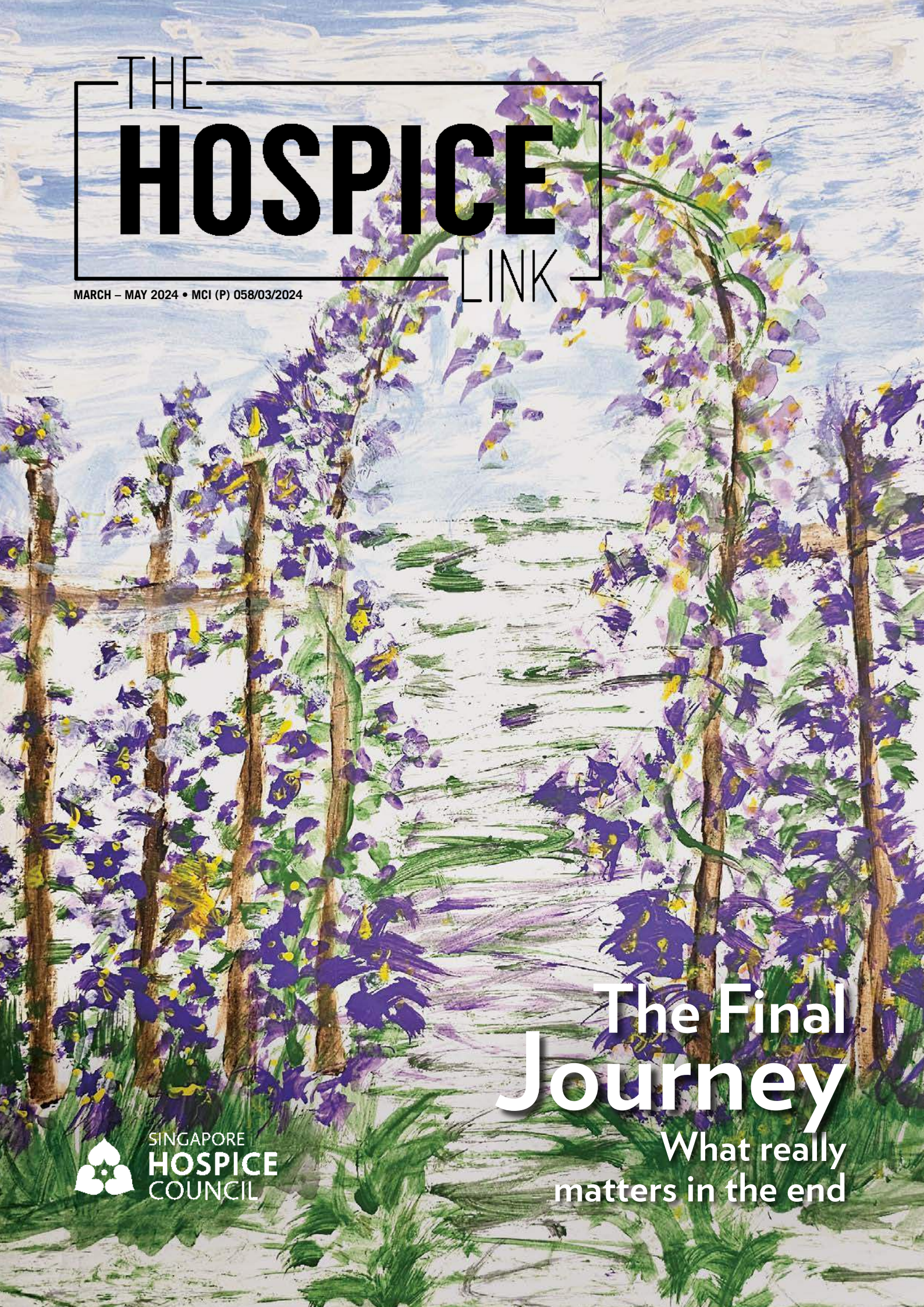
THE HOSPICE LINK

MARCH – MAY 2024 • MCI (P) 058/03/2024



The Final Journey

What really matters in the end

SINGAPORE HOSPICE COUNCIL

SHC MEMBERS

Alexandra Hospital
378 Alexandra Road, S(159964)
T: 6908 2222
www.ah.com.sg
contactus@nuhs.edu.sg

Assisi Hospice
832 Thomson Road, S(574627)
T: 6832 2650
www.assisihospice.org.sg
assisi@assisihospice.org.sg

Buddhist Compassion Relief Tzu-Chi Foundation (Singapore)
9 Elias Road, S(519937)
T: 6582 9958 F: 6582 9952
www.tzuchi.org.sg/en

Changi General Hospital
2 Simei Street 3, S(529889)
T: 6788 8833
www.cgh.com.sg

Dover Park Hospice
TTSH Integrated Care Hub
1 Tan Tock Seng Link, S(307382)
T: 6500 7272
www.doverpark.org.sg
info@doverpark.org.sg

HCA Hospice Limited
705 Serangoon Road, Block A #03-01
@Kwong Wai Shiu Hospital, S(328127)
T: 6251 2561
www.hca.org.sg
contactus@hcahospicecare.org.sg

Khoo Teck Puat Hospital
90 Yishun Central, S(768828)
T: 6555 8000
www.ktph.com.sg

KK Women's and Children's Hospital
100 Bukit Timah Road, S(229899)
T: 6225 5554
www.kkh.com.sg

Lien Centre for Palliative Care
Duke-NUS Medical School
8 College Road, S(169857)
T: 6601 1097 / 6601 2034 [Education]
T: 6601 6840 [Research]
www.duke-nus.edu.sg/lcpc

Metta Hospice Care
32 Simei Street 1,
Metta Building, S(529950)
T: 6580 4695
www.metta.org.sg
hhospice@metta.org.sg

MWS Home Care & Home Hospice
2 Kallang Avenue,
CT Hub #08-14, S(339407)
T: 6435 0270
www.mws.sg
MWShh@mws.sg

National Cancer Centre Singapore
30 Hospital Boulevard, S(168583)
T: 6436 8000
www.nccs.com.sg

Ng Teng Fong General Hospital
1 Jurong East Street 21, S(609606)
T: 6908 2222
www.ntfgh.com.sg
contactus@nuhs.edu.sg

The Palliative Care Centre for Excellence in Research and Education (PalC)
TTSH Integrated Care Hub
1 Tan Tock Seng Link, S(307382)
T: 6500 7269
www.palc.org.sg
enquiries@palc.org.sg

Ren Ci Hospital
71 Irrawaddy Road, S(329562)
T: 6385 0288 F: 6358 0900
www.renci.org.sg
renci@renci.org.sg

Sengkang General Hospital
110 Sengkang East Way, S(544886)
T: 6930 6000
www.skh.com.sg

Singapore Cancer Society
30 Hospital Boulevard
#16-02 NCCS Building, S(168583)
T: 1800 727 3333
www.singaporecancersociety.org.sg
hospice@singaporecancersociety.org.sg

Singapore General Hospital
Department of Internal Medicine,
Outram Road, S(169608)
T: 6222 3322
www.sgh.com.sg
sghfeedback@sgh.com.sg

SingHealth Community Hospitals (Bright Vision Community Hospital, Outram Community Hospital, Sengkang Community Hospital)
10 Hospital Boulevard, S(168582)
T: 6970 3000
www.singhealth.com.sg/SCH

St. Andrew's Community Hospital
8 Simei Street 3, S(529895)
T: 6586 1000
www.sach.org.sg
general@sach.org.sg

St Joseph's Home
36 Jurong West St 24, S(648141)
T: 6268 0482
www.stjh.org.sg
general@stjh.org.sg

St Luke's Hospital
2 Bukit Batok Street 11, S(659674)
T: 6563 2281
www.slh.org.sg
general@stluke.org.sg

Tan Tock Seng Hospital
11 Jalan Tan Tock Seng, S(308433)
T: 6256 6011
www.ttsh.com.sg

Tsao Foundation
298 Tiong Bahru Road
Central Plaza, #15-01/06, S(168730)
T: 6593 9500
tsaofoundation.org
info@tsaofoundation.org

Woodlands Health
17 Woodlands Drive 17, S(737628)
T: 6383 3000
www.wh.com.sg
enquiry@wh.com.sg

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Make a Donation!

Singapore Hospice Council (SHC) is committed to improving the lives of patients with serious life-limiting illnesses and to giving support to their loved ones. Support SHC today to impact lives.

**Cash donations are eligible for 250% tax deductions.*

EXECUTIVE DIRECTOR'S NOTE

Recently, someone I work with closely was diagnosed with cancer. It came as a shock as she is young, energetic, runs and has a mostly healthy lifestyle. She has everything going for her, both at work and at home. We had so many plans to work on. Everything is now on pause while she works on getting well. She is taking everything in her stride. It was a wakeup call and made me ponder what if it had been me? Would I be as strong as she is? Would I be able to share this as openly and candidly as she did?

Just two weeks ago, I had this conversation with a cancer survivor. "I was diagnosed with cancer at 35 and given just a few years to live. I am now 53 and at the end of the year, I congratulated myself for still being alive, beating all odds, 17 years on!"

I found myself wondering and picturing myself as a patient with a limited lifespan. What would be my first thoughts and priorities? Should I eat all the food I love to eat, without concern for sugar and salt intake? Go to the temple to pray? Throw away all fears and do bungee jumps and skydives? How should I manage my loved ones and friends? What is my care plan? How do I wish to go?

What really matters in the end? To me, the last chapter is one of no or minimal pain, not only for

PHOTO FREEPIK.COM

me but also for my loved ones. I will need to prepare them for it, starting with hard conversations. Equally important is to make sure I have the financial ability to pay for my care without burdening my nieces and nephews. Lastly, I would love for my palliative care team to treat me with dignity, care, love and compassion.

There's nothing quite like facing the end of life to distil what is most important to us, and for the palliative patients who appear in the stories within these pages, to fulfil their final hearts' desires with the support of their care teams, and leaving behind memories that their loved ones could tap into time and again. The extra time that Rokiya, Isaruddin and Bian Teck could spend with their families with peace of mind just by being provided with home palliative care created cherished moments for their families and loved ones (page 20). Being able to spend his last moments at home was something that Mr Lee had also set his heart on, while that one last temple visit that Madam Lye was able to make allowed her to leave at peace with herself, both made possible by their care team (page 18). And if a tangible keepsake in the form of a handmade gift (page 17) or a hand cast (page 16) were on the patients' wish list, the arts therapy members on the multidisciplinary care teams swung into action to make them a reality.

After reading the stories within these pages, I hope you will start thinking and having conversations with your loved ones, like what I am doing. Just do it!

Sim Bee Hia
Executive Director
Singapore Hospice Council

ABOUT THE ARTWORK ON THE COVER

By Mr Allan
Patient, Outram Community Hospital (OCH)

Allan was a gentle yet outgoing person who encouraged fellow patients around him. He demonstrated courage, grace and resilience when he faced challenges at the end of his life in OCH.

Allan was very proud of his artwork and shared that he would like to pass his work to OCH after he passed away. It is his legacy for his care team at OCH.

BONDING IN CARE

NEWS, VIEWS, UPDATES AND SPOTLIGHTS

Meet *the* Team

SENIOR STAFF NURSE **WOO CAI LING**

Methodist Welfare Services

A palliative care nurse visits patients in their homes and performs a wide range of tasks, including managing symptoms, providing psychosocial support, and offering caregiver training. Home care nurses also focus on creating a comfortable environment for patients who have been compassionately discharged, as well as a supportive presence during their final hours, facilitating meaningful farewells between the patients and their loved ones.

What do you love most about your job?

I enjoy working in community settings where the elderly find solace at home. This makes it easier for healthcare workers to assess how they are managing their illness and challenges, be it in the short or long term, or even at the end of life. We provide holistic care and advice during every home visit, including psychosocial-spiritual support for end-of-life patients; and bereavement care for their loved ones.

What is one memorable story from your career?

I once provided end-of-life care to a loving elderly couple where the wife was suffering from an acute disease. They had been married for 70 years. During my final visit, the husband sat by his wife's bedside and while holding her hand, expressed his gratitude, saying, "Thanks for living with and tolerating me till now. Don't worry, I will take care of the rest." As she left him with silent tears, this touching moment became etched in my mind. Facing the imminent loss of a loved one is challenging. It reminded me of the three things that matter most in life: forgiveness, gratitude and love. Let's express these sentiments while we still have the chance, so as not to leave with regrets.

ASK ME ANYTHING

By Senior Staff Nurse
Woo Cai Ling

What do I do if I know I am dying?

While grappling emotionally with acceptance, it is important that you attend to matters such as living arrangements, legal affairs (e.g, last will, CPF nomination, etc) and fulfilling last wishes (e.g, travel or enjoying favourite foods) while you still can. Cherish remaining moments with loved ones, and seize the opportunity to express forgiveness, gratitude, love and farewell so that you don't leave with regrets.

Follow SHC on social media @singaporehospice if you have any questions you want answered by our friendly palliative care team members.

Signs of the final hours to look out for in our loved ones

1 Lowered body temperature
◀ Limbs become cool to the touch, especially the fingers and toes

2 Mottling
▶ Purplish blue discolouration appearing on palms and soles of their feet

3 Drowsiness
◀ Sleepiness and perhaps a lack of response

4 Weak pulse
▶ The pulse will be very weak or may not even be felt

5 Not eating
◀ A lack of interest in food and eating may cause discomfort

6 Confusion
▶ Signs of restlessness and discomfort in bed

7 Sounds
◀ Gurgling sounds may be heard during breathing

8 Change in breathing pattern
▶ A tendency of open-mouth breathing

Visit SHC's e-Library for more palliative care resources on end-of-life matters, planning and more.

Scan to read
Understanding the Final Hours (available in four languages).

Upcoming Events

SHC "LIVE WELL. LEAVE WELL." EXHIBITION @ THE PUBLIC LIBRARIES

Find out more about palliative care, how to get started on end-of-life planning and why die-logues are essential. Come on down to pick up free resources and participate in our interactive exhibit!

When:
1 April to 30 May
Venue:
Clementi Public Library,
3155 Commonwealth Avenue West
#05-13/14/15,
The Clementi Mall,
Singapore 129588

SHC PALLIATIVE CARE 101

Learn more about palliative care and how to start end-of-life conversations with loved ones in this two-hour course that is free and open to the public.

Visit singaporehospice.org.sg/training-courses or scan this QR code to find out more.

SHC "LIVE WELL. LEAVE WELL."

EXHIBITION @ THE PUBLIC LIBRARIES

From far left: SHC Ambassador Helen Ding at the "Live Well. Leave Well." Exhibition sharing about the importance of end-of-life planning; "Live Well. Leave Well." Exhibition at Sengkang Public Library

In 2023, Singapore Hospice Council (SHC) brought the roving "Live Well. Leave Well." Exhibition to five locations: Sengkang Public Library, Woodlands Regional Library, Ang Mo Kio Public Library, Bedok Public Library and Jurong Regional Library.

The SHC Community Engagement team and volunteers engaged visitors with interactive activities and shared more about the services and resources available to help those with life-limiting illness and their loved ones.

Visitors were asked to pen down their thoughts on what "a good death" is and place the written cards according to the values that were most important to them. "Across the different neighbourhoods, we found that most people wanted a pain-free death at home surrounded by their loved ones," shared SHC Community Engagement & Public Education Manager, Ms Vanessa Ho.

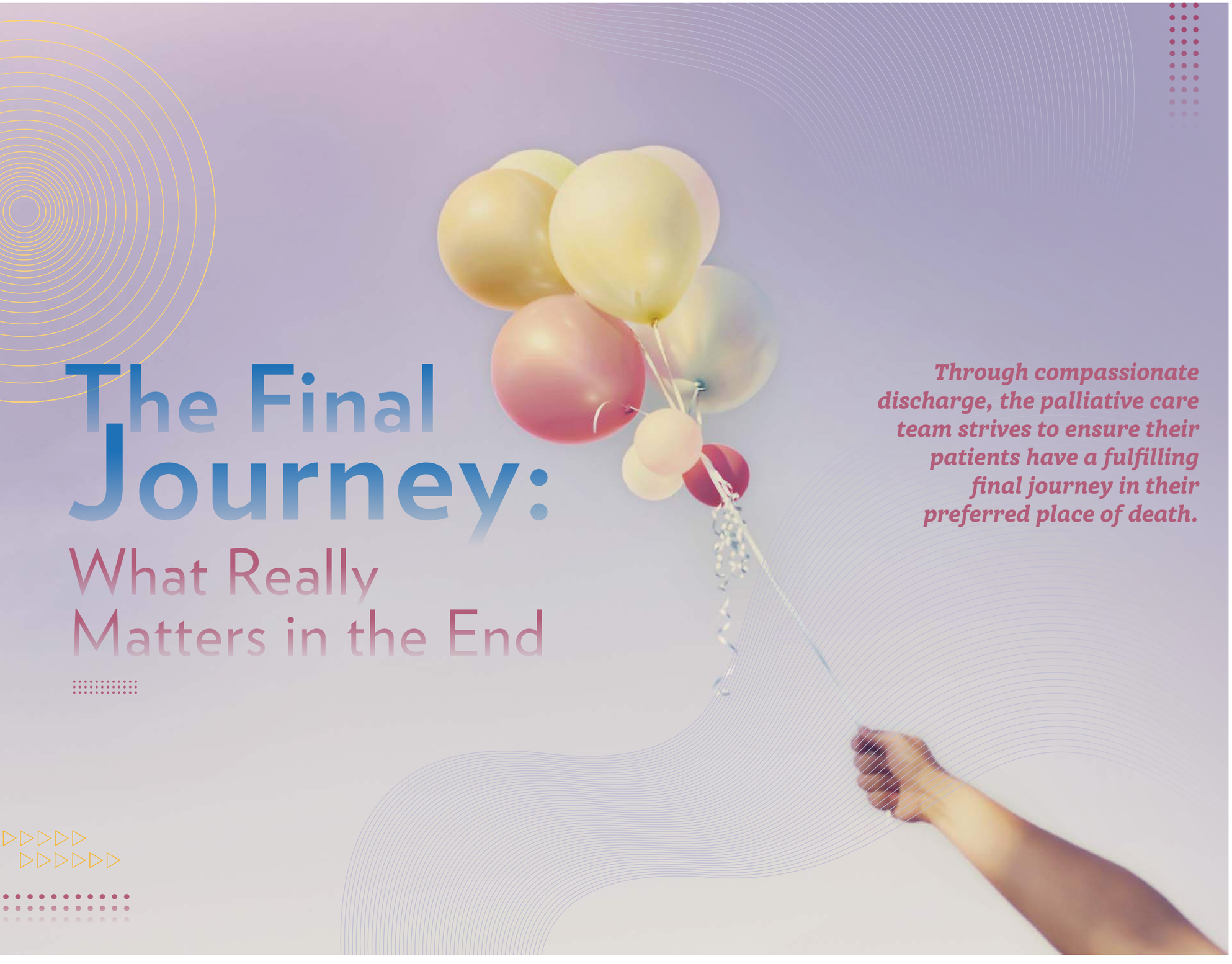
SHC regularly organises outreach events to encourage the Singaporean public to start making these essential preparations early so they are empowered to achieve an end-of-life journey according to their wishes and preferences. Look forward to the "Live Well. Leave Well." Exhibition's brand new look at upcoming public library locations in 2024!

Don't know where to start when going about owning your end-of-life journey? You can take the first step by thinking about what "a good death" means to you.

Heartfelt thanks for the wonderful responses from participants in past exhibitions:

Follow SHC on social media to receive updates on the "Live Well. Leave Well." Exhibition

@singaporehospice



The Final Journey: What Really Matters in the End

Through compassionate discharge, the palliative care team strives to ensure their patients have a fulfilling final journey in their preferred place of death.

The journey to prepare for one's death is never easy and can often feel overwhelming, as seen in the case of liver cancer patient Mr Simon Lee in the story "On Your Own Terms" (page 18). Mr Lee was restless and frustrated during his stay in the hospital and told his wife of his wish to spend his last days at home. The Tzu Chi palliative care team stepped forward to arrange for compassionate discharge and the required support for home care.

Six days after being discharged from the hospital, Mr Lee passed away peacefully at home. His wife, seeing his last wish fulfilled, was grateful for Tzu Chi's guidance and help in navigating the challenges and uncertainties during her husband's final days.

Like Mr Lee, most end-of-life patients express a preference to die at home, seeking peace, privacy and comfort in familiar settings surrounded by loved ones. For them, fulfilling this desire to spend their final days at home is of utmost importance.

Seventy-seven per cent of Singaporeans wish to die at home, but only 27 per cent were able to do so, the 2014 Lien Foundation's Death Attitudes Survey found.

To close this gap, the Ministry of Health has set out to expand and improve palliative care in Singapore so that more professional and social support is available to meet patients' preferences on this last journey.

In this vein, it is key to empower patients with the choice of where they would like to spend their last days, be it at the hospital, nursing home, hospice or home. Singapore Hospice Council's member organisations (page 2) offer a range of palliative care services, ranging from inpatient to home-based support, with the aim of allowing patients a dignified farewell according to their wishes.

For patients who have stated that they wish to pass on at home, compassionate discharge is a special arrangement to transfer a dying patient out of the hospital to spend their final days and die at home. This process ensures continuity of care as the patient transitions from inpatient services to the home. Before compassionate discharge can take place, however, patients and their families need to take some factors into consideration.

PREPARING TO PASS AT HOME

The patient's end-of-life preferences should be discussed with the family and the healthcare team as early as possible. The patient may have stated their care preferences in their Advance Care Plan, Lasting Power of Attorney, or Will, or expressed them in conversation.

Once the patient expresses the wish to die at home, a joint discussion between the patient, family, hospital and home hospice team (where feasible) will take place to plan and prepare for discharge. Some of the points of discussion may include the suitability of the patient for compassionate discharge as well as the patient's condition and care needs.

Before opting for compassionate discharge, the family also has to consider their ability to cope with the various caregiving duties and the emotional stress of caring for their dying loved one at home. It is a heavy responsibility, as the patient may need constant care and support with activities of daily living such as showering and feeding.

For instance, the patient may spend most of their time in bed. Their caregivers would need to know how to help them in and out of bed safely and how to prevent bedsores.

In addition, some caregivers might be ill-equipped to care for the discharged patients' medical needs. For example, they might not know how to administer medication, give an injection correctly or manage their symptoms.

The patient's family may also need to make some home modifications to make it easier to carry out caregiving tasks. This could require the installation of medical or home care equipment, such as a hospital bed or oxygen supply, and even rearranging the home.

The family might have to consider designating more than one caregiver for the patient in order to spread out the care duties, as it is important for caregivers to have time for rest.

For those struggling with the care load at home, turning to a home hospice service may offer some respite. Caregivers can approach the patient's doctor for a referral to a home hospice service for assistance.

Home care starts with a visit from the home hospice team at the patient's residence. The team will visit regularly to help manage the patient's pain and symptoms, train caregivers to provide care for the patient at home, and offer emotional support to caregivers and the patient. The frequency of these visits will depend on the patient's condition, but the home hospice team is contactable around the clock for assistance.

BREAKING THE TABOO

In an Asian society, it isn't easy to broach the topic of end-of-life care, according to Methodist Welfare Services (MWS) Senior Staff Nurse Hing Kai Kia.

On first contact with the hospice provider, family members may express surprise and respond negatively when the option of home hospice is initially offered.

"To these patients and their families, the word 'hospice' is already a taboo. Many of them feel secure when the medical team is there to manage symptoms, but they shut off when we talk about end-of-life care. Most of them are not mentally prepared to think about the topic of end-of-life

Clockwise from top left: Local musician, Rai, performed at HCA patient Michelle Ng's living funeral; Michelle smiling brightly; Michelle preparing a delicious array of food for her guests; Michelle (left) and HCA Principal Medical Social Worker Jayne Leong (right)

SINGAPORE HOSPICE COUNCIL'S MEMBER ORGANISATIONS OFFER A RANGE OF PALLIATIVE CARE SERVICES, RANGING FROM INPATIENT TO HOME-BASED SUPPORT, WITH THE AIM OF ALLOWING PATIENTS A DIGNIFIED FAREWELL ACCORDING TO THEIR WISHES.

care; they are just not there yet," explained Ms Hing.

A former administrative staff member in a paediatric clinic, Ms Hing longed for a job that would bring her more joy and meaning. Although it would be her first time working with palliative patients, she decided to take up the challenge and join MWS in 2020.

Since then, she has worked with patients in their homes who had conditions ranging from cancer, kidney failure, heart failure, advanced lung disease, liver disease, and advanced dementia. They often have a prognosis of less than a year.

CARING BEYOND PHYSICAL NEEDS

To deliver "whole-person" care, Ms Hing works with a multidisciplinary team comprising doctors, nurses, social workers, counsellors, therapists, and trained volunteers.

There have been growing efforts to boost support for home-based palliative care services to provide patients at the end of life with comfort and dignity in their home. Through drawing up personalised care plans, the aim is to provide a holistic approach to end-of-life care that addresses patients' physical, emotional, social and spiritual needs.

As part of her work, she helps to manage patients' pain and symptoms, ensure patients adhere to their medication schedule and protocols, and train caregivers to administer oral medication or injections for their loved ones

Left: Friends and family of Michelle gathered to attend her living funeral

at home. Going the extra mile, she offers a listening ear and a comforting presence to patients and caregivers when they need it.

Ms Hing shared, "You must show a willingness to listen to their stories and precious moments while making sure they are as comfortable as possible. Just your presence and empathy could bring the greatest gift to the dying patient and their family members."

On occasion, she has connected patients with MWS social workers to complete various legacy projects which make a world of difference to her patients. One such example was for a breast cancer patient who penned down her homemade recipes for her son. As a result of her dedication, caregivers of former patients have at times recognised her on the streets and expressed gratitude for her help.

It is worth noting that everyone has different needs during the last days of their lives. Some patients may have symptoms that can be challenging to manage at home. If that is the case, caregivers can consider allowing their loved one to be cared for in an inpatient setting, which can enable the patient to receive the appropriate care that they need.

MEANINGFUL LAST DAYS

As patients spend the last hours or days of their lives at home, palliative care services are focused on offering them comfort, dignity and compassion, and creating meaning for them.

There are various home- and hospice-based programmes dedicated to caring for patients as they approach their final hours, for example, MWS Home Care & Home Hospice, HCA Hospice Care's (HCA) Vigil Angels and Assisi Hospice's No One Dies Alone, to name a few.

The multidisciplinary care team, when possible, would go the extra mile to support the patients in fulfilling their last wishes in the remaining time. One such example was a living funeral organised by HCA for cancer patient Michelle Ng.

HCA Principal Medical Social Worker Jayne Leong had first floated the idea to her.

Though such a concept was relatively new locally, Michelle embraced the idea with open arms. She saw it as a precious occasion to celebrate her life, express her love for the people around her, and say goodbye.

A plucky entrepreneur, Michelle was a go-getter who enjoyed cycling and running and working on her own wearables business, Kléo. In 2021, Michelle was just 27 when she was diagnosed with a rare ovarian cancer. A year later, the cancer had spread rapidly and chemotherapy had little success. With a poor prognosis of just months and her health on a decline, Michelle decided to spend her remaining time at home with her loved ones, supported by the HCA team.

In late December 2023, Michelle organised an intimate gathering for her family and dearest friends in her humble HDB flat. The cosy space had been newly renovated and was decked out in sage green and cream colours. Her favourite singer Rai — one half of her favourite local band, Jack and Rai — performed a couple of sets.

At Michelle's request, friends brought along a book gift to exchange to symbolise the exchange of knowledge. Others penned heartfelt final letters to Michelle, which she would read later in private. The event saw many tears shed, hugs exchanged, and heartfelt words.

Addressing her friends, she said, "Thank you for making me so happy today. Your presence is so much appreciated. I am grateful to hear every single laugh, to see every single smile."

She passed away peacefully on 2 January, 2024.

As patients and their families navigate the twilight of life, they treasure each day as a precious gift. With the support of home hospice teams, patients can spend their final days in the comfort of their own home, focusing their remaining time and energy on meaningful connections and cherished goodbyes.

WORDS **SINGAPORE HOSPICE COUNCIL**
PHOTOS **FREEPIK (MAIN IMAGE), HCA HOSPICE**

LEAVING MEANINGFUL MEMENTOS

The Assisi Hospice Care Team helped a husband and soon-to-be father leave keepsakes behind for his loved ones and unborn child at the end of his life.

Top: Mr & Mrs Yiu, creating the mould for the hand cast; Below: the completed hand cast

Mrs Yiu sat at the bedside of her husband in Assisi Hospice. They held hands tightly and dipped them in an alginate mixture, which was part of the process of creating the mould of a hand cast. It was a loving and touching moment, as Mrs Yiu smiled with tears in her eyes.

Mr Yiu was diagnosed with end-stage liver cancer in February 2023, which was discovered due to persistent pain in his abdominal area. After conducting scans, the doctor observed that his tumour was too big, and that his condition was not suitable for surgery nor chemotherapy.

This diagnosis shocked Mrs Yiu, who was seven months pregnant at the time. The doctor recommended palliative care, and Mr Yiu was admitted to Assisi Hospice's Inpatient ward in March 2023, barely a month after his diagnosis.

WORDS & PHOTOS **ASSISI HOSPICE**

Mrs Yiu said, "My husband's final wishes were to get closer to God, share the gospel and to spend more time with the family. He also wanted to do something that he could leave as a remembrance for us."

The social worker, art therapist, and music therapist on the Assisi Hospice Care Team launched into creating legacy projects as a remembrance for his unborn child and family.

"The art therapist suggested a hand cast, so that our child could hold it after he was born. Even though my husband was already very weak, he persisted and even did one more hand cast, holding my hand," Mrs Yiu shared.

Mr Yiu deteriorated quickly and passed away the day after he did the hand cast. The completed hand cast was presented to Mrs Yiu by the care team at her husband's wake. During his short stay of three days in the hospice, our art therapist also helped to create an artwork featuring handprints of his family. In addition our music therapist recorded Mr Yiu's heartbeat, as a memento for his unborn child.

Mrs Yiu said, "Even though his stay was short, we are very grateful for the care he received. What he managed to do was meaningful and he was comfortable. His pain was well-managed. With the full-length window, he could see outside even when he was lying in bed. Being in a single room, his friends were able to visit him and we could spend as much time with him as possible. We would also like to thank the social worker and therapists for helping to create the meaningful mementos."

She ended with gratitude, "The hand cast looks very real, you can see the lines on his hand. When I miss him, I will look at his photos, and also the hand cast that we made."

CARING FOR EVERY STAGE OF LIFE

Training primary care doctors to provide palliative care empowers them to journey with their community from cradle to grave.

In celebration of commitment and knowledge, the 8th Graduate Diploma in Palliative Medicine (GDPM) Graduation Ceremony in September 2023 brought together 28 graduates to honour their accomplishments. The 2022/23 cohort from this postgraduate programme, a collaboration between the Division of Graduate Medical Studies, an academic unit at the National University of Singapore Yong Loo Lin School of Medicine, and the Chapter of Palliative Medicine Physicians, comprised a diverse group of professionals with medical backgrounds, including five General Practitioners (GPs). Since its inception in 2014, the 10-month programme has seen more than 180 graduates, whose motivations for participation are as varied as the backgrounds of the graduates themselves.

TAKING ON PALLIATIVE CARE TRAINING

One of the graduates, Dr Tan Sai Tiang, is a GP at Hua Mei Clinic, an initiative by the Tsao Foundation. In her work at the clinic and Hua Mei Centre for Successful Ageing's Home Care programme, she took care of many elderly patients — some had advanced dementia while others were frail, experiencing limited mobility, and grappling with multiple end-stage medical issues.

For Dr Tan, the lectures on symptom control and disease trajectories of different cancer and non-cancer conditions gave her the confidence to manage patients with life-limiting conditions. "In my work as a GP managing patients with advanced dementia and frailty, I have learnt to adopt a gentler pace focusing on communication and shared decision-making. For my patients with end-organ impairment, I am able to anticipate the potential complications and start conversations early and opportunistically about their values and care goals," shared Dr Tan.

Beyond managing physical symptoms, Dr Tan is also able to address psychosocial aspects such as patients' questions and worries related to end-of-life matters. "Spirituality and death are subjects that most people, including doctors, avoid discussing until an existential crisis. The GDPM programme gave me the knowledge to help patients and their families face the future, including death, without excessive anxiety and fear," she added.

"IN MY WORK AS A GP MANAGING PATIENTS WITH ADVANCED DEMENTIA AND FRAILTY, I HAVE LEARNT TO ADOPT A GENTLER PACE FOCUSING ON COMMUNICATION AND SHARED DECISION-MAKING."

DR TAN SAI TIANG

WORDS **SINGAPORE HOSPICE COUNCIL** PHOTOS **NUS YONG LOO LIN SCHOOL OF MEDICINE, DR CHRISTOPHER ONG, DR TAN SAI TIANG**

Another graduate from the programme is Dr Christopher Ong, a GP with healthcare platform Speedoc who makes in-person house visits. Like Dr Tan, he encounters many elderly patients with life-limiting illnesses during his home visits and nursing home rounds. With only basic palliative care knowledge from medical school, Dr Ong expressed, "I often felt inadequate and inexperienced in their clinical management." After going through the training and clinical attachments in different palliative care settings, the experiences and knowledge gained from the GDPM programme were invaluable in informing his daily work.

TURNING THEORY INTO PRACTICE

The graduates wasted no time in applying what they learned to their medical practice. One such example was illustrated by Dr Ong who looked after an increasingly frail elderly lady with advanced dementia. He was able to build a strong rapport with her family and treated her for many acute illnesses along the way. During conversations with her and her family, he discussed Advance Care Planning, explored her family concerns, wishes and helped them achieve their goals. The patient's illness eventually worsened and she passed away at home in the presence of her family, who was well-prepared to look after her. Dr Ong was present throughout the journey with them and was eventually the doctor who signed her death certificate.

When Dr Tan's own brother was placed under palliative care in early 2023, the knowledge she was gaining from the GDPM programme came in useful in helping her guide her family through various challenges. "At each crisis point, I was able to use the techniques I learnt from the course on communications to empathise with my niece's feelings and affirm her positive efforts in caring for her father," Dr Tan recounted.

ENGAGING PRIMARY CARE DOCTORS

In line with the 2023 National Strategy for Palliative Care to increase palliative care capacity

Top and left: Lecture and break-out dicussions during the GDPM programme; Opposite page: Dr Tan's brother, James, with his daughter, taken on the day before his passing

"PALLIATIVE CARE COMPLETES THE CARE MANDATE OF EVERY FAMILY PHYSICIAN TO PROVIDE...HOLISTIC CRADLE-TO-GRAVE CARE FOR OUR PATIENTS."

DR RAYMOND NG

and train more healthcare workers, Singapore Hospice Council (SHC) is working towards increasing engagement with GPs and polyclinic doctors in the delivery of palliative care to Singaporeans.

Early palliative care can benefit patients diagnosed with life-limiting illnesses by supporting them to live well with their condition. Symptom management, caring for the mental and emotional well-being of patients and having conversations related to end-of-life care planning are some of the various ways primary care doctors can play a part.

Dr Tan emphasised that "the rapport and relationship a GP has built over the years with their patients place them in an excellent position to help the patients and family navigate this difficult last chapter". With primary care doctors providing palliative care alongside specialists and community care providers, patients and their loved ones can receive more comprehensive and continuous support on their illness journey.

Dr Raymond Ng, chairperson of the GDPM programme, said, "Palliative care completes the care mandate of every family physician to provide continuing, comprehensive and holistic cradle-to-grave care for our patients. It is hoped that with more primary care professionals gaining knowledge and skills in palliative care, we are able to realise the fullest potential and privilege that family physicians have in caring for their patients, right to the end."

Scan to read
more information on the GDPM Programme

Top: Dr Christopher Ong; right: Discussions in class allow for the sharing of experiences

EXPRESSING LOVE THROUGH ART

Outram Community Hospital's Arts for Healing programme enabled a patient on life's last journey to show his appreciation for his beloved wife by creating a thoughtful piece of art.

As patients spend time away from their homes in hospital, a lack of social engagement and purpose will start to affect their mental well-being. Realising the importance of social interaction to their patients' recovery, SingHealth Community Hospitals (SCH) launched the Arts for Healing programme, which aims to keep patients meaningfully active and engaged during their stay by having them take part in various forms of art.

Art allows patients to express their creativity and emotions in many ways such as painting, drawing or crafting.

One of the patients who truly appreciated the programme was Mr A, a palliative care patient at Outram Community Hospital (OCH) who spent his last days learning to paint. He found solace in the strokes of his paintbrush on the blank canvas. It was during one of the art sessions that he expressed his wish to present a handmade gift to his loving wife before passing on.

The care team obliged and provided him with a gift box, which he dutifully decorated despite his ailing condition. To him, overcoming his condition to apply each stroke of paint was a testament to his love for his wife and reflective of the beautiful memories that they created together.

This was his way of expressing his love and gratitude for her dedication to him all these years.

"Many of our palliative patients have last wishes. In our care for them, we help them and their families realise how precious these last moments are and also facilitate the fulfilment of those last wishes," explained Dr Loo Yu Xian, Director of SCH Supportive and Palliative Care Service.

He added, "Introducing art to our patients is a simple but effective way of hearing their inner voice. It allows many of our patients to express their feelings when they are shy or uncomfortable speaking out."

Understanding patients is crucial and the care team would learn more through guiding them, listening to their needs and working on the necessary steps to be taken when accommodating their needs. In this case, the art instructor will guide the patients, allowing them to choose the subjects which they wish to focus on. At the same time, patients would be reassured that there is no right or wrong in art making.

Facilitated by the Outreach and Volunteers team at OCH, the Arts for Healing programme enlists the help of volunteers and professional instructors to introduce patients to different types of community art such as rangoli, batik painting, clay making and pastel nagomi. The programme is not only open to palliative care patients but also those undergoing rehabilitative care, such as after strokes. It is also designed to connect patients to different forms of visual and performing arts that can be commonly found in the community.

"Guided by professional instructors and supported by our dedicated staff and volunteers, the programme aims to create a meaningful connection between instructors, volunteers and patients during their sessions, inspiring creativity and hope," said Ding Xin Yi, an executive on the Outreach and Volunteers team, with a smile.

WORDS & PHOTOS **SINGHEALTH COMMUNITY HOSPITALS**

From left: Outreach and Volunteers executive Ding Xin Yi, Director of SCH Supportive and Palliative Care Service Dr Loo Yu Xian

ON YOUR OWN TERMS

The Tzu Chi palliative care team shares how they have helped fulfil two patients' last wishes as they approach the end of their lives.

WORDS **PAN ZAIXIANG** PHOTOS **TZU-CHI FOUNDATION (SINGAPORE)**

Clockwise from far left: Madam Regina Tan looking through some old photos of her husband, including one taken on holiday (left); Physiotherapist Lim Beng Kooi (right) during a regular therapy session with Madam Lye (left); Dr Ho Xin Qin providing support during patient visits; Tzu Chi palliative care nurse Nancy Tan (right) preparing Madam Lye for her long-awaited visit to the temple

Initially admitted to the hospital due to liver cancer, Mr Simon Lee's condition, unfortunately, took a turn for the worse soon after. It then became clear that he did not have long to live. According to his wife, Madam Regina Tan, he threw a fit and was adamant about returning home to spend his final days.

She recalled, "He was shouting and kept insisting on going home. He said that if he were to go home this time, he would not return to the hospital. Therefore, I understood what he meant: he wanted to spend his last days at home."

While she wanted to fulfil her husband's wish, she was unsure how it could be carried out. It was then that the Tzu Chi palliative care team came forward to provide the required support and help with hospital discharge procedures.

"I didn't know what to do, but Nurse Nancy Tan comforted me and told me not to be afraid and that she would help my husband fulfil his wish," Madam Tan added.

Six days after being discharged from the hospital, Mr Lee passed away peacefully in the comfort of his home. With her late husband's wish fulfilled, Madam Tan was deeply appreciative of Tzu Chi's help, as the team's presence had given her the confidence to handle the uncertainties during her husband's final days. It also gave her the closure she needed.

Dr Ho Xin Qin, a medical doctor on the Tzu Chi palliative care team, explained, "The patients usually wish to remain at home but sometimes feel helpless as their family members may not be able to care for them. The role we can play is to support them at home together with their families."

FINDING FULFILMENT

Another patient under home palliative care, Madam Lye Qui Ying, also fulfilled one of her last wishes despite her ailing health with the help of the Tzu Chi palliative care team. When she was first referred to Tzu Chi, Madam Lye was lacking in energy and seemingly just waiting for the end.

Physiotherapist Lim Beng Kooi on Tzu Chi's palliative care team shared, "When I first met Madam Lye, she was listless and lying in bed. Our mission was to get her out of bed, so we needed to help her regain confidence and give her something to look forward to."

Madam Lye had been harbouring hopes of visiting a temple to listen to scriptures for quite some time. However, she had been unable to do so due to poor health and mobility issues. When the Tzu Chi palliative care team found out about this, they decided to make plans to realise her wish. One objective was also to give her something to look forward to despite her limited time.

"Once the therapist agrees that she can sit for a longer period of time, we will arrange to bring her to the temple. Going out will give her positive energy from seeing beyond the four walls of her home," explained palliative care nurse Ms Tan.

While bringing her to the temple was already on the cards, the entire plan had to be brought forward after Madam Lye's condition took a turn for the worse. Her tumour had suddenly ruptured, and she had to be sent to the hospital. On seeing Madam Lye's situation and how she was gradually sinking into depression, her son, Mr Ho Miaw Choong, asked if Tzu Chi could help to arrange for the temple visit that very month.

The Tzu Chi team then began their preparations for the visit. Given that she was wheelchair-bound, significant logistics had to be involved. Suitable transport, which could accommodate the patient and wheelchair, was arranged beforehand. While the overall process was rather tedious for a seemingly simple visit, all the effort felt worthwhile upon seeing the smile on Madam Lye's face when she went about her prayers.

After witnessing his mother's joy firsthand, Mr Ho was naturally very thankful for the support from the Tzu Chi team. He shared, "My mother had mentioned this (visiting the temple) before, but we did not dare to bring her because she had injured her spine after a fall. My car could not ferry her, so I needed to find a suitable vehicle, and Tzu Chi came forward to help.

"She is old and tires very easily. But if it is something that she wants to do, even if it is just being there for a short while, I think it is still worth it. I am very pleased that we managed to fulfil one of her wishes, and this is made possible with so many people helping."

As palliative patients approach the tail end of their lives, they are bound to have certain unfulfilled last wishes. Although it might not always be possible to realise all of them, the Tzu Chi palliative care team still strives to do its part by accompanying the patients right until the end. With this unwavering support and close companionship, it will hopefully allow them to complete their final journey with dignity and no regrets.

On the last leg of life's journey, while there may be many things that we hope to do, they might yet be beyond our limits due to worsening health and circumstances. Helping patients to complete their final journey in life without pain and regret is our goal. The Tzu Chi palliative care team has been tirelessly supporting patients over the years, accompanying them through their final journey with love and quality care.

Scan to watch
more inspiring stories from Tzu Chi

PREPARING FOR WHAT MATTERS IN THE END

The Singapore Cancer Society Hospice Care team's state of preparedness and keen assessment of patients ensure they spend their remaining days in comfort with their family.

WORDS DR. TEOH REN SHANG, SENIOR RESIDENT PHYSICIAN; AMANDA TAY, SENIOR SOCIAL WORKER; LIM YI XI, ASSISTANT SENIOR SOCIAL WORKER; VIVIAN KOO, SOCIAL WORKER (SINGAPORE CANCER SOCIETY (SCS) HOSPICE CARE TEAM & SCS PSYCHOSOCIAL SERVICES) PHOTOS SINGAPORE CANCER SOCIETY

From far left: The family's much-treasured celebration of the first daughter's birthday while on staycation with Rokiya 10 days before her passing.

Planning for a patient's death begins even before the Singapore Cancer Society (SCS) Hospice Care team embarks on home visitations. While vetting referral notes, our clinicians would have begun analysing the patient's information, such as the diagnosis, co-morbidities, current clinical condition, symptoms, and prognostication. By the first visit, the hospice team would have sized up the possibilities for end-of-life care — symptom burden, caregiving competency and dynamics, suitability of the home environment, and their preferences for terminal care.

As the reality of death draws nearer, the things that truly matter may start to reveal themselves. Patients' deeply seated wants tend to revolve around relationships with loved ones and may involve aspects of grief and needs for closure. Their requests to fulfil these wants vary from meeting particular people and family get-togethers, to doing a legacy project for their loved ones. Choosing to pass away at home or in an institution also reflects what matters to patients and the kind of experiences and memories they would like to leave their loved ones. The SCS Hospice Care team strives to prepare patients and their caregivers to face death in a way that matters the most to them.

EMBRACED BY FAMILY

Many terminal cancer patients like Rokiya wish to be cared for and surrounded by their loved ones as they pass on at home. Prior to her death, Rokiya wished to spend as much time as possible with her children, aged between 13 to 22 years old. Rokiya was referred to Ambulance Wish Singapore (AWS) to fulfil her wish for a staycation with her family and extended relatives. AWS prepared a series of bonding activities for the family from games to cooking, including a baking class for Rokiya and her family to enjoy together.

As her cancer progressed, Rokiya was unable to move around independently without assistance. Her husband, Rafi, resigned from his full-time job to dedicate his time and love to care for Rokiya at home throughout her illness.

During her final weeks, Rafi and the family saw Rokiya's condition fluctuate. At times, she would lose consciousness before becoming communicative again. "When her health went downhill again, we were prepared because SCS doctors told us what to expect," said Rafi.

Rokiya's wish to pass away at home with loved ones by her side was fulfilled through the dedication of family members and relatives who took turns caring for her, alongside the support from the SCS Hospice Care team who ensured Rokiya's symptoms were managed well to keep her as comfortable as possible.

LOVE-FILLED SEND-OFF

Diana and Isarudin had promised to be there for each other in sickness and in health. When Isarudin was diagnosed with cancer and became completely bed-bound, it was important for Diana to be able to care for Isarudin in his last days, just as he had cared well for her in their marriage.

When Isarudin's condition took a turn for the worse, he was hospitalised and had to rely on an oxygen concentrator to breathe better. Knowing that her husband would want to pass on at home with loved ones by his side, Diana sought the help of the SCS Hospice Care team to consult with the hospital on the possibility of Isarudin returning home for his last days. The team was able to bring about a compassionate discharge, as well as the provision of portable oxygen concentrators so that Isarudin could be cared for in comfort in his last days.

Diana expressed her gratitude to the team, "Without the SCS Hospice Care team's help to speak to the hospital doctors, my husband would not have been able to return home and pass on peacefully with his family and friends around him." By honouring his wishes, Diana was also doing her best for Isarudin as a caregiver and spouse.

ASSURANCE AND PEACE

With multiple concerns and needs surrounding end-of-life care, Bian Teck did not know if receiving medical care at home was a possibility. Furthermore, he was an easy-going person who did not wish to burden his family. Nevertheless, his family and healthcare team rallied together towards the final weeks of life, so that he could be discharged from hospital to receive palliative care at home. The SCS Hospice Care team prepared for Bian Teck's various care needs, from subsidised nursing aid to medical supplies, giving him the assurance he needed.

With adequate preparation and management from the SCS Hospice Care team, his passing as described by his brother Bian Sing, was "very comfortable". Bian Teck was with his cherished loved ones — his wife, siblings and niece — by his side. As a cancer survivor, Bian Sing started participating in the SCS Race Against Cancer and SCS Relay For Life in memory of his late brother and in support of people impacted by cancer.

These stories of Rokiya, Isarudin and Bian Teck illustrate the profound impact of having a palliative care team that not only takes care of their patients' physical comfort but also facilitates the fulfilment of their last wishes. Whether it is creating cherished moments with family, honouring their vows, or ensuring a comfortable and peaceful transition at home, the SCS Hospice Care team plays a pivotal role in making these preferences and desires a reality. HL

WHETHER IT IS CREATING CHERISHED MOMENTS WITH FAMILY OR ENSURING A PEACEFUL TRANSITION AT HOME, THE SCS HOSPICE CARE TEAM PLAYS A PIVOTAL ROLE IN MAKING THESE DESIRES A REALITY.

EASING THE BURDEN FOR PAEDIATRIC PATIENTS

A medical social worker in the Star PALS (Paediatric Advanced Life Support) programme at HCA Hospice since 2016, Desmond Tan works closely with families and journeys with them, supporting them through their challenges and helping patients and their families live well.

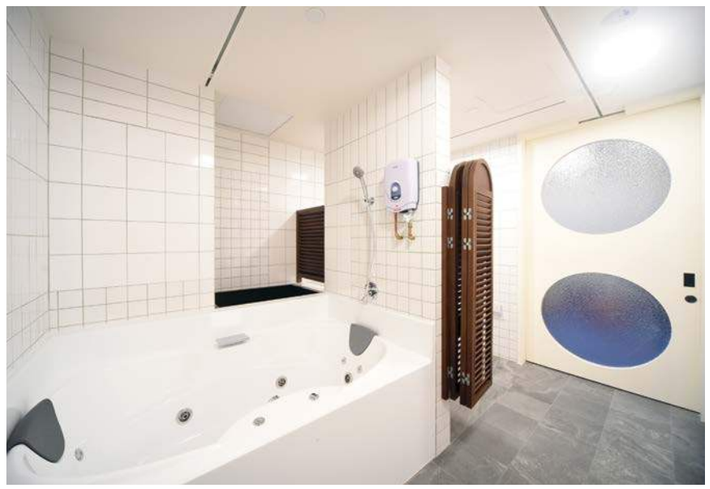
Please describe your role as a medical social worker in palliative care. What are some typical challenges that you help families resolve?
We help patients and families to address the impact of illness, loss and bereavement by connecting them to the support that they need. Typical challenges include navigating the healthcare and social service systems to gain access to the right resources and fostering improved family dynamics to support patient care.

Please share with us about an experience or case study that had a profound impact on your work.
Even the smallest acts can have a positive impact on patients and their families, so I have learned not to downplay the value of seemingly small gestures. It is not uncommon to encounter family members who are openly unreceptive towards healthcare professionals. This was a case where my attempts to engage a family member, F, were particularly challenging and unsuccessful. I continued to work with other family members on managing their grief and providing other small acts of practical assistance over time. The patient eventually passed away. I managed to catch up with F again who behaved in a warm and appreciative manner towards me as my modest contributions to the family were recognised.

What are unique aspects of working with paediatric patients? How do you adapt your communication style to engage them effectively?
I consider their developmental stages based on their age and varying levels of understanding, and I use simple words to match their comprehension level. It is essential to include parents and caregivers in the process by seeking consent and keeping them informed.

What are some programmes or activities at HCA that help maintain a sense of normalcy and bring joy to patients and their families amidst their challenges?
To address the emotional and social well-being of our paediatric patients and their caregivers, we have a dedicated space at our Oasis@Outram day hospice for them to spend quality time together or for respite. They may choose to use the jacuzzi, bake, or even join in the daily activities for the adult patients, such as arts and crafts.

We also run the Twilight programme to support the unique needs of our patients who are aged 18 and older. Navigating emerging adulthood is particularly challenging for individuals with serious illnesses, as their aspirations often take a back seat. By empowering and supporting these patients to pursue their goals and aspirations, we hope to enhance their quality of life.



Left: Jacuzzi at Oasis@Outram Day Hopsice where paediatric patients can enjoy with their family; Opposite page: Medical social worker Desmond Tan (second from right) with his colleagues

INTERVIEW **SINGAPORE HOSPICE COUNCIL** PHOTOS **HCA HOSPICE**

What advice would you like to share with families about having open conversations on matters relating to end-of-life and being supportive of their loved ones' wishes and preferences?
This is the elephant in the room, despite many families knowing these conversations are important, it is helpful to reflect on and pay attention to the negative effects that avoiding such conversations can have on family dynamics. People may notice relationships becoming distant or even strained. Open conversations can draw people closer and foster reconciliation.

For families considering a home death, what should they take note of?
Caregiver training is essential, and respite support will be helpful to manage caregiver burnout. Families may consider arranging for a trusted person to take care of practical post-death matters (such as the wake arrangement or notifying family members) so that they have time to be fully present for their loved one.

How can families best prepare themselves emotionally and find closure in the final days leading to the farewell?
Each individual and family's journey is unique. It is generally helpful to create a safe space to allow for reflection on what truly matters, expression of feelings, and fostering meaningful connections during the final days. For instance, exchanging words of forgiveness, love, and gratitude can be cathartic.

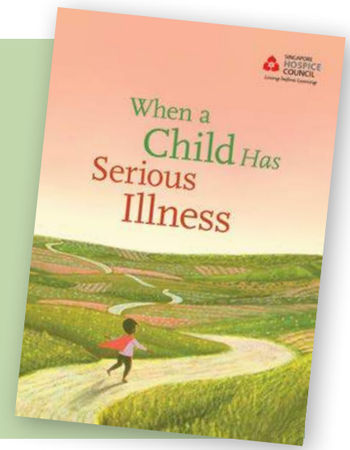
What are your self-care practices?
I am focused on getting the basics right: eat right, exercise, have sufficient me time, and quality sleep.

What is the biggest takeaway from your work?
Life will always be a mixture of positive and negative experiences, and embracing both allows us to foster greater resilience, and empathy towards others with differing views.

What does "Living before Leaving" mean to you?
Strive to be mindful of the present, instead of being preoccupied with the past or future.

Desmond is also a contributor to Singapore Hospice Council's paediatric palliative care resource, *When a Child Has Serious Illness*. In this book, he shares how legacy building can bring comfort and connection to families.

Scan to read
When a Child Has Serious Illness



LIVE WELL TO LEAVE WELL

If today were your last day on Earth, would you be completely satisfied with the life you have lived so far, or might there be a few lingering regrets?

Although talking about death and dying might be uncomfortable, in palliative care, it serves as a gateway to understanding and addressing unmet needs, fostering open communication, and guiding patients and their loved ones towards a more meaningful end-of-life experience.

Some patients share regrets they have, such as wishing they spent more time with family or went on that trip they always wanted. Others feel at peace; they take each day as it comes, satisfied with the life they had. The way you lead your life can profoundly influence the experience of its conclusion.

Living life with the end in mind allows us to reflect on what really matters. It is a call to live each day authentically and with purpose. Whether you are a patient, a caregiver, or just living your life normally, starting to live well on your own terms ensures that when the time comes, you can leave well.

Here are some things to consider:

- What values are most important to you?
- What life goals do you want to achieve?
- Are you holding back on anything because of fear or doubt?
- What are you currently doing that does not fulfil you?

Listen to the *Live Well. Leave Well.* podcast to hear different perspectives from caregivers, patients, and healthcare professionals from the world of palliative care sharing their life lessons on love, dignity, strength, and more.

LIVE WELL Leave WELL
by Singapore Hospice Council

Scan to listen
to the *Live Well. Leave Well.* podcast

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535 Kallang Bahru #03-09 GB Point, S (339351)
T: 6538 2231 • E: info@singaporehospice.org.sg
www.singaporehospice.org.sg

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