medical care in advance. While ACP may vary slightly between the states, the advance care plan generally includes legally binding components (such as a Medical Enduring Power of Attorney, Refusal of Treatment) and a Statement of Choices (including plans for Cardiopulmonary Resuscitation (CPR) and life prolonging treatment and other issues nearing death) which is not legally binding. Programmes in the other states vary.\(^2\)

Canada

7 In Canada, ACP is not limited to the preparation of a legal advance directive, although it may include this. In all Canadian jurisdictions, the care wishes of the patient must be taken into consideration if they are known, regardless of whether the patient has prepared a legal advance directive or not. There are ACP programmes in Canada, such as the ACP initiative in Calgary Health Region (now Alberta Health Services) and the Fraser Health Authority ACP program.\(^2\)

8 Although the Fraser Health Authority ACP program resulted from an expanded mandate for the Hospice Palliative Care Program to address issues in other areas of end-of-life care, the ACP approach has been carried to the general public and many segments of the population, including those in home care, acute care, primary care and residential care.

9 The Calgary Health Region ACP initiative consists of two inter-related parts: (1) a consumer-focused program, My Voice - Planning Ahead, and (2) the Advance Care Planning: Goals of Care Designation Policy. The first part provides a mechanism for people to understand and document their choices and views regarding future health care decision making, and may lead to the formulation of a legally valid personal directive (or advance directive). The second part standardizes nomenclature regarding care decisions throughout all sectors of care in the region and supports a communication process that helps care providers and care recipients determine ideal and intentional care choices at any point, including at the end of life.

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\(^1\) The Respecting Patient Choices (RPC) Programme was first introduced as a pilot program at the Austin Hospital, in Melbourne. During 2002-03, the success of the pilot prompted the Victorian and Federal Government’s Department of Human Services and Department of Health and Aging respectively to support the program’s introduction to other health services in Victoria and interstate.
FACTORS AFFECTING THE MAKING OF ADVANCE CARE PLANS

Decisions made through ACP may be shaped or affected by many factors, including:

(i) **Culture and religion.** Culture shapes the way people perceive illness, and the experience of suffering and dying. ACP may be variably interpreted or even rejected by some groups e.g. by African Americans, whose Christian’s religious view is that suffering is redemptive, and is to be endured rather than avoided. In other cultures the topic of death might also be a taboo subject, and to be avoided.

(ii) **Communication process.** As cultural diversity permeates our societies, the healthcare team too would similarly be formed by persons with diverse cultural backgrounds. Miscommunication of medical diagnosis and prognosis caused by lack of cultural sensitivity and skills could lead to misrepresented wishes and unwanted, inappropriate clinical outcomes.

(iii) **Ethnicity.** Ethnicity may be an important predictor of decision-making styles in healthcare. The family was believed to be the primary decision-maker by a larger proportion of elderly Korean Americans and Mexicans American surveyed as compared to European Americans or African Americans surveyed.

(iv) **The individual’s concerns, important values and personal goals of care.** Anyone who does not trust doctors in the Western healthcare system, and who had always relied on alternative therapies would likely choose to refuse any life-sustaining care or even medical treatment in the hospital setting.

(v) **The individual’s knowledge and understanding.** His knowledge and understanding about his illness and prognosis, particular preferences for types of care/treatment that may be beneficial in the future and the availability of the treatment can affect his preferences and refusal of treatments. For example, patients who requested for cardiopulmonary resuscitation (CPR) based on the misperception of its good long-term survival might have declined CPR if they knew that the actual in-hospital survival rates were lower depending on medical circumstances.

(vi) **Source of information.** Studies have shown that prior information about advance directives were mainly obtained from the media rather than the patient’s physician. Of those that had previous discussions regarding end of life issues, discussions were usually with family members rather than physicians.

(vii) **Relationship between the individual and family members.** Unless the individuals explicitly do not permit their family’s participation in decision making process, family involvement is usually inevitable. With more parties involved, disagreements may occur. One reason may be that the decisions made by the individual do not adhere to dominant culture. Sufficient time should be provided for discussions between individuals and their family members to acknowledge and respect the goals, values and wishes that the individual chooses.
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