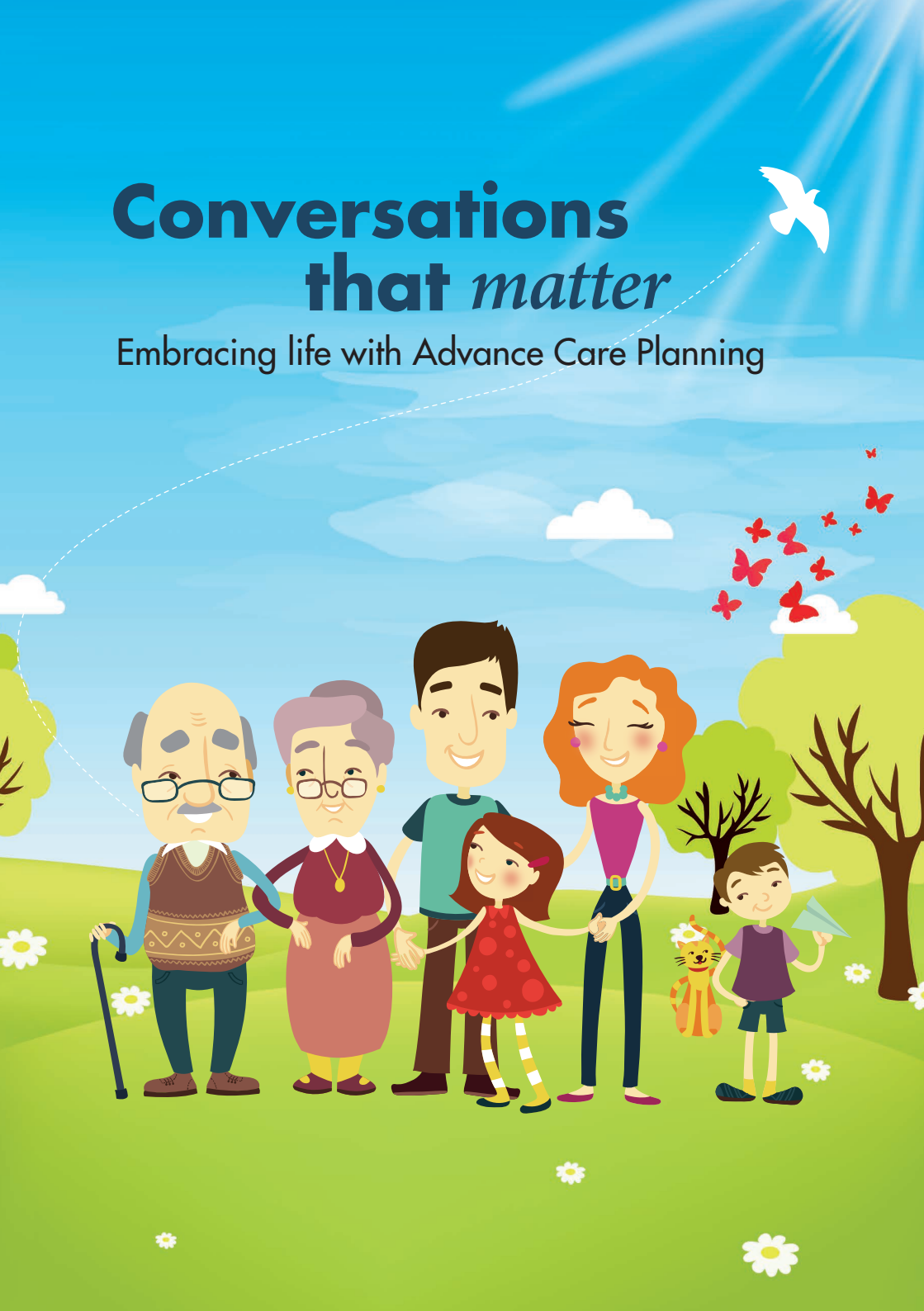


# Conversations that *matter*

Embracing life with Advance Care Planning



# Foreword

Advance Care Planning (ACP) is a conversation between people about their values and wishes regarding future care preferences. Many people have misconceptions about what ACP is, and think it is a taboo conversation about death and dying, or a technical discussion about medical treatments.

In truth, ACP is a conversation from the heart, exploring what living well really means and what matters to people, whilst communicating so with people who matters to them. ACP is about life stories and life journeys, the joys and achievements and the deepest fears and concerns of people.

This book is a compilation of short stories written by our patients, their caregivers, and our healthcare professionals across disciplines in Tan Tock Seng Hospital. These stories contain heart warming vignettes based on their personal experiences in ACP and serve to illustrate the nature of ACP; a person centred approach to patients in healthcare.

We would like to thank our contributors for sharing their stories, and our sponsors for their generous support in the production of this book.

*Brought to you by the TTSH ACP Team*

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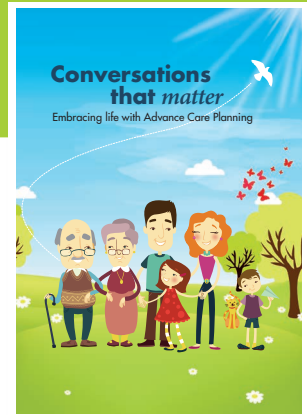
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# Introduction



As individuals with hopes and dreams, we constantly make plans for the future. Plans regarding studies, work, vacation, marriage, housing, children and retirement. However, not many would plan for the day when they are seriously ill and unable to make decisions for themselves. Making such plans requires us to consider what living well means to us. It can be a difficult and challenging conversation to have with our loved ones.

Yet, having discussions about future care plans ensures that critical medical decisions can be made while honouring your personal preferences and beliefs in the event that you are unable to make your own decisions. They also reduce unnecessary stress that loved ones go through while making decisions during times of crisis.



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

In general, ACP is a process of communication between yourself, your loved ones, and your healthcare team. It helps you to...

- 1 Understand your medical condition as well as potential complications that might occur
- 2 Explore the meaning of living well, your experiences with illness and healthcare, and your perception of quality of life
- 3 Reflect upon and clarify your goals of care, values and personal beliefs
- 4 Understand the options for future medical care in relation to your current health condition
- 5 Consider the benefits and burden of different treatments
- 6 Nominate a loved one as your healthcare spokesperson in the event that you are unable to make healthcare decisions
- 7 Document and retain a copy of your Advance Care Plan
- 8 Review your Advance Care Plan when you change your mind, or when your medical conditions or circumstances change

### *With ACP, you can...*

*Make your wishes regarding future care known to your loved ones*

*Have your wishes honoured*

*Increase your quality of life near the end of life*

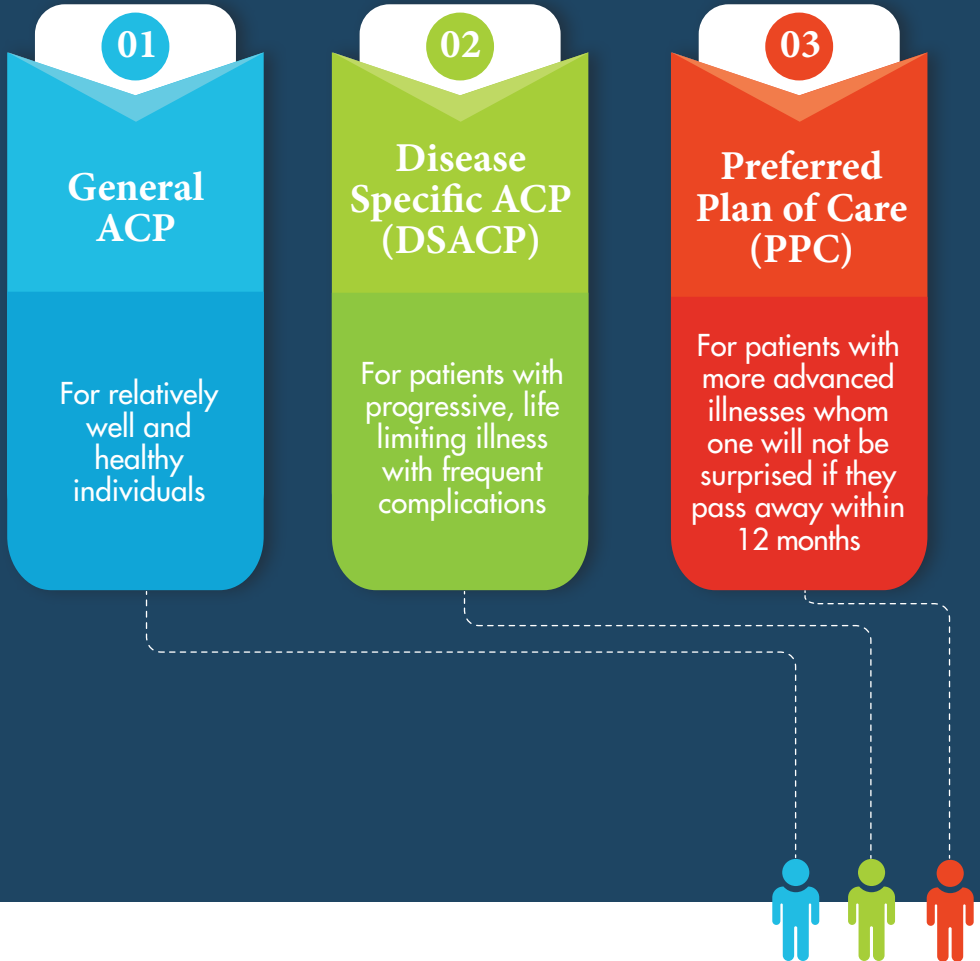
*Reduce stress for your loved ones in decision-making during medical crisis*

*Enhance communication and relationships between you, your loved ones and your healthcare team*

# Different Types of ACP

ACP is a discussion suitable for anyone in any stage of health or illness.

*There are three tiers of ACP discussion, depending on a person's medical condition:*



Above information is adapted from Respecting Choices by Gundersen Health System. For more information, visit <http://www.gundersenhealth.org/respecting-choices>

It is important to start the conversation early as it is difficult to predict when a medical catastrophe might happen. Everyone faces the eventuality of illness and death at some point in time, and Advance Care Planning helps you to live life out to the fullest according to your wishes.

In the following pages, we have included the stories of some individuals who have benefitted from the process of ACP and insights from healthcare professionals who are helping others with their skills in conducting ACP discussions. Also, included are some tips to help you think about your personal healthcare preferences.

We hope that these stories give you an insight on how healthcare professionals approach ACP while encouraging you and your family members to embark on this rewarding journey of sharing.

Having a conversation about what matters with your loved ones is truly a gift of love.

*We do not have to wait for a crisis before having an ACP conversation*



# Let's Talk About Living and Dying Well, Today

Extracted from *The Straits Times*, 29 Aug 2015  
Contributed by Dr Raymond Ng, Clinical Lead for Advance Care  
Planning and Consultant in Palliative Care at Tan Tock Seng Hospital

## Dr Raymond Ng

- ▲ Consultant
- ▲ ACP Clinical Lead
- ▲ Department of Palliative Medicine
- ▲ Tan Tock Seng Hospital

*Such conversations always seem too early  
- until one day when it might be too late.*

Death and dying engender complex emotions in people. To some, death is a remote event far removed from life's daily pursuits or a taboo subject to be avoided, yet, to others, there is peaceful acceptance of death as a final chapter of the natural cycle of life.


As a palliative care physician treating patients with advanced illness, I have witnessed an entire gamut of emotions and reactions to death and dying.

However, my first personal experience with death was not with my patients.

It was when my mother died when I was 18 years old. She had advanced ovarian cancer and battled the disease for five years through multiple operations and cycles of chemotherapy.







Those years were like a blur as we tried to have a normal family life, and I coped by burying myself in my studies. Though she grew cachectic and weak and was literally wasting away nearing the end, death was a taboo subject which never surfaced in our conversations. It just hit one day when I received a phone call during my basic military training at the army camp. It was only then that I knew she had died and was gone forever. My mother died without the family's presence and with a certain degree of pain in the final stage. My only goodbye was a tender kiss on her cheek as she lay lifeless on her bed.

Perhaps my parents wanted to shield us from the spectre of dying, or perhaps her doctor did not adequately prepare us. Death and dying were issues that we did not talk about. It was not just about death and dying, there were many things I would have liked to say to or ask her, if only I knew.


After my mother's death, I entered medical school and found my way into palliative care some years after graduation. My experience with my mother was one of the reasons why I chose this speciality. Many have asked if it is a depressing practice.

Personally, it has been a rewarding experience of professional and personal growth. I have been privileged to journey with many patients in their final act of life and to be let into their life stories and deepest thoughts.

## ADVANCE CARE PLANNING

Through these experiences, I have also become an advocate for advance care planning (ACP), or what most would commonly understand as end of life conversations. ACP is a voluntary process in which people discuss, state and document their values and wishes regarding future medical care, in the event that they are incapacitated from making decisions on their own.

In a developed country like Singapore, most people will die after experiencing a chronic, progressive and, ultimately, fatal illness. When patients are seriously ill, they are frequently incapable of making important end of life decisions. In those circumstances, without knowing what loved ones would have wanted, caregivers may face intense stress and feel burdened when making decisions in consultation with doctors.



*ACP is not just suitable for patients with advanced illness; it is suitable for everyone, in any state of health or illness. Even when one appears to be in the pink of health, one cannot predict when medical catastrophes might suddenly strike.*



In this epoch of rapid medical advancement, we are technically successful in prolonging life, often with variable outcomes in terms of quality of life. For example, a person who is clinically brain dead with no reasonable prospect of neurological recovery can be kept alive on life support for a considerable period of time.

With a rise in the consumer and patient-rights movement as well as landmark cases, the ACP movement began in the West. By the 1970s, most states in the United States had passed legislation enabling patients to record end of life wishes. In 1996, the advance medical directive (AMD) Act was enacted in Singapore. It allows a person to sign a legal document in advance, informing his doctor that he does not want the use of any extraordinary life-sustaining treatment to prolong his life in the event he becomes terminally ill and unconscious and where death is imminent for him.

### CONVERSATION BEYOND FORMS

Early efforts at ACP were focused on completing advance directives, also known as living wills, stating what decisions should be made for their health in the event they are ill and incapacitated from making decisions. However, completing forms alone has limitations, and recent efforts are focused on framing and implementing ACP as a deep, reflective and iterative conversation, a communication process between patients, their loved ones and their healthcare professionals. Documents, such as the AMD, are only one aspect of the broader framework of ACP. Even when preferences are documented, they can be verbally revoked by the patient at any time and should be constantly reviewed.

Within the last two decades, there is gathering evidence that ACP as a process increases patient and caregiver satisfaction with care, improves surrogates' understanding of patients' goals and preferences, reduces post-bereavement stress and depression in family members, reduces use of potentially burdensome treatment, as well as improves quality of life near the end of life.

It is also known that patients desire autonomy over end of life decisions and expect their physicians to initiate these conversations. Locally, in 2009, the National Healthcare Group end of life task force invited the faculty of Respecting Choices from Wisconsin, US, to train healthcare professionals in ACP facilitation and implementation.

In 2011, the Agency of Integrated Care (AIC) was designated by the Ministry of Health (MOH) to be the agency to coordinate and disburse funds to various regional health systems to implement ACP.

Since then, pilot projects in ACP have sprung up in various hospitals, nursing homes, hospices, community hospitals and home medical care teams. There are ongoing efforts at training ACP facilitators, engaging and raising awareness of ACP among healthcare professionals, patients and their caregivers, as

well as setting up processes and systems to capture and honour outcomes of ACP facilitation.

Nevertheless, there are barriers to ACP practice and potential misconceptions. Some people, including healthcare professionals, may view the subject as taboo. Some clinicians fear that broaching ACP takes away hope and will send the wrong message to patients. Patients may also not be open to ACP, especially when they are better and do not see the need to make plans. Some may also confuse ACP with euthanasia.

### MELISSA'S STORY

My personal experience in facilitating ACP with my patients is far removed from the myths and controversies swirling around it.



*ACP is about finding out what living well means to each unique individual, his or her values, deepest thoughts, joys, beliefs, as well as fears and concerns. It is not about death and dying, it is about helping each patient to live well and to preserve his or her dignity, until the very end.*

Melissa (name changed to maintain confidentiality) was a patient whom I had looked after for two years from the time she was diagnosed with metastatic lung cancer. She was near death at diagnosis but responded well to targeted therapy in cancer treatment. During the two years she was on treatment, we controlled her pain and she was able to enjoy time spent and overseas trips with her family. However, predictably, her cancer cells became resistant to the drug and started to spread further.

During one of my conversations with her, she spoke of how living well meant being able to spend time with her family. She shared her hopes of seeing her first daughter marry well and her second daughter graduate from school the following year.

She spoke of her fear of pain, of being in a prolonged vegetative state, as well as fear of being a burden to her family.

If she were to deteriorate despite a trial of treatment, she would not want aggressive interventions such as cardiopulmonary resuscitation or to be hooked to a ventilator.

She nominated one of her sisters as her healthcare proxy as this sister was level-headed and better able to make decisions under duress. Through this heartfelt conversation, her family was able to understand what really mattered to her.

Her condition deteriorated soon after and she died in the hospital in the presence of her family. When I attended her wake, I discovered her family had carried out her wishes with regard to what she would wear, the photo to be used and her preferred colour theme of white. She wanted her funeral to be a celebration of her life and her transition to a better place.

She chose a niche in the columbarium that overlooked a bench, where her daughters could sit and feel her love bathing them from above.

Current efforts at ACP are focused on patients with advanced illness and chronic disease in hospitals as well as in most community hospice care services.

If you are a patient at any of the public hospitals, you can ask your doctor about ACP. ACP may then be carried out by your doctor or anyone else who may be trained, such as a nurse or a social worker.

At this stage, while ACP is implemented in pilot projects with seed funding from MOH, there is usually no extra charge to the patient when it is done.

Though most relevant then, broaching ACP when one is seriously ill is not the most ideal. It is often too early, until it is too late.

Talking about end of life choices is difficult, but we do not have to wait for a crisis before having the conversation. There is a need for a culture shift when it comes to death – discussions about it have to be de-stigmatised. ACP conversations should be normalised and embraced early, conducted out of hospital settings and at the dinner table, as a process of communication between ourselves and our loved ones.

If one is not a patient of any hospital and does not have access to an ACP facilitator, one can download ACP workbooks freely available on the Internet and start the process of discussion with loved ones. One useful resource to browse for more information is the website [www.livingmatters.sg](http://www.livingmatters.sg), which is set up by AIC.

*Nothing puts life in sharper perspective than death. Someone once said that it is when you learn to die, that you learn to live. Having end of life conversations do not hasten death. On the contrary, these discussions allow us to reflect what really matters to each one of us and to communicate so to those who matter to us.*



*There is a need for a culture shift when it comes to death – discussions about it have to be de-stigmatised.*

*Advance care planning conversations should be normalised and embraced early, conducted out of hospital settings and at the dinner table, as a process of communication between ourselves and our loved ones.*

Byline: **Dr RAYMOND NG**  
Published on: The Straits Times  
Date: Saturday, 29 Aug 2015



# Doing an Advance Care Plan When You're Young and Healthy

Chai Gek and Chai Hong first found out about ACP when their mother was admitted to Tan Tock Seng Hospital. On top of doing up a plan with their mother, they decided to draw up their own as well. Both sisters conducted their ACP conversations separately; Chai Gek at Changi General Hospital and Chai Hong with Tan Tock Seng Hospital, as they had existing medical records with the respective healthcare institutions.

"We've seen many relatives fall sick and the burdens it creates," explained Chai Hong. "Medical bills nowadays are very high, and my greatest worry about old age and illness is the financial burden it would be on my family." She added that negative encounters with the healthcare system made her glad that the ACP exists to speak for her in a situation in which she is unable to do so herself.



*Chai Gek said, "I didn't want to waste this opportunity to make my views known – it'll avoid trouble among family members later. Everybody has a different opinion, and the worst thing that can happen is that my family ends up arguing about what to do with me. At least now they all have my ACP to refer to."*

Both Lim sisters believe that it is better to have a meaningful death than to be alive but thoroughly dependent, though they recognise that their decisions may not agree with those made by their spouses or children. Chai Hong said, "After our families did their ACP, I realised that, for our own reasons, my husband and I have directly opposing views – he wants to be kept alive no matter what, while I would rather be left to die in peace and comfort."

She then reconsidered making her husband her nominated healthcare spokesperson. "It's clear that he believes in prolonging life through whatever means necessary. What if he decides to resuscitate me despite my wishes not to be?"

Chai Hong concluded, "It's good that we know all this now through ACP discussion; it's not exactly something that we would have talked about in our daily lives, is it?"

# Frequently Asked Questions (FAQs)



## When and how can one initiate ACP?

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ACP is suitable for everyone, in any stage of health. Anyone who is interested in making plans should have the conversation with their loved ones using ACP conversation starter tools freely available over the internet. One can also use the tool at the end of this book. ACP is particularly pertinent for people with chronic progressive illness or potentially life-limiting illness. You can ask your healthcare team about ACP.



# Every ACP conversation is unique to each patient



*Sister*

**Tan Siew Peng**

- ▲ Senior Nurse Manager
- ▲ Project CARE
- ▲ Department of Continuing & Community Care
- ▲ Tan Tock Seng Hospital

Before I joined Project CARE, I have never heard of ACP. When I first observed an ACP facilitation in a nursing home, I felt that it can be rather emotional. When the patient or next-of-kin is emotional, we need to allow them to ventilate and overcome the moment of sadness.

Through these ACP conversations, I gain an understanding of different family dynamics and the challenges patients and their loved ones face when dealing with life changes and illnesses.

Having been with the department for over two years now, I have learnt that ACP is more than just the completion of forms. To me, every ACP conversation is unique to every patient. Every ACP facilitation is a totally new experience for me to understand the personhood of each patient. For example, in an ACP facilitation I sat in, the facilitator took the opportunity to explore issues of forgiveness within the family.

It can be stressful when family members are engaged by healthcare professionals during a medical crisis when the patient is non-communicative and no conversations has taken place before, when the patient was better. Another benefit of ACP is that it allows the patient and family to reflect and prepare for future decision making. It also lets the patient make his/her wishes known.

There have been challenges such as capturing and translating the narrative of ACP conversations from multiple languages and dialects into words that best describe the person's story. *Nevertheless, my journey in ACP reminds me not to just nurse the patient but to nurse the person as a whole.* With these experiences I have, I hope that more nursing home staff can be trained in ACP to foster understanding of the values and personhood of the patients they are caring for.

# Making a Decision for Your *Loved One*

At 93, Mdm Goh Huey Lan had a fulfilling life. With seven children and fifteen grandchildren, she was loved and well looked after even into her old age. She was admitted to All Saints Home in February, and fell ill in April due to a urinary tract infection.

“She was too ill to articulate her own wishes,” said Ms Christina Tay, Mdm Goh’s daughter. “Dr Lee Yun, the resident doctor at the nursing home, mentioned about ACP to our family, and we felt that it would be good to sit down and talk about the inevitable.

“We were advised that it was a matter of time. My mother was on antibiotics, but even after three rounds of medication, there was little response. Initially we wanted to insist on resuscitation, but Dr Lee laid out all the facts for us clearly, and let us know what she was going through. That’s when we unanimously decided against it, and to let things happen naturally.”

The discussion and plan was made just in time, noted Ms Tay, as Mdm Goh passed away just weeks after the ACP was completed. “She was breathing very erratically,” Ms Tay recalled.

*Knowing that your wishes have been fulfilled can bring comfort to your loved ones*





"The team gave her morphine and she looked more comfortable almost immediately, which was much better than having invasive procedures and tests that would inflict more discomfort."

She added, "The medical team was very caring. When the time came, they really respected her ACP wishes, and made her as comfortable and pain-free as possible."

As for the ACP itself, Ms Tay commented,

*"Having an ACP would erase the issue of your loved ones having to decide for you. We couldn't ask my mother what she wanted, and had to make the decision for her. It would be good to have a well-thought-out plan when you are well enough and in a position to decide for yourself. That way, it's very clear-cut, and you don't subject your loved ones to any doubt or burden."*

# *Common Misconceptions about ACP*



## **Misconception**

ACP is only for the elderly and the sick.



## **Reality**

ACP is for everyone. Healthy individuals, young adults, working professionals and retired seniors are encouraged to discuss the type of healthcare they prefer.

# Fulfilling Patients' Last Wishes

*Patients are in a vulnerable state when they are unable to make medical decisions for themselves during their journey. Relatives are equally vulnerable and in a dilemma when they are trying to decide what is best for the patient in their own logical thinking.*

In 2011, my beloved aunt was placed on life support machine. She was hooked on dialysis in the ICU. It was difficult for me to decide on her behalf to either prolong her life with zero quality or terminate her suffering.

I heard of ACP and how it can help patients who still have decision-making capacity to voice their preferences, and know their wishes will be honoured when they are unable to speak for themselves one day, I was elated to embark on this journey in January 2015.

The 2-day ACP facilitator's course has imparted me the knowledge on how to facilitate an ACP discussion. It has given me an in-depth understanding of both the patients and their loved ones. I learned that ACP is a channel for them to express their heartfelt wishes, healthcare choices, values, feelings and a better end of life plan.

My first ACP case has benefitted a patient as it has helped to bring her family closure regarding her deep-rooted wish (to be legally married). She passed away in April 2015.

It is truly a joy for me to be able to help patients fulfill their desired medical plans through the ACP discussions.



*Sister*

***Lim Lay Hoon***

- ▲ Nurse Clinician II
- ▲ Nursing Service
- ▲ Department of Urology
- ▲ Tan Tock Seng Hospital

# Frequently Asked Questions (FAQs)

*Let me be your voice and represent your views*



## What is the role of a Nominated Healthcare Spokesperson

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The nominated healthcare spokesperson (NHS) as nominated by an individual during ACP is identified by the individual as someone who understands him or her and who can represent his or her views and preferences in the event that he or she loses capacity to make decisions.

# *Common Misconceptions* about ACP



## **Misconception**

ACP is a conversation about death.



## **Reality**

ACP is an ongoing discussion about your healthcare preferences. It encourages you and your loved ones to discuss and understand your values, beliefs and wishes.

# Being Prepared, *Feeling At Peace*

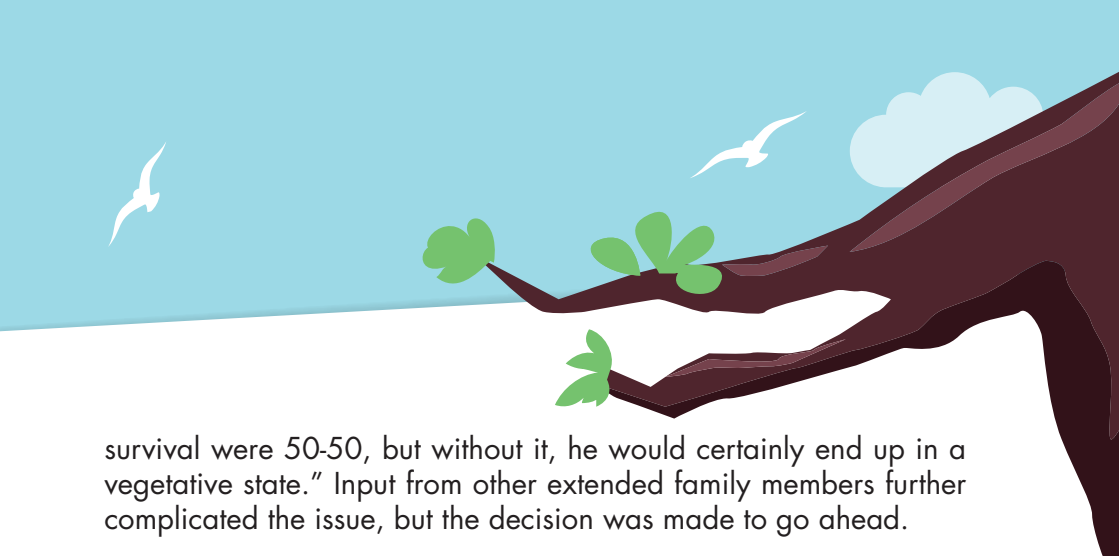
"It was a tsunami," said Mrs Amurutham Naidu about a series of events that changed her family's life forever. "It was extremely frightening, and entirely unexpected."

With four grown-up children and a strong marriage, Mr Thanapathy Naidu and Mrs Naidu were happily retired and preparing for their golden years together. When Mr Naidu started becoming weaker, they began planning long-term care options for their youngest son, who is physically and mentally disabled and had been cared for at home by his parents his whole life. Mrs Naidu describes the search as arduous, "We visited eight nursing homes that were completely inadequate before deciding on the Sunshine Welfare Action Mission – he was admitted in June 2011."

The arrangements were made just in time. From May 2012, Mr Naidu visited Emergency Department many times after having multiple falls. The stress took a toll on his wife, and both of them ended up hospitalised at the same time: Mrs Naidu for severe sodium and potassium deficiency, and Mr Naidu for bleeding in the brain.

"Our three other children live overseas, but our daughter flew into Singapore for a month during that period," Mrs Naidu recounted. "She took care of us, and had to make the decision for her father to go ahead with a risky surgery. Chances of





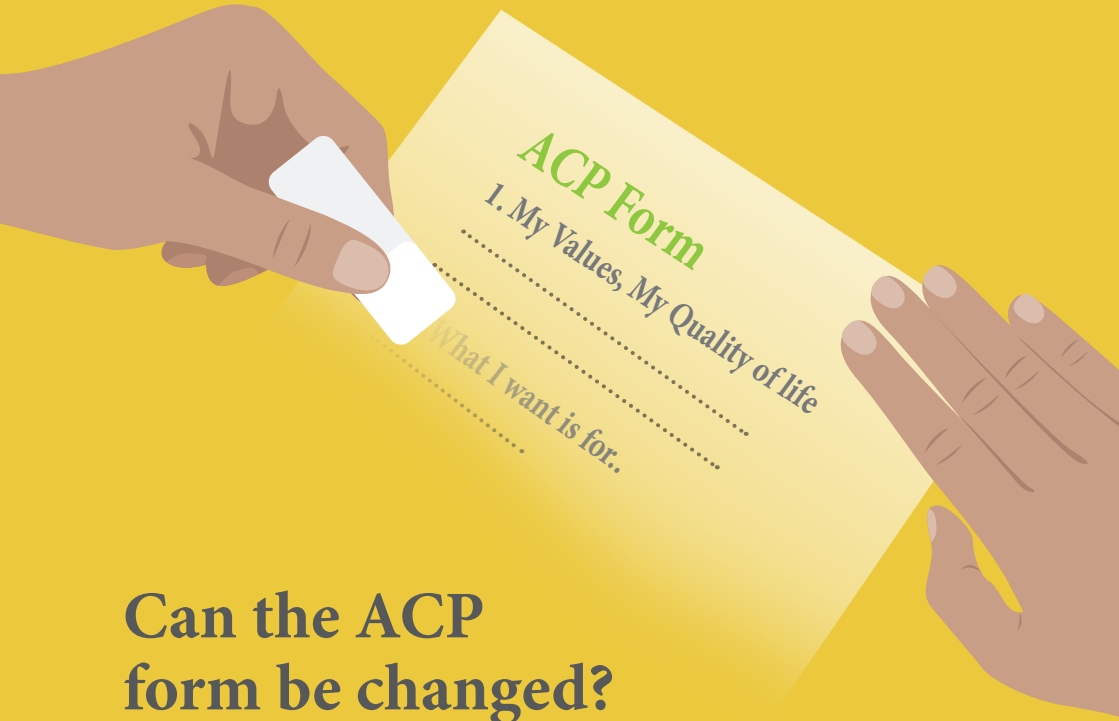
survival were 50-50, but without it, he would certainly end up in a vegetative state.” Input from other extended family members further complicated the issue, but the decision was made to go ahead.

It took months for both Mr and Mrs Naidu to recover, especially when a sudden bout of shingles brought Mrs Naidu back into the hospital. Even today, Mr Naidu relies on a wheelchair to get around. “Our lives were completely changed,” Mrs Naidu said. “When our doctor brought up ACP and told us that it would help with decisions in the future, we were more than happy to do it.”

She explained that they did not want their older selves and their son to be dependent on a single caregiver, making known in their ACPs that when one of them passes away, the other spouse will be cared for in a nursing home once mobility and functional ability is an issue. “Practicality triumphs sentiment,” said Mrs Naidu firmly. “We sold the house that we worked our whole lives to get, because it has stairs that we cannot climb; we had to get used to other people caring for our son, because we cannot provide good care anymore.”

*“We’re physically weaker now, but we feel at peace,” she continued. “Knowing that our wishes have been made clear gives us an unbeatable sense of security – you have to be prepared for the unexpected as you age, and the ACP framework really helps to plan for all these situations.”*

# Frequently Asked Questions (FAQs)



## Can the ACP form be changed?

---

The ACP form can be reviewed and updated when the individual verbalises changes in wishes and preferences, and the previous ACP form would no longer be valid. In general, ACP is an ongoing process and it should be reviewed regularly especially when the individual's medical condition changes.

# Deepening Connections Between Family Members

I am a Medical Social Worker providing support to the Department of Haematology. In my experience as an ACP facilitator, I have learnt that ACP is more than just documenting wishes and preferences.

*Whilst one of the challenges I faced was patients and family members being unready for the conversation, I observed that most patients and family members are better able to cope with the illness after my conversations with them.*

When patients share about their illness, experience, wishes and preferences for treatment, they share deeply and reflect about their lives. For family members, being involved in the ACP conversations helps to enhance their understanding of patient's illness. It also prepares them emotionally and psychologically for when the patient's condition deteriorates. Through ACP, I have had the opportunity to journey with patients and their family members in their lives.

A patient's sister shared with me that she experienced a sense of relief after the ACP discussion. She was the patient's only next-of-kin and she felt lost when she witnessed her loved one's condition gradually deteriorate over time. Upon hearing her loved one's wishes, she shared that "the stone in her heart" disappeared. She was relieved that the patient made his own decisions and that she heard his wishes.

ACP is a process where meaningful communication between patients, family members and healthcare professionals take place and the voices of everyone, not just the patients', are heard.



Ms  
**Kelly Tan**

- ▲ Senior Medical Social Worker
- ▲ Department of Care and Counselling
- ▲ Tan Tock Seng Hospital

# Talking About *Hopes and Wishes*

When he was diagnosed with stomach cancer in mid of 2014, the former firefighter thought not of his prognosis, nor of medical bills. Instead, the first words out of Mr Pandi Karuppiyah's mouth were, "Will my son get it too?" His own father had died of the same cancer.

The love that prompted the question was what kept Mr Pandi going throughout his illness. His wife Ms Meeravathy described a man who loved his family fiercely, and had a firm mind on many subjects, including his own treatment.

Mr Pandi had done a General ACP years before his diagnosis, but when he was hospitalised, he sat down with the Tan Tock Seng Hospital's palliative care team to do up his Preferred Plan of Care (PPC), which has more detailed questions about the specifics of care that he would want. However, Ms Meera was not present for the session – she left it to her daughter to accompany Mr Pandi.

*"Death is taboo in Hinduism. We never discussed it, both before and after he was diagnosed, but we could discuss the ACP," Ms Meera explained. "It lets us talk about his wishes without the discomfort of talking about death directly."*

She added that the structure of the ACP also allowed her and her family to understand Mr Pandi's wishes for his treatment more clearly.



“He was adamant that he didn’t want any invasive treatments – no surgeries, no tubes, no drips – and made those wishes very clear during the ACP,” said Ms Meera. “We went straight to chemotherapy, and except for an emergency surgery when his stomach ruptured, his care team complied with every wish all the way.”

With two children, three grandchildren, and a loving wife, Mr Pandi spent the last 6 months of his life surrounded by love and care. He passed away in December 2014. Ms Meera described the scene as peaceful,

*“He didn’t have any drips or tubes in him, just as he wanted. Even though he wasn’t able to speak, he waved goodbye at me before closing his eyes and leaving for the last time.”*

As a former nurse, she is positive about the benefits of the ACP. “It brings patients, families, and caregivers together for a dialogue about end of life care,” she said. “Sometimes you can’t bring yourself to talk about your loved ones dying, but you can talk about this framework, and use it as a starting point.”

# A Chance to Do It Right


## Dr Lee Yun

Senior Resident, All Saints Home

I first came across ACP when I was a junior Medical Officer with the Alexandra Health Geriatric Medicine department. At the time, I was more of an observer and scribe while my senior spoke with the patient and family. Now, I facilitate ACP discussions once or twice a month.

Often, the ACP helps to kick-start a much-desired discussion with the patient and family. In one case, Mrs A had expressed her wishes to her family, and was leaning in the direction of palliative care, rather than aggressive, continued treatment.





Her family was keen to respect her wishes but found it difficult to start the conversation with the healthcare workers. They were worried that they might be perceived as 'abandoning' Mrs A, or had ulterior motives in limiting the extent of care of the patient. It was also difficult for them to talk about palliative care, as we live in a culture where medical intervention is still the norm for healthcare. While they knew what the patient wanted, they were at a loss about how the palliative care would be delivered.

Their relief was palpable when we initiated the ACP discussion. Various healthcare scenarios were discussed and we ran through the corresponding palliative care arrangements that would be made in each scenario.

*This was exactly what Mrs A and her family had needed: the opportunity to highlight issues, provide information, and express their views while Mrs A was still able to. It can be more difficult to discuss ACP when the patient is acutely ill.*

Mrs A received the palliative care she wanted and passed away peacefully. Her family could attend to her wake and funeral with lighter hearts as her last wishes had been respected and fulfilled.

# Frequently Asked Questions (FAQs)



## What is the difference between ACP and the Advance Medical Directive (AMD)?

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An Advance Medical Directive, more commonly known as AMD, is a legal document to inform the doctor that you do not want the use of any life-sustaining treatment to prolong your life in the event you become terminally ill and unconscious and where death is imminent.

ACP is an approach to communication regarding future healthcare wishes reflecting not just specific refusal of treatment in certain circumstances but encompassing a person's illness representation, values and wishes guiding care as well as choice of Nominated Healthcare Spokesperson (NHS). It is an on-going communication process and an ACP form is created as an outcome of the ACP process. Anyone can make an AMD as well as an ACP.

Above information is adapted from Advance Medical Directive (AMD) by Ministry of Health Singapore. For more information, visit: [https://www.moh.gov.sg/content/moh\\_web/home/policies-and-issues/advance\\_medical\\_directiveamd.htm](https://www.moh.gov.sg/content/moh_web/home/policies-and-issues/advance_medical_directiveamd.htm)



# My Journey in Advance Care Planning



Dr

**Violet Tang**

- ▲ Resident Physician
- ▲ Post Acute Care at Home (PACH) Programme
- ▲ Department of Continuing & Community Care
- ▲ Tan Tock Seng Hospital

Talking about end of life choices seems like a taboo subject in our society.

Despite having worked for five years as a doctor, I still find it hard to broach such a subject with my patients. This is especially true when the role of a doctor indoctrinated in all of us is that of a person who saves lives. Even as a medical student, I was not taught how to manage a dying patient, let alone conduct an ACP discussion.

It was only after my first encounter with a terminally-ill patient as a newly-minted House Officer that I realised the importance of ACP. The process helps the family to understand their loved one's wishes, come to terms with his/her prognosis and prepares them for any complications that may arise from the patient's illness.

*In Singapore's aging society, I strongly believe that ACP will become an integral part of patient-centred healthcare and that it is prudent for one to be equipped with skills in ACP. In my experience, it has certainly helped my patients and their families foster communication, understanding and peace during a stressful period of their lives.*

# *Common Misconceptions about ACP*



## **Misconception**

ACP is about withdrawing life-sustaining treatment.



## **Reality**

ACP is a discussion about your healthcare preferences. You may indicate your preference for less aggressive measures, or to receive other treatment where clinically appropriate.



# Frequently Asked Questions (FAQs)



## What is the relationship between ACP and the Lasting Power of Attorney (LPA)?

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An LPA is a legal document provided for under the Mental Capacity Act where an individual who is at least 21 years of age, voluntarily appoints one or more persons (donee[s]) to make decisions and act on his behalf should he lose the capacity in the future to make his own decisions. Donees may be appointed to act in two broad areas – personal welfare (may include healthcare decisions) and property and affairs matters. Both ACP and LPA are important planning instruments which all individuals are encouraged to make. Ideally, the donee for healthcare decisions under the LPA and nominated healthcare spokesperson in the ACP process should be the same person.

To find out more about LPA, visit:  
<http://www.publicguardian.gov.sg>

# Fostering Closer Relationships With Patients and Their Families



*Sister*

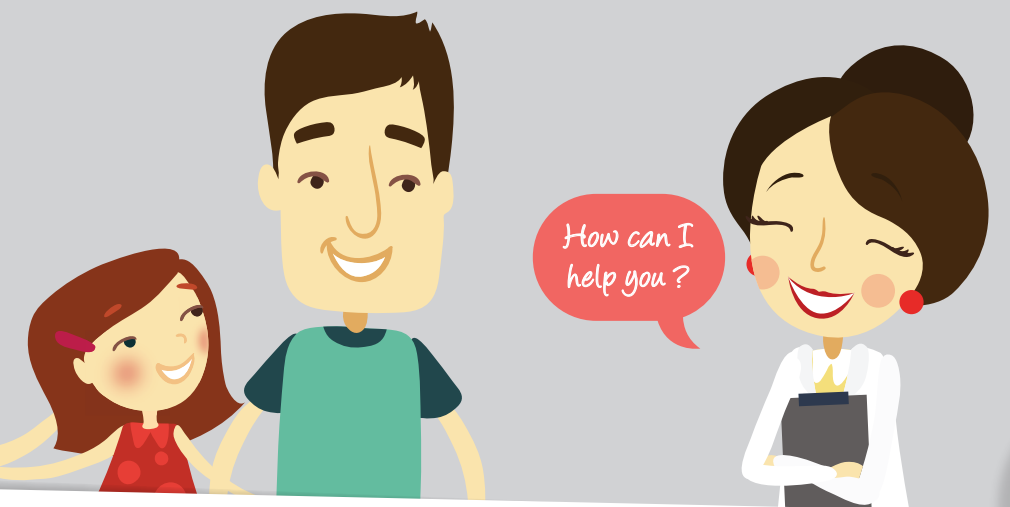
**Geraldine Ng**

- ▲ Advanced Practice Nurse
- ▲ Nursing Service
- ▲ Department of General Medicine
- ▲ Tan Tock Seng Hospital

Many years in nursing has equipped me with skills in saving patients' lives. Helping patients achieve quality and comfort care at the end of life is what I have heard of but never been able to practise well.

In recent years, I have managed patients who were ill and unable to make decisions for themselves, and medical treatment was decided without knowing what the patients would have really wanted.

One day, I chanced upon an opportunity to sit in an ACP facilitation. I learned that an ACP facilitation is more than just talking to patients about their goals of care. In ACP facilitation, one is able to understand an individual's health choices, values and feelings, as well as the family's understanding of the patient and the whole situation.



However, it is not just about discussing ACP, but also about building rapport and a relationship with the patient and family. Since then, I have proactively sat in ACP sessions to get more experience and attended trainings. ACP facilitation is a unique skill that I have now acquired!

*I feel that, when patients are ill and unable to make decisions for themselves, they are at their most vulnerable. We can make a deep impact on this important part of their journey in the healthcare system.*

Nurses, who have close contact with patients and families, should be trained for ACP facilitation because it builds and enhances rapport with those we care for. It has been both a challenge and a rewarding endeavour!

# *Advance Care Planning:* A Choice of Independence

"Live life simply," advised Mr Wong Meng Keng. After fighting colorectal cancer for over four years, he keeps his days occupied with simple pleasures, grateful that he is able to enjoy them independently. "Going for a walk around town, buying groceries and cooking – it keeps me from thinking too much."

Mr Wong was diagnosed with stage 2 colorectal cancer in 2010, and underwent surgery, radiotherapy, and chemotherapy. Two years later, the tumour returned, prompting another surgery. When the cancer returned in 2014, it had spread to his lungs. "There's not much to be done anymore," he said matter-of-factly. "I just stay positive and take things as they come. In fact, I'm even less worried after doing ACP." He explained that ACP helped him better understand his options, and gave him the chance to make his wishes known and alleviate his worries.

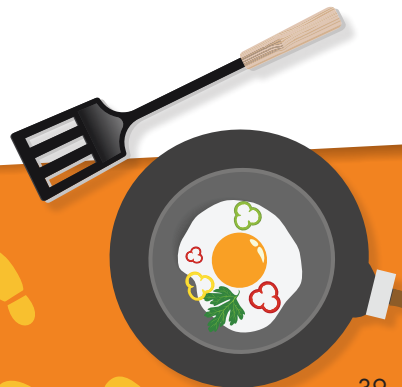




*"I don't want to be in a vegetative state or fully dependent on someone, but it's not something I had expressed to my wife or children," he said. "If I hadn't done the ACP, nobody would know what to do. I'd be brain-dead or in pain, but kept alive artificially. It'd just cause my family even more pain. At least now I am rest assured I can go naturally, in peace, and in a place of my choosing."*

Mr Wong recounted the way his father passed away from lung cancer in a hospital, and how the family received help with the procedures that inevitably followed. He explained, "If I die at home and my kids aren't around, I'm afraid my wife wouldn't know what to do. I don't want to put her through that."

"My wishes have been heard," he concluded. "My children are grown and married; my responsibilities as a father have been fulfilled. Right now, I'm thankful that I'm able to do what I want, and that I have made my choices about the end."



# The Goals of Living

*As I journey with patients and their caregivers, the ACP helps me focus on finding out patients' goals of living – things that matter most to them in living with dying – while crafting a realistic and achievable care plan.*



Ms

**Lim Li Zhen**

- ▲ Senior Medical Social Worker
- ▲ Dover Park Hospice

I came to know the late Mr M through an urgent referral raised by my hospice home care doctor to look into his financial and accommodation issues. Mr M was in his late forties when he was diagnosed with advanced stage colon cancer.

When I first met Mr M in the hospital, he was not ready for more negative news about his condition, nor in the right frame of mind to make plans for future healthcare decisions. The knowledge of his life-threatening illness, coupled with secondary losses of the roles he held as provider for the household and protector of the family, was just too much for him to bear. It was painful for him to even think about the losses he was facing, let alone think ahead of options in the event of deterioration. All he wanted was to pursue chemotherapy treatment so that he could get back to normal and start work again.



I acknowledged his expressed hopes with nods in silence. After a few minutes, I remarked to Mr M, "it seems like living on and regaining a normal life is very important to you."

Mr M's reply was immediate, "yes! If all else fails, I want to at least secure a rental flat for my family so that they can reside here, and my boys can continue to study here. Would you be able to help me?"

Surprised by his openness to talk about his goals at that point of time, I responded by collaborating with the attending physician to appeal to Housing Development Board (HDB) for a rental flat as soon as possible. As the family's sole breadwinner, Mr M travelled to and from Johor every day for work, where he lived with his wife and two teenage sons. They had bought a new HDB flat twice and sold both times, so their only option was to buy a resale flat. Unable to afford it, the family rented a place in Johor.

As time went on and the team got to know Mr M better, we managed to support his goal of receiving treatment in Singapore to prolong his life by more than four months.

We had a few ACP sessions with Mr M and his wife, who was his main caregiver. The planning covered topics such as how to continue supporting his care at home, as he preferred being cared for at home. He would only consider hospitalisation if he needed treatment to prolong his life, like chemotherapy.

After a wait of over four months, Mr M's appeal to HDB was finally granted and he secured a rental unit. However, the good news was tempered by a relapse. Mr M was sent back to hospital for an urgent blood transfusion, and this time his prognosis was not good.



When I visited him in the hospital, he could barely speak in full sentences. I had to be direct in asking him where he would prefer to be cared for, knowing that his rental flat had just arrived.

“Home, my new rental flat,” he said firmly.

By then, Mr M was mainly bedbound and required total care and two full-time caregivers. Because of his ACP, his wife and sons were aware of his goals and wishes. With the help of his extended family as well as his sons’ school counsellor and friends, we painted and furnished the new rental unit in three days. We also used the Respectance Fund\*, to engage a home care nurse to assist Mrs M.

Mr M passed away peacefully in his new rental unit a week later. His family and all of us in his healthcare team felt a sense of closure in the midst of grief, as we fulfilled and honoured his wishes before he passed away.



\*A charity fund set up by the Lien Foundation to help needy terminally ill patients with the cost of dying at home.

# *Common Misconceptions* about ACP



## **Misconception**

ACP means the medical team has given up on me.



## **Reality**

ACP helps the medical team understand your wishes and deliver the type of healthcare and services that align with your care preferences.



## Interview with

*Dr*

### **Adrian Tan**

- ▲ Family Physician, Consultant
- ▲ Deputy Director, Home Ventilation and Respiratory Support Service (HVRSS)
- ▲ Department of Continuing & Community Care
- ▲ Tan Tock Seng Hospital

***Can you share with us your experience in your double role as a doctor in HVRSS and an ACP facilitator?***

As a doctor and ACP facilitator, I find myself having to walk the balance between advising patients as well as listening to their wishes. In our discussion, there needs to be a keen awareness of the availability and limitation of resources and support services. We should consider various scenarios as well as practical aspects of care. For example, when patients express their wish to pass away at home, we need to ascertain that the systems and services are in place to support their wish.

***Your role as an ACP facilitator in HVRSS is unique. What are some challenges you face doing ACP facilitation in patients' homes?***

There are certainly many challenges; for example, distraction due to noises from construction activities in the neighbourhood, and family members finding it difficult to be present during office hours. There are also barriers in communication because many patients are tracheostomised and have poor expiratory voice quality as well as sustainability. Sometimes we may need a caregiver like a domestic helper to help decipher what the patient is communicating and we need to ensure the patient is comfortable sharing. We may use eye communication charts to spell words making the process laborious and tiring.

## ***How has ACP been beneficial for your patients?***

In conducting ACP discussion with my patients, I learn about their stories in facing advanced illness and disability and their raison d'être.

*Many a times, I am touched by their resilience and bravery. New roles and meaning in life can be explored for those determined to make the most of their lives.*


For example, I had a patient who is tetraplegic from an accident and dependent on a ventilator, who can no longer be breadwinner for his family. He found a new role in being a listening ear and counsellor to his teenage daughters who share their struggles in school and in life with him.



# Advance Care Planning

Advance Care Planning (ACP) is a voluntary discussion on future health and personal care. It encourages you to think about your personal beliefs and share the goals of care with your family members and healthcare providers. It includes:

- Sharing your personal values, beliefs and goals for care with your loved ones and healthcare providers;
- Exploring your healthcare preferences in difficult medical situations, which could include circumstances at the end of life; and
- Appointing a Nominated Healthcare Spokesperson (NHS) to represent your voice and make your preferred care decision should you be unable to speak for yourself one day.



Who should consider ACP?

Everyone, regardless of your age or your health condition.



# My Voice, My Care

## ACP Conversation Starter



Interested to do an Advance Care Plan (ACP), but clueless as to where to start? Below are some guiding questions for you and your loved ones to reflect and discuss.




The questions below are merely a guide, and not meant to be a substitute for an ACP conversation done in the presence of a trained ACP facilitator. If you wish to complete an ACP, please approach your respective healthcare provider for more information.

There are no right or wrong answers to the questions below. Remember, this exercise is all about expressing your thoughts and wishes.

### 1. My Values, My Quality of life

To me, living well means:

Please tick the following options which are most applicable to you.

- Being able to care for myself
  - Being healthy and independent
  - Spending time with my family
  - Spending time with my friends
  - Being able to practise my spiritual beliefs
  - Being able to enjoy my favourite past-times and hobbies
  - Others: .....
- 
- 
- 



To me, these abilities are so essential that life would be unbearable without them (e.g. ability to walk and talk, make decisions, interact with people, etc):

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.....

**2. My Health Status**

Currently, these are the health conditions that I have:

- 1. ....
- 2. ....
- 3. ....
- 4. ....

At the same time, these are the worries and fears I have about my health:

.....

.....

.....








### 3. My Experience with Healthcare

So far, I have received care in the following settings:

Please tick the following options which are most applicable to you.

- 
- General Practitioner (GP) Clinic
  - Polyclinic
  - Hospital Outpatient Clinic
  - Hospital Inpatient Stay
  - ICU stay
  - Others: .....

In the past, I have had encounters with family members or friends who were very ill. While being by their sides, I have learnt that:



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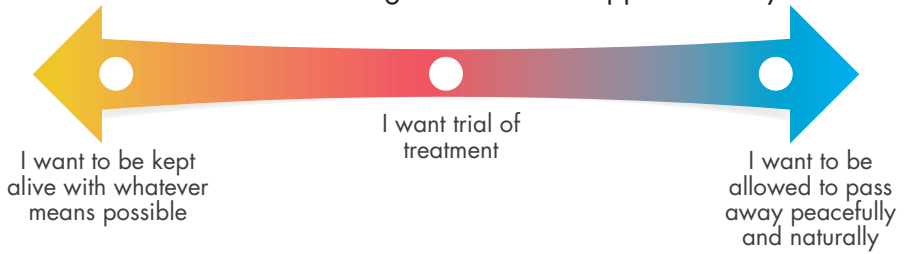
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#### 4. My Care Wishes

In the event that I have a serious illness or injury to the extent that I do not know who I am, who is by my side, nor where I am, and my doctors believe that I would have a very low chance of ever recovering my ability to make decisions for myself:

Please tick one of the following which is most applicable to you.



I cannot make a decision with regards to the above scenario because

.....

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## 5. My End of life Care Preferences

When I think about death and dying, I'm concerned and worried about:

Please tick the following options which are most applicable to you.

- Being alone
- Being breathless
- Having no appetite
- Having financial concerns
- Being in pain and suffering
- Being a burden to my loved ones
- Others: .....

When the end is near, I would like the following (e.g. have my family around, have my favourite food, etc):

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These are the spiritual and religious beliefs and practices that would affect my care at the end of life:

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**6. My Nominated Healthcare Spokespersons (NHS)**

A Nominated Healthcare Spokesperson(s) should<sup>1</sup>:

- Be above 21 years old;
- Be willing to speak on your behalf;
- Know you well and understand your wishes and concerns;
- Be able to tell your doctors about the care you would like to receive;
- Be able to follow through with your care preferences; and
- Be able to handle stressful situation.



With these considerations in mind, the person(s) that I trust to understand me, respect my wishes and make decisions for me are:

1. Name : .....  
Relationship to me : .....  
Phone : .....

2. Name : .....  
Relationship to me : .....  
Phone : .....

Interested to have a comprehensive ACP conversation with a trained facilitator? Approach your healthcare provider for more details! Most restructured hospitals in Singapore have trained facilitators who would be able to facilitate ACP sessions between you, your loved ones, and your healthcare professionals.

**You are encouraged to:**

- 1 Schedule an appointment for Advance Care Planning (ACP)
- 2 Communicate your wishes to your family, healthcare team and hospital
- 3 Review your plans regularly as your health status, life circumstances and goals may change. It is important to communicate any changes to your healthcare team and family
- 4 If you're a patient of TTSH and would like an ACP facilitation, please contact 6359 6410 or [acp@ttsh.com.sg](mailto:acp@ttsh.com.sg)

## What are the benefits of ACP

- Allows you to understand and reflect on your medical condition;
- Allows you an opportunity to make choices about your future healthcare preferences;
- Allows you to appoint a Nominated Healthcare Spokesperson (NHS);
- Allows you a sense of control and individual autonomy;
- Allows you to reduce your loved ones' burden in decision-making during difficult situations; and
- Allows you to strengthen your relationships with your family members and healthcare providers.



## **✘ Misconception**

ACP is a conversation about death.

ACP is only for the elderly and sick.

ACP is to withdraw life-sustaining treatment.

ACP means the medical team has given up on me.

## **✔ Reality**

ACP is an ongoing discussion about your healthcare preferences. It encourages you and your loved ones to discuss and understand your values, beliefs and wishes.

ACP is for everyone. Healthy individuals, young adults, working professionals and retired seniors are encouraged to discuss about the type of healthcare they prefer.

ACP is a discussion about your healthcare preferences. You may indicate your preference is to withdraw active treatment, or receive other treatment where clinically appropriate.

ACP helps the medical team to understand your wishes and deliver the type of healthcare and services that align with your care preferences.

## **Useful Resources**

[www.ttsh.com.sg/acp](http://www.ttsh.com.sg/acp)  
[www.livingmatters.sg](http://www.livingmatters.sg)  
[www.advancecareplanning.ca](http://www.advancecareplanning.ca)  
[www.gundersenhealth.org/respecting-choices](http://www.gundersenhealth.org/respecting-choices)





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