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LIVE WELL. LEAVE WELL.

DISCOVER, RESPECT, IGNITE

LEAVING A LEGACY OF HOPE



PLUS
Views from
the pros

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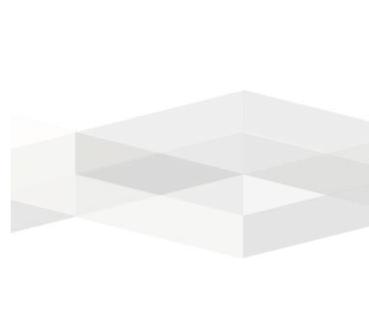
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# **Building a legacy**



and lasting memories for both the patients and their loved ones. We all enjoy doing something meaningful with our families and friends, be it going on an outing, taking family photos, giving memorabilia or writing letters. Sometimes, it can even be a way of creating space for reconciliation. These simple acts can mean a world to those who have limited time with their families.

We are thankful for the many angels in our midst from the palliative care medical teams.

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focuses on creating meaningful

We are thankful for the many angels in our midst, from the palliative care medical teams to the volunteers, venturing great lengths to help fulfil the wishes of patients. This work would not have been possible without their sheer determination and heart for the patients.

Legacy building can start right now for anyone. In June 2018, the Singapore Hospice Council launched our "Live Well. Leave Well" national campaign, with the aim of raising awareness and generating conversations on end-of-life matters. There are tools to help you along. One such tool is "Time of My Life – Past Perfect, a Journal of Self-Discovery", which can be downloaded from our website at www.singaporehospice.org.sg.

I wish the best for you even as you explore shared values together with your loved ones, and find a deeper meaning to building your legacies together.

Ms Yeo Tan Tan Chief Executive Singapore Hospice Council

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Legacy building is an important aspect of palliative care. It focuses on creating lasting memories for both the patients and their loved ones."

### Live well. Leave well.

Singapore Hospice Council launches a campaign to raise awareness of end-of-life issues and to encourage end-of-life conversations

hat do you say when a loved one is diagnosed with a terminal illness?

What are the important

What are the important topics to talk about when considering end-of-life care?

How do you approach the topic of end-of-life care with your loved ones?

According to a survey conducted in 2014, 82% of respondents agree that the general public needs to know more about hospice and palliative care, and 71% agree that there should be national conversations about death and dying.

But, almost half of the respondents have not started the conversations, for the simple reason that they do not know how to broach the topic.







The two-day event attracted over 1,800 participants and featured informative and interactive booths with different patient care settings. Other programme highlights included: talks on palliative care in four languages, tips on starting early conversations on end-of-life care, performances by various performing groups.

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EVENT REFLECTION

On 9 and 10 June 2018, the Singapore Hospice Council (SHC), with active participation by our member organisations and community partners, organised a Community Engagement Event at Bedok Town Square to encourage early end-of-life conversations.

The campaign, themed "Live Well. Leave Well.", was officially launched by Guest-of-Honour, Dr Amy Khor, Senior Minister of State, Ministry of the Environment & Water Resources and Ministry of Health, together with Mr Lee Yi Shyan, Member of Parliament, East Coast Group Representation Constituency.

The launch included a two-minute television commercial entitled "Because I love you" and a community engagement kit developed by SHC.

Through community partnerships and media engagement, SHC hopes to use the developed materials to generate public awareness and encourage Singaporeans to start conversations early regarding end-of-life care.



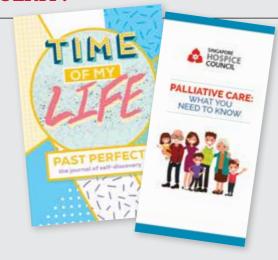


Top: Launch of the SHC Television Commercial – Because I love you. From left: Dr Angel Lee, Chairperson, SHC; SMS for Health Amy Khor; Mr Lee Yi Shyan, MP of East Coast GRC; Dr Patricia Neo, Vice-chairperson, SHC; & Ms Yeo Tan Tan, Chief Executive, SHC. Left: Launch of the SHC Community Engagement Kit. From left: Ms Yeo Tan Tan, Chief Executive, SHC; Dr Angel Lee, Chairperson, SHC; SMS for Health Amy Khor; Mr Lee Yi Shyan, MP of East Coast GRC; Dr Patricia Neo, Vice-chairperson, SHC.

### WHAT'S INSIDE THE COMMUNITY ENGAGEMENT TOOLKIT?

The Community Engagement kit is to equip community partners to help patients and caregivers to better understand what palliative care can offer and to provide tips on how to start early conversations about end-of-life matters.

- i. "Palliative care What You Need to Know" brochure by Singapore Hospice Council (in four languages)
- ii. "Planning for My Care" brochure by Agency for Integrated Care (in four languages).
- iii. Lasting Power of Attorney brochures by Office of the Public Guardian (in four languages).
- iv. "Time of My Life Past Perfect, the Journal of Self-Discovery" by Yang Xinyan Alexis, a reflection journal to help one reflect on their life experiences whilst discovering values that matter to them.
- v. Conversation Cards jointly created by Tan Tock Seng Hospital Advance Care Planning team and SHC.



The purpose of these cards is to help players discover what is important for them to live and leave well including their values, motivation, beliefs, life goals etc.

For more information on the "Live Well. Leave Well." campaign and the community engagement toolkit, visit the website: singaporehospice.org.sq.

WORDS SINGAPORE HOSPICE COUNCIL PHOTOS KOH SHU JUN' SINGAPORE HOSPICE COUNCIL

## Talking about death? No problem.

Megan Teo, an intern at the St. Andrew's Community Hospital's Medical Social Work Department, reflects on talking about death.

he community
engagement event,
"Live Well, Leave Well"
held on 9 and 10 June
2018 and organised by the Singapore
Hospice Council, left a lasting
impression on me. The event allowed
me to view death as a natural
process that all of us have to accept,
be it our own death or that of of our
loved ones.

Together with the Palliative Care
Teams from Changi General Hospital
and St. Andrew's Community
Hospital (SACH), SACH Medical Social
Workers and volunteers, we "set up
shop" in Bedok Town Square with
several other organisations.

Before the event, I had wondered: "Who would want to be at such an event? Who would want to talk about such a morbid topic?"

I was befuddled when the crowds came. At our booth alone, we counted 982 participants who were willing to engage in conversations about the end-of-life care. It dawned on me that it is indeed important to be able to express our feelings towards our loved ones.

Tallking to people, I found the phrase that struck me the most was, "I'm sorry". I can understand it when people feel the need to say "Thank you", "I love you" or "Good-bye". But, "Sorry"? Who would ever say that they are sorry?

I find it most challenging to say
"I'm sorry" to a loved one because it
is difficult to admit that I am wrong.
When I found that there were indeed
people who wished for the courage to

say "I'm sorry" to their loved ones, I was amazed and humbled.

Before the event, death was also very much a taboo topic for me and I would avoid such discussions. The large crowd participating in the event also showed me that increasingly people are open to such discussions. Although the topic of death and dying can sometimes trigger negative emotions, it can be a great relief to some who find it difficult to express their feelings.

This experience has given me greater insight into the topic of death and how people respond to it. It has also encouraged me to talk about my feelings with my loved ones as I have come to realise that it is important to convey my feelings and not wait till the last minute.  $\blacksquare$ 



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# A legacy of hope

A young patient's dream of publishing his biography to inspire others is being fulfilled, courtesy of Project Legacy, run by students from the NUS Yong Loo Lin School of Medicine.

t's a story of gratitude and perseverance," says 23-year old Wong Choon How. One of HCA Hospice Care's patients under the Star PALS paediatric palliative care service, life has been fraught with challenges ever since Choon How was diagnosed with Duchenne Muscular Dystrophy (DMD) when he was just five years old.

But it is these same challenges that have served as inspiration for his biography. It is a dream project that is in progress and nearing completion, with a few more chapters to be written.

Chronicling his experiences living with DMD, being bullied at school and the personal pursuits that fuel his zest for life, Choon How hopes that his story will raise awareness on the condition and offer hope and encouragement for others in similar situations. It is also an avenue through which he hopes to express his gratitude for the ample support he has received.

### The Spirit of Giving

Like many people with special needs, Choon How can attest to the difficulties associated with daily routines. He uses a motorised wheelchair to get around and a BiPAP machine to aid in his breathing. While these may seem like inconveniences to most, it has made Choon How ever more appreciative of the support and kindness he has received from his family, volunteers and HCA's clinical staff.

Putting together his biography was a dream made a reality by a group of

students from NUS Yong Loo Lin School of Medicine, who are running Project Legacy this year, to help palliative patients create a keepsake for their loved ones and leave a legacy through telling their stories.

Project Legacy was founded in 2011. "We hope that during their journey in search of their legacy, patients will find a renewed sense of personal power, purpose and importance and be able to reconcile their feelings with their prognosis," says Rachel Goh, 22, who is leading Project Legacy this year.

### A Flair for Storytelling

Choon How and his mother, Madam Susan Tan, were linked up with the Project Legacy volunteers last year, when Lily Li, Nurse Manager of Star PALS, first mooted the idea of publishing a biography.

"Choon How was inspired to produce his own biography after attending a talk given by actor Li Nanxing at the Bukit Panjang Methodist Church on his personal failures and successes," Mdm Tan explains. "We also got an autographed copy of the actor's biography, 'The Real Picture'."

Seeing a parallel between his personal challenges and the trials and tribulations the local veteran actor had faced, Choon How was inspired to follow in the footsteps of his idol, by writing his story.

The Project Legacy volunteers jumped into action almost immediately, paying numerous visits to Choon How's place to listen to him and his mother share

Diagnosed with Duchenne Muscular Dystrophy since he was five years old, Choon How has not let that stop him from living his life with zest, zeal and gratitude. Seen here with his mother, Choon How was inspired to write his biography as a legacy for

about their struggles and personal victories. "During these sessions, I was struck by his fighting spirit and zest for life," Rachel shares.

The biography, which will be written in both English and Chinese, is Choon How's way of leaving his legacy of hope for his loved ones and others who are facing similar difficulties. It is the same flair for creative expression that manifests in his watercolour and oil paintings, which he sells locally. He often paints tranquil scenes depicting flowers and birds wandering idly through the forest, which are perhaps a reflection of his inner strength and calmness.

It is our collective wish that his biography, when published, will touch the hearts of others and evoke the same sense of hope and positivity Choon How encapsulates.

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# A legacy of gratitude

He may not have much material wealth to leave for his family, but Geok Seng left behind much more – a life of gratitude.



ixty-one year-old Lim Geok Lian smiled as she looked through her mobile phone. Her finger was fast scrolling through the dozens of photos in her albums. She stopped when she found what she was looking for.

Beside her was elder sister, Lim Keok. They were back at Bright Vision Hospital (BVH) a year after their brother passed away.

### My Brother, Geok Seng

"This is Geok Seng," said Geok Lian as she showed us her family photo. "He is the 5th child among my nine siblings."

As a sole breadwinner, Geok Seng worked hard as a fishmonger to support his family. It was not easy for him. His wife suffered from mental illness while his son was born with autism and Attention Deficit Hyperactive Disorder (ADHD).

Geok Seng would wake up at 10pm daily to travel to Jurong to collect the fish. By 3am, he would be back at the market to set up his stall. Once work was over, he would make his way home to help with the household chores.

"His business was the best among the other fishmongers. He always ended work early," praised Geok Lian. It was obvious that he was well liked by his customers.

Things took a turn for Geok Seng in October 2016. He began to experience pain in his leg and made the painful decision to stop working when it became unbearable.

A medical check-up at Singapore General Hospital (SGH) diagnosed him with end-stage liver cancer. He had to go for surgery immediately, but by then the cancer cells had already spread to other parts of his body.

Although life is on the downside, Geok Seng still counted his blessings – his siblings eased his financial burden by providing him with the necessities for his family, and his church friends visited him, prepared his meals and even celebrated his birthday.

When his condition deteriorated in June 2017, Geok Seng was admitted to the palliative care programme at BVH.

### A tough man with a soft heart

Geok Lian remembers her brother as one tough cookie. Despite his condition, he was still able to smile and put up a brave front. Never once did he complain about his illness.

He was nice to everyone at BVH especially the nurses and other patients. They made him feel at home and would invite him to karaoke and movie sessions.

"He said that he was comfortable here. We knew he was prepared to go," shared Geok Lian.

Before he passed away, Geok Seng made a handwritten thank you card to each of his family member. As he did not receive a formal education, Geok Seng requested help from BVH staff to assist him in preparing cards. It was his way to show gratitude to them. That was how Geok Seng as a person: always thanking everyone and counting his blessings.

### Geok Seng's Legacy

Receiving the thank you card was the saddest moment for Geok Lian. She was touched by his gesture. It was the most beautiful card she has ever received.

"He is actually a gifted man. From young, he can play the guitar. He just has to listen once to recognise the keys," said Geok Lian.

His family missed him very much. The weekly gatherings were not the same without him. "We used to meet each other weekly, on Saturday or Sunday, to eat," said Geok Lian. They would gather at Lim Keok's place at Pasir Ris when Geok Seng was still healthy. She still remembers his favourite food, which was pork curry.

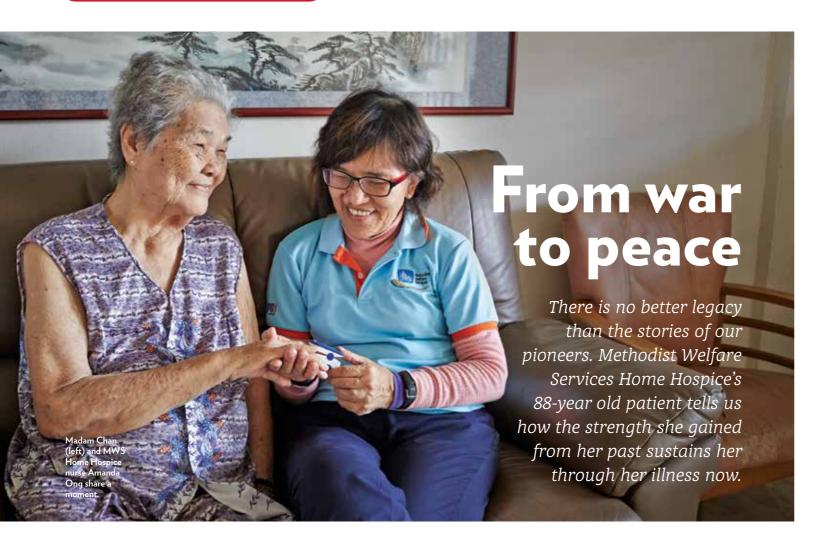
The card and his photographs in her mobile phone would be his legacy. It brings back fond memories of Geok Seng.

As the saying goes, the ones who leave behind great remembrances will live on in our hearts.  $\blacksquare$ 

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udging by 88-year-old
Madam Chan Geok
Sian's cheeky grin, it
is impossible to guess
how hard her life has been. As an
8-year-old, she was shipped off
from China to Singapore alone to
escape the Chinese civil war. She
lost contact with her entire family
shortly after.

When she arrived in Singapore, she was sold to a Peranakan family to work as a servant. "I wasn't paid, but they provided me with food and lodging," says Madam Chan. "My job was to carry the matriarch's purse wherever she went."

To her horror, the war soon followed her to Singapore. Fearing that she would be taken away by Japanese soldiers, Mdm Chan tried her best to look as unattractive as possible.

The octogenarian vividly recalls hiding in the canal outside her employer's house, clutching their valuables to her chest, while bomber planes flew overhead. Her employers

had fled to a bomb shelter, leaving her to guard their belongings, alone.

As a young girl then, Mdm Chan did not understand much about the war. She remembers being intrigued by the sight of the planes. After the war ended, her employer matchmade her with an acquaintance's son. She was only 16.

Today, the widowed Mdm Chan faces hardships of a different kind. She lost her eldest son to lung cancer in December 2017, and she has end-stage renal failure and possible malignancy of her stomach and pancreas. She declined further investigation and dialysis treatment due to her advanced age and fear of discomfort. She opted for homebased medical and nursing care provided by MWS Home Hospice to manage her symptoms.

To cope with her living and medical expenses, she supplements the allowances from her two remaining children by renting out a room in her 3-room HDB flat. While she used to enjoy mahjong sessions

with three other friends, the death of one of them ended their gatherings.

Today, she looks forward to seeing MWS Home Hospice nurse Amanda Ong, who has been visiting her regularly since March 2015. Mdm Chan enjoys reminiscing about her past and chatting about everyday affairs with Amanda, whom she considers a friend.

The hospice has a full-fledged medical team providing palliative care to Mdm Chan in the comfort of her own home. They also trained and equipped volunteers and caregivers to care for her.

The hospice's 24-hour nursing hotline also gave Mdm Chan and her family the assurance that they could seek medical advice round-the-clock.

In spite of her illness and frailty, Mdm Chan is determined to live life fully. Her courage and resilience show through her daily life. She still meets family and friends for coffee and chats at the void deck, and enjoys going for social outings organised by MWS Home Hospice.

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SENIOR MEDICAL SOCIAL WORKER, ITAL PHOTO TAN TOCK SENG HOSPI

# Flowers always blooming

Legacy work is not just an activity with an end product; it can also be a therapeutic process of reflective and creative exploration.

lowers Always
Blooming" - this was
Madam Mia Sari's
belief, and the one
important thing she wanted people
to know.

That was quite a contrast to what my eyes initially tell me about her – frail, sleeping most of the time, and a lady of few words. Lethargy has been getting the better of her in the preceding days. But this afternoon, she mustered the energy to prop herself up in the hospital bed, searched for her spectacles and was ready for something different.

It was one of those days where I had no confident idea of what to do.

When I sit down with a patient, I do not always bring up the issue of "doing a legacy", or asking, "how would you like to leave a legacy?" in the first instance.

The concept of leaving a legacy may often be foreign to many of our patients. In a fast-paced and transitory environment such as that of a hospital, and more so with palliative care, I have realised the importance of recognising opportunistic, ordinary moments, and capitalising them for therapeutic and meaningful exchanges.

Such is also the case with legacy work: it is more of a therapeutic process as oppose to a mere aim of producing something.

What appeared to be a spontaneous activity that afternoon with Mdm Mia Sari soon became a heartwarming family session and legacy creation, one that brought to the surface words not spoken before.

"I'm no artist," she wanted that said first. There may be some truth to that, but we have to remind

ourselves that the process of creating space, encouraging reflections, and allowing stories to be told is just as important.

Mdm Mia Sari started drawing a tree, with leaves, and a big red flower. She then added on roots for the tree: "Trees must have roots, so that they will be strong like us humans." For her, roots are akin to values such as willingness to work hard, perseverance in completing what we started, and not giving up in life. "And if these leaves fall, know that new ones will surely grow out again." So much wisdom, so much faith in those few words.

That afternoon, Mdm Mia Sari spent every ounce of her energy immersing in this precious moment, with her family who contributed their own pieces to this tapestry of narratives.

Her husband and son were clearly heartened by her spontaneity, but more so, by the meanings embedded within every stroke and colour. In that sacred time and space, love transcended beyond what words alone can do.

The butterfly, bee and sun Mdm Mia Sari drew symbolised her family – always with her and forever shining for her. This was exactly what she wanted them to remember – bloom, shine, be happy. "Be like this flower - be bright, be blooming".

She requested a pink ribbon to be added at the corner of her art work. It represented her support for women with breast cancer. It was almost as if she was declaring it is not a fight she had lost, but a long journey she is completing, and now cheering the others on. With a smile she said: "This, is good enough."

Legacy creation can take on various forms. But at its purest, it is found in the everyday life. It's in the narratives of what defines us, the building of memories, the celebration of both joys and pains, and the unfolding of a unique story – we all have one to tell. •



Mdm Mia Sari's legacy For her family To a drawing Symbolising Strength, hope

# A legacy of spirit

A legacy is not always necessarily monetary or tangible objects; leaving behind a spiritual legacy is just as treasured.

r. B\* was one of the patients I encountered during my first year of practice as a palliative nurse. I had always thought that the story plot in TV dramas would never be portrayed in real life scenarios, but his life story was one of the examples that made me think otherwise.

The 45 year-old Indian architect was diagnosed with end-stage lung cancer, which had spread to bones and pleural cavity. He went through multiple treatment sessions, none of which helped. Instead, they caused him much physical pain, emotional burdens and also financial drain for the family.

He became increasingly frail and had symptoms of breathlessness which made him feel suffocated. The palliative team has been referred to help in managing his symptom. Medications were titrated to help Mr. B feel less breathless. At the same time, we talked to Mrs. B to enquire about family's setup, goals of care and patient's expectations of treatment in the hospital.

Mrs. B said they had been married to patient for 15 years, and have two beautiful girls (14 years old and 12 years old respectively) who were very close to the patient. The cancer specialist told Mrs. B to be mentally prepared for the worst, as the patient has only less than three months to live. Their girls

were aware of their father's condition but do not know that his time is short.

"I know time is very short, but I don't know how to help him. He used to be very jovial and chatty, but now, he always keeps to himself," Mrs. B said, with tears flowing profusely. Tissues were offered, reassurance and validations were given to her that she was doing great to stay involved and informed at every stage and most importantly, she was not alone. The palliative team would aim to get optimal dose of medications to relieve Mr. B's breathlessness during his stay.

During a review, Mr B spoke to our team before we left his bedside.

"I overheard the conversation between you and my wife. I know my time is short, and I had not much money to leave for my wife and two girls....I had always wanted to leave something for them before I depart from this world, but I don't know what to give and I do not have much money left after all the treatments," he told the doctor.

The doctor reassured him that a legacy does not always mean leaving monetary items for his loved ones. "It can be something unique and memorable to them; example your own handwritten letter to your wife and 2 daughters in their favorite letter design or cartoon characters. You can also prewrite the letters to your 2 daughters and give them

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Legacy can be something that is very simple. It can be an album of photos that keep the memory of the deceased and the living being together. One can only imagine the meaning the letters carry when the family reads such letter every year."



every year at their birthdays till they are 21 years old. This is a big task, which means you have got several letters to write," the doctor told Mr B.

The palliative team help purchase stationeries for Mr B to write his letters during his hospitalisation. We got the Medical Social Worker (MSW) involved to help with this legacy activity, assisting with placement for patient to move to an inpatient hospice for end-of-life care (as wife is not able to cope with care at home), providing psychosocial support to family and helping in liaising with school counsellor to help and support the patient's two daughters during this difficult journey.

Mr. B was accepted to be placed in an inpatient hospice where he could spend his end-of-life moments. Some of the hospital's palliative team members visited him before he left for inpatient hospice's admission, and he told them that he had finished writing the letters to his wife and children.

As a novice nurse then, I began to understand the meaning of leaving legacy after the team's explanation and began to be aware that such a simple act could make a patient and his family be connected deeply even after the departure

Legacy can be something that is very simple. It can be an album of photos that keep the memory of the deceased and the living being together. One can only imagine the meaning the letters carry when the family reads such letter every year.

Legacy can be the record or artwork that the deceased is good at doing, such as a book of recipe, book of poems, a book of articles, a book of artwork, or a record of music. Legacy can be even spiritual, such as the spirit of being filial, caring and loving; the spirit of being hardworking, brave and resilient.

Legacy is not necessary to be monetary or tangible objects, spiritual legacy is equally important, because the living can pass down this gift in the family and it is a better way to remember the spirit of the deceased who has set an excellent model in life.

\*Name has been changed to protect his confidentiality

After thirty years of practising medicine, I realised that physicians are actually gardeners of the garden of life. The gardener can't change the four seasons of spring, summer, autumn and winter, but he can help the flowers in the garden bloom brightly during the four seasons. In the same way, doctors can't cure the elderly or the sick, but they can make the elderly and sick comfortable."

Professor Ke Wenzhe, renowned and respected intensive care physician from National Taiwan University Hospital; Mayor of Taipei.

after she had received her "death sentence"? Dr Ong Eng Koon, the team consultant, gave Dr James Cai and I a special task: to talk with Mdm Lo without using any medical jargons. If one of us mentioned a medical term, the person must be warned to stop the conversation.

With uncertainty, we took up the challenge.

Madam Lo told us she had never worked before, and that she was a housewife. She had dedicated her entire life to taking care of her family. A typical day for her included watching drama serials and cooking for the family. Her specialty was stirfired cauliflower with meat. She has been cooking this dish for more than 20 years and her children still enjoy this dish very much.

Madam Lo also revealed that she loved watching Korean dramas and said the Korean actors were very handsome. At that moment, I saw a smile appear on her face.

I asked her what her favourite show was. Although she could not recall the name of the drama, she described the drama in great detail to us. She continued to comment on the characters in the drama. She even analysed her preference for Korean dramas over Singaporean or Taiwanese ones: the Taiwanese drama serials were too long to follow and the current Singaporean serials did not live up to her expectations.

In between, she sighed and said that due to recent illness she did not manage to catch up with her shows.

Mdm Lo also shared with us that she has been to Europe, when her daughter brought her along during her own honeymoon. She fondly remembers that period as the happiest time of her life.

At the end of the conversation, we asked Mdm Lo for permission to let her children know what we discussed. We wondered if they could bring a device to let her watch her favourite drama series and bring some of the dishes she used to prepare for the children. She declined quickly as she did not want to trouble her children.

A terminal illness may rip away a person's freedom to live the way

that is enjoyable to them, but as the gardener of the life, we can make an effort to provide extra care to them during the extreme chill of winter. We can put aside the medical diagnosis, scans, blood results, and look at the persons that our patients were before they became dependent and disabled, with their unique interests and desires.

I picked up the phone, called Mdm Lo's son to discuss what I have learned about her, and asked whether the family could bring a device for her to watch her favourite shows. I also offered to arrange home leave for them to bring her home for a meal. Her son gladly agreed and expressed his appreciation at the suggestions.

The last lap of the life is not about dying, it is about living. To help the patient live before leaving this world, it is important for us to learn how to drop our "armour" of medicine and to don on a heart of humility and talk about life. Behind every life there is always a special chapter belonging to it. Discover it, respect it and ignite it till the last drop.

disappointment, and hopelessness.

Discover, respect, ignite

Sometimes, the last thing someone needs in

the final lap of life is the complexity of medical

jargons. A simple conversation about life may

t was just another morning round, just

understanding of their condition. But,

Madam Lo was different from most of

another routine assessment of a patient's

be all that is needed to bring on a smile.

our patients. That morning, she told us that there is

less than three months to live, and that she would be

going to a hospice. Her face was drowned in sadness,

Mdm Lo has reached the winter of her life. What

does it mean to be able to live happily and comfortably

no more treatment for her, that she may have left

CONVERSATION

# Why is legacy building important?

Ms Violet Yang has over 30 years of experience as a Medical Social Worker, and mangement in eldercare and psychological services, eight of which are in the palliative care industry. She has joined the Singapore Hospice Council as the Community Engagement Manager to train and share the latest updates with community workers about hospice and palliative care.



### What are legacies in hospice work and why is it important for patients to "leave legacies"?

Legacy work means leaving good memories of the individual to their families and friends. This could include activities from creating recipe books, photo journals, lifestory montages, to giving testimonies, or compiling love messages for their loved ones. This is important for both the patients and their loved ones.

The concept relates to the highest tier of Maslow's "Hierarchy of Needs", which is self-actualisation. It refers to one's needs to reach full potential and feel fulfilled. Even at the end-of-life, the patient is still an individual who still carries with them hopes and dreams.

Once, I had a cancer patient who used to actively participate in singing competitions. In the later stage of her illness, the cancer had damaged her voice, but she still insisted on participating in one last singing competition.

The medical team understood her intentions to leave good memories for herself and her loved ones. But the team was also stuck with the dilemma that it may be too physically challenging for her throughout the entire competition. Instead, they asked the organiser to allow her to join the competition as a guest singer. She did so, enjoying herself in the process.

Patients may occasionally present some challenging wishes that they have, but our palliative care team work within the limits of what the patient's goals are.

Additionally, we also do other types of legacy building, such as allowing patients to express their gratitude, or to value their contribution. This also helps in the coping of their emotional pain.

### Who can start legacy work and how do we do so?

Legacy work can be done by anyone, from nurses, social workers or even volunteers. The key is to have a personal connection with the patient so that the facilitator can act in the best interest of the patient.

The execution takes a team effort. Once, we worked to help bring a patient to an outdoor event so that she could share her journey's testimony to a crowd. There were weeks of planning involving everyone in the medical team. The list of to-dos ranged from logistical preparations to nursing needs, to mental preparation by the therapists, and rallying the family members to attend the event for support. No stone was left unturned.

### How does building legacy for the patients help their loved ones?

There are two ways legacy building can benefit their loved ones. Firstly, it

gives the family comfort and fulfilment that they have done something together with the patient before the patient eventually departs, which also helps in the grieving and bereavement process thereafter.

Secondly, it can bring reconciliation to families. I once had a male patient who was divorced. When he was close to dying, he asked to see his ex-wife, whom he had not met for years. I decided to make a trip down to meet his ex-wife. Unexpectedly, I met another volunteer who was on the same mission as mine. We talked to

her, but she vehemently refused.

But in an unexpected turn of an event, she came to visit him in the hospice. They reconciled despite having not spoken to each other for years. Past grievances were put aside, tears were shed. Even as my patient breathed his last, his heart was light, and he left with no regrets.

Are patients the only ones who should build their legacies?
Who should do it?

Anyone can start building their

legacies now and we could start by having conversations with our loved ones. To aid the process, you can visit www.singaporehospice. org.sg to download "Time of My Life – Past Perfect, a Journal of Self-Discovery" by Yang Xinyan Alexis. The journal is part of the Community Engagement Kit designed by the Singapore Hospice Council as a tool for individuals to do a life review so that they can be better prepared to talk about end-of-life conversations with their loved ones.

### **Tips for Caregivers**

#### DR JAMIE ZHOU

Resident Consultant (Palliative Care), St Joseph's Home

This issue's theme is about leaving behind a legacy. A legacy does not just mean leaving a will or expensive items to your loved ones. It means leaving behind something that people can remember you by. It can come in the form of a physical object (e.g. a watch, a letter, etc) or something non-physical (e.g. a memory, a life story, etc). Here are some tips on how you can help in legacy work:

### Caregiver tip #1: It's best to discuss and plan legacy work early.

Many leave it to the last minute when there is little energy left. This may result in incomplete legacy work especially if the intended legacy takes time to complete.

### Caregiver tip #2: Be ever-ready to take photos.

Thankfully for us, camera-phones are now a norm. It does not take much effort to capture a happy memory. It will go a long way.



### Caregiver tip #3: Inspire your loved ones to leave a legacy by reviewing their life with them.

A life review is allowing your loved ones to tell their life story. You can tell them how you would remember them and this may inspire them to leave a legacy behind for their loved ones.

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# **Upcoming Events**

### 19 - 22 SEP 2018

### **LAST DANCE**

A son throws a party to commemorate the 100th day of his father's passing. Through dancing, conversations and sharing of stories, LAST DANCE invites the audience to reflect and "come closer to death". A collaboration between Both Sides, Now and Yishun Health.

Venue: Basketball court next to Blk 109 Yishun Ring Road

Time: 7.30pm - 9.30pm (19 & 21 Sept 2018 - performed in English; 20 & 22 Sept 2018 - performed in Mandarin) Contact: connect@bothsidesnow.sg/

6324 5434

### 19 SEP - 6 OCT 2018

#### **CLOSER**

Created in collaboration with Chong Pang's seniors, this public art installation trail hopes to inspire vistors to reflect on what it means to be living. Jointly organised by Both Sides, Now and Yishun Health.

**Venue:** Various locations between Blk 108 to Blk 115 Yishun Ring Road

**Time:** Various timing

**Contact:** connect@bothsidesnow.sg/

6324 5434

### 20 SEP 2018

### **HCA Charity Golf 2018**

The HCA Charity Golf 2018 aims to raise at least \$200,000, which will enable us to make 800 more visits to our home hospice patients.

**Venue:** Singapore Island Country

Club, Island Course

Time: 11.30am - 9pm (Tee-off at 1pm,

dinner at 6.30pm)

Contact: Ms Mel Basuki, Fundraising Manager/melb@hcahospicecare.org. sg/6891 9392

#### 25 SEP 2018

### SHC Multidisciplinary Palliative Care Forum

Hear a pharmacist's perspective of managing cancer patients.

**Venue:** KK Women's and Children's Hospital, Women Tower Level 1,

Lecture Theatre **Time:** 1.00 pm - 2.00pm Contact: secretariat@

singaporehospice.org.sg/6538 2231

#### 1-31 OCT 2018

### NLB-SHC "Live Well. Leave Well" Event

In collaboration with the National Library Board, SHC, its members and partners will hold a series of talks and exhibitions in various libraries island-wide.

Website: singaporehospice.org.sg

Contact: secretariat@

singaporehospice.org.sg/6538 2231

#### 23 OCT 2018

### **SHC** Multidisciplinary Palliative Care Forum

Guest speaker is Dr Richard Harding, Reader in Palliative Care at the Cicely Saunders Institute, Department of Palliative Care Policy and Rehabilitation, King's College London. Venue: Assisi Hospice, Essery Hall,

Level 5

Time: 1.00 pm - 2.00pm

Contact: secretariat@singaporehospice. org.sg/ 6538 2231

#### 31 OCT - 1 NOV 2018

### **Grief and Bereavement Conference** (GBC 2018)

Organised by SHC, the inaugural GBC 2018 hopes bring together community workers to foster a network of support for the bereaved. Registrations closes on 15 October 2018.

Website: www.gbcs.sg

Contact: gbc2018@singaporehospice.

org.sg/ 8823 3686

### 3 NOV 2018

#### Celebration of Life!

Held in conjunction with World Hospice & Palliative Care Day 2018, this event aims to raise awareness and understanding of the needs and concerns of Singaporean about endof-life matters. Jointly organised by Tan Tock Seng Hospital (TTSH) and ACE Seniors.

**Venue:** National Museum of Singapore, Gallery Theatre and Canyon at B1

**Time:** 11.00 am - 4.00 pm

Event participation is free-of-charge.

#### 27 NOV 2018

### SHC Multidisciplinary Palliative Care Forum

Spiritual Beliefs in Palliative Care **Venue:** HCA Hospice Care Auditorium, Level 3

**Time:** 1.00 pm - 2.00pm

Contact: secretariat@singaporehospice.

org.sg/6538 2231

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