

ABSTRACT

Advance Care Planning (ACP) is increasingly recognised as part of holistic patient-centred care. The goal of ACP is to help the patient explore and express his preferences regarding options and goal of care before the event of a catastrophic illness. Family physicians are well sited to conduct ACP in the community with their patients. It should be offered, with discernment and empathy, to individuals, ranging from the well healthy patient to those with organ complications from chronic diseases, who are ready to participate in such dialogue. It should always be paced at the patient's pace.

Keywords:

Advance Care Planning, Preferred Choices, Options, Goals Of Care

SFP2015; 41(1): 22-27

INTRODUCTION**What is Advance Care Planning (ACP)?**

ACP is a process of discussion to help individuals reflect on their goals, values and beliefs, on what living well means to them and start thinking about their preferred choices of care in the event of a catastrophic health event that renders them unable to make decisions or communicate their wishes to others. This is loosely based on the definition adopted by the UK National Health Services.¹ The goal of ACP is to help an individual participate in the decision-making of his future care and aid his health care providers and his loved ones to make decisions that respect his autonomy in a situation when he is unable to express his wishes.

What It Is Not

It is NOT a legal document, e.g. it is not a will which is operational only after the death of a person. It is also not a lasting Power of Attorney (LPA), whereby a person (donor) may appoint someone else (donee) to make decisions on his behalf in the event he loses his mental capacity. Nor is it an Advance Medical Directive (AMD), which is a legal document that states a patient's wishes regarding prolongation of life by artificial means.

ACP can lead to the drafting of all the above documents, but essentially is a process of discussion to explore the patient's disease understanding and his preferences on available options of care in the event of catastrophic illness. The wishes expressed can be documented and kept by the patient and/or filed into the patient's notes. Revisiting the subject along the patient's journey is encouraged when there is a change of the patient's health status and/or occurrence of other significant life events, and for as long as the patient's health status allows. The patient

is free to change his mind on choices made earlier.

Present Situation

Presently, health care providers are faced with an ageing population, 60% of which have at least one chronic disease that can lead to serious organ complications.² At the same time, the advance of medical technology has made available many treatment modalities which may prolong life but add little to quality of life, and/or may even paradoxically increase suffering, in the face of severe disease complications. This has increasingly widened the spectrum of decisions health care providers and patients must make regarding meaningful health care, especially regarding end-of-life issues.

Many Singaporeans remain uncomfortable with talking about death and dying. A street poll survey conducted by the Lien Foundation revealed that about 60% of respondents said they were comfortable with talking about their own death or dying.³ However, when asked about talking to someone who is terminally ill, more than half of them said they were not comfortable. The most common reasons for not being comfortable talking about death were fear and a lack of knowledge on this topic. There is a need to increase the comfort level of health care providers, especially in the light of the present patient demographics, through general awareness talks and formal training to be ACP facilitators.

Statistics show that >50% of patients end up dying in hospital.⁴ It would seem that more opportunities should be created for patients to express their wishes on their future care before the days of catastrophic events or terminal ill health. This may increase the likelihood of their previously expressed wishes being carried out rather than those of their well-meaning family members or health care providers who will make decisions for them with a best guess or best interest approach.

ACP discussion is presently not widespread in Singapore, especially in the community. Many doctors in the community may not feel confident about starting the conversation, even though patients may be waiting for the doctor to initiate this. There are perceived and real barriers to communication on both sides. However, some events may act as facilitators to initiating the discussion (Table 1).⁵

The Role of the Family Physician in Advance Care Planning

ACP should begin in the community and can be initiated among well individuals, long before disease occurs, and certainly would be appropriate for patients with chronic disease before or with complications setting in. There are several reasons which make a compelling case for the general practitioner or family physician in the community to engage in advance care planning discussions with his patients.

NG LEE BENG

Department of Family Medicine and Continuing Care,
Singapore General Hospital

Table 1: Barriers and Facilitators to ACP Discussion⁵

Barriers	Facilitators
<ul style="list-style-type: none"> • Difficult subject matter • Variation in patient preferences for information and discussion • Perception that the doctor does not want to and/or have time for discussion • The doctor does not have time for discussion • Fear of removing hope, causing alarm and distress • “Clinics are for balancing and monitoring medical treatment” • Emphasis on a curative model of care • Unpredictability of illness • Inadequate communication skills of professionals • High incidence of depression • Language barrier and ambiguities 	<ul style="list-style-type: none"> • Patient experience of family/friends who have died • Trusting ongoing relationship with doctor • Patient feeling cared for as a person • Doctor broaches the subject skillfully • Patient had started ACP discussion with others previously • Patient’s recent experience of hospitalisation or being very ill • Health system that expects doctors to have end-of-life discussions with patients

Many general practitioners (GPs) or family physicians (FPs) in the community, through their practice of continuity of care, have looked after patients and their families for many years. Their patients’ children have grown up and now bring their own children to the same GP. Their patients themselves have grown older/old. Many have remained well but a number have chronic disease and some have developed serious disease complications. Through the years, these health care providers have developed a long-term therapeutic relationship with many patients. They would certainly seem to fit the bill of being the trusted person to bring up the subject of disease progress and discuss care options and preferred choices of care before a crisis occurs.

The primary care physician is the first point of contact for

many patients. As he becomes comfortable himself in talking about disease and death, he may be able to discern which patient may be ready or may benefit from ACP discussion, as part of a holistic management of an existing medical condition he is being consulted on. He is well sited to be proactive, always discerning patients’ readiness and comfort level, to start well individuals reflecting on their life goals and ideas of living well. This can contribute towards increasing the awareness level of well individuals to start thinking of their future care and making their preferences known to their loved ones.

Though it is an intensely private topic, a trusted primary care physician plays an important role in providing needed, accurate information on the disease course and complications, the benefits and burdens of each option of care, as well as the

realistic consequences of refusing treatment and following the natural course of events.

The GP is in a setting where he is able to revisit the ACP discussion over a number of visits, and need not rush through the dialogue in one sitting. Moreover, there is space and time to have the loved ones join in the discussion on another visit if they are not able to attend the first. He is well poised to facilitate family discussions and help the patient to express his wishes and the relatives to understand and accept their loved one's wishes.

When/ Who/How To Get Started

1. Be aware, and convinced, of importance /benefit of ACP

Firstly one needs to be convinced that, increasingly, ACP needs to be part of the holistic patient-centred care the primary care physician is rendering to his patient. This patient is often aged, with chronic disease/s which is/are putting him on an inevitable trajectory towards deteriorating health, through eventual terminal organ failure and/or repeated acute crises (sepsis, or episodes of acute or chronic organ failure). No longer are we dealing only with patients who will bounce back from a bout of acute illness.

Dettering, in her single-armed randomised controlled trial,⁶ found that a coordinated, systematic model of patient-centred advance care planning, assists in identifying and respecting patient's wishes about end-of-life care, improves such care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives. Box 1 refers to a sample of patient responses to a questionnaire on patient satisfaction.

The research team also surveyed the impact of death on family members about 100 days after the death. Compared with the control group (usual care, no ACP initiated), the family members of patients who had undergone ACP (the intervention group) had fewer symptoms of post-traumatic stress, depression, and anxiety. Family members of the intervention group were more likely than those of the control group to be very satisfied with the quality of death from both their own perspective and the perceived perspective of the patient. Box 2 lists some of the family members' responses.

2. Identify the patients who will benefit from ACP discussion

ACP may be initiated with anyone, from well individuals (your own family members for instance) to patients with chronic disease with or without target organ complications, to those who are terminally ill.

For the busy GP dealing with a number of elderly with chronic disease, the question "Would I be surprised if my patient died in the next 12 months?" can help him identify and prioritise those with whom to start the conversation.

Other possible triggers include:

- a new diagnosis of a life-limiting condition;

- a deterioration in prognostic markers;
- a step change in treatment;
- multiple hospital admissions;
- admission to a care home; or
- whenever a thorough reassessment of the patient's needs is required.

3. Know Your Patient

Explore whether the patient is ready and open to you broaching ACP discussion. Explore his understanding of his disease status, course, and complications. What does he know of the prognosis and the possible events that lie ahead? What does his family know about his health status?

The National Medical Ethics Committee in 2010 stated, "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."⁷

It is important to have an idea of the cultural and religious norms and beliefs the patient's social group holds, yet not stereotype the patient, but explore whether the patient's perspective varies from expected traditional views.

The patient should be encouraged to include his loved ones in any ACP discussion. If not present at first discussion, another discussion can be scheduled for him and his family member/s to continue the ACP conversation. This also allows time for initial information to sink in and allow the patient time to reflect and decide on his choices, and choose a substitute decision maker. Appointing a loved one to be his substitute decision maker (SDM), entrusted to carry out his expressed wishes or make decisions on his behalf based on his expressed preferences, in a setting when he himself is unable to express his wishes, is to be encouraged.

4. Know Yourself

How comfortable are you regarding conversations on death and dying? Perhaps this is a time to increase one's self-awareness and examine one's own values and goals and beliefs, and consider first what living well means to yourself. Conversely one may ask oneself: what is unbearable for me to live with?

No one is ever totally prepared for a catastrophic event (such as a road traffic accident rendering one terribly injured) but it may be timely to ask yourself: If I were ever struck down with an injury or illness, where there is little/no likelihood of recovery and I am unable to communicate and relate to those around me, unable to convey my wishes to the medical team, what would be my preferences regarding options and goal of care? Do I want all the treatment that is available, to keep me alive, or would I prefer to only be kept comfortable, free from pain, but not be given any treatment that increases pain and suffering and that prolongs physical life but doesn't increase quality of life?

Box 1: Patients' responses on discharge questionnaire⁶	
Intervention group	Control group
<ul style="list-style-type: none"> • Outstanding staff • Very caring staff, no-one has asked me before what I would want when I get really sick. It was really great. It made me feel relieved • Everyone should have an opportunity to discuss these things • They asked me what I wanted and I told them and they listened . . . wow they really cared • They were so interested in what I thought 	<ul style="list-style-type: none"> • It was very hard to get information on what was happening • The doctors didn't really listen • They all kept talking about me, but didn't let me have a say. It was like I wasn't important • They made me think that I was too old, and a nuisance and in the way • They didn't speak to me and kept discussing everything with my family. I think they thought I was too old and couldn't understand

Box 2: Family members' responses on quality of end-of-life care questionnaire	
Intervention group	Control group
<ul style="list-style-type: none"> • His death was really peaceful, and everyone knew what to do • We had a clear plan so could just relax and enjoy time with dad • Even though we already knew what he wanted it was great to be given the opportunity to talk about it and get it out into the open • We felt really comfortable making decisions because we had discussed it with him • He had a very peaceful death, just as it should have been and I would like to thank all staff for this 	<ul style="list-style-type: none"> • He knew he was dying, and it was very hard for him. We should have talked with him about it • He should have had more say. He couldn't do the rehabilitation. He knew he was dying, but the doctors didn't seem to get it • The hospital has a responsibility to talk with patients about these things. My sister never got a say and that is wrong • They wouldn't let her go. They kept doing tests and things she would not have wanted • Mum didn't want heroics. She knew she was dying. I was horrified when I heard she got 45 minutes of CPR. She did not want it. All anyone had to do was ask. I feel very hurt and hurt for mum and my sister

Such a personal exercise may reveal your comfort level with the topic, and will likely help you empathise with your patient's challenges in participating in ACP discussion.

5. Familiarise Yourself With What is Needed

a. Communication skills

Nowhere is sensitivity to the patient's conversation cues, and empathy, more needed than in a dialogue on such a private and potentially emotionally charged topic.

Pace yourself at the patient's pace, and be ready to clarify and explain without hurrying through the discussion. The patient should be allowed to feel in control of the timing, place, and pace of discussion with the option to stop at any time.

b. Disease and treatment knowledge

ACP discussion requires the doctor to know the disease evolution adequately, the benefits and burdens of treatment options, and the local resources and services available. He will then have to communicate them effectively to the patient. The facts need to be presented objectively to help the patient make informed choices. Patients may choose a supportive or palliative care approach, without fear or guilt, if this is presented to them as a reasonable or positive choice.

The question "How long have I got?" provides an opportunity to discuss progress and expectations and to set realistic goals, even if a precise answer is impossible and often inappropriate. Prognostication is notoriously inaccurate and there should be no attempt to crush hope or give false hope through hazarding number of days to live. Many individuals fear that confronting and admitting that death is inevitable will take away hope, or they will be abandoned, or given second-class care. The patient needs assurance that he will not be abandoned. He can be encouraged to have an approach of "hoping for the best, preparing for the worst".

c. Familiarity and comfort with ACP communication

For many health care professionals, exposure to the dying process and learning to address end-of-life issues usually occur on the job. Few have undergone formal training. Some have, over the years, through clinical experience, become unconsciously competent in handling ACP.

For the rest, awareness and the equipping of skills in ACP facilitation may be informally gathered through general awareness sessions such as this, and/or through self reading or sourcing for relevant online materials.

When a patient nears or reaches the last stage of care, having exhausted the potential of scientifically based curative therapy, and it becomes "just a matter of time" for "nature to take its course", Dr Atul Gawande suggested 5 questions one could ask such a patient:⁸

1. What is your understanding of your current health or condition?

2. If your current condition worsens, what are your goals?
3. What are your fears?
4. Are there any tradeoffs you are willing to make, or not?
5. What would a good day be like?

The patient's answers to these questions may be the springboard for a meaningful and needed discussion on his choices on care options in his future care.

In Singapore, formal training in ACP facilitation started in 2009, and is being rolled out under a nationwide ACP implementation framework in line with the developing Regional Health Systems. This initiative, called Living Matters ACP, adapted from the Respecting Choices programme in Wisconsin, USA,⁹ is being operationalised by the Agency for Integrated Care (AIC).

Workshops to train ACP facilitators are being rolled out in line with the developing Regional Health Systems. In time, training is expected to reach the community doctors. In these workshops health care providers are trained to begin a conversation to explore an individual's life goals, values, and beliefs, touching on his ideas on what it means to be living well. Trainee facilitators use a conversation guide to lead the individual to reflect on a friend's or relative's catastrophic illness or a recent personal health crisis, if any, and to consider a hypothetical scenario of a catastrophic illness rendering him uncommunicative. Through role play, trainees at the workshop learn to ask relevant open-ended questions, enabling a patient to think about his preferences for care options and the goal of care in such a scenario. They learn to engage loved ones of patients in the conversation and to help the patient appoint someone he trusts to be his substitute decision maker (SDM).

More information may be obtained on ACP from the Agency for Integrated Care's website at its "About Living Matters" section.¹⁰ An ACP workbook can also be downloaded to start an ACP conversation with patients.¹⁰

Pitfalls and Ethical Considerations in ACP⁷

In 2010, the National Committee on Medical ethics issued some guidelines on "the ethical handling of communication in advance care planning". Some of the guidelines are listed below:

a. Avoid imposing one's personal views and stands on EOL issues

Health care professionals should take into account 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 can be sought.

b. Avoid stereotyping

Although the individual's culture, religion and beliefs should

be properly acknowledged, respected and addressed during the ACP discussion, these must be interpreted in the context of a patient's unique background. Health care workers should not make simplistic assumptions of the patient's beliefs or values based on his/her gender, race or ethnicity, religious or cultural background.

c. Respect patient's autonomy

Facilitate choices that are not made under undue pressure and that do not lead to guilt. Present all options of care impartially, explaining their benefits and burdens, as well as the natural course of the disease when treatment is rejected.

d. 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. Clarify any ambiguous terms used by the individual, e.g. "Could you explain what you mean by not wanting any heroics?" Check your understanding of the patient's wishes by summarising, checking and reflecting.

CONCLUSION

ACP is a process of assisting the individual to understand their medical condition and potential future complications, reflect on their goals, and beliefs, consider the benefits and burdens of present and future treatment, and discuss choices on future care with family members and health care providers. The physician in primary care is well positioned to initiate ACP to selected patients who may find ACP beneficial. Initiating ACP requires a level of comfort which in turn depends on the physician being equipped in communication

skills, disease knowledge of disease and treatment options, and familiarity in ACP dialogue.

REFERENCES

1. National Health Service (NHS) End of Life Care Programme. Advance Care Planning: A guide for Health and Social Care Staff. Aug 2008. Available at <http://www.endoflifecareforadults.nhs.uk/eolc/acp.htm>. (Accessed 1 May 2010.)
2. Ministry of Health (MOH). National Health Survey. 2004.
3. Lien Foundation. Life Before Death: a survey on death attitudes in Singapore. 2009. Available at <http://www.lienfoundation.org/Death%20Attitudes%20Findings%20LB D%20RIse%20Final%20.pdf>.
4. Registry of Births and Deaths, Singapore.
5. Kite S. Advance care planning. *Clinical Medicine*. 2010; 10(3):275–8.
6. Detering KM, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.
7. National Medical Ethics Committee Guide For Health care Professionals On The Ethical Handling Of Communication In Advance Care Planning Sep 2010.
8. Gawande A. *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books, Henry Holt and Company, 2014.
9. Respecting Choices® Advance Care Planning <http://www.gundersenhealth.org/respecting-choices>
10. Agency for Integrated Care website: <http://www.livingmatters.sg> or <http://www.livingmatters.sg/uploadedFiles/ACP%20workbook%20-%20English.PDF> (to download ACP workbook)

LEARNING POINTS

- Advance care planning is a process of discussion to help patients reflect on their goals, values and beliefs, and express their preferred options and goal of care in the event of a catastrophic illness/injury that renders him unable to communicate with his loved ones or health care providers.
- Engagement of loved ones and the appointment of a substitute decision maker is encouraged.
- ACP is NOT a legal document and the patient can change his decisions in the light of disease progression or a new life event.
- The physician in primary care is ideally suited to carry out ACP discussions with patients he has looked after for many years.
- ACP should always be paced by the patient who has the option to stop the discussion at any point.