

THE HOSPICE LINK

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**Starting the
conversation**

**End-of-life:
Start at the
beginning**

**It's never too
early to make
your final
wishes known**

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In the end, it's not the years in your life that count.
It's the life in your years.”

ABRAHAM LINCOLN

Our legacy is vital and for that reason we should live with a well-planned life journey. There are many who understood and saw the importance of making the right decision to pre-plan for their final wishes as it provides peace of mind. Ironically, talking about end-of-life decisions and final wishes would probably never be ranked as the most pleasurable or anticipated conversation.

The peace-of-mind benefits will not be complete if it is not discussed with the relevant loved ones. Therefore, it's essential to actualise that discussion even if you think your family may question or not be prepared to go through what you have decided.

Letting your family know your plans will enable them to carry out your wishes and minimise any financial burden on loved ones in the future. It is also among the most unselfish and loving things that one generation can do for another.

We are great planners only if our plan includes our final wishes for:

UNFORESEEN CIRCUMSTANCES

You never know what life has in store and therefore it is sensible, necessary and timely to pre-plan your end-of-life care and wishes. This will enable your family to be aware of your preferences or decisions, which will make it easier for them to cope at a time of crisis or loss.

EASE OF MIND

Knowing that you have put your final affairs and arrangements in order will give you a sense of contentment and relief as you are aware that your options will be honoured as planned. Pre-planning would make it more affordable as the plans will be locked within your means where it is cost-effective and practical.

It's never too early to make your final wishes known as letting your loved ones know about your plans will relieve them from unnecessary conflicts and stress about making decisions during a time of grief.

Consider talking about your final wishes with these professionals and anyone else you believe will have an impact on your final arrangements:



Ms Evelyn Leong
Chief Executive
Singapore Hospice Council

Starting the conversation

Planning for end-of-life early empowers us to make the best decisions for ourselves and also reassures our loved ones. HCA Senior Medical Social Worker Yap Ching Sian shares some tips on beginning the end-of-life conversation.

At what age should I start planning for end-of-life?

Planning for your end-of-life (EOL) requires you to start thinking about how you would like to be cared for when you are diagnosed with a life-threatening illness or when your prognosis is guarded.

It also requires considerations to be given to who you want to appoint as a decision-maker, in the event that you lose your mental capacity. These decisions include how your assets should be managed, funeral arrangements to be made and the legacy you want to leave behind.

As these considerations require significant deliberation, it is advisable that you only start to plan for EOL when you are sufficiently mature. While there is no specific age to start planning for one's EOL, a good gauge is when one enters adulthood. When planning your EOL, you must have a good understanding of your values and preferences.

I am young and healthy. Why do I have to plan for EOL so soon?

Having a plan for your EOL is about being prepared should unforeseen circumstances arise. We often get emotionally overwhelmed when we find out about a major illness or when we meet with an accident.

Under these difficult situations, it would be challenging for us to think about EOL matters rationally. Hence, EOL plans are ideally made when you are healthy and in a good emotional and mental state. Decisions

Planning for end-of-life early enables your loved ones and medical team to understand and act in accordance to your wishes.

made under such circumstances would likely be ones that are thought through rationally and carefully.

Where do I start?

A good place to start is Advance Care Planning (ACP). It involves the process of planning for one's future personal and health care. It requires you to identify a spokesperson to make medical decisions on your behalf, while being guided by the medical team, when you are unable to make your own decisions.

ACP also reflects your views on what gives meaning to your life, elements of care that are important to you and how you would like to be cared for in the event of an illness or injury.

How do I include my loved ones in the conversation?

You would know your loved ones best. You could start by asking questions to gauge how far your loved ones can go with the conversation. Sometimes, the conversation



WORDS & PHOTO: HCA HOSPICE CARE

can begin spontaneously. For example, you and your loved ones might have watched a TV programme, in which one of the characters fell ill, or you and your loved ones might have visited someone at the hospital. These are good opportunities to start having EOL conversations with your loved ones in a more natural and less threatening way.

What are some of the obstacles that I might encounter during the conversation?


Your loved ones may not be ready for the topic due to many reasons. They may find it inauspicious or taboo to be talking about such topics. Others may find it difficult to dive into the conversations as the fear and sadness of losing you are too much to bear.

Care and consideration about your loved ones' readiness to have these conversations should be taken into account. However, getting your loved ones involved in your EOL conversations is equally important, as they get a chance to hear you out and also to express their views about your EOL plans.

These conversations can lead to powerful moments, where affirmations and words of love and gratitude get conveyed and expressed. These conversations sometimes become shared and precious experiences for you and your loved ones, which can be deeply moving, meaningful and life-giving.

What are the advantages of planning for EOL early?

Planning for EOL early allows you to prepare for any unfinished business to be completed, reconcile with people whom you might not have spoken to for a while and have proper time to say goodbye to your loved ones.

It also gives you the chance for your wishes regarding your care, financial matters and funeral matters to be heard. In doing so, your loved ones will not feel the burden of having to make guesses about your preferences. They can be empowered and assured that they are carrying out your preferences and can even take comfort knowing that things are being carried out in accordance to your wishes. 

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Planning for EOL early allows you to prepare for any unfinished business to be completed, reconcile with people whom you might not have spoken to for a while and have proper time to say goodbye to your loved ones.”

A life-affirming project

Despite an ongoing pandemic, St. Andrew's Community Hospital's successful initiative saw the extension of Advance Care Planning beyond the Palliative Care ward to the Rehabilitation ward.

Save for a rainy day, prepare for our future, what would you like to do when you grow up, what are your retirement plans. These are some commonly heard sayings as we go through life in Singapore. We make many of such preparations but what about our health?

We can also make plans for our future health.

Due to restrictions as a result of the COVID-19 pandemic, I found myself serving in St. Andrew's Community Hospital (SACH) for six months longer than I had anticipated. Harboured a passion for Advance Care Planning (ACP), my initial efforts to learn more about this work blossomed into a full-fledged effort to introduce ACP into the Rehabilitation ward of SACH. A Quality Improvement Initiative was started in July after discussions with team members during the Circuit Breaker. Patients admitted into the ward are usually elderly and have suffered a health-related setback such as a stroke, a serious infection

or surgery, and require some time to regain or improve their functional state. They prove to be a captive audience between therapy sessions!

ACP influencers, who are staff such as nurses, pastors and therapists, were trained to reach out to patients and their families to raise awareness of ACP. Using materials such as videos, brochures and workbooks from the Agency of Integrated Care, the team found that there was interest among patients in attending ACP awareness sessions.

During one such session, a patient raised his hand to show interest in having the discussion in the hospital. Another heard how we engaged another patient on ACP and said he too wanted to do it all along but did not have the time, and "this is the best time for me to do so while being an inpatient". Some patients who live alone felt assured that they have been given the opportunity to think and discuss their end-of-life care plans. This only goes to show that many do wish to talk about how they wish to be cared for when

they reach the end of their lives and to share what is important to them.

Our multidisciplinary team was really thrilled that this little project yielded very encouraging results. Over 30 patients in just one ward managed to complete an ACP discussion with a facilitator over a span of six months. Families have expressed gratitude towards the ACP team, as now they know more about what their loved ones would like for their future and will not feel guilty at making a wrong decision. They are thankful that these discussions bring the family closer together. Our staff awareness has also increased through this initiative and they are now more capable of carrying out an ACP discussion.

We aim to eventually roll out this initiative to the rest of the wards in SACH.

This year may have bought great disruption to the world. Amidst this, I was glad for the opportunity to carry out this life-affirming initiative and leave a legacy for others to build on. 🙏



The team members of the Quality Improvement Initiative are (left to right): Tabitha Low (Senior Executive, Healthcare Performance Office), Marcia Chung (Principal Medical Social Worker), Dr Ng Han Xian (Medical Officer), Leong Peiyu (Associate Chaplain, Pastoral Care Services), Dr Melissa Abamonga (Resident Physician) and Dr Kyi Theint Theint Thu (Principal Resident Physician)

WORDS: DR NG HAN XIAN, MEDICAL OFFICER, ST. ANDREW'S COMMUNITY HOSPITAL PHOTO: ST. ANDREW'S COMMUNITY HOSPITAL



SPCC 2021

Embrace • Engage • Envision

7TH SINGAPORE PALLIATIVE CARE CONFERENCE

9 - 10 Dec 2021 | www.singaporepalliativecare.com

9 - 10 December 2021
(Thursday - Friday)



7th SPCC

is a biennial conference that engages professionals beyond the palliative care community.

We are proud to announce that SPCC is back! The virtual event will be held from 9 to 10 December 2021, with an on-site component (depending on the evolving COVID-19 situation).

Given the rapidly evolving COVID-19 situation, please visit www.singaporepalliativecare.com for updates. Your safety remains our top priority.

For enquires, contact us at secretariat@singaporepalliativecare.com

In the meantime, to provide a safe environment for everyone, we would like to urge everyone to adhere to the safe management measures and comply with the COVID-19 regulations.

Organised by:



Held in:



PROGRAMME HIGHLIGHTS

- Communicating in Challenging Clinical Situations
- Dementia
- Empowerment, Engagement, Environment and Economic: the 4 Es in Promoting Palliative Care
- Immunotherapy and Immunotoxicity
- Long Term Use of Opioids in Cancer and Non-cancer Patients
- Mental Wellness in Palliative Care
- Nurturing Engaged Patients
- Pain Management
- Palliative Care Education in Singapore
- Palliative Care – from Hospital to Community
- Palliative Care Research in Singapore
- Towards a Social Model in End-of-Life Care – How Can Social Work Offer Leadership in Health and Social Care Integration
- Through Music and Art Making - Bring Your Inner World into Practice



Far left: Senior Staff Nurse Hasnah bte Abdullah with Nurse Clinician Sahnun bin Rahim work together on ACP outreach; Below: SSN Hasnah guides ACP sessions with relevant materials



The value of Advance Care Planning

Changi General Hospital Senior Staff Nurse Hasnah bte Abdullah shares the importance of making your final wishes known through a case study.

Contrary to popular perception, Advance Care Planning (ACP) is much more about life than death. It is about helping people live out the final stage of life as fully as possible and to make the most of each remaining moment. In the end, when the time comes, ACP is a means to help people die with dignity in the place and manner of their choice.

ACP discussions include talking about preparation for end-of-life care and death, dealing with unfinished business, avoiding unnecessary prolongation of dying, strengthening of personal relationships, and relieving burdens placed on family. They are a key step towards provision of care that is in line with a person's wishes, at a time when it matters most.

Let me share this through a memorable meeting with Mr L, who was referred to me in November 2019. Mr L had received bad news of metastatic cancer and limited prognosis from a urologist. He was devastated, at a loss, anxious, angry, and in denial. I was asked to see him as soon as I could.

I went to see him with two other senior nurses who wanted to

experience an ACP discussion. Mr L was initially very angry; he felt that he did not get much time with doctors and had many unanswered questions. Although he was a soft-spoken and respectful man, he got so agitated that we had to calm him down. We assured him that we would help him where we could. He soon became very appreciative of the time we spent talking to him. He finally felt heard and taken seriously.

As a single 68-year-old man, Mr L's main concern was not to burden his siblings with his care. I explained that the ACP is an ongoing discussion that can be revisited anytime. At the end of the discussion, referrals were made to a psychiatrist, medical social worker and a private nursing service provider to meet the needs he had described. As a result of the discussion, he also agreed to nominate a Lasting Power of

Attorney (LPA) and to draw up a will.

However, he was still very much in denial about his life-limiting illness. After that initial discussion, he subsequently underwent aggressive chemotherapy and many medical interventions. The next time I saw him was one year later. He was admitted and again referred to me. This time, he was much weaker, wheelchair-bound, and appeared to have accepted that further treatment was not going to reverse the course of his disease. It had progressed to a very advanced stage and he was given a prognosis of less than three months. He was seen by the palliative team and referred to Assisi Hospice.

I revisited his ACP with his sister who was the nominated healthcare spokesperson. During that discussion, Mr L made the decision for his preferred place of

death to be in a hospice. I guided him and his sister with information about the signs of active dying, what the final hours might be like, and how his sister should take care of herself after her brother's death. Both Mr L and his sister were very open to hearing this. They were thankful for the information as it prepared them for the end through knowing what to expect.

Relevant information provided at a pace suited to both Mr L and his family meant that he could make decisions that prioritised what was important to him. It might have seemed premature to talk about end-of-life care right at the start of the disease, but it got him to carry out certain important actions early, such as appointing an LPA, before he was not able to do so. The discussions respected his desire not to burden his siblings and facilitated his eventual death in a place of his choice. 🕊

WORDS: SENIOR STAFF NURSE HASNAH BTE ABDULLAH, ADVANCE CARE PLANNING NURSE, CHANGI GENERAL HOSPITAL PHOTOS: CHANGI GENERAL HOSPITAL UNsplash.COM

It's never too early to plan for the end

Hilda sat down and did her Advance Care Plan at the tender age of 23. We find out more about her motivations.



“

Having an ACP done does not mean that you have everything figured out. It also does not mean that you must be fearless of your own death. You simply accept that death is inevitable; it will come to everyone eventually.”

It always seems too early until it is too late. Advance Care Planning (ACP) is for everyone, including healthy adults, and does not need to be done only in our senior years. More often than not, it usually takes a major illness to prompt such discussions with our loved ones. However, it is always better to plan for our future healthcare preferences when we are still well. In this way, it allows our needs and wishes to be met should we be unable to speak or communicate for ourselves and relieves our loved ones of having to make these difficult decisions.

Hilda (as she wants to be known) at 23 years old is one of the many who had their ACP done with an ACP Facilitator at Khoo Teck Puat Hospital. The hospital hopes more young adults will consider having their ACP done.

How did you first know about ACP?

I found out about it at a volunteer training on ACP in August 2018.

Was there any past experience, e.g. from a loved one, that contributed to your decision of doing an ACP?

No. However, months after I got my ACP done, I had my first experience of death in the family. It does not feel real that someone I knew for my whole life is now gone. When I was a child, I was close to my grandfather who taught me watercolour painting. We grew distant as I got older because it became harder for us to communicate due to my limited vocabulary and his hearing loss. Upon knowing about his death, I did not know how to react. In the days leading to my grandfather's death, he

was in a lot of pain and could not communicate his wishes to my mother and her sister. Both of them could not come to an agreement on whether to prolong his life or to let him go. I am bringing this story up to illustrate that these difficult decisions may have been easier if they had talked about it before it became too late.

What made you decide to finally do your ACP?

I had wanted to try it myself and use the experience to persuade my parents to get their ACP done as well — it's still a work in progress. As I am an only child, I worry about not knowing what to do when my parents pass away. We do not talk about end-of-life matters as they are resistant to it.

Did you discuss with your family and/or friend(s) while considering to get your ACP done?

No. I simply did a search online on where I could get my ACP done without charge, then proceeded to make an appointment for myself. On hindsight, it may be more effective to talk to my parents

and have one of them join the session. After all, an ACP is a piece of document. What matters more is the conversation, where we have a nominated healthcare spokesperson listen to you and respect your wishes.

Did you encourage your family and/or friend(s) to do their ACP as well?


Yes, I shared about my experience during my volunteering work and if I sense that my friends are interested, I would encourage them to get their ACP done. However, I do not rush people into it. I rather trust that they will do it when they are ready.

What do you think is one major advantage of having an ACP done?

ACP covers a broad range of questions beyond healthcare preferences. For example: “What makes each day meaningful?”, “What are the important aspects about your well-being?”, “Who or what helps you face serious challenges in life?”. Thinking about the answers to these questions gives one the opportunity to

reflect on what is truly important to them. This is then a chance for them to make choices that are congruent with their values. Life and death are two sides of the same coin; in planning for their death, they also plan how they want to live.

It always seems too early, until it's too late. How would you encourage young adults like yourself to start planning for their future healthcare preferences, while they are still healthy?

I understand that thinking about your own mortality can be scary, and that is normal. In your youth, you want to savour your own vitality, to feel alive and delay adult responsibilities for as long as you can. Having an ACP done does not mean that you have everything figured out. It also does not mean that you must be fearless of your own death. You simply accept that death is inevitable; it will come to everyone eventually. Hence, what we can do is really to prepare as much as we can. Starting your ACP conversation early will bring you comfort in the future. 



It is never too early to start a conversation about Advance Care Planning. Opposite page: Hilda having a tele-ACP discussion with the ACP Facilitator

WORDS: TRICIA TAN, EXECUTIVE, ADVANCE CARE PLANNING, KHOO TECK PUAT HOSPITAL. PHOTOS: KHOO TECK PUAT HOSPITAL, PIXABAY



Advantages of early Advance Care Planning

Assisi Hospice's Senior Medical Social Worker/Counsellor Ms Ivey Tee shares a patient's case study.

Sixty-four-year-old Mr Tan (name has been changed) was diagnosed with cancer and referred to Assisi Hospice for palliative care and symptom management in July 2020. Even though Mr Tan could still care for himself at that point in time, he decided to discuss Advance Care Planning (ACP) with Assisi Hospice's Medical Social Worker (MSW) as he was concerned that his wife, who was his sole caregiver, would be confronted with disagreements with his siblings regarding his decisions on his care plan at his end-of-life. Mr Tan's siblings visited him regularly even though they were not involved

in his direct care, and they were not on good terms with his wife.

Assisi Hospice's MSW visited Mr Tan and his wife twice to discuss ACP. During the MSW's first visit, she identified and brought to his attention the family dynamics and possible challenges his wife might face regarding his end-of-life care. She then introduced ACP to him and his wife, engaging them in a series of discussions to understand their values and wishes regarding the various important elements of care, including preferences relating to resuscitation, care and treatment, place of care and death. After Mr Tan and his wife



Opposite page: Assisi Hospice's Senior Medical Social Worker/Counsellor Ms Ivey Tee (left) facilitates Advance Care Planning discussions with patients and their caregivers

Mr Tan's wife's worries were addressed and eased with assurance of the available resources, decreasing her sense of uncertainty over her caregiving journey.

had thought through their decisions, the MSW proceeded to discuss the details with them.

Mr Tan's wife did not really want to talk about end-of-life initially as she had been grieving due to his illness. The ACP conversation gave the couple a platform to talk about Mr Tan's wishes for his care openly and helped his wife to understand what he wanted. This also gave her more time to prepare herself mentally in caring for Mr Tan. Her worries were addressed and eased with assurance of the available resources, decreasing her sense of uncertainty over her caregiving journey.

Mr Tan conveyed his decision to his siblings. They respected it and gave their full support to his wife.

Mr Tan passed on in September 2020. 🕯️

Why ACP?

Why should we do ACP early?

- Illness can strike any time
- It reduces the pressure of decision-making on our loved ones

What should the conversation cover?

- Sharing of your values and beliefs
- Exploring how your values and beliefs affect your medical/care decisions when you are seriously ill
- Choosing one or more spokesperson(s) who can represent you when you are unable to express your wishes

Should I and how do I document my ACP?

- Though ACP is not a legal document in Singapore, documenting it would enable your loved ones and the medical team to provide care according to your wishes when you lose your mental capacity.
- You can use your own ways to document it and share with your loved ones.
- You may also document your plans in the ACP workbook available at www.livingmatters.sg

Never a better time than now

COVID-19 is a clarion call for Advance Care Planning, highlighting how an unexpected and sudden health crisis increases the urgency of making our care preferences known.

The COVID-19 pandemic has irrevocably changed our lives — how we work, how we socialise, and even how we eat. The global spread and impact of the virus have demonstrated that we humans are not as invulnerable as we think we are, despite the many advancements of modern medicine. The COVID-19 virus has afflicted young and old, rich and poor, and brought many of us, perhaps for the first time, face to face with our mortality.

In pre-COVID times, acute serious illnesses could happen to anyone at any time as well — a sudden bout of acute pancreatitis triggered by previously silent gallstones, an insidious skin infection in the leg from poorly controlled diabetes resulting in septic shock, a road traffic accident causing severe irreversible brain injury. But these incidents of human vulnerability and mortality were largely kept away from public view, contained by the healthcare teams in hospitals; the resulting grief and loss, no less painful, leaving their indelible marks on individual families rather than whole nations. Now,

we cannot hide from death. Every day, we receive news on the rising caseloads and death tolls worldwide. COVID-19 is a stark reminder of what we have always known but do not openly acknowledge — anyone can suddenly fall seriously ill.

In a serious illness, healthcare decisions are complicated, with no single best answer. With the advice of the healthcare team, the patient can then make a choice after weighing the benefits and risks of various treatments, based on their own personal values and goals. But when someone becomes seriously ill and is unable to make decisions for themselves, it becomes very challenging for their healthcare team. Without knowing a patient's unique preferences and values, healthcare teams default to choosing treatments that aim to prolong life as much as possible, as well as consult patients' families or loved ones to make decisions on treatment options.

However, in our experience, most family members are uncertain as this topic has never been discussed before. In the face of time pressures,

we have witnessed how this uncertainty causes significant stress to the family members who struggle to make decisions on their loved one's care. This is why we are calling for people, even those who are young and well, to do their Advance Care Planning (ACP).

ACP is a series of conversations where a person's values and preferences are shared with their loved ones and healthcare providers. These values and preferences are what shape an individual's healthcare decisions. They are unique to each individual and allow for person-centred care. These conversations are documented and used to guide both family members and healthcare teams when the patient cannot make decisions for themselves during serious illness. When you are well and have the time and mental space to think about what matters most to you, do your ACP; it allows you to achieve a clear understanding of what your health journey may look like, the potential complications that may occur,

WORDS: DR EUNICE CHUA, CONSULTANT, DEPARTMENT OF GENERAL MEDICINE & CLINICAL CO-LEAD FOR ACP, TAN TOCK SENG HOSPITAL & DR RAYMOND NG, SENIOR CONSULTANT & HEAD, PALLIATIVE MEDICINE, WOODLANDS HEALTH CAMPUS. THIS ARTICLE FIRST APPEARED IN LIFEWISE (JAN-MAR2021), AN NHG PUBLICATION. PHOTO: SHUTTERSTOCK

We need to change, en masse, our attitude towards talking about death and dying, and embrace having these important conversations early with our families and healthcare practitioners.



Everyone should take the time to talk to their families and loved ones about what they value in terms of their health and lives

and the risks, benefits and trade-offs of various treatment options.

The Circuit Breaker period created many challenges and even a certain degree of suffering for some, but it also brought great clarity. We began to appreciate what we used to take for granted — the freedom to simply sit outdoors and have a conversation with a loved one, to hug a friend, or share a meal with extended family. We learned that living well is more than just being physically alive. As we move forward as a country, we should not lose sight of this clarity.

We should take the time to talk to our families and our loved ones about what we value in terms of our health and lives. By doing our ACP, we could empower them with the right information so that if we cannot make decisions for ourselves, our loved ones will be able to have certainty and peace of mind to make healthcare decisions on our behalf.


To help you get started, here are some questions that you can think about and discuss with your loved ones:

1. What are the things in life that give me meaning and purpose?
2. How would I like my loved ones to remember me?
3. What would I be most fearful of should I become seriously ill?
4. If I should become dependent and require a full-time caregiver, what are my concerns and preferences?
5. How do I feel about the use of life-support machines?
6. Who knows me best and would be able to share my values with the doctors, to make healthcare decisions for me?

We plan for everything in life: our studies, our career, vacations, whom we marry, how many kids we want, and our retirement. However, studies have shown that the large majority of us do not plan for serious illness or share our values and preferences on our care with our families.

This public health crisis could be an impetus for us to turn the tide for ACP. In some countries, such as the US and Australia, there are COVID-specific advisories

and telemedicine consultations right now on how to conduct and implement ACP. In Singapore, while there are some fledgling tele-health efforts to help people do their ACP, we think there needs to be a louder call to promote ACP in our population and systemically entrench it in our healthcare system. We need to change, en masse, our attitude towards talking about death and dying, and embrace having these important conversations early with our families and healthcare practitioners.

ACP is not to a panacea for the pain and suffering one might face when one is seriously ill. But it can be very helpful — for you, your family, and your healthcare team. Most importantly, the ACP is not cast in stone. As an on-going conversation, it provides a way for us to talk about our fiercest loves and our deepest fears and allows our loved ones to make difficult decisions should they be called upon. Rather than thinking about this as taboo, embrace it as a gift of love to those you care about. 

Seize the moment

With seniors being more susceptible to the adverse effects of COVID-19, it may be time to get the conversation going with your loved one sooner rather than later.



An MWS Home Care & Home Hospice patient receives holistic care


While the COVID-19 situation has improved in Singapore, especially with the vaccine now available, it is widely acknowledged that the crisis has been particularly hard on seniors. From being more susceptible to dying from the virus to experiencing adverse effects of various containment measures, seniors have borne the brunt of the impact.

This makes it more important than ever to start that end-of-life conversation with your loved one as soon as possible. One way to broach the topic could be to share about the COVID-19 situation and its serious impact on seniors.

According to a press release issued by the Ministry of Health, Singapore*, seniors aged 60 and above form at least 80% of all COVID-19 deaths. The number is even higher in Singapore, where seniors made up 95% of all COVID-19 deaths. The statistics also indicated that nearly 1 in 6 or 16% developed severe symptoms and required intensive care in the hospital compared to just 0.2% of non-seniors.

Although the various measures to safeguard the health and well-being of seniors may have kept the death toll low, these may have resulted in undesirable effects.

At MWS Home Care & Home Hospice, many patients are facing limited access to care resources, such as foreign domestic workers

who are in short supply as many have returned home and there are travel restrictions for their replacements. This results in them not being able to receive the optimal care required. Many are also more emotionally distressed due to myriad reasons, such as having to adhere to strict safe distancing guidelines and juggling the needs of other family members. In addition, they may be experiencing a higher level of anxiety when visiting hospitals and polyclinics for fear of getting infected by the virus. 

**Ministry of Health, Support Measures for Seniors During COVID-19, 8 May 2020. Retrieved from <https://www.moh.gov.sg/news-highlights/details/support-measures-for-seniors-during-covid-19>.*

WORDS & PHOTO: METHODIST WELFARE SERVICES

Carrying on the conversation

Once you've started the conversation, what can you talk about? Here are three ideas to consider.

Providing companionship

If your loved one is home-bound and living alone, there is a high chance that he or she is feeling lonely. The rapid pace at which the world is moving may also add to the feeling of being isolated or left behind. Palliative home care, which provides a range of services, may be an option. At MWS Home Care & Home Hospice, there are teams of doctors, nurses and medical social workers who make regular home visits and provide round-the-clock support. Many seniors actually look forward to the visits even when they are well because of the companionship and camaraderie.

Getting care according to their wishes

While you may be focused on curative treatment to treat your loved one's condition, he or she may have other thoughts about the care they want. Hence, it may be a good time to bring up Advance Care Planning (ACP), which promotes care that is consistent with his or her values and preferences. It guides you and the healthcare team to make decisions in your loved one's best interests should he or she lose the mental capacity to do so. One tool that often complements ACP is the Advance Medical Directive, which informs the doctor treating your loved one to stop aggressive life-prolonging treatments should this be what he or she wishes. This helps to avoid disputes between family members when the time comes for critical medical decisions to be made.

Having a better quality of life

We all want our loved ones to be comfortable, not suffering towards the end. Yet, more often than not, the curative treatment route may cause pain and side effects. This makes it important to talk about palliative care, which gives him or her the option for pain and symptom management, as well as a higher quality of life by meeting their physical, psychological and spiritual needs. Giving your loved ones better control over their pain and symptoms will also enable them to spend their remaining time in a more meaningful manner. Palliative care could also be helpful for those who are struggling with the emotional distress and anxiety brought on by the COVID-19 situation.

End-of-life conversations: start at the beginning

Patients and their caregivers can use the recently published A Family Dignity Intervention Journey: Our Lasting Legacy to create their own legacy document.

Did you know that the most important and meaningful stories in our lives are actually our own? The ones that were created since the day we were born, continued as we walk through life, and shared with special people we meet along the way.

Sometimes, painful events such as the diagnosis of a serious illness can seem to consume our entire lives. As patients, we may feel overwhelmed by the daily physical discomfort, and the emotional rollercoaster of uncertainty, hope and fear that accompany our illnesses. As family caregivers, we may feel completely absorbed by our caregiving responsibilities, while coping with the tiredness that comes with our devoted acts of caregiving. On top of all these, we are asked to participate in end-of-life care conversations, such as Advance Care Planning or Lasting Power of Attorney, something many of us had never even thought about before the illness. Suddenly, our present lives seem to revolve solely around the illness and its repercussions; the 'good old days' feel like a distant memory, or even a figment of our imagination.

But we are not just 'the patient'. We are not just 'the caregiver'.

We are unique individuals with wonderful stories to tell. We are spouses, children, siblings, parents and friends. We have loved and lost, given and received, dreamed and accomplished, failed and learned. Most importantly, we have shared these precious experiences and memories with some special people in our lives. All of these cannot be undermined by the presence of a life-threatening illness.

FAMILY DIGNITY INTERVENTION - CREATING LASTING LEGACIES

Associate Professor Andy Ho and his team at the Action Research for Community Health (ARCH) Lab designed the Family Dignity Intervention (FDI) in 2017 to facilitate valuable conversations between patients and family

caregivers, with the goal of deepening emotional connections, creating lasting legacies and paving the way for end-of-life discussions. The FDI is conducted by a trained therapist who delves into an exploration of recollections, life accomplishments, words of wisdom and expressions of appreciation between patients and their family caregiver. This interview is later transformed into a 'legacy document' — an edited and personalised copy of the interview transcript that is designed like an autobiography — and given to patients and their families. Last year, the team published *A Family Dignity Intervention Journey: Our Lasting Legacy*, a book with activities based on the FDI for patients and caregivers to create their own legacy document. This book has been distributed to local hospices, hospital palliative care units and intermediate long-term care facilities (ILTC) such as nursing homes. An interactive web version of the book is also underway.

A/Prof Andy Ho observes that a significant feature of the FDI is that while the interview questions did not ask about end-of-life care planning, many patients and caregivers brought up these topics organically during the interview.



WORDS: GERALDINE TAN-HO, SENIOR COUNSELLOR, NANYANG TECHNOLOGICAL UNIVERSITY SINGAPORE AND A MEMBER OF SHC'S COMMUNITY ENGAGEMENT & COMMUNICATIONS COMMITTEE
PHOTOS: NANYANG TECHNOLOGICAL UNIVERSITY SINGAPORE CORPORATE COMMUNICATIONS



Senior counsellor Geraldine Tan-Ho and Associate Professor Andy Ho with their publication *A Family Dignity Intervention Journey: Our Lasting Legacy*

"When they have the opportunity to first recall shared memories from childhood to adulthood and think about what they have accomplished and learned in life, they begin to reflect also on what they would like for themselves and their loved ones in the future. The FDI provides a gentle and empowering way of inviting patients and caregivers into these difficult but crucial conversations."

START AT THE BEGINNING

Mr. Ahmed*, a patient who had received *Family Dignity Intervention*, once wisely declared, "If someone does not ask about your life, how can they ask about your death?"

Indeed, end-of-life care conversations must begin from a place of love and concern, and not simply from a place of urgent necessity. Whether or not we are in a hurry to acquire or convey final wishes and plans for the very end,

we should always remember to start at the beginning. Based on the FDI interview, patients, family caregivers and healthcare professionals can embark on a meaningful storytelling journey with such questions:

1. Tell me about your childhood. What are some of the important and memorable times in your life?
2. How has your relationship with your loved one influenced your life?
3. What do you think are your most meaningful accomplishments in life?
4. What do you think your loved one is most proud of you for?
5. What do you appreciate most about your loved one?
6. What would you like to thank your loved one for?
7. Are there any words of wisdom or advice that you would like to offer to your family?

8. What are your hopes and dreams for yourself, and your loved ones?
9. What are some things you would want your loved one to know about you, or to remember about you?

In bringing back old memories, new and cherished ones are made. In expressing appreciation and love, family bonds are rekindled. In talking about our lives, we pave the way to reflections about our death. The end-of-life conversation must be dignifying, empowering and meaningful; perhaps a lasting legacy and a story in itself.

After all, life is a gift to us, and sharing our life stories can be our gift to the ones we love. 📖

**Name has been changed for confidentiality*

A lifetime of love and memories are wrapped up in the legacy works left behind for patients' families



A mother's love

To most, it's merely a cookbook. But for one palliative patient at Sengkang Community Hospital, the collection of recipes was part of her legacy that allowed her to live out the remainder of her life meaningfully.

Madam Julie Wee's life was not always smooth sailing. Ever since her husband passed away many years ago, she worked hard to raise her three children on her own. It was tough being a single parent, but her love for them was far greater than anything else.

HER LAST WISH

Madam Wee was known by her fellow patients and the hospital staff to be a reserved person. She only opened up and shared about her life experiences when spoken to in the Teochew dialect.

The fluent Teochew speaker knew that time was not on her side. She could feel her condition worsening each day and so, expressed her wish to write a card for each of her children and also to create a recipe book that contained their favourite dishes.

She envisioned the book to be filled with traditional dishes that she used to make for their birthday celebrations. A part of her will stay with them as memories and remind them how she used to prepare their favourite dishes on those special occasions.

It will also help her children to continue with the tradition of cooking for the family at home.

The Rehabilitation team then initiated this piece of legacy work — something that allowed palliative patients to reflect on what's important to them, and motivate them to have a dignified rest-of-their-lives during their stay in a community hospital.

"The Rehabilitation team provided her with different art materials to create her cards and recipe book. She would request for what she needed and the designs she wanted," shared Tricia Ng, SKCH Senior Occupational Therapist.

WORDS: SINGHEALTH COMMUNITY HOSPITALS
PHOTOS: SINGHEALTH COMMUNITY HOSPITALS, PEXELS.COM



Left: The ties bound by shared food memories are unbreakable and a strong legacy. Below: This recipe book will help Mdm Wee's children continue the tradition of cooking for the family.

“

Some examples of legacy work are conducting a life review, creating a recipe book, written or audio letters, or photograph albums to family members.”

**PRABHA D/O TECHNA MITI,
SKCH SENIOR MEDICAL SOCIAL WORKER**

The Medical Social Services (MSS) team on the other hand provided psycho-emotional support for her to complete the project.

But the process was not as easy as the team thought it would be. Madam Wee was lethargic and needed rest most of the time due to her condition.

To help her complete her wish, the Rehabilitation team focused on getting one recipe done at a time. They broke down the tasks into smaller steps and completed them day by day. For example, the team would start with getting the list of ingredients followed by recording the methods the next day.

Once they have gotten all the information, they began to decorate the recipe book based on Madam Wee's instructions. There was also the language barrier that the team had to overcome. The team had to enlist the help of Teochew-speaking colleagues so they could understand Madam Wee's wishes.

With all the help from the team, Madam Wee was finally able to complete her recipe book. She passed away three months later in August 2020 in her late 80s, but not without leaving something very valuable behind.

Madam Wee's legacy work taught many staff and patients about a mother's unconditional love. She was able to be a part of her children's life despite her illness, continuing to celebrate their birthdays whenever her recipes are recreated in the kitchen she left behind.

Starting legacy work

Legacy works help patients to reflect and initiate a review of their life experiences and document it as a tangible item so that their stories can be passed on to the future generations.

Some questions that can be asked are:

- What activities are meaningful to them to create a tangible memory?
- What are some tips or life experiences that they would like to share with others?
- What would they want their family to remember them for?
- What would they like to leave behind for their loved ones?



Get started on end-of-life care planning with SHC resources!

Conversation Cards

It's important to know your values, motivations, beliefs and life goals, and identify people in your life that could act as spokespersons in times of critical need. There are 30 questions classified in three levels of complexity. Here are some examples you can try with your loved ones!

1. Easy

- What is one life lesson I have learnt from my grandparents?
- What is the most memorable event that has happened in my life?

2. Intermediate

- Who and/or what encourages or inspires me most?
- When am I most comfortable being myself?

3. Advanced

- What do I think about death and dying?
- Who can speak for me if I'm admitted to hospital?



Time Of My Life: Past Perfect, The Journal of Self-Discovery

The first step in creating a legacy and the beginning of important conversations with your loved ones is by sharing your own story, desires and experiences. There are 10 chapters to explore! Here are some questions from the "Favourites" chapter, so you can better care for your loved ones when they are terminally ill.

1. What is your favourite: colour, country, TV show, radio station, animal, celebrity?
2. What are your favourite childhood food or snacks?
3. Where can you find your favourite dishes now?
4. What are your hobbies and favourite activities?
5. What is your memorable moment during your favourite public holiday?



Palliative Care Communicator (PCC) online training course

To get physical copies of these resources in English and Mandarin, which are part of SHC's Community Engagement Kit, sign up for SHC's Palliative Care Communicator (PCC) online training course today!

Course Objectives:

- At the end of the two-hour free course, participants will:
- Gain knowledge to start conversations with their service recipients on palliative care and end-of-life care
 - Develop skills in using the Community Engagement Kit and to help the service recipients reflect on life and end-of-life matters

Mode of Course Delivery:

The course can be conducted in English or Mandarin. It will be delivered through lecture, structured group discussions, case studies and interactive role-plays.

Who Should Attend:

Social workers, psychologists, counsellors, allied health professionals, education and social service practitioners, volunteers and general public. We invite social service agencies to organise the training course for their staff and volunteers, and members of the public to form a group of minimum three participants.

Course Requirement:

Each participant is required to use the Community Engagement Kit to have conversations with at least two individuals and provide feedback of experience in a survey form.

SHC will send a trained professional to conduct the training.

Sign up via the online form at <https://singaporehospice.org.sg/training-courses/>.



Participants role play with conversation cards



SHC Silver Jubilee Charity Show

Saturday, 27 March 2021 | 7.30pm



Cheryl Yao
Host



Mr Mohamed
Abdullah
Alhabshee &
First Fusion Band
Performing Band



Joanna Dong
Singer



Rahimah Rahim
Performing Artist



Nick Shen
Performing Artist



Dr Alex Su
and more talents!

Singapore Hospice Council (SHC) celebrates 25 years of positive transformational journey in the hospice and palliative care movement in Singapore.

Support SHC to make a difference. We invite you to join us for an evening of delightful virtual entertainment with a specially arranged dinner from Shangri-La Hotel which will be delivered to your doorstep with every donation of \$500 and above.

For enquiries, please call 6538 2231 or email rsvpshc@singaporehospice.org.sg

For more details of the programme and to download the response form, please visit <https://singaporehospice.org.sg/events/charity-show-25>



Please complete the response form and email to rsvpshc@singaporehospice.org.sg.

SHC welcomes Ren Ci Hospital as our 25th member



Ren Ci Hospital is a charity healthcare institution founded in 1994 with the primary mission of providing affordable medical, nursing and rehabilitative care services for the community, based on the principles of loving kindness and compassion, regardless of race, religion and background. Over the years, Ren Ci has played an active role in the lives of a growing silver population in Singapore through expanding its spectrum of services to support the healthcare needs of the senior community. Partnering the community remains pivotal to the sustainability of our care delivery, providing those we serve with the hope for quality and meaningful living.

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Upcoming Events

MARCH - MAY 2021

SHC "Live Well. Leave Well.":

All You Need To Know About Palliative Care Talk

Join us for an informative session to understand palliative care and end-of-life matters. The session also aims to increase awareness of the attitude towards death and its impact on the willingness to converse with family or loved ones. It also aims to provide the participants with the suite of Community Resources available for palliative care in Singapore.

Time: 2.00pm - 3.30pm

Venue: Online via Zoom

Contact: contact@singaporehospice.org.sg

Registration*: <https://tinyurl.com/shctalks21eng>

*Please indicate your interest in the link and we will contact you via email.

23 MARCH 2021

SDSPCC-SHC Palliative Care MDF* -

Patient-Centred Outcomes That Matter

Speaker: Professor of Palliative Care Fliss Murtagh, Hull York Medical School, UK

Time: 12:00pm - 1:00pm

Venue: Zoom Webinar

Registration: <https://bit.ly/3cOTxoz>

*SingHealth Duke-NUS Supportive and Palliative Care Centre - Singapore Hospice Council Palliative Care Multidisciplinary Forum

20-28 MARCH 2021

Singapore Cancer Society -

TalkMed Relay For Life 2021

This event offers everyone a chance to celebrate cancer survivors and caregivers' triumphs against the disease, remember loved ones lost to cancer and fight back against the disease. Participants can fundraise for the cancer community by running / walking / cycling / swimming or come up with their own fundraising challenge to show cancer patients that they are not alone in the fight against cancer.

Venue: Anywhere (Virtual Event)

Admission: Free

Registration: <https://scsrelayforlife.sg/> (Registration closes on 19 March 2021)

1 APRIL 2021 - 31 MAY 2021

SHC @ Ang Mo Kio Public Library

Explore and learn more about palliative care and end-of-life care planning through stories and printed resources!

Venue: Level 1, 4300 Ang Mo Kio Avenue 6, S(569842)

In view of the COVID-19 situation, please check our website www.singaporehospice.org.sg for updates.



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