

THE HOSPICE

LINK

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**6 key things to do in
end-of-life planning**

Beyond the end

**LEAVING WITH
PEACE OF MIND**



SINGAPORE
HOSPICE
COUNCIL

PLUS
Tips for
caregivers

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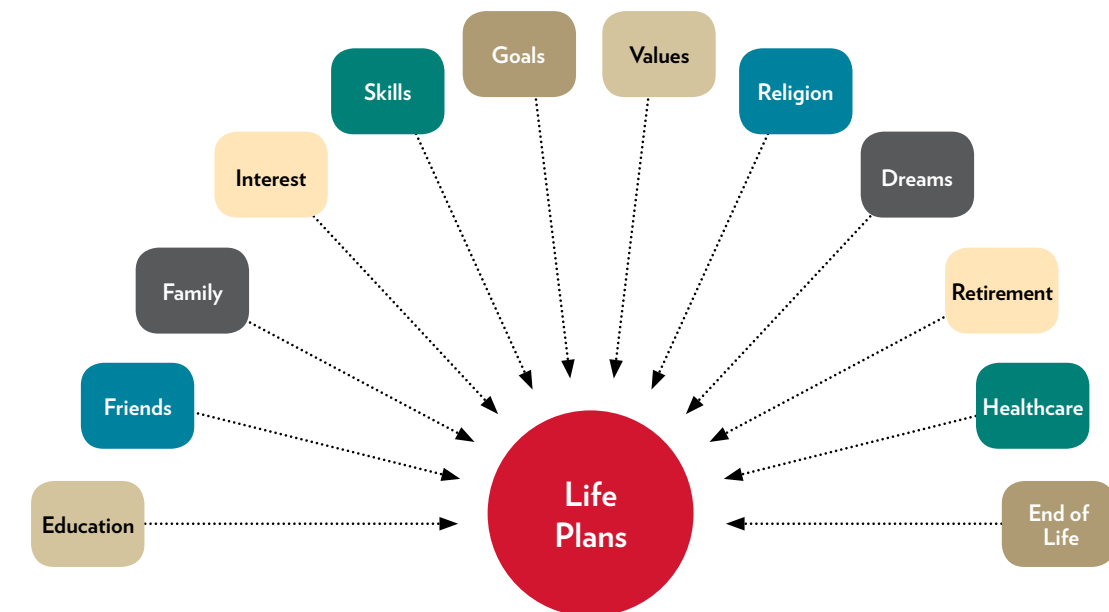
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A perfect planner for your life



We have always been busy making life plans, from how much we wish to earn to the type of house we wish to live in and eventually, to retire comfortably. Looking back, many of us will smile at our achievements and agree that we are our life's great planners.

The irony is, how many of us actually plan for our end-of-life care and to lower the stress of our loved ones in the final sprint? At the back of our minds, most of us may have at least a vague idea of wanting a good last chapter in life but may fumble to pen or define what is deemed a "well-planned" one.

Indeed, it may not be an easy task to think about our own end-of-life (EOL) plans and decide what we want. Some may even shun broaching the topic, leaving their family members to guess and make assumptions about their wishes when that time comes.

As Abraham Lincoln said, "In the end, it's not the years in your life that count. It's the life in your years."

Therefore, only your desired plan for EOL care can bring you the peace of mind knowing your wishes will be honoured. Your six key EOL plans should aim at "Live Well. Leave Well." which is Singapore Hospice Council's campaign slogan and at least include the following:



Ms Evelyn Leong
Chief Executive
Singapore Hospice Council

6 important things to remember when doing end-of-life planning

Assisi Hospice's Psychosocial Support Services team, which assists patients in their end-of-life planning, shares the important things that you should not forget, and the experiences of their patients.

Every individual's life story is unique. Death is part of our life story, and we can choose how we want to write it on our pages by doing end-of-life planning. It is important to plan ahead so that you can put your mind at ease.

1

DO ADVANCE CARE PLANNING

Advance Care Planning (ACP) allows a person to make his or her wishes and care preferences known before being faced with a medical crisis. Discussing these issues with the people around you will help them understand your goals, values and beliefs, and help to ensure that your wishes are respected should you lose the capacity to make your own decisions. Without these conversations, it is not uncommon for distressed family members to have disagreements, for example, about whether to keep you alive using any means possible or focus on your quality of life. This does not need to be a one-time conversation. Attitudes, feelings and preferences may change over time, depending on your circumstances, and if they do, let your loved ones know. Keep a copy of your ACP and make copies for your loved ones/ medical professionals.

The Family Meeting

Mr X called for a family meeting and spoke to his children about his wishes and preferences. Knowing his condition, he did not want to undergo dialysis even though it might help him



Ms Peh Cheng Wan (right), Head of Psychosocial Support Services interacting with a patient

feel better. His son was very upset with his decision, but he wanted him to know that this is a choice he made.

Changing View on CPR

Mr R's opinion on cardiopulmonary resuscitation (CPR) changed after his heart attack. He had earlier expressed that he did not wish to go through CPR but eventually did after the heart attack. Although he was in ICU for 10 days and was in great pain, he was happy to be alive and be with his family once again.

2

CHOOSE YOUR SPOKESPERSON

It is important to identify your preferred healthcare proxy — the person who will make decisions for you in the event you are not able to do so. The person should best understand and support your wishes. This person may not necessarily be the one you feel closest to but is someone whom you trust and is willing and capable of making decisions on your behalf when you are not able to.

3

SETTLE ANY UNFINISHED BUSINESS OR REGRETS

This may include reconciling with family and friends, settling personal issues which you have yet to resolve, and bidding farewell and thanking those who matter to you.

Creating Beautiful Moments

Mr S said he was not an involved husband as he was away from home most of the time due to his work commitments. When he knew his time was limited, he wanted to spend time with his beloved wife to make up for the time lost. He wanted to create happy moments with her. The couple spent time together visiting places and capturing beautiful pictures.



4

PLAN YOUR FINANCES

Create a Power of Attorney (POA) with the help of a lawyer to appoint another person to act on your behalf upon your death or incapacity. Organise your assets, estate, insurance, debts and bank accounts, and make a will regarding distribution of assets. If you have children, the guardianship of your children should be included.

5

LEAVE A LEGACY

You can prepare notes, letters, gifts and keepsakes in a memory box for loved ones. You may also request for gifts to be delivered on your behalf on special occasions.

Celebrating Milestones

Mr X sought assistance from Assisi Hospice's care team to leave notes for his son. We helped Mr X write handmade cards, sealed them and passed them to his family. Mr X wanted his son to open them during the important milestones of his life — 21st birthday, graduation ceremony and wedding — when he would no longer be around.

6

MAKE PRE- AND POST-DEATH ARRANGEMENTS

Let your family know how you envisage your funeral to be. You can personalise your funeral in a way that meets your spiritual and cultural preferences. For example, you may choose the poems to be read or music to be played. Make known your preference on cremation or burial, placement of ashes and memorial service.

Celebration with free-flow beer

Mr Z loved partying and usually spent weekends with friends. He told his wife that he did not want a solemn funeral but a celebration. He instructed his wife to have a beer fridge and to have free flow of beer for his friends who attend his wake.



Leaving with no regrets

Dover Park Hospice's Resident Physician Dr Hoh Sek Yew talks about the importance of preparing for end-of-life and choosing home hospice care.

When should planning and preparation for end-of-life begin?

When diagnosed with a life-limiting or terminal illness, patients and their loved ones tend to struggle emotionally, as they try to cope with the bad news. They may be shocked or numbed by the news — questioning whether the diagnosis is true, asking themselves whether the illness can be cured, or its course can be delayed. They may worry, or feel very sad and lonely. They may also feel angry, thinking that if they do things differently, maybe the future will turn out better.

Planning and preparation for end-of-life may only begin when the patient or his/her loved ones acknowledge that, at the very least, death is a possibility. If they feel overwhelmed, they can seek professional help from the primary healthcare team attending to the patient, and referral may be made to the palliative care team in the hospitals or the different hospices in the community.

There will always be uncertainty ahead, despite proper planning and preparation, but it is always good to start conversations on end-of-life early.

How can one plan and prepare for end-of-life?

In planning and preparing for end-of-life, it is important to take a proactive rather than reactive approach.

While death is a topic shunned by most people, it is crucial that we start conversations early through Advance Care Planning (ACP). This includes patients being open and honest with their family on their care preferences and sharing their thoughts on important life topics such as death and personal beliefs. ACP allows you to communicate or document your values and wishes regarding your future medical care. In addition, one should plan for financial and legal matters and consider drawing up a will and a Lasting Power of Attorney.

Palliative care can be provided in patients' homes, in a daycare facility or inpatient palliative care services. Day hospice care offers a supportive environment for patients who require care in the day. Recreational activities and therapy-based programmes are organised to encourage social engagement and enhance quality of life. It also provides caregivers with respite.

For inpatient hospice care, patients with life-limiting illness receive specialised palliative care in a hospice facility.

What is hospice home care?

Hospice home care refers to the care and support provided to patients with life-limiting illnesses and generally with estimated prognoses of 12 months or less, in the comfort of their own homes. It comprises a multidisciplinary team of doctors, nurses, medical social workers and volunteers, working closely together to care for the physical, psychosocial and spiritual needs of the patients with advanced illnesses, in an environment that they are familiar with. Most hospice home care services provide 24-hour on-call service.

What are the key areas to consider in planning for end-of-life care at home?

Families should take time to weigh the options available for palliative care and make a choice that will not only benefit the patients but also for the family, taking into considerations the patients' symptoms and level of care required.



Dr Hoh Sek Yew, Resident Physician (Home Care) at Dover Park Hospice

Check if there is a caregiver available to attend to the patient's needs round the clock. Although most hospice home care providers offer a 24-hour on-call service, the healthcare team is not physically around all the time. Having a caregiver at home is essential for a patient who requires assistance with activities of daily living, such as eating, dressing, showering and walking.

Depending on the caregiver's abilities, further training could be required, in order to ensure that patients are being well taken care of at home. The home care team can also provide tips and advice on caregiving. Caregiver training courses are also available at the Agency for Integrated Care.

Prior to receiving hospice home care and if the patient is in hospital, it is important to discuss with the attending healthcare team on any need for special medical or assistive equipment (for example, a hospital bed with a pressure-relief

mattress, an oxygen concentrator, a commode, a walking aid and/or a wheelchair) so that necessary arrangements can be made.

How can one apply for hospice home care?

To apply for hospice home care in Singapore, one should get a referral from a hospital or polyclinic doctor, or a general practitioner/family physician who can apply through the Agency for Integrated Care. A doctor must certify that the patient is suffering from an advanced and progressive illness, such as an advanced and incurable cancer, end-stage heart, kidney or liver failure, a severe chronic lung disease or advanced dementia or a degenerative nerve disease, in order for application and admission to be considered.


How much does home hospice cost? Are subsidies available?

Most palliative home care services do not charge for visits but there

might be charges for some non-subsidised items. There are also a few specialised home care programmes which requires co-payment.

Government subsidies are available for hospice home care through means-testing based on household monthly income to determine the level of subsidy.

What happens when a patient can no longer be cared for at home?

In situations where a patient's condition and care needs can no longer be supported by family members at home, because the symptoms become difficult to control or the caregivers are exhausted, then institutional care may be required. This is when the hospice home care team can help to arrange for the patient to be transferred to a hospital, an inpatient hospice or a nursing home, depending on the needs of the patient. 

“

There will always be uncertainty ahead, despite proper planning and preparation, but it is always good to start conversations on end-of-life early.”

Talking about leaving

A Khoo Teck Puat Hospital volunteer's experience with planning and advocating end-of-life matters sheds light on work that still needs to be done.

Mr. Chui Peng Sang has been an advocate for Advance Care Planning (ACP) since 2015. Before his current stint as an ACP volunteer for Khoo Teck Puat Hospital (KTPH), Mr. Chui had worked with elderly individuals throughout his career in the social service industry. He was first introduced to ACP while working as a case manager with Thye Hua Kwan, where he managed elderly individuals in the community. During their consultation sessions with him, he would also introduce ACP to them. "In the past, only the hospitals or institutions would conduct ACP sessions with the elderly," explained the 55-year-old.

Eventually, the ACP scheme was expanded to target the larger population of elderly living in the community due to the need to educate them on end-of-life (EOL) matters as well. Hence, it was individuals such as Mr. Chui who have worked at raising awareness about ACP to the elderly outside of hospitals and institutions during its early stages of implementation. Despite having a chronic medical condition, it was the knowledge and experience that Mr Chui had gained while working with the elderly population as well as previously being an ACP facilitator that made him want to continue contributing to ACP in any way possible. He became an ACP volunteer with KTPH.

The lack of awareness about Advance Care Planning among the general public remains a challenge.



CHALLENGES AND BARRIERS TO ACCEPTANCE

Mr. Chui volunteers every Monday for two hours, starting from 10 am. Each time, he sets up and prepares the booth for the throng of visitors who traverse the hospital walkway. Armed with several ACP brochures, he offers them to passing members of the public. If there are any interested individuals, he introduces them to ACP and clarifies any doubts that they may have. Once they decide to do an ACP, Mr. Chui then records their particulars so that the ACP facilitators can arrange an appointment with them. However, while volunteering, Mr. Chui shares that the lack of awareness about ACP among the general public remains a challenge in getting people to decide to take it up. Without having prior knowledge of ACP, many remain unaware of its existence in the first place and hence do not bother to find out more.

WORDS AND PHOTOS JOY KANG YUE

Besides the generally low level of awareness among Singaporeans, he also noted the existing cultural barrier and sensitive nature of speaking about EOL matters. "The sensitive subject of death has to be treaded carefully during the discussion. Most of those who are older, like those in the Pioneer Generation, are sensitive to these things. You can sense that they're reluctant to talk about it and can even become quite upset (when you try to discuss with them)," he recalled. Though it is usually the seniors who shy away from the taboo topic of death, he shares that it is sometimes the latter's adult children who refuse to discuss such subject matters and prevent their elderly parents from taking up ACP. Therefore, several complex factors hinder peoples' acceptance and attitudes towards ACP.

BENEFITS OF DOING ACP


Mr. Chui has always been receptive to the idea of discussing EOL matters and broaching the supposedly taboo subject of death. "Death is the only certainty in life. The doctor cannot promise you anything, but the certainty is that death will come one day," he said. With this mindset, he hopes to bring up the sensitive subject carefully to those who are not so aware of ACP by encouraging them to think about EOL in a deeper sense.

Furthermore, he also shared about the benefits of ACP, which he believes in and similarly hopes for more people to know. These benefits include allowing doctors to know your preferred medical treatment during an emergency, as well as relieving the

burdens of your loved ones when faced with the challenge of making important medical decisions on your behalf. While he acknowledges that some may find it difficult to discuss and share their preferences and beliefs before death, he maintains that if one can overcome this barrier, it will greatly reduce the burdens that their loved ones may have to undergo during a crisis.

"I think it still boils down to the fact that you don't want to put your loved ones in that difficult situation," he said. "So, explaining or making known earlier how you would like things to be managed would allow your loved ones to be more able to manage things in a more controlled manner."

NEED FOR MORE AWARENESS

While ACP has gained some traction since its introduction to Singapore in 2009, Mr. Chui hopes that the mindset and level of acceptance will increase in the years to come. He suggests that there be increased publicity effort and more initiatives to bring the matter closer to the community, through platforms such as community events to create awareness about ACP and its benefits. "I would hope for more participation by the elderly, but then again it's also a personal choice that cannot be forced upon the individual," he said. Ultimately, Mr. Chui believes that first spreading more awareness and explaining ACP's rationale is crucial in conveying the message across to the public. 

Opposite page: Mr. Chui, an ACP volunteer with KTPH; Below: ACP brochures available at the pushcart stationed in the KTPH Lobby





Beyond the end

In the case that hospice home care is the only option when the prognosis fails, a caregiver shares about finding comfort in the support and care.

When my husband came home in May 2019, he had outlived his prognosis. About six weeks before, we were told that he might not survive his perforated intestine since he had opted not to have surgery.

After about a month's stay in the palliative care ward of a community hospital, the doctors told us that we had to move on. My husband was adamant that he did not want to come home because he would be a burden to me.

I started searching for a nursing home in earnest, which, due to the subsidy issue, was fraught and ultimately unsuccessful. We never thought that staying at a nursing home could cost so much. My feeling of helplessness increased as the search progressed.

Although the hospital doctors were kind to extend more time to me to find a suitable placement, yet after every search, I felt more desperate. The situation seemed so grim. The overstay pressure made me decide that he should

come home first and we would continue the search. So I made swift arrangements to get one room ready for his homecoming.

The journey home on the day of discharge was a hair-raising one: he was sick in the car because he had not been up-and-about for almost six weeks. By and large, he was disorientated and unwell.

All of a sudden, we felt as if we had been abandoned — by the doctors, the nurses, the world. The feeling was one of despair and fear. We missed the round-the-clock consultation and help. We missed the care and comfort. We missed the sense of security and safety above all.

Now I have to be the nurse, the cook, the doctor, the psychiatrist, the pharmacist, the cleaner. I felt like giving up.

It was especially scary and frightening at night. The fear was inexplicable. What if he suddenly becomes unconscious? What if his temperature goes up? What if his pain increases? There seemed to be a thousand what ifs and no answers. The first few weeks at home was a struggle.

My husband has been home for four months now. We have settled into a routine. The Metta Hospice Care doctor and nurse are always available for consultation. The helper and I have settled on our roles in caring for him. Modifications to the room and other arrangements were made to cater to his comfort. The support of family, friends and the church is invaluable in getting us through each day.


My husband agrees that his current feeling is a far cry from how he had felt when he first came home. He shares that he was terrified of the uncertainty of coming home. The lack of in-depth information on how hospice home care works added to the fear and isolation. We did miss the daily visits by doctors while we were at the hospital and the palliative care ward. The feeling of being abandoned was felt the most by both of us.

The support of family, friends and the church is invaluable in getting us through each day. We are thankful for the support of the palliative care doctor, nurse and social worker who journey with us.

Despite the fact that one has decided on one's Advanced Care Planning (ACP), one is never fully prepared when confronted with death. But with ACP, it provides a kind of guide for the care options that the patient wishes. However, in reality, it is always a struggle for the loved ones when critical decisions have to be made.

The challenge now is in the day-to-day care decisions and issues to be faced. For example: his inability to sleep; constipation; pain; nausea; giddiness; lack of physical activities; the feeds.

Emotional issues like the meaning of life, boredom and helplessness are also felt at times. Unlike the desperate feelings we had when we first came home, we are thankful for the support of the palliative care doctor, nurse and social worker who journey with us.

The questions remains: my husband has outlived his prognosis, so what's next? 

Right: Madam Lok and her husband Mr Cheng Wei Hsien have settled into days of routine after adjustment to home hospice care



“Live Well. Leave Well.” – Voices of My HeART

It is more important than ever to start conversations on planning for end-of-life care, even at a young age.

In celebration of World Hospice and Palliative Care Day, Singapore Hospice Council (SHC) spent the afternoon of 5 October 2019 at *SCAPE in Orchard Link to raise awareness among young adults about palliative care and caregiving support resources through creative arts. Close to 700 visitors attended the event and were greeted by live song and dance performances at the Bandstand. There were also informative and interactive booths put up by SHC's member organisations. For the first time, SHC collaborated with non-member

partners outside the palliative care sector at a public outreach. These were new start-ups such as Mind Palace, which specialises in virtual reality experiences, and an avid photographer displaying his photo-documentary works — just to name a couple.

Continuing our efforts to raise awareness about palliative care through the community's rich repository of stories, the final edition of the three-part Life Book series titled *Dr. Guardian Angel* was launched at the event. The story centres around 20-year-old teenage gamer Zach's battle with cancer, with the constant support from his

palliative care doctor, Jane. This book is now available in four languages for the public to download from <https://singaporehospice.org.sg/lifebook/>

Talking about and planning for end-of-life matters can be challenging and is something that is rarely discussed, especially among the young. Many are often unsure of where to start or are hesitant to bring up the topic with their loved ones. Through this event, SHC hopes to increase palliative care awareness and encourage young adults to engage their parents and elderly grandparents in Advance Care Planning. Death is inevitable; when we go is not up to us, but how we go is. 🙏



Clockwise from top left:
Emcee Sebastian Tan,
MADDspace, Buddhist
Compassion Relief Tzu Chi
Foundation (Singapore),
Urban Terrain Groovers,
Dover Park Hospice GEMS
Showchoir, YOKEZ (叶玉棧)

WORDS AND PHOTOS SINGAPORE HOSPICE COUNCIL



#shcvoh #livewellleavewell #singaporehospice #palliativecare #hospicecare

Rethinking the quality of palliative care

A strong turnout of healthcare professionals for the annual National Palliative Care Quality Improvement Conference showed the commitment to better meet the needs of Singaporeans.



National Palliative Care Quality Improvement Conference 2019

The National Palliative Care Quality Improvement Conference 2019 organised by the Singapore Hospice Council (SHC) Quality Improvement (QI) Steering Committee on 22 and 23 August 2019 at Furama RiverFront Hotel, Singapore saw an attendance of almost 200 healthcare professionals from 26 institutions.

Themed “Rethinking Quality Improvement”, the conference featured presentations across four tracks: rethinking quality indicators, rethinking patient safety, rethinking approaches to problem-solving, and rethinking professionals’ place in the

healthcare system. The participants benefited from the Q&A sessions and panel discussions that filled all the tracks.

In his opening speech, the Guest-of-Honour, Mr. Titus Lee who is Director of Aged Care Services at the Ageing Planning Office of the Ministry of Health (MOH), said that the Ministry has been increasing the accessibility of palliative care services across the various settings in the past few years, with a particular focus on home and day hospice care in order to better meet the needs of Singaporeans and caregivers, and also to shift care beyond the

hospital to the community. Mr. Lee assured the audience that Singapore is on track to having 6,000 home palliative care places a year by 2020.

Mr. Lee also shared that MOH is increasing the affordability of palliative care services by upping subsidies and MediSave withdrawal limits, for example. Beyond accessibility and affordability, there is also a critical need to enhance the quality of palliative care in Singapore.

One of the speakers was University of Technology Sydney Professor of Palliative Medicine David Currow who shared Australia’s best practices on improving healthcare at the national level, such as using national metrics to measure quality of care. Prior to the conference, Prof Currow had made site visits to Assisi Hospice and Tan Tock Seng Hospital, and facilitated discussion sessions on the use of symptom assessment scales.

The QI Conference brought together international and Singapore experts in an effort to regroup and chart the way forward for quality improvement in palliative care. There were ample opportunities to share ideas and learn from each other in order to promote best practices. Many participants felt that the Conference had enhanced their knowledge and understanding of quality improvement. We hope the new insights will spur participants to make sustainable changes in palliative care providers and institutions for the benefit of our patients.

Recognising the importance of leadership in driving a sustainable push for quality palliative care and patient safety, a session was conducted

The QI Conference brought together international and Singapore experts in an effort to regroup and chart the way forward for quality improvement in palliative care.

on the second day of the conference to discuss challenges and strategies for building QI capability and nurturing a culture for quality improvement in the leaders.

The Conference ended on a positive note with SHC Chairperson Dr. Angel Lee inspiring us to continue our efforts to improve the care for our patients. SHC will continue to organise forums and workshops to serve as platforms for shared learning, and we hope to have the continued support and participation from all in our palliative care community. 



From left to right:
Dr. Lo Tong Jen,
Ms. Evelyn Leong,
Adjunct Associate
Professor Tan Hui
Ling, Dr. Angel Lee,
Mr. Titus Lee,
Professor David
Currow, Dr. Grace
Yang, Ms. Sylvia Lee,
Ms. Chee Wai Yee,
Dr. Yee Choon Meng,
Dr. Patricia Neo and
Dr. Laurence Tan

WORDS: DR LO TONG JEN, CHAIRPERSON OF NATIONAL PALLIATIVE CARE QUALITY IMPROVEMENT CONFERENCE COMMITTEE; NUR RAIHAN, PROJECT EXECUTIVE FOR NATIONAL PALLIATIVE CARE QUALITY IMPROVEMENT PROGRAMME. PHOTOS: SHC

Concerning the end of life

Death is an inevitable part of life and with appropriate support and preparation, dying well is accessible to all. HCA Hospice Care Nurse Educator Amy Lim shares some of the common concerns patients and their families often have and how planning well can bring immeasurable comfort at the end of life.



What happens on the first visit to a patient's home after referral to HCA Hospice Care?

Depending on the urgency and well-being of the patient and caregiver, the first home visit may be on the same day or as soon as possible — usually within 48 hours after the referral has been accepted.

We hope to establish trust and confidence, forming a very professional therapeutic relationship on the first visit. The first home visit is very much about gathering valuable and relevant insights into the patient and his/her family. Having a good understanding of what matters most to the patient and family is fundamental and necessary.

Over the next visits, several assessments — medical, nursing, psychosocial and spiritual — will be done to determine the level of care required. In addition, a care plan will be discussed and established with the patient and family.

What are some common concerns patients and their loved ones might have?

They are often worried and anxious about the physical and emotional suffering that may occur at the end of life. Patients are fretful about losing their dignity and becoming a burden to their loved ones.

This sense of burden alone can drive many patients to despair with a deep desire to hasten death, so as to free their loved ones from fatigue and misery. Financial challenges are often high on the list of concerns as well.

Right: It takes the combined efforts of HCA's multidisciplinary team to ensure patients and their loved ones are supported on the end-of-life journey; opposite page: HCA Assistant Nurse Manager Tan Joo Eng examines a patient during a home visit. The HCA team establishes rapport with patients and their loved ones and walks them through their preferred care options

How do you address these concerns?

These issues are not easy to address. It takes the concerted efforts of the entire multidisciplinary team and collective experience and wisdom to heal such pain and concerns. The hallmark of palliative care is to be sensitive and respectful.

How do you help patients and their loved ones plan for end-of-life?

The most important and valuable information to gather is what matters most to the patient at this time. It is the end of their life journey — we listen to them attentively on what finishing well means to them.

Professionally, we prepare them for the likely possible symptoms that they may experience and the options that are available to manage them. We encourage them to share their preferred plan of care with us. We walk them through the care options that are available so that they can make informed choices. It brings immeasurable comfort and healing benefits when patients and their loved ones are assured of vigilant support, available to them round the clock.

Could you share a case you've encountered and how preparing ahead helped the patient and his/her family?

I had a 38-year-old female patient who was referred to HCA with a prognosis of three to six months. It was difficult to discuss end-of-life matters with her and her husband initially, even though her oncologist had told her that all treatment options had been exhausted and that she had a short prognosis.



Her husband was her caregiver and he, too, believed that she would do well, given her positive attitude.

Being attentive, sensitive and respectful were the keys to success for the team. We listened to their hopes and dreams. We provided our strong support, but we also seized whatever opportunity that came our way to prepare them for the eventuality of death. It was not so easy to convince her husband of the need to be prepared for the worst, as he held on to hope for the best.

Death came quite quickly for her, sooner than we expected — but we attended to all her

wishes; nothing was ignored. Her last days were exactly how she hoped for. Her husband, though distraught, was able to cope with the grief resiliently.

I would like to believe that the end is not as important as compared to the kind of journey we have made with patients and their loved ones. The richness of compassion, the quality of respect, the undivided attention and the light that we shower during the journey is enough for the patient, and enough also to heal those who are left behind, including us. 🙏

We provided our strong support, but we also seized whatever opportunity that came our way to prepare them for the eventuality of death.

A warm farewell with heart

The pastoral care staff of St Joseph's Home put loving thought into giving residents a final send-off with the Peace Room and the memorial table.

When you're working in a hospice, the topic of death is not too far away. Memorial services and funerals are part and parcel of life. We naturally pay attention to giving residents a good death — preferably without pain and with family. What is as important but often overlooked is that a good death of a loved one is just as important to the living.

Being able to freely discuss the topic of death brings that topic to the forefront. It normalises death as a natural season in life. In

witnessing and talking about death of others, we can start to prepare for our own death.

Here at St Joseph's Home, the Peace Room and memorial table are important places for opening up conversations about death. The Peace Room is the resident's final resting place. It is positioned at the front door and where residents wait for the undertaker to arrive. The memorial table sits outside the bedrooms of residents who have passed away. It is a place for staff, volunteers and fellow residents to spend a moment of silence in respect of the resident.

As a pastoral care staff, I visit these two places often. I have seen how the death of loved ones can affect the living. My work has taught me valuable lessons in preparing for one's death.

THE HOME IS WHAT HOUSES THE HEART

Our executive director, Sr Geraldine Tan, once said: "It is easy to house a person, but not easy to house a heart."

The heart of a grieving family and friend is even more difficult to hold. It is what challenges me in my job, and also what I consider

The heart of a grieving family and friend is even more difficult to hold. It is...what I consider sacred about my job.

sacred about my job. If anything, I have found that being able to see the resident rest peacefully brings comfort to those who are living and witnessing that moment. This is where the Peace Room comes in.

The Peace Room is where residents, wheeled down in their own beds, wait for the undertaker to arrive. This room is positioned at the front door — not tucked away at the backyard of the Home. It sends the message that residents deserve the same dignity and respect when they come, when they leave and in the days between. Having it at the front door, in clear view, makes it easier to open up conversations about death with the residents.

In the Peace Room, there are also plush turquoise sofas, flower vases and lavender candles. The room is intentionally decorated like a home to bring warmth and comfort. Even though the resident has already passed away, the ambience of the Peace Room is important to the family and friends who are visiting. When we usher loved ones into the room, we see that they are comforted knowing

Opposite page, right:
The setting up of the Peace Room and memorial table allows for the warm send-off of a departed resident



that the resident has passed away peacefully. Because of that, we encourage residents to think about what their resting place would be.

THE PEOPLE AROUND YOU MATTER MOST

Aside from visiting the resident and their loved ones in the Peace Room, the pastoral team also sets up a memorial table. There, staff, volunteers and fellow residents gather for a moment of silence. There is a guestbook available for anyone to pen their thoughts. There are also words of prayers and well-wishes available for both Catholics and non-Catholics to read aloud.


It is a sacred space that respects the relationships that the residents had with those around them. We have seen staff who has taken care of a particular resident for more than a decade stop for a moment alone. They stay at the memorial table, internally acknowledging the memories shared with that resident.

I realise that your date of birth or your date of death is not as important as the dates in between. The people that you form

relationships with are the ones who matter the most.

WORDS SPOKEN IMPERFECTLY ARE BETTER THAN THOUGHTS LEFT UNHEARD

As pastoral care staff, we are called upon when residents are in their final hours and we have the privilege of accompanying them. We would sit with them, sometimes offering an assuring word or a comforting touch. When family or friends visit, we encourage them to speak aloud any words that they have in their hearts. It could be to express their gratitude or to seek forgiveness. Even though residents are getting weaker, their hearing remains the last to leave.

In my 40 years as a pastoral care staff, I have seen residents let out their last breath after they have heard the voice of their beloved spouses. I have also journeyed with loved ones who dwell on the what ifs, after a loved one has passed on. In preparing for death, it is important to speak the final words of gratitude, forgiveness and humble apologies before it is too late. 



WORDS: ROSE LEE PHOTO: ST JOSEPH'S HOME

Staring death in the face everyday

Since 2017, Ms Chua Chiew Poh has been working as a full-time assistant chaplain with MWS, journeying with MWS Home Hospice patients through their final days. We find out more about how she helps patients plan and prepare for the end of their lives spiritually.

Death is no stranger to Methodist Welfare Services Assistant Chaplain Ms Chua Chiew Poh. Her current comfortable relationship with death began when she lost her husband to pancreatic cancer before the age of 40. Although she was thriving in the property finance industry then, she felt called into hospice work, and in 2010, she became a regular volunteer with MWS Home Hospice.

What happens in a typical visit to an MWS Home Hospice patient?

I listen. I let them talk about their lives and share their stories, with no judgment from me. When they cry, I am there to encourage them, and I sometimes cry with them.

I always listen carefully and intentionally to their stories, so I can point out the good in their lives, the blessings they have received, and remind them of the moments they spent with their loved ones.

Most of our patients either have a god, or know there is a god. I pray with them and encourage them to give thanks to God for their lives and for the blessings they received. Acknowledging their belief brings them comfort.

How does belief in a higher power help them on their deathbeds?

I ask every patient how they think God has helped them in their lives. A commonly told story is about their darkest moments, and how in those moments, they are always granted a miraculous strength that carries them through. Everything points to divine grace, and a reminder that we are all loved by a higher being.

Dying is a lonely journey which one must embark on alone. The process of dying also often opens up unhealed wounds, which makes it scarier.

I have seen patients who do not believe in a higher power or divine being, and there was so

much uncertainty in their final moments. I have come to realise that believing there is a god who created us and who loves us gives patients peace in their final moments. An awareness that they are not alone and that God is with them gives them strength and grace to bear it.

Do you have any advice for patients approaching their final stage of life?

This advice is for everyone: we need to live life planning for death. Regardless of where you are in life, you should draw up your will, do your Advance Care Planning, and make a decision regarding the Do-Not-Resuscitate order. Although we are aware that death happens to everyone, seeing people dying scares us and we often do not believe it will happen to us. I have learned that life is like a mist which can evaporate any time. If we are aware that everything in life, even life itself, is a gift from the divine, we will be more prepared for death.

“

I let them talk about their lives and share their stories, with no judgment from me. When they cry, I am there to encourage them, and I sometimes cry with them.”



At the final stage of their life, hospice patients may succumb to depression and grief. Being prepared, viewing life and death as something we all go through, and being thankful for every blessing we receive in our lives every day helps. We are all gifts to the people around us, and the impact we leave is long-lasting, even after we are gone.

Do you have a memorable story you would like to share?

I had an end-stage Christian patient who was in pain, depressed, and unwilling to engage or open up to us. After a few weeks, I received a call from the medical social worker, asking me to visit her to pray as she was near the end. As we prayed, the presence of God came and surrounded us. She then requested for a red shawl or dress to be placed in her coffin, so I went to shop for one. When she saw the bright red shawl

I bought her, she smiled. The week after, she called me to her bedside, and told me she loved me.

I believe God's love carried her through. She came in depressed but when she passed on, she was at peace, and her hair was glowing. She was not alone at her moment of passing because God was with her.

What are some challenges you face as a hospice chaplain?

I experience deep regret when I am not alerted when my patients pass on. I question if they had anyone accompanying them on their final journey, or whether they were lonely. I hope I spent sufficient quality time with them and that they got to experience God's love.

My goal is to recruit more volunteers so that everyone has someone to journey with them in their final moments. 🙏

Top: Assistant Chaplain Ms Chua Chiew Poh encourages patients to be thankful for their blessings and put their trust in a higher power

WORDS: NICOLE ANDREA TAN, EXECUTIVE, COMMUNICATIONS AND ENGAGEMENT
PHOTO: METHODIST WELFARE SERVICES

Planning well for the future of our loved ones

"Here is another CPF Board query..." I was passed a request for a medical report from the Central Provident Fund (CPF) Board.

Decisions made at the end of life can have a big impact, long after a person has passed away. This became very clear to us with a patient we previously had on our ward. Suffering from lung cancer which had spread to the brain, he had difficulty expressing himself with words and in writing. Previously divorced, he knew who he wanted to leave his assets to after he had passed away. That was his main preoccupation while he was with us: to ensure that the people he cared for would be adequately provided for with the assets he was leaving behind. With the help of a lawyer, he was able to make his wishes known and signed a will while on the ward. Despite his speech difficulties, we were able to assess his decision-making capacity on that same day and documented this in his case notes.

Some months after he passed on, we received news that his ex-wife was challenging the will he drew up while he was with us. We felt aggrieved with the turn of events. Thankfully, we had taken pains to document his preferences, concerns and reasons, and he was consistent in his decision making.

Section 3(2) of the Mental Capacity Act states: "A person must be assumed to have capacity unless it is established that he lacks capacity." If there is doubt of this due to illness, then a person may need to be assessed if they have decision-making capacity.

A two-stage test for mental capacity is provided in Section 4(1) of the Mental Capacity Act. Step 1: Is the person suffering from an impairment of, or disturbance in, the functioning of the mind or brain? Step 2: If yes to step 1, does the impairment or disturbance cause the person to be unable to make a decision when he needs to? For the patient, there was every reason for concern as he had a tumour in the brain, potentially affecting his decision-making capacity.

So, how do we assess this? We go "Under the Red WheelChair" when we need to assess someone's decision-making capacity. They have to be able to:

1. Understand the information given regarding the decision.

Examples:

"What are you doing?"

"Why are you doing this (e.g. the will)?"

2. Retain the information given.

It is sufficient if the person remembers the information for a short period of time as long as he can remember it long enough to understand it, weigh it up and communicate his decision.

3. Weigh up the information as part of the process of making the decision.

Examples:

"What happens if you...?"

"What happens if you do not...?"

"Is there another way to do this?"

4. Communicate the decision to others - this may be as simple as ensuring that hearing or visual aids are used.

In this way, we are able to allow each individual to make choices and still express their autonomy. When in doubt, we refer to a psychiatrist. For our patient, the discussion with him was through drawings and many sessions of patient "listening". He was able, through his limited mobility and difficult speech, to express what he wished consistently. This happened in tandem with trying to engage his family and working through family conflicts in order to ensure a good "closure" for him.

This situation served as a reminder of the role we play. We live in hope that the patient's wishes will be honoured.

Of course, we would much rather that the patient had not left it so late when it became so challenging. However, the sad fact remains, many people simply do not plan ahead when they are well, leaving matters to the very end when they are unwell. In a palliative care ward, failure to carry out such anticipatory planning is, unfortunately, rather common. It is par for the course for us to receive a letter from the CPF Board, months after a patient has passed away, to ask if the patient had the decision-making capacity to make such nominations just before they passed away. It is due diligence on the part of CPF Board, but it can be unnecessary stress for the family.

Dr Loi Jun Yi

Resident Physician, St. Andrew's Community Hospital



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• Sister Geraldine TAN, St Joseph's Hospice
• Ms Yee Pin TAN, National Cancer Centre Singapore
• Dr Huei Yaw WU, Tan Tock Seng Hospital
• Dr Alethea YEE, National Cancer Centre Singapore

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1 SEP'19	31 JAN'20	28 FEB'20	30 APR'20	8-9 JUL'20	10-11 JUL'20
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Upcoming Events

9 JAN 2020, THURS

SHC Multidisciplinary Palliative Care Forum: Enhancing Resiliency of Care Providers in the Face of Death, Dying and Suffering

Speaker: Professor Susan Gerbino and Dr Esther Chachkes

Time: 1:00pm - 2:00pm

Venue: Assisi Essery Hall

Contact: secretariat@

singaporehospice.org.sg / 6538 2231

15 - 16 FEB 2020, SAT-SUN

**Singapore Cancer Society
- TalkMed Relay For Life 2020**

Join as a team or individual to walk or run overnight around the track, to symbolise that no one fights cancer alone and that the fight against cancer never sleeps. Event highlights include live performances, workout sessions and carnival activities. This 15-hour overnight event celebrates cancer survivors and caregivers, and remembers lost ones to the disease.

Time: 6pm (15 Feb) - 9am (16 Feb)

Venue: National Stadium, Singapore Sports Hub

Registration:

<https://scsrelayforlife.sg/>
(closes on 24 Jan 2020)

Tips for Caregivers

DR JAMIE ZHOU

Consultant, Division of Supportive and Palliative Care, National Cancer Centre, Singapore

Some choose to hide the dire diagnosis from their loved ones so as to protect them from negative thoughts and emotions, but it also prevents them from preparing for death. You ask, "Is preparing for death more important than keeping our loved ones worry-free?"

Imagine this situation: You are getting weaker, going through various medical tests, procedures and hospitalisation with everyone telling you that "everything is ok". But the fact is, you don't feel ok. Even the doctors are speaking to your family, not you. By the time you know that something is seriously wrong, you have no strength or time to settle other matters and find closure in relationships.

While keeping information from the person usually stems from love, it can also take away the dignity and respect of a loved one's sense of control. Here are some tips on how to start speaking to a loved one about their illness.

#1: "Do you think your illness is serious?"

Most patients are aware of how serious an illness is based on how their body feels. If they are aware that it is serious, you can explore further about why they think so. Respond to the sharing by reassuring them about your unreserved support, "Whether it is serious or not, we will be there for you."

#2: Consider this: Who can they confide in if the 'subject matter is closed'?

Along with the secrecy of hiding the condition, the patient is often encouraged to be positive and "not think too much" since "everything is ok". However, this often leaves them feeling isolated with no outlet to express their worries and fears. In fact, getting increasingly weak without any condition to attribute it to may be more frightening than knowing the actual illness.

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