

Embracing

every moment of life's journey

Leaving memories behind

Palliative Care Beyond Cancer

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Mohd Soud

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CONTENTS



- 2 SHC Members
- **3** Executive Director's Note
- **4** Bonding in Care
- **8** Embracing every moment of life's journey
- 11 Honouring the legacy
- 12 Palliative care beyond cancer
- **16** Living life with meaning and jov
- 18 Enhancing healing through art therapy
- **20** Breaking free from the limits of art
- 22 Never give up
- **24** Ask the Experts: Compassion and dedication in care
- 26 Leaving memories behind
- 28 Navigating grief in the workplace

Make a Donation!



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

> Donations above \$50 are eligible for 250% tax deductions.

EXECUTIVE DIRECTOR'S NOTE

■ he World Health Organization defines palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual". Hence, while the palliative care movement started with helping cancer patients, palliative care at all levels of care is available for patients of all life-limiting illnesses, including but not limited to cardiovascular disease, major organ failure, advanced dementia, or the extreme frailty of old age.

Unfortunately, many a time, during outreach activities, we have heard the general public respond, "Oh, I thought it was only for cancer patients."; "I didn't know that!"; or "If I had only known..."

This issue of *The Hospice Link* looks into the work our member organisations are doing on non-cancer conditions, such as the Integrated Care for Advanced Respiratory Disorders (ICARE) rehabilitation programme that Ren Ci Community Hospital developed with Tan Tock Seng Hospital (page 18), the home care and caregiver support for stroke patients offered by Tzu-Chi Foundation (page 22), and the progression from home care to day care for Haslina Wannor, a patient with advanced lung disease whose care team has helped manage her symptoms more effectively (page 16).

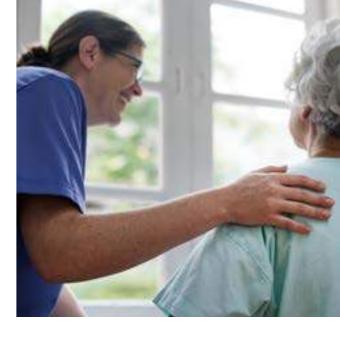
ABOUT THE ARTWORK ON THE COVER

Family Trip to the Waterfall, 2022 Acrylic and Marker on Canvas

By Mohammed Saad Bin Hussin

Patient, Dover Park Hospice Daycare

Saad created this artwork as he reminisced on his younger days when he travelled to Malaysia and visited the waterfalls with his family. These precious memories with his family are very important to him.



It is also heartening to learn that patients under palliative care are supported in living out the last chapters of their lives with meaning and fulfillment. Haslina embraced art therapy and used her newfound interest to raise funds for Assisi Hospice. St Joseph's Home resident Mr Thong Chew Lim found passion in reaching out to youths to inspire them with his life stories and his art (page 20).

While the common perception that palliative care is only for those facing cancer still remains, this is gradually changing as more people with other types of illnesses are introduced to this option. We can all do our part by spreading the message that palliative care for non-cancer patients is also worthwhile in improving the quality of life on the journey at the end of life.

Sim Bee Hia **Executive Director** Singapore Hospice Council

BONDING IN CARE

NEWS, VIEWS, UPDATES AND SPOTLIGHTS



SENIOR DIETITIAN KUA PEI SAN

Outram Community Hospital

Dietitians collaborate with the palliative care team to offer personalised dietary advice to patients with life-limiting illness, in order to optimise their nutrition needs and improve their quality of life. Dietitians assist in the formulation of customised meal plans that cater to individual dietary needs, symptom management and taste preferences, all the while aligning with family expectations and addressing their concerns.

Tell us about a memorable incident and what you learned from it.

When I was working as a junior dietitian at a private hospital, I had to advise an elderly husband on tube feeding for his wife, who had a stroke, as the family had chosen home care. He was in distress, fearing the consequences of stopping feeding. This experience taught me that a dietitian's role involves emotional support, managing expectations, and the importance of empathy and caution in providing practical dietary suggestions that impact a patient's survival and quality of life.

What inspired you to join this profession?

Growing up, my family battled diabetes, kidney failure, and different cancers. I witnessed how surgeries and dialysis impacted their lives. My aim was to provide dietary guidance to prevent non-communicable diseases. As a dietitian, I now see malnutrition affecting elderly patients. I hope to reduce its impact through diet counselling and collaborative projects with other healthcare professionals.

Upcoming Events

ST LUKE'S HOSPITAL COMPASSIONATE CARE CONFERENCE 2023

Themed "Healer, Heal Thyself: Rising to the Challenges of Compassionate Care", learn how you can play a pivotal role in fostering a culture of compassion to uplift your patients, clients and teams from renowned experts through impactful keynotes, panel discussions and workshops. Register at slh.org.sg

When: 31 January 2024, 8.30am - 5.30pm
Venue: One Farrer Hotel, Ballroom, Level 6
Contact: 68952786 / event_secretariat@stluke.org.sq

"LIVING BEFORE LEAVING" ASK THE EXPERT SERIES

Ask the Expert series is a Q&A format with a multidisciplinary care team via Zoom covering a wide range of topics, from psychosocial care to food and nutrition. Join us to delve deeper into these topics and engage with our experts in these informative and interactive sessions. Look out for more information on the next session on our social media and website: singaporehospice.org.sg.



DYING WELL STARTS WITH YOU

Facing the end of life can seem scary when we are unprepared and lack information. Let's debunk some common myths about palliative care. Prepare for a good death by owning your end-life-journey with the right facts!



THE HOSPICE LINK • DECEMBER 2023 - FEBRUARY 2024

SWEATING IT OUT FOR LIVE WELL CHALLENGE 2023

More than \$100,000 raised in support of quality palliative care for everyone









Singapore Hospice Council (SHC) organised the #SHCLiveWellChallenge from 26 August to 8 October 2023, a virtual fundraising event that encompassed cycling, running and walking in support of quality palliative care. Over six weeks, individual participants pledged to cover target distances and reached out to their family and friends for donations.

The campaign culminated in an inperson finale event at the SHC "Live Well. Leave Well." Festival held at The Plaza, National Library Building. On Saturday, 21 October, BFT Geylang Bahru gym members and the public signed up to clock distances on skiing, rowing, and cycling exercise machines. All participants were thoroughly committed and surpassed the set target distance goal, raising a total of \$60,000 by noon!

- BFT Geylang Bahru members cheering or teammates at the ski machine
- 2 Participants were challenged to cover as much distance as possible on the machines in
- 3 The wheels on the bike go round and
- ound for charity

 Temperature of the base government of the registed participants posing with their SHC goodie bags after the workout

 Presentation of tokens of appreciation for
- BFT Geylang Bahru instructors. Left to right: Mr Syam, SHC Executive Director Ms Sim Bee Hia, Mr Richardo Chua, Ms Melia
- 6 A total distance of 150km was covered to raise \$60,000 at the "Live Well. Leave Well." Festival on 21 October



Living Well is living a meaningful life by bringing meaning to other people's lives."

MR GEORGE WONG



"The #SHCLiveWellChallenge is not just a fundraiser; it's a movement that empowers individuals and communities to embrace wellness as a way of life while supporting patients and families on palliative care," said the gym's owner, Mr Richardo Chua. "We believe that by coming together, we can make a significant impact on the lives of those with life-limiting illness."

By the end of the fundraising campaign more than \$100,000 had been raised by over 150 challengers, which will go towards advancing general public understanding of hospice and palliative care in Singapore through SHC's community outreach events and activities, training, conferences and talks for healthcare professionals, caregivers, volunteers, and more. SHC would like to thank





TOP FUNDRAISER

Mr George Wong Distance covered: 258km Funds raised: \$16,700



BFT Geylang Bahru for its generous contribution of their time and the use of exercise machines, and every single individual who participated and made a difference in the #SHCLiveWellChallenge 2023.



The SHC Live Well Challenge continues until 31 December on Giving.sg. Scan here to donate or find

EMBRACING EVERY MOMENT

OF LIFE'S JOURNEY

The highlights of the 10-day "Live Well. Leave Well." Festival included the launch of a podcast and a book, art-making, a chat show, therapy pets, a forest therapy session, and more.

The "Live Well. Leave Well. Festival" (LWLW Festival), organised by Singapore Hospice Council (SHC), was a transformative 10-day event that took place from 13 to 22 October 2023, designed to foster a deeper understanding of palliative care and promote early conversations around end-of-life care within our community.

Marking World Hospice and Palliative Care Day, in recognition and support of the critical role of hospice and palliative care, the LWLW Festival at The Plaza at the National Library Building featured family-friendly programmes with 39 partners, including a diverse range of talks and activities showcasing different disciplines of palliative care.

On 13 October, the Opening Ceremony was graced by SHC Founding Chairman and Trustee Dr Seet Ai Mee, who also launched the *Live Well. Leave Well.* podcast with a few of its featured guests. Produced in collaboration with SHC member organisations and individuals from all walks of life, each episode will share a collection of stories and reflections centred on life values from the world of palliative care.

Another highlight was the launch of SHC's paediatric palliative care book on 19 October, targeted at families of children with serious life-limiting illness. *When a Child Has Serious Illness* was put together by an expert panel of medical professionals to offer insights and practical advice to help parents navigate myriad challenges. The Guest of Honour, Ms Rahayu Mahzam, Senior Parliamentary Secretary for the Ministry of Health and Ministry of Law, was invited to present the books to SHC member organisations, charities supporting seriously ill children and their families, libraries, and institutes of higher learning.

The LWLW Festival was an incredible journey celebrating life, compassion, and the importance of a dignified farewell. SHC would like extend its heartfelt thanks to everyone who made this event possible. Together, we can create a community of compassion and care.





SHC Executive Director Ms Sim Bee Hia, SHC Board Members and GOH, Dr Seet Ai Mee, officially opened the LWLW Festival.
Q Launch of the Live Well. Leave Well. podcast with featured guests and GOH at the Opening Ceremony.
Left to right: Lim Yu Beng, Nurse Nancy Tan, SHC ED Ms Sim Bee Hia, Dr Seet Ai Mee, Lee Wai Leng, and Remesh Panicker











Senior Boleh Chimes Choir from Assisi Day Hospice took to the stage with their musical talents to bring the opening ceremony to a wonderful close.

Sit back and relax at the screening of the movie Up.

 "What's in my safe box? An Advance Care Planning Art-Based Workshop" participant creating her safe box.

Therapy Dogs Singapore and furry volunteers were on site to share about how pet therapy plays a part in palliative care.

Participants showing off their beautiful creations at the Nagomi Art Corner.

3 SHC ED Ms Sim Bee Hia and participants with their artwork after the "Expressing Gratitude through Art Therapy" workshop conducted by Dover Park Hospice.





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







- Emcee Carine Ang and Tzu-Chi Foundation volunteer Dr Chee Chen Sin performed songs in dedication and celebration of the lives of
- 10 "You Light Up My Life" In Memory of Our Loved Ones Memorial Night attendees made memory jars and shared fond me to commemorate their loved ones who have passed on.
- TRejuvenated participants after a forest therapy session at Singapore Botanic Gardens conducted by Art Therapist and certified Fores Therapy Guide Ms Yenn Ang.
- (Die Die Also Must Say" chatshow by Lin Ru Ping and Chen Jian Bing where they shared more about the importance of end-of-life conversations, planning and palliative care.
- Big smiles at the Stages of Life Angel Wings Display.
- Visitors were able to learn more about palliative care services and
- sign up for various talks and workshops.

 The cover of When a Child Has Serious Illness was unveiled at the book launch with GOH Ms Rahayu, SHC Board members, SHC ED Ms Sim Bee Hia, and book contributors Dr Siti Nur Hanim and Ms Ren Hui







Scan to watch the LWLW Festival

HONOURING THE LEGACY

Recognising each patient's value and life story provides peace, comfort and purpose in the time that remains.

heartbeat of a loved one embedded in a song can be a precious and tangible memory that families can hold on to after their passing. For Ceron, daughter of the late Mr Tan Ann Seng, listening to her dad's heartbeat in sync with the rhythm of his favourite song "always brings back fond memories and closeness which had never left, offering comfort and reassurance".

Mr Tan, affectionately known as Uncle Tan, was St Luke's Hospital's (SLH) patient-turned-volunteer-andstaff who found a new lease on life and a strong network of friends when he was admitted to SLH for stroke rehabilitation. Realising his improvement could be a motivation for others, he started volunteering as a patient-motivator and later joined SLH as a Service Ambassador. A friendly face who greeted all who passed through the hospital lobby, he chatted with patients and their families, helping them to see possibilities despite health challenges.

After a cancer relapse last year, Mr Tan was warded in the High Dependency Unit of an acute hospital. His last wish was to be transferred

back to SLH, but his deteriorating condition made it impossible. After a family discussion, he became the first patient in SLH's Project Heartbeat, where a music therapist recorded his heartbeat over a 12-hour period before his passing. In a poignant tribute to his life, his heartbeat was masterfully integrated into his most beloved song, "Amazing Grace". Filled with gratitude, Ceron shared, "This unique piece of music is a precious gift that can even be shared with the next generation of my family. It has given me strength during the grieving process and continues to remind me of my dad's perseverance and resilience."

For patients at the end of life, reflecting on their life's legacy can help them find peace and closure, as well as comfort and purpose during their final days. Drawing upon the late pioneer in near-death studies, Dr Elisabeth Kübler-Ross' Five Stages of Grief™ model, paired with SLH's music therapy model for palliative care, an assessment is conducted to determine patients' suitability for Project Heartbeat.

The music therapy team approaches each patient with care

and is respectful of their needs and goals for therapy interventions. Music therapists will integrate patients' heartbeats, recorded with a digital stethoscope, into their song of choice. "The resulting piece beautifully encapsulates the essence of each patient and will forever serve as a tribute to their legacy," said Dr Tan Xue Li, SLH's Principal Music Therapist.

To allow more palliative patients to benefit from music therapy interventions and in memory of the late Mr Tan. SLH launched Project Heartbeat, an innovative music therapy legacy project, at its "Celebrating Silver: Circle of Life" charity dinner on 15 September 2023. The annual fundraising event aimed to raise public awareness and underscore the importance of holistic palliative care and support in maintaining the quality of life for patients at the end of life. With a rapidly ageing population, the demand for palliative care is expected to surge in the years ahead.

Project Heartbeat is one of the hospital's many initiatives that are part of its larger commitment to care compassionately for the 'whole person', including the patient's clinical, social, and emotional needs. SLH Chief Executive Officer Associate Professor Tan Boon Yeow added, "Palliative care often goes beyond providing medical support. Through our efforts, we hope to destigmatise death and dying and spread the message that death can be a form of celebration in memory of the person's impact on the lives of many."

Over the years, SLH has been dedicated to enriching lives in the community through the expansion of its core services to provide continuity of care and continues to deepen its specialised capabilities in dementia, rehabilitation, wound and palliative care.



Left: The late Mr Tan interacting with others at SLH as Service



While the majority of palliative care recipients are cancer patients currently, an increasing number of people with other life-limiting serious illnesses also benefit from the multidisciplinary care team's support to maximise their quality of life to the last moment.

he Ministry of Health
Singapore (MOH)
Principal Causes of
Death list for 2022 has
ranked cancer at the top
at almost 24%, with the other lifelimiting non-cancer causes on that list
making up over 57% of the total. In
addition, with Singapore's super-aged
population, demand for healthcare is
projected to increase from those with
conditions such as heart diseases,
advanced dementia, end-stage liver
disease, lung disease, kidney failure,
and stroke, to name a few.

In May 2023, Senior Parliamentary Secretary for Health Ms Rahayu Mahzam reported in Parliament that the number of terminally ill individuals receiving community palliative care has risen by 30% over the last five years, reaching 8,800 patients in 2022. MOH anticipates this rate to increase.

Advanced Practice Nurse Tang Ping Sin at St Luke's Hospital, the expert interviewed for this issue's Ask the Expert column (page 24) has cared for more non-cancer patients, not just in her current position but also throughout her previous placements at Assisi Hospice and Outram Community Hospital, "I've been seeing more palliative patients with endstage organ failure being admitted."

Woodlands Health Senior Medical Social Worker Janice Tng has also experienced a similar increase in her capacity, seeing more patients with kidney disease and end-stage kidney failure opting for palliative care. "For frail patients, dialysis may be associated more with risks than benefits, while others perceive it as a routine that impacts their perceived quality of life, so they prefer conservative management, and thus require palliative care support towards the end of their life."

The founder of the modern hospice movement, the late Dame Cicely Saunders, envisioned compassionate care to address the "total pain" of those facing progressive life-limiting illnesses. This pain can be emotional, spiritual and psychological, and afflicts both cancer patients and those with serious non-cancer illnesses alike.

Palliative care for both cancer and non-cancer patients is a holistic patient-centred approach that recognises each individual's personhood and respects their unique wishes and preferences. The dedicated care team cares for the whole person, taking into account patients' symptoms, psychosocial and spiritual aspects. Palliative care further extends to practical, emotional and spiritual support to their caregivers and loved ones. According to Nurse Ping Sin, the palliative care team seeks to support patients and their families throughout this last journey.



Nevertheless, there are challenges in getting more non-cancer patients to accept palliative care.

ADDRESSING NON-CANCER PATIENT CONCERNS

One challenge for non-cancer patients in accepting palliative care is the uncertainty in their prognosis, according to Deputy Medical Director and Head of Home Care Services at St. Andrew's Community Hospital (SACH) Dr Angeline Seah. "People with non-cancer life-limiting conditions have more uncertainty in their prognosis, with many at high chances of dying if not provided with careful, full active, specialist care, with some dying in spite of that because of the difficulty and complexity of providing such care," she said. There are also those whose life could not be prolonged due to complete organ non-response to treatment, and accelerated deterioration, giving little time to bring in an additional palliative care team.

Dr Seah's colleague, Dr Ng Liling who heads the Community Medical Services, feels that awareness and referral could also play a part. "In the context of the nursing home, the care staff needs to be able to identify residents who are deteriorating so as to make appropriate and timely

referrals. The lack of knowledge or experience to identify a dying resident can result in a delayed transition to palliative care," she said.

To improve access to palliative care, the 2023 National Strategy for Palliative Care by MOH states that one factor is clear training requirements to "build basic palliative care capabilities in nursing homes, home care and primary care".

"At St. Andrew's Nursing Home (Henderson), the nursing home care staff works closely with the SACH Violet Programme Team (VIP@Home), SACH Home Palliative Care Programme, and refers to the VIP team when the criteria for referral is fulfilled," said Dr Ng. This programme was developed by SACH in collaboration with Changi General Hospital and St. Andrew's Nursing Homes to provide care to non-cancer patients; it took home the Singapore Health Quality Service Award 2022 for the Best Team.

Assisi Hospice's Senior Consultant Dr Gwendoline Soh revealed that in 2022, a third of patients admitted into the Hospice's Inpatient, Home Care and Day Care services were noncancer patients and this number is expected to rise. "Available education opportunities in palliative care have allowed and encouraged physicians

and other healthcare professions from different training backgrounds to embark on generalist palliative care provisions within their own scope of practices. More community services have sprouted to serve the increasing demands and recognition of persons with serious illnesses. Assisi Hospice has also worked closely with referring hospital teams from noncancer specialities in assisting with continued holistic care for patients within the community through our interdisciplinary care approach," she said. Despite current efforts, more still needs to be done to reach out to and support this particular group of patients and their caregivers.

However, there are some common barriers that patients' loved ones, caregivers, care teams and even community outreach groups have to contend with.

OVERCOMING COMMON BARRIERS

There are psychological and social barriers that have to be addressed. As medical science progresses, it has become a sort of 'own goal' in that people would rather believe in the success of the treatments than think about palliative care. Death and dying are also considered taboo topics, particularly for the older generation. Furthermore, there is reluctance to

"PROVIDING RESPONSIVE DISEASE
MANAGEMENT AND SYMPTOM CONTROL,
SUPPORTING PSYCHOSOCIAL ASPECTS
AND MAINTAINING QUALITY OF LIFE...
ARE HALLMARK FEATURES THAT CAN
CONVINCE PEOPLE."

DR ANGELINE SEAH, SACH DEPUTY MEDICAL DIRECTOR & HEAD OF HOME CARE SERVICES

make changes while clinging on to a course of treatment, especially where a familiar clinical team is concerned.

"People often prefer the status quo, especially when change is perceived for the worse," said Dr Soh. "Having their own trusted non-cancer physician journey alongside with them through the difficult times remains comforting for patients who have good long-term relationships with them."

This prevalent mindset is also pointed out by Dr Seah, in addition to other factors for patients' reluctance to go for palliative care. "The family's hope of their loved ones being able to survive a bit longer, the patient's willingness to tolerate pain and other symptoms for the possibility of being able to live a little longer, the ability of curative treatment to relieve symptoms, and the worry that complexity of their medical care requires much medical oversight that cannot be performed by the palliative team are some barriers," said Dr Seah.

People are generally not aware that palliative care can go hand-in-hand with active illness management, if deemed appropriate, and should not be looked upon as a sign of 'giving up'. "At the heart of palliative care is holistic patient care, encompassing the physical, emotional, mental and spiritual," said Dr Ng.

Ms Tng agrees, "The general public may not be aware of the psychosocial aspect of palliative care that preserves quality of life for patients and their caregivers by enhancing support for patients who are going through serious or lifelimiting illnesses as well as assisting their caregivers or next-of-kin."

Therefore, healthcare literacy is an aspect that cannot be ignored. Dr Soh stressed, "As our population ages in this current world where information sources are abundantly available, it is also important for systems to support people as they navigate through the information to increase one's healthcare literacy."

ACCEPTING PALLIATIVE CARE FOR NON-CANCER PATIENTS

According to Dr Ng, what she has described as "the pearls" of palliative care for cancer patients can also benefit non-cancer patients as well, such as physical symptom management for the patients and grief management for their loved ones and families.

Although the patients' trajectory of illness has to be communicated clearly, such as the expected restriction on "Daily Activities of Living" and decline, both of which could be unpredictable and more rapid in non-cancer patients in comparison, detecting palliative care needs and responding to them makes it worthwhile. "Providing responsive disease management

and symptom control, supporting psychosocial aspects, and maintaining quality of life in the comfort of their homes without detracting from longevity are all hallmark features that can convince people," said Dr Seah.

In addition, psychosocial interventions and support for non-cancer and cancer patients and their loved ones provided by medical social workers are similar. "Counselling for issues relating to grief, death, and dying, as well as practical ones like financial assistance and care planning, can be offered to patients and their caregivers or next-of-kin as appropriate," said Ms Tng.

"Early conversations about palliative care are essential," said Dr Ng. "It's important to talk about the benefits of palliative care for both would-be residents and their caregivers and families."

Dr Soh concurs. "Raising awareness and enhancing engagement through events, for example roadshows, seminars, workshops, conferences, within the community and within the healthcare sector is important."

Singapore Hospice Council regularly runs a "Living Before Leaving" Ask the Expert series as well as Palliative Care 101 courses. Look out for other activities they organise by visiting their website or following them on their social media platforms.

These awareness-raising activities are meant to serve as conversation-starters about the benefits of accepting palliative care and an end-of-life journey that maximises one's quality of life and provides support for families and loved ones. "Having the difficult and important conversations between healthcare professionals, patients and their loved ones early enough will help with care planning and enhance understanding of patients' hopes and concerns, giving them a chance to address their worries," said Dr Soh.

As Nurse Tang stated in her interview (page 24), "It's a meaningful journey to ensure that it is as smooth and painless as possible for the patients. Each loss is real to us."

And that is the ultimate gift of Dame Cicely's vision, the legacy that every palliative care practitioner upholds: "You matter because you are you, and you matter to the end of your life."



LIVING LIFE WITH MEANING AND JOY

Assisi Hospice is extending palliative care to non-cancer patients in order to improve their quality of life.

hen Dame Cicely
Saunders first pioneered
the modern hospice
movement in the UK in 1967,
she started by caring for dying
cancer patients. Similarly, the
late Professor Cynthia Goh began
the first hospice service with the
Canossian Sisters at St Joseph's
Home in Singapore, by caring for
terminally ill cancer patients. Over
time, palliative care has become an
integral part of cancer care.

In 2022, only 23.9% of deaths in Singapore were from cancer, whereas 57.7% were from chronic, non-cancer serious illnesses,

such as end-stage organ failures in particular (source: Ministry of Health). These include end-stage kidney disease, end-stage lung disease, end-stage liver diseases and advanced neurological conditions (especially advanced dementia). It is only in the recent decade that the role of palliative care has been increasingly recognised for non-cancer conditions. Last year, about a third of admissions into Assisi Hospice's three services — Inpatient, Home Care and Day Care — were for noncancers and this is expected to rise in the near future.

Non-cancer patients are often referred earlier in their illness trajectory, so there are more opportunities for Assisi Hospice's Home Care and Day Care services to improve their quality of life. Last year, Assisi Hospice started to accept selected patients on dialysis into its Home Care and Day Care services, some of whom are struggling with dialysis but are not quite ready to stop. Nevertheless, they benefit from the interdisciplinary team approach to addressing their needs holistically — a few have even improved and have been discharged from Assisi Hospice's service.

t ept s om eh lly

LAST CHRISTMAS, HASLINA CREATED A SERIES OF POSTCARDS WITH HER WATERCOLOUR DESIGNS, ACCOMPANIED BY A SHORT SHARING OF HER PERSPECTIVE ON HOPE, RESILIENCE AND THE UNEXPECTED WISDOM GAINED THROUGH LIVING WITH A CHRONIC TERMINAL CONDITION.

Assisi Hospice also took in more patients with advanced lung disease. This story of Haslina Wannor is a good example of how community palliative care can help such patients live life fully with meaning and joy.

GIVING BACK

Forty-three-year-old Haslina Wannor used to work as a phlebotomist in a hospital, drawing blood from patients for tests. When she was 27 years old, she was shocked to be diagnosed with systemic sclerosis, which is a rare and chronic autoimmune disorder with no cure. Her condition deteriorated and she developed advanced pulmonary hypertension. Over the years, the disease caused severe scarring of her lungs, and her breathlessness continued to worsen. Currently, she needs additional oxygen supply from an oxygen concentrator around the clock.

In January 2021, Haslina came under the care of Assisi Hospice Home Care service and started receiving regular visits from the doctors and nurses. The Care team adjusted her medication to control her symptoms more effectively. In 2022, she started attending Assisi Hospice Day Care Centre where she benefitted from clinical care and therapy sessions, maintaining her strength as much as possible through strength and endurance exercises.

Being dependent on continuous oxygen therapy, it has been challenging for her to go out on her own, but she enjoys the outings organised by staff and volunteers as she gets to explore different parts of Singapore in a safe manner.

Art therapy sessions and the leather craft interest group at Assisi Hospice Day Care Centre bring the joy of learning new skills into her life. Last Christmas, she created a series of postcards that were printed with her watercolour designs, accompanied by a short sharing of her perspective on hope, resilience and the unexpected wisdom gained through living with a chronic terminal condition. Proceeds went towards Assisi Hospice's patient care. It gives her great joy to be able to give back. She said, "I receive more than I give." 🕕



Left: Haslina created a series of postcards to raise funds for Assisi Hospice; Opposite page: Haslina entered the care of Assisi Hospice's Home Care service in 2021

16

ENHANCING HEALING THROUGH ART THERAPY

Ren Ci Community Hospital offers art therapy as part of its ICARE palliative care programme to support their patients' psychosocial and spiritual well-being.



atients who are admitted to an acute hospital due to respiratory problems are usually discharged when they are medically fit, with an outpatient respiratory clinic follow-up and pulmonary rehabilitation programme. However, each exacerbation of breathlessness often worsens physical function, and patients become more homebound and dependent. Often, they may not have the social support to go for outpatient pulmonary rehabilitation and decline even further with recurrent admissions.

This is where Integrated Care for Advanced Respiratory Disorders (ICARE), a rehabilitative palliative programme at Ren Ci Community Hospital (Ren Ci), jointly developed with Tan Tock Seng Hospital (TTSH), comes in. Holistically designed to improve symptom control for patients suffering from chronic breathlessness due to advanced lung diseases, selfmastery and quality of life for patients, suitable candidates are selected at TTSH before being transferred to Ren Ci for inpatient pulmonary rehabilitation.

Left: Mr Ong Chwee Aik with his art therapist, Ms Poh Shu Ning, and his medical social worker Ms Nadirah Aseelah Chee, at his solo art exhibition in the ward

Opioids are initiated and titrated to relieve the patients' breathlessness, and other common symptoms like constipation and anxiety are screened for and treated. They are taught coping techniques, and oxygen concentrators and mobility devices will be prescribed if necessary. After discharge, patients follow up at the TTSH ICARE clinic or are referred to palliative day care services or palliative home care, according to their needs.

Since ICARE began in July 2016, over 300 patients have benefitted from this programme, and there has been a reduction in the number of hospitalisations, length of stay, as well as fewer visits to the emergency department. The team also observed improved function, especially in frail older persons with frequent readmissions and prolonged hospitalisation.

A patient who benefited from ICARE was Mr Ong Chwee Aik, who was frequently hospitalised due to chronic obstructive pulmonary disease (COPD), which also limited his physical functions.

Mr Ong was enrolled in ICARE at Ren Ci and stayed for three months, during which he had to bear with the isolation caused by pandemic lockdowns and visitation restrictions. Weekly art therapy sessions MR ONG'S CREATIVE
LEGACY AND
SPIRIT OF SHARING
CONTINUE TO
INSPIRE AND SHOW
HOW CREATIVITY
CAN BE HEALING IN
THE FACE OF LOSS.

enhanced his emotional well-being and improved his overall care and clinical outcomes.

Having never formally created art, Mr Ong was initially hesitant, selfconscious and critical of his efforts. However, with the support of the Ren Ci art therapist, Ms Poh Shu Ning, he embraced his instinctual flow of creativity and began drawing prolifically. He even requested a box of charcoal pencils from Ms Poh to practise drawing, depicting still life and the hospital environment around him, including staff and patients, but above all, the parakeet display that was a birthday gift from his granddaughter. His family encouraged him by bringing him colouring materials and a sketchbook.

Through his art, Mr Ong identified what was important to him and explored feelings of loneliness and frustration from his recurrent hospitalisations, the impact of COPD, his hopes, wishes and mortality. When his wish to share his art was discovered, a team comprising Ms Poh, medical social worker Ms Nadirah Aseelah Chee, and ward staff organised a solo art exhibition for him in the ward, titled "随心所欲的画" (Creating to My Heart's Content). The art show was well received by Mr Ong's family, staff and patients alike. An online edition was also curated to enable him to share his art with

extended family members and friends who were unable to visit. The exhibition was eventually replicated in the linkway connecting Ren Ci and TTSH, enabling other staff and visitors to appreciate Mr Ong's art. An ex-classmate even wrote in to Singapore's Chinese newspaper, Lianhe Zaobao, which covered Mr Ong's story.

Unfortunately, Mr Ong's condition took an unexpected turn for the worse and he passed on suddenly. As part of bereavement support, the art therapist checked in with

Mr Ong's family through an art activity, which allowed them to express their feelings of loss through the creation of a "nest" that encouraged the use of imagination and play. The nest was symbolic of a resting place for the parakeet, which can be viewed as a symbol of self that Mr Ong had explored repeatedly in his art.

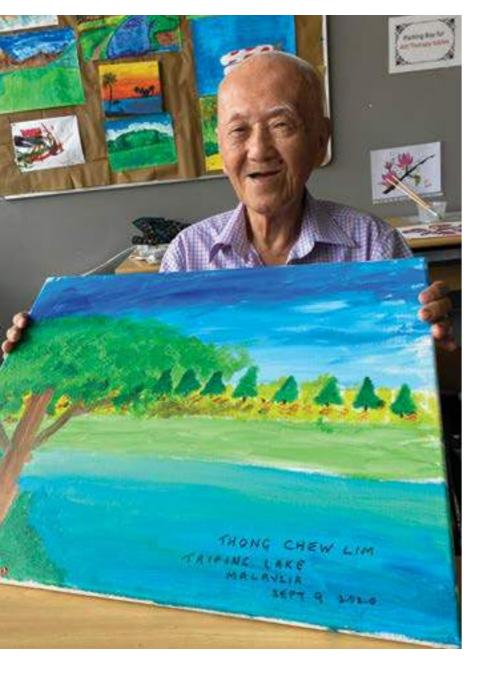
Although he has since passed on, Mr Ong's creative legacy and spirit of sharing continue to inspire and show how creativity can be healing in the face of loss.



Left: Mr Ong Chwee Aik with his treasured birthday gift from his granddaughter; Top: (from left) a charcoal sketch depicting a ward staff; an artwork of the parakeet with an explanation

WORDS DR TAN HONG WENG, CONSULTANT, MEDICAL; POH SHU NING, SENIOR ART THERAPIST, PSYCHOSOCIAL SERVICES PHOTOS POH SHU NING, SENIOR ART THERAPIST, PSYCHOSOCIAL SERVICES

18



BREAKING FREE FROM THE LIMITS OF ART

Art is everywhere around us. What does art look like when it co-exists with the provision of palliative care?



magine living in a colourful world but only being able to see the darker shades. That's the reality for Mr Thong Chew Lim, a resident at St Joseph's Home, who lives with colour blindness. However, that did not stop him from doing what he currently loves at the age of 96, which is creating artwork.

Upon meeting the warm-hearted Mr Thong, he would show you his folder of almost 30 artworks, each one featuring his fond memories, including scenes from Taiping, Malaysia, where he grew up.

As Mr Thong reminisces about his younger days, it's evident that he loves sharing his story with others, especially his growing-up years and leaving life's lessons as a legacy.

ART AS EXPRESSION

Going through his paintings of Taiping, Mr Thong would fondly share about his first 14 years of life there. Living with his grandmother, uncle, and cousins, life was simple. On some days, his grandmother would bring him along to watch Cantonese opera. And on other days, he relished a rewarding fishing trip or a bicycle ride around his house.

"Art offers residents an opportunity to be seen beyond their medical conditions. They become people with different roles, memories, and values. These memories, when made tangible by artwork, serve as a visual aid that empowers residents to share about themselves. It also helps staff understand and appreciate residents, especially when they do not speak the same language," says Ms Tan Hsiu Li, an art therapist at St Joseph's Home.

Hsiu Li uses the visual arts as the primary form of expression to promote overall well-being, such as by reducing negative psychological symptoms and improving the selfesteem and self-identity of residents like Mr Thong. Given that he had never held a paintbrush before, Mr Thong initially refused Hsiu Li's invitation to art-making. She took a few months to build rapport with him and understand his unique needs and interests. She then made adaptations, such as increasing the sessions to an hour and writing or spelling the colours onto the paint palette to inform Mr Thong of the colours available. These efforts familiarised him with the media and empowered him to use art as a form of expression.

Now, Mr Thong can proclaim, "I love art! It brings me back to my younger days, and I feel happy seeing my precious memories come to life."

Left: Mr Thong Chew Lim, with the assistance of St Joseph's Home Art Therapist Ms Tan Hsiu Li, sharing his art-making process with students and teachers from Corporation Primary School; Opposite page: Mr Thong displaying one of his artworks entitled Taiping Lake

ART AS IDENTITY

To build his confidence and interest in art, Hsiu Li scheduled regular sessions with him and encouraged him. She also introduced him to various artists and their artistic styles, showing him that he was free to develop his own.

Art-making also strengthened his sense of self-identity. Painting by painting, his life stories were uncovered, and he had a chance to not only recall but to retell them through art exhibitions. He discovered a passion for the arts!

Through the art-making process, his attributes of perseverance and hard work shone through. Being colour-blind, he needed more time to understand the mood of the images and find the right colours. He also needed practice handling a brush. His first artwork was of a hand, completed weeks after his first session with Hsiu Li.

Believing in the potential he has shown through his courageous attitude, focus, and confident brush strokes has finally led to him taking the lead in deciding what he wants to paint by himself and utilising art as an alternate way of sharing his life stories with others.

ART AS LEGACY

This year, Mr Thong produced two masterpieces for the art exhibitions at Corporation Primary School, one of our long-standing community partners. Residents visited the school to share their artwork with teachers and students.

Proudly presenting his favourite of the two — a sunset by the seaside inspired by Indonesia's Thousand Islands — he talked about how he loved the peacefulness it brings. Sketching the outline and then adding in yellow, orange, and blue hues also reminded him of the years spent working in Indonesia as an accountant, as he encourages teachers and pupils alike to make the best memories of their time.

Mr Thong also gave a talk during the school morning assembly this August, sharing his bliss of growing up and settling down in Singapore, as well as his art-making process and encouragement for the younger ones.

His artwork left a deep impression on teachers and students, who were inspired by his resilience, perseverance, and demonstration of endurance through his every word and action. He even received handwritten appreciation cards from the students with messages such as "Mr Thong, you're really good at drawing", "I like your drawing so much" and "Please come to our school again".

It's what drives him to connect with the community through art. He even hopes to one day sell his paintings to raise funds for others in need. ①

MR THONG'S ARTWORK LEFT A DEEP IMPRESSION ON TEACHERS AND STUDENTS, WHO WERE INSPIRED BY HIS RESILIENCE, PERSEVERANCE, AND DEMONSTRATION OF ENDURANCE THROUGH HIS EVERY WORD AND ACTION.

NEVER GIVE UP

For seven years, Mr Ramlee Rais has held firm to the belief that as long as his wife is still breathing, he will continue caring for her with all his heart.

or the past seven years, Mr
Ramlee Rais has diligently
cared for his wife, Madam
Zainon Buang, who was rendered
bedridden due to a second stroke.
Every two to three hours, he
would check in on her, observe
her breathing patterns, and
ensure she was not running
a fever.

This level of meticulousness and conscientious care was best encapsulated by how Mr Ramlee would always keep a keen eye on his wife's well-being, even when he was not by her side. For instance, when he was in the kitchen preparing food, he could view live video footage of Madam Zainon resting on her bed on his mobile phone. While cooking, he would constantly turn to look at the phone's screen, not wanting to let her out of his sight even for a single minute.

The process of caring for his wife is a challenging one. Sometimes, she would only sleep for two hours a day. Mr Ramlee would also have to help draw



out her phlegm every now and then, especially at night when it accumulates at an increased rate. His health has been affected by disrupted sleep, and he frequently experiences bouts of headaches, dizziness and fatigue.

"THEY ARE VERY SINCERE IN OFFERING
THEIR HELP. IF MY WIFE EXPERIENCES ANY
DISCOMFORT, WE CAN CONTACT THEM AT
ANY TIME OF THE DAY. SINCE ACCEPTING
PALLIATIVE CARE, I FEEL WELL-SUPPORTED,
AND EVERYONE IS LIKE A TEAM."

The Tzu Chi palliative care team has been by his side through the years, helping to alleviate some of the challenges he faced while caring for Madam Zainon. Dr Tan Chun Yeal and palliative care nurse Nancy Tan would check in regularly on both the patient and caregiver on visits. For these routine checks, they not only monitored their physical health conditions but their mental states as well.

TZU-CHI FOUNDATION (SINGAPORE)

Over time, Mr Ramlee observed that his wife frequently appeared dispirited and downcast, leaving him at a loss as to what to do. "Sometimes, when I see her crying, it feels so pitiful, but I don't know how to help her. I have tried various methods, and when she keeps crying, I just try to give her a massage," he said.

Right from top: A mobile phone with live video footage of his wife resting on the bed allows Mr Ramlee to prepare food in the kitchen with peace of mind; Dr Tan Chun Yeal checking in on Mr Ramlee's health by looking at his medication; Opposite page: Tzu Chi palliative care nurse Nancy Tan regularly converses with Mr Ramlee to ensure his well-being and to provide emotional support



Aware of Madam Zainon's challenges, the Tzu Chi palliative care team stepped in to provide solutions to alleviate her suffering.

"The family said she was crying all the time, and it felt like she had symptoms of depression.

To help her, we chose medicine with relatively mild side effects. If they reported to us that it did not work, we would then observe first before making adjustments later on," said Dr Tan.

Palliative care nurse Ms Tan would also constantly be by the family's side, providing both medical and emotional support. One aspect of Ms Tan's work includes mentally preparing the caregiver for the patient's eventual passing and she has already initiated the process with Mr Ramlee.

During her regular home visits, Ms Tan would delicately bring up the topic of Madam Zainon's circumstances, hoping to help him face the situation bravely when the day to send her off arrives.

On one such visit, she advised Mr Ramlee, "You must learn to let go. To do so is difficult, but you must understand that it is a part of life." Through her conversations with him, it seems that he is gradually coming to terms with his wife's situation and the prospect of her leaving him at any time.





BEACON OF LIGHT

During this trying time for the family, the Tzu Chi palliative care team has been a shining beacon of light, helping to pave their way out of darkness by providing medical and psychosocial support.

"They are very sincere in offering their help. If my wife experiences any discomfort, we can contact them at any time of the day," said a grateful Mr Ramlee. "Since accepting palliative care, I feel well-supported, and everyone is like a team."

Caring for sick family members on the last leg of their life's journey is never easy. But with proper support, it is not all doom and gloom. Mr Ramlee is determined to hold on and accompany his wife right to the end.

"This is God's will. As long as she is alive and I still have energy, I will continue caring for her," he said.

COMPASSION AND **DEDICATION IN CARE**

With nearly two decades' experience in healthcare, Advanced Practice Nurse Tang Ping Sin specialises in palliative care at St Luke's Hospital, where she continues to be dedicated to patient-centred care, offering solace, empathy and support to those facing life-limiting diseases.



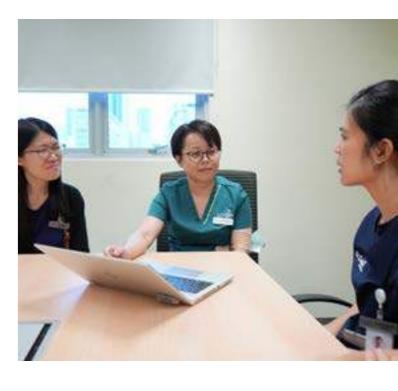
hat inspired you to transition into palliative care after many years in different specialities?

I was praying for an open door through which I could contribute more and make an impact on more people's lives, and out of curiosity I first took up the challenge of palliative care with a role at Assisi Hospice in 2020 for over a year. I realised then that I could make a significant contribution to the lives of patients and their loved ones, to journey with them till the last, giving patients relief from their symptoms, and guiding their family members on how to care for their loved ones.

Someone once told me, "There is only one chance to make it right", so if we can give our best care to patients and their families during this phase, it will make a great difference to the family members who will live on with a better memory of their loved ones.

Can you share some examples of serious illnesses, in addition to cancer, that you have experience caring for in a palliative care setting?

"THE GOLD STANDARD FOR MANAGING THOSE SYMPTOMS IS TO IDENTIFY THEIR ROOT CAUSE AND DEAL WITH IT, WHETHER THROUGH PHARMACOLOGICAL MEANS OR NOT, THERE IS NO ONE-SIZE-FITS-ALL SOLUTION: **EVERY PATIENT'S CARE IS** DEPENDENT ON THEIR NEEDS."



across are advanced dementia, advanced Parkinson's disease. end-stage heart failure, end-stage renal failure, advanced chronic obstructive pulmonary disease, and neuromuscular disease, to name a few.

The gold standard for managing the symptoms is to identify their root cause and deal with it, whether through pharmacological means or not. There is no one-size-fitsall solution; every patient's care is dependent on their needs.

To what extent is taking care of a non-cancer patient different? What unique challenges do caregivers face?

Taking care of a non-cancer patient comprises managing chronic illness with added-on end-of-life symptom management such as pain, breathlessness, delirium, psychosocial issues, and emotional and spiritual pain, to name a few.

How would you guide patients and caregivers who may be uncertain as to the right time for palliative care?

I would advise them to initiate the conversation with their primary physician and to share the type of care they need to continue with the life they want.

What are some difficulties you face as a palliative care nurse? What keeps you going?

One challenge is compassion fatigue. In the palliative care setting, as part of the palliative care team, we are constantly taking care of seriously ill or dying patients and witnessing the pain, trauma, and suffering experienced by both patients and their caregivers.

The many levels of stress can cause us compassion fatigue, but I'm blessed to have the support of the great team and leadership at St Luke's Hospital (SLH). I find it meaningful to continue serving in this "mission field" and that's what keeps me going.

At the end of a work day, what does a job well done look like for you?

The whole team's aim is to address the loved ones and their family members' concerns, and for them to have a good closure.

What does "Live Well. Leave Well." mean to you?

To me, "Live Well" means to obev His will on earth, and "Leave Well" means to complete the race faithfully and run into His arms. 🕕



page: Advanced Practice Nurse Tang Ping Sin with the multidisciplinary palliative care tear at the post-SLH ervice debrief

What strategies do you use to manage pain and other symptoms? Other serious illnesses that I have come



LEAVING MEMORIES BEHIND

Palliative care patients benefit immensely from Creative Arts Therapy at the Tan Tock Seng Hospital Palliative Care Unit beyond just the passing of time. reative Arts Therapy comprising music and art, is often misunderstood. The sessions are not for keeping the patients occupied but rather serve as a medium that provides a unique and compassionate outlet for them to meet their physical, emotional and psychological needs. Contrary to popular belief, patients do not need to have any formal art or music education to participate in these sessions.

This form of therapy helps patients refocus their minds on aspects of their lives aside from their illness. From concentrating on creating an art piece to simply immersing themselves in a piece of music, patients talk about how their minds are taken off their physical symptoms such as pain or breathlessness. This often gives them a much-needed night of rest.

There is a sense of accomplishment when given the opportunity to create a memento, such as a customised painting or song recording, for themselves or their loved ones. This allows patients who are more reserved to express their gratitude towards their caregivers in a safe space, leaving their work behind as a valuable keepsake for their bereaved loved ones.

COMMUNICATING THROUGH ART

Mr A, a 58-year-old patient with metastatic pancreatic cancer, shared with his art therapist during his 18-month illness journey about his inability to continue buying his wife flowers for their wedding anniversaries since his diagnosis. With minimal guidance, he was able to paint her favourite flower — a perennial purple rose with the meaning "永远陪伴在您身旁" (Forever by your side).

During one of the sessions, Mr A revealed that he also struggled to connect with his young adult son, even though they lived under the same roof. He reminisced about the time spent together when his son was still a toddler. He wanted to communicate this phrase of encouragement — 风来雨挡 — that there will always be a way to handle any problem he may face in life. He wrote these words on a jigsaw puzzle for his son.

A LOVE SONG LEGACY

Madam T, a 52-year-old patient, had aggressive stage 4 breast cancer. Even though she was actively dying, she had always loved music, and music therapy provided the chance for her to be engaged in an activity that raised her self-esteem and lifted her mood while in the hospital. She could participate in something she loved despite gradually losing autonomy over basic bodily functions.

Rapport during music therapy was built through music engagement, and it provided a safe space for Madam T to share her hopes and fears and to reminisce about better times with family and colleagues at work. The music therapist assessed her musical preferences, the extent of her relationship with her family, how good her social support was, and, more importantly, how she was coping with her diagnosis and her gradual loss of autonomy.

During a session with the music therapist, Madam T divulged that she was extremely close to her daughter, who had asked to have a memento from her mother. The music therapist suggested creating a musical piece as a legacy for her daughter. Such legacy-making

SUCH LEGACY-MAKING PROJECTS

MAY BE BENEFICIAL... FACILITATING

CONVERSATIONS ABOUT

REMEMBRANCE TO HELP FAMILY

MEMBERS COME TO TERMS WITH THE

EVENTUAL LOSS OF A LOVED ONE.

projects may be beneficial to both patients and their loved ones in a variety of ways, such as facilitating conversations about remembrance to help family members come to terms with the eventual loss of a loved one.

Madam T, under the guidance of the music therapist, worked on a heartbeat-recording project — an audio file of her singing Theresa Teng's "You Matter the Most" layered with her heartbeat, which had been separately recorded with a digital stethoscope. The final product, put together by the music therapist, was saved on a piano-

shaped USB thumb drive and gifted to Madam T's daughter.

THE IMPACT OF SOFT THERAPY

The Department of Palliative Medicine at Tan Tock Seng Hospital is currently conducting a study, supported by Temasek Foundation, to gauge the benefits of Creative Arts Therapy on patients' overall well-being and quality of life. The tertiary hospital aims to eventually incorporate music and art therapy into standard care in the next few years in order to bring about the sustainable provision of creative arts therapies to patients.



Left: "风来雨挡", jigsaw puzzle, acrylic paint; Opposite page: "永远陪伴 在您身旁", 9" × 12"

26

NAVIGATING GRIEF IN THE WORKPLACE

During the Live Well. Leave Well. Festival, the Singapore Hospice Council hosted a lunchtime talk titled "Quiet Cubicles: Facilitating Workplace Grief and Loss with Compassion" led by Dr Paul Victor Patinadan, Assistant Professor in the Psychology Programme at Nanyang Technological University, Singapore.

The talk threw a spotlight on the prevailing culture of silence around workplace grief and loss. It explored how the need to maintain professionalism often suppresses negative emotions and the challenges of acknowledging a colleague's death. Dr Paul offered insights on being present for bereaved coworkers with mindfulness and compassion, promoting a more compassionate workplace.

In today's workforce, where people spend more of their lives working, encountering the loss of a colleague becomes more common. This situation often leaves teams

uncertain about when and how to move forward. Dr Paul introduced the concept of a communal Office "Last Office" process at the office, which acknowledges the loss, addresses emotions, honours the coworker's

memory, and facilitates the respectful return of personal effects to the family. Workplaces should consider conducting an Office "Last Office" as a dignified way to celebrate and bid farewell to a departed friend or colleague.

Steps of the Office "Last Office":

- I. Carve out protected time (with managerial support).
 - 2. Gather around the workstation and introduce the session.
 - 3. Acknowledge all levels of relationships and enunciate that it is a safe space and that if anyone is uncomfortable, they can step away.
 - 4. Observe a moment of silence (it also provides an opportunity to gather thoughts and emotions).
 - s. Gently instruct individuals to pick up a personal artefact of the deceased and place it in a pre-prepared box. As they do so, invite them to share a special memory, what they would most remember, or what they are most thankful to their colleague for.
 - 6. Rotate among all those present.
 - 7. Present another opportunity for sharing, then respectfully bring the session to a close.



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