

THE HOSPICE LINK

JUNE – AUGUST 2023 • MCI (P) 105/03/2023

The Best Care Possible

Opening gateways
to conversation

Meaningful
last moments



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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



The vision of Singapore Hospice Council is “quality palliative care for everyone”. But what is ‘quality’ palliative care? How does a multidisciplinary palliative care team work with patients and families to deliver quality palliative care?

Patients and families are at the centre of quality palliative care. Every patient is unique. Each is not just a case with an illness and symptoms to manage. Each patient has a name, personality, likes, dislikes and most importantly, a voice. To the loved ones, the patient may be a father, a mother, a son, a daughter, a sibling, a spouse or a friend. As loved ones, we strive to give them the best care possible — the best care a giver of care can provide and the best care a recipient of care can receive on the final important journey of our lives.

The 8th Singapore Palliative Care Conference will be held in July this year. This will be an exciting time for the palliative care community, public agencies and healthcare professionals from each discipline to come together to build collaborative structures, forge new partnerships, and strengthen old ones in the pursuit of providing the best care possible.

I hope you will find inspiration from the wisdom and compassion of Hairil Fahmi (p10), Steven Kuah (p11), Esther Koh (p12), Dr Tan Su-Yen and Joyce Cheah (p14), Dr Sharon Harvinder (p16), Imelda Anthony (p18), and Dr Grace Yang and Dr Raphael Lee (p20).

Sim Bee Hia
Executive Director
Singapore Hospice Council

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BONDING IN CARE

NEWS, VIEWS, UPDATES AND SPOTLIGHTS

Meet the Team

REGISTERED NURSE **WANG LIYUN**

Changi General Hospital

Palliative care nurses perform a wide range of tasks that include managing symptoms and ensuring patients adhere to their medication schedules and protocols. Many patients need help with mobility, and nurses assist them in maintaining physical activity and accomplishing everyday tasks. They maintain and monitor equipment in addition to assisting with personal care needs such as bathing and feeding.

Tell us about one memorable experience.

The memories of those I journeyed with at work shine like stars. One of the brightest stars is a young man who wrote a short letter to me.

“Dear Nurse Liyun, when you receive this note, my cancer would have progressed to stage 5. Thank you for chatting with me, giving me painkillers in the form of juices, candy pills, and body masks...”

Remembering his rare attitude towards death and unique sense of humour lifts my spirits and gives me the courage to continue in palliative work.



Nurse Wang Liyun (front row, second from the left) with CGH palliative care nurses

“Palliative care makes me grow and become resilient in the face of uncertainty and loss, and from witnessing pain and suffering, so I can continue to journey with others I will meet in the future.”



ASSISI FUN DAY

This charity carnival returns with more than 100 food and game stalls that will appeal to all ages. A community event put together by staff and volunteers from all walks of life, all proceeds will go towards the care of Assisi Hospice patients. Visit www.assisihospice.org.sg to purchase coupons or donate. Coupons are also available onsite.

Date: Sunday, 11 June

Time: 10am-4pm

Venue: St Joseph's Institution International School (SJII)
19 Toa Payoh West, Singapore 318876



WHY CHOOSE PALLIATIVE CARE

Palliative care aims to relieve suffering and improve quality of life for patients and their family members by caring for the “whole person” throughout the treatment process

PALLIATIVE CARE SERVICES INCLUDE:

- 1 Physical, emotional, psychosocial and spiritual care
- 2 Grief and bereavement support
- 3 Practical assistance such as financial counselling, caregiver training, and Advance Care Planning (ACP).
- 4 Home care, day care, inpatient care and consultative services.

**Source: Singapore Hospice Council*

“Alone we can do so little; together we can do so much.”

HELEN KELLER

Upcoming Events



SHC “LIVE WELL. LEAVE WELL.” EXHIBITION @ THE PUBLIC LIBRARIES

Come down and check out the exhibition's brand new look! With more interactive activities and fresh content, find out more about palliative and hospice care, how to get started on end-of-life planning, and why conversations on death and dying are essential.

Date: Till 28 Jun

Venue: Woodlands Regional Library, L2
900 S Woodlands Dr, Civic Centre,
Singapore 730900

Date: 5 Jul - 31 Aug

Venue: Ang Mo Kio Public Library, L1
4300 Ang Mo Kio Avenue 6, Singapore 569842

“LIVING BEFORE LEAVING” ASK THE EXPERT SERIES

SHC-NLB 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.

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 open to the public free of charge. Visit singaporehospice.org.sg/training-courses or scan this QR code to find out more.





The best care. **possible**

Caregivers, family and friends can work together with their loved ones' care team to ensure the best possible palliative care.

The study “Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021” published in the *Journal of Pain and Symptom Management* in December led by Professor of Health Services and Systems Research at the Duke-NUS Medical School, Singapore and the Executive Director of the Lien Centre for Palliative Care, Dr Eric Andrew Finkelstein, ranked 81 countries on end-of-life (EOL) care based on the assessments of a total of 181 experts. Prof Finkelstein, who also holds appointments at NUS School of Public Health and Duke University Global Health Institute, carried out this survey with six other colleagues from Singapore, India, the US and the UK based on 13 EOL key indicators over five categories: quality of care, palliative and healthcare environments, affordability of care, human resources and community engagement.

In the article “Where is the Best Place to Die?” by Alicia Banks published on the Duke Global Health Institute website upon the release of the study, Prof Finkelstein said, “Society should also be judged by how well people die.”

Perhaps it should come as no surprise that the UK ranked first; after all, it is acknowledged to be the birthplace of palliative care, born out of the hospice movement founded by Dame Cecily Saunders when she opened St Christopher's Hospice in London in 1967.

Singapore was in 23rd place, behind Sri Lanka and Mongolia, but ahead of Japan and Belgium. The country experts surveyed have identified the contributing factors — both positive and negative — that impact these results.

One of the positive factors cited by these experts is the existence of a national strategy for palliative care or making palliative care a priority at the national level. While the National Strategy for Palliative Care was first drafted in 2011, Singapore's Minister for Health Ong Ye Kung had announced the need to ramp it up on 9 December 2021 — increase awareness, boost training for palliative and healthcare professionals, broaden palliative care capacity in healthcare institutions, provide more support for caregivers and expand home palliative care, to name a few key objectives.

The palliative care movement in Singapore took off in 1985 with just 16 inpatient beds allocated for palliative care patients at St Joseph's Home. Drawing on the wealth of knowledge amassed by experts across the world who have paved the way with an established system of comprehensive best practices, new hospices, dedicated palliative care departments in community hospitals, as well as palliative healthcare specialists have emerged over the past few decades. Notably,

St Joseph's Home served as the starting point for the late Professor Cynthia Goh, a leading figure on Singapore's palliative care scene, who began her journey as a volunteer doctor while collaborating closely with St Christopher's Hospice.

Prof Goh established the Singapore Hospice Council (SHC) in 1995 with four founding members — Catholic Welfare Services, Singapore Cancer Society, Hospice Care Association (currently HCA Hospice) and Dover Park Hospice — with the belief that an umbrella organisation managing common needs would allow each organisation to focus on providing the best care to their patients. Today, SHC has grown to 25 members and has made strides in improving the quality of palliative care in Singapore.

With support from the Ministry of Health, the palliative care sector in Singapore will be empowered to build best practices aligned to local sociocultural needs and prepare for the projected increase in demand for palliative care services in line with an ageing population.

What the best care looks like, however, depends on the recipient of that care.

"The 'best' possible care for anyone is the 'best' they want for themselves at the end of their life journey. Generally, most people will want to pass on peacefully — to be comfortable and pain-free both physically and mentally," said Dr Dennis Chia, Acting Cluster Director, Community Eldercare Services and Deputy Director, MWS Home Care & Home Hospice and Senior Care Centre. "The principles of palliative care remind us to look at the bio-psycho-social and spiritual needs of the patient and support the family through the journey."

COMMUNICATION IS KEY

In Prof Finkelstein's study, "personalised, patient-centred and integrated care delivery" was cited by experts as a positive factor for high-quality care. How palliative care providers — be they hospice or hospital — accomplish this is through communication and engagement, not only with the patient but also caregivers, family and friends.

Advance Care Planning (ACP) or Advance Medical Directive (AMD) are recommended documented "wishes" in the event that the patients are unable to speak for themselves, whether due to physical or mental reasons, will guide their loved ones and caregivers in making decisions.

"Patient advocacy in palliative care starts with an early conversation with everyone, whether it is formally done up like ACP, or informally done as a conversation where loved ones can understand more about one's care preferences. Although it may be taboo in some cultures or families, especially in Asian countries, it is best to hold such conversations early when we are all well. This allows us to articulate to our loved ones how we wish our end-of-life journey to look like," said Dr Chia.

To illustrate this, Dr Chia shared this story about his friend's late father, who had suddenly collapsed at home from a brain bleed. While he was admitted to the intensive care unit (ICU), the family had to decide between withdrawing life support and aggressive treatment. "It was fortunate that my friend had conversations with his parents two years prior about the quality of life they want and care preferences. They were clear about what his father would want, and made the difficult and painful decision to withdraw life support and let him pass on peacefully."

ON MULTIDISCIPLINARY WINGS

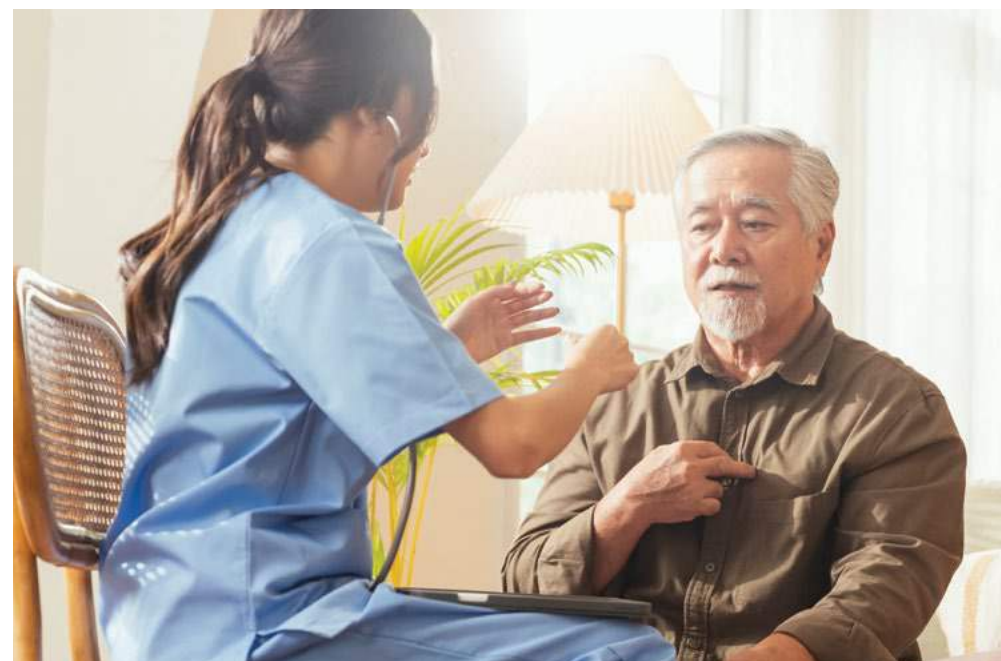
Nowadays, the increasingly patient-centric approach to palliative care requires a multidisciplinary care team, with each team member providing individualised attention to the patient who benefits from an improved quality of care that contributes to better outcomes. In addition to doctors and nurses, the team includes religious and spiritual support, counsellors, therapists and a medical social worker. Caregivers, family and friends are roped in as part of the care team for a more holistic approach.

"At EOL, having the multidisciplinary team, caregivers, family and even friends of the patient making up the different pieces of the puzzle to care for the patient from the bio-psycho-social and spiritual angles is important, especially when the patient is no longer cognitively able to make decisions," said Dr Chia. "We must also remember that on this journey, the multidisciplinary team also supports the caregivers, family and friends who are co-participating in the care, ensuring that they also receive the necessary caregiver training, support, and counselling when needed."

BREAKING NEW GROUND

The palliative care community is constantly launching new initiatives and collaborations to elevate the level of care provided, as well as finding new ways to meet patients' preferences regarding their last days and where they would like to pass away.

Through listening to patients and caregivers, a multitude of new initiatives have come about that allow many to arrive at the end of their life's journey as they wish, whether at home or in a palliative care facility, but still in comfort, free from pain, and with peace of mind. It may seem contradictory to think of palliative care patients maximising quality of life but with holistic support from a multidisciplinary



care team, as well as well-equipped caregivers, it is not only possible but expected.


Member of Parliament for Ang Mo Kio GRC, Ms Ng Ling Ling, lauded Ng Teng Fong General Hospital's IAmGoingHome programme in Parliament in May 2023 and enquired if it would be possible to roll this out across Singapore, in both public and private hospitals, and hospices. Launched in October 2022, the programme is a pilot effort by the ICU and Division of Supportive Care and Palliative Medicine at the hospital to safely discharge critically ill patients who wish to pass away at home. When speaking about the Singapore government's push to enhance EOL care, Senior Parliamentary Secretary for Health, Rahayu Rahzam, shared that the government is working with hospitals and palliative care providers to work on expanding such a "compassionate discharge".

Hospices and hospitals often collaborate to provide integrated care to patients. One such example is Programme Dignity, a collaboration between Dover Park Hospice (DPH) and Tan Tock Seng Hospital (TTSH) launched in 2014 that provides home palliative care for patients with advanced dementia to enhance their quality of life and be cared for at home. Since then, such collaborations have flourished, usually between palliative care providers and hospitals in close proximity.

LEAVING ON A CLOUD

Many care teams work on not just the ailing physical body, but also their patients' mental and spiritual health. This might involve helping their patients realise last wishes, providing closure for any regrets they might have, or creating a beautiful lasting memory for those left behind.

Dr Chia shared a poignant story of an MWS patient in his 50s who had wished for a last date with his wife on the same beach where he proposed to her 24 years ago. "MWS worked with Ambulance Wish to arrange for this final date with his wife days before he passed away. His wish was fulfilled, and he passed away peacefully. What remained was a beautiful memory deeply etched in the minds of his wife and two children," he said. "You'll be surprised how the fulfilment of such wishes can sometimes help patients with their symptoms, much more than what medication can do!"

Keeping morale and spirits high while undergoing palliative care does a lot of good for patients. The best palliative care needs a multidisciplinary team with a broad spectrum of expertise to ensure that patients live the best quality of life possible and achieve a good death. 

GETTING THE BEST CARE POSSIBLE

1. Visit the SHC website for e-Library resources

Learn more about the variety of palliative care services available and which is the most suitable for you or your loved one.

2. Get your doctor's referral

Discuss personal circumstances and any concerns so that your doctor can recommend the most suitable care plan for you.

3. Plan ahead

Tools such as ACP can help you plan for future health and personal care options should you lose the capacity to do so. This allows one to align their future care with their personal beliefs and goals and share them with their loved ones and healthcare providers.

4. Choose your preferred type of care

Palliative care can be provided at home, in nursing homes, hospices, specialist clinics, as well as general and community hospitals, catering to every patient's needs. Take the time to carefully consider how you would like to live out your remaining days and the type of care to do so.

5. Meet the care team

If possible, get to know your palliative care team and let them know your preferences and comforts. Every patient is different, and by sharing how you would like to be cared for, it allows your team to provide the best care for you.

6. Ask for help

Facing a life-limiting illness is a difficult process. Do not be afraid to seek emotional, mental and/or spiritual support to help you navigate the array of complex emotions and thoughts you might encounter.

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HEEDING THE CALL TO CARE

We hear from a new palliative care nurse about his experience on the job.

I have worked as an intensive care unit nurse for seven years, and when COVID-19 hit, I was directly involved in taking care of infected patients. Working during the pandemic was the most difficult experience of my career because while I feared the deadly virus, I still needed to care for my cardiac, surgical, neurologic and pandemic patients. Having cared for COVID-19 patients for the past three years, the experience sparked an interest in palliative care. To pursue my dream, I joined the Singapore Cancer Society in 2022, where I took care of terminally ill patients.

Being a palliative nurse is more of a calling because it is demanding, stressful and challenging. However, through workshops, mentoring and support programmes, I have become better adapted and equipped for my career in palliative care.


As a palliative nurse, I spend most of my time caring for terminally ill individuals to relieve their pain, suffering and symptoms. While it has been fulfilling working as a palliative nurse, I often encounter complex situations that have no clear answer or immediate solution. This is because patients at the end of life often experience complicated emotions and are less able to make clear decisions about their own care. I once had a male patient who was diagnosed with stage 4 lung cancer. He was in denial of his condition, refusing care and even forbade me from visiting him at home. I was in a quandary, as I needed to respect his autonomy and privacy, yet ensure he received the support needed to improve his quality of life.

It was frustrating for me to go to his house; sometimes, he would chase me out, but there were times when he welcomed me too. However, I did not give up. I kept trying to establish rapport with the patient to gain his trust and accept care. Soon, we started communicating about his health



over WhatsApp. I also managed to develop a close relationship with his wife and son, and when he got very sick and weak, the family worked with me to promote his well-being. When his health deteriorated and he could no longer chat on WhatsApp, the family decided to include me in their family chat group where we would update each other and decide on ways to improve the patient's quality of life. This was a very fulfilling moment for me. Sadly, the patient passed on a few months later, but his family was grateful for my care and support. In this case, I learned the need for perseverance in building strong relationships.

Another issue I faced working in palliative care is burnout and compassion fatigue, which have affected my health and well-being. Spending a lot of time with people in chronic pain and suffering is emotionally draining and demanding for me. At first, I was so focused on the job that I neglected personal care, health, and well-being.

Soon, I realised the need to balance work and life, and I have become more self-aware and take regular breaks to engage in physical exercise and other leisure activities to relax and rest. Since starting this routine, I have been coping well with the stressful working conditions in the palliative care unit and enjoying good physical and psychological health outcomes. The palliative care journey is not easy, but it makes me feel grounded and more appreciative of life. I thank my patients daily as they are my best teachers in palliative care, as well as being my friends too. 

Top: Hairil Fahmi with one of his patients

WORDS HAIRIL FAHMI, SENIOR STAFF NURSE, SCS HOSPICE CARE PHOTO SCS HOSPICE CARE

WORDS METTA HOSPICE CARE PHOTO LEO MIKE, SENIOR COMMUNITY PARTNERSHIP EXECUTIVE

STAY THE DISTANCE

A social worker shares his thoughts on burnout and self-care when facing challenges working in the palliative care space.

Mr Steven Kuah is a senior social worker at Metta Hospice Care, with more than 10 years of experience in the social service sector, including over two years in hospice care. Like many healthcare professionals, Steven also experienced physical and mental burnout when helping patients and their caregivers, and managing his workloads. He realised that neglecting one's needs may result in more stress and can be energy-draining; it's important to take care of yourself.

WAYS TO MANAGE BURNOUT At the Workplace

It's important to promote work-life balance. Restful spaces can be created at the workplace for members of the palliative care team to take a few minutes' respite in the middle of a hectic day. Just a few thoughtful touches like plants and artful décor, such as comfortable chairs, can instantly create a less stressful environment. Flexible work arrangements can also be offered depending on individual needs.

Steven's seniors in the social work sector always advised him not to choose a work environment that is not a good fit, as this would compromise his health and happiness. This advice reminded him of a quote by the late Indian Hindu monk and yogi Paramahansa Yogananda: "The greatest influence in your life, stronger than your willpower, is your environment." To resolve burnout issues and meet job demands, supervisors must look after their team's well-being and communicate frequently.

Our hospice team has kept to Metta's motto, "Compassionate love


to share. Brightens hope to those we care." leaning into kindness and practising compassion, which is immensely helpful to the family members coping with the loss and death of their loved one. Often, hospice workers become part of their patients' lives, grieving for a patient's death can sometimes become personal, and they can easily forget to care for themselves. As team members may need emotional support for their work, it is beneficial for them to maintain positive relationships, and spend time with their family members during their free time. Providing a platform for the team members to share their experiences and support one another will make a difference, as well as offering counselling services.

At Home

Home is a place of comfort and sanctuary for many of us. Steven

recommends practising healthy habits such as getting sufficient sleep, eating regular meals and having time for exercise and recreational activities. A simple meditation of 30 minutes or walking around the neighbourhood may help relieve stress. Finally, speak to family and friends if you need a listening ear.

In conclusion, he points out that while many of those who work in palliative care may be passionate about their job, it is more often the knowledge, skills and competencies acquired over time that will help them to manage complex cases and demanding workloads.

Committing to remaining in the profession is good, but palliative care workers must continue to upskill and stay relevant. Organisations should also be supportive in this aspect. In this way, we will be able to always meet the needs of those in our care. 



Left: Steven Kuah sharing his experiences and supporting colleagues



From far left: Wearing a stylish beret and riding a lightweight electric mobility scooter, 84-year-old CKD patient Ahamed lives at his own pace of life and leaves his house on his own for fresh air every day; Tzu Chi Community Nurse Esther Koh (right) carefully recording her observations in a notebook

A BETTER QUALITY OF LIFE

For frail, elderly patients with advanced chronic kidney disease (CKD) who also suffer from multiple other ailing conditions, choosing conservative care with non-dialysis treatment and spending more time in the community or at home may be their preferred choice.

Although 84-year-old Ahamed has lower limb weakness, he becomes instantly mobile upon getting on his electric scooter. He can then swiftly make his way to the nearby market to buy his wife's favourite breakfast.

Reaching his golden years, Ahamed is living his best possible life. Diagnosed with kidney failure in 2021, he had chosen the conservative non-dialysis treatment as he did not want his family to bear the burden of caring for a dialysis patient.

This treatment option is part of the Renal Conservative (Non-Dialysis) Care (RCC) Programme, a three-year pilot project launched

in May 2021 between Sengkang General Hospital (SKH) and Tzu-Chi Foundation (Singapore) for elderly CKD patients aged 60 and above.

This programme aims to provide better support to patients in the community, optimise their care to slow down kidney disease progression, and maintain their quality of life via a holistic approach to controlling symptoms. The programme also includes Advance Care Planning (ACP) and timely transition to hospice care. Following assessment and referral by SKH, Tzu Chi community nurses will conduct routine home visits. As of December 2022, 68 patients have enrolled in the programme.

HOME VISIT NURSING CARE

At least once a month, a familiar figure, Tzu Chi Community Nurse Esther Koh, will come knocking on Ahamed's door. With a suitcase packed with the necessary medical supplies, she is ready to begin nursing care that afternoon.

Upon her arrival, Ahamed offered her coconut water, which she likes. He slowly got up from the sofa and made his way to the refrigerator to bring out the coconuts. He cut them open and served them. Subsequently, he retrieved erythropoietin (commonly known as a "blood booster") from the refrigerator and a notebook where he records his blood pressure and blood sugar levels.

"I usually let them handle it by themselves," said Ms Koh.

Although she was patiently sitting on the sofa while Ahamed got busy, she had been observing him since the moment she arrived — checking for swollen feet and whether he had any difficulties moving, among other observations.

Throughout the visit, Ms Koh and Ahamed conversed in Malay. "We must use the language that the patient is familiar with," she shared.

Ms Koh, who is fluent in several languages, usually finds out about her patients' physical condition, diet, lifestyle, emotional state and household financial situation through

conversation. Whenever necessary, she refers them to medical services, social workers and psychological counselling services.

While chatting with Ahamed, Ms Koh took out a blood pressure machine, glucose meter and thermometer from her suitcase to measure his blood pressure, blood sugar level and body temperature. She then administered erythropoietin subcutaneously and carefully recorded her observations in a notebook. This data would later be transferred into the electronic medical record system.

"We will inform the doctor of any abnormality and he will then evaluate and recommend the appropriate action plan," she explained.

AN ALTERNATIVE TREATMENT

Kidney failure, also known as end-stage kidney disease, occurs when kidney function is severely impaired, causing the build-up of toxins, waste and excess fluid in the body. In Singapore, 5.7 people are diagnosed with kidney failure every day, mostly those in their 70s and 80s living with chronic disease, just like Ahamed.

Common treatment options for kidney failure are haemodialysis

(HD), peritoneal dialysis (PD) and kidney transplantation. While Ahamed did not fully understand the similarities and differences between these treatments, he could clearly explain the reasons for not choosing them.

Initially, he was very resistant to going to the dialysis centre three times a week, for HD treatment that lasts four hours per session. As a person with mobility issues, he felt it would be a challenge. The doctor also assessed that he was not suitable for HD due to his weak heart and asked him to consider doing PD at home. Unfortunately, his poor eyesight meant that performing the PD procedures on his own would be tough. Moreover, his wife could not assist him as she has Parkinson's disease.


When confronting declining health and physical function, and being unlikely to ever recover their kidney function, many elderly CKD patients such as Ahamed decided that they did not want to endure the suffering from sickness and burden of treatment.

According to the literature, frail, elderly patients with multiple diseases can only prolong their lives by one to two years after undergoing dialysis. Even though they might live longer, they might not wish to spend their remaining years living with a poorer quality of life.

LOOKING AHEAD

Many patients have certainly benefited from the launch of the RCC programme but it has had to overcome its fair share of challenges.

"When implementing a new programme like RCC, it is common to encounter unforeseen issues that may require some tweaks and adjustments. Some of these include areas such as staff training, data collection and patient education. Making improvements will ensure smoother running of the programme moving forward," said Tzu Chi RCC Project Lead Lai Mee Horng.

Given the limits of dialysis and the importance of administering appropriate treatment that aligns with the individual's values and preferences, RCC could be a viable alternative, one that can allow terminally ill patients to continue living with dignity and a good quality of life for their remaining days. 

WORDS HOLLY FOONG PHOTOS TZU-CHI FOUNDATION (SINGAPORE)

THE RCC PROGRAMME AIMS TO PROVIDE BETTER SUPPORT TO PATIENTS IN THE COMMUNITY AND MAINTAIN THEIR QUALITY OF LIFE VIA A HOLISTIC APPROACH TO CONTROLLING SYMPTOMS

CARING FOR THE PERSON

The team from Assisi Hospice shares how the Personhood Headboard impacts the way they care for patients as unique individuals.

At every bed in the inpatient ward at Assisi Hospice, you will find a small board with the following sections: “Call me..”, “I enjoy...”, “What comforts me...”, “I dislike...”, “I want you to know...” and “Tips to care”. This is each patient’s Personhood Headboard (PHB). The idea was first conceptualised in early 2022 by Assisi Hospice Resident Physician Dr Tan Su-Yen, after being inspired by the Clinical Director of Assisi Hospice, Dr Alethea Yee. The first draft of PHB was drawn up in March 2022 and launched in all wards by the end of May that year.

Dr Tan explained, “Just like pieces of a puzzle, we try to piece together information about the patient we care for from the first day we meet — we try to understand them, their values, and what makes them who they are. Understanding their personhood facilitates care and allows us to care for the patients in ways aligned with their values, thereby allowing them to maintain their dignity and quality of life.”

The PHB is dynamic as patients, family members, caregivers and the Care Team are encouraged to update the board whenever necessary. Dr Tan elaborated, “Different members of the interdisciplinary Care Team have daily encounters with

patients and learn more about them in their own way. The PHB allows the team to call patients by their preferred name from the first day of admission, provides a platform for the team to explore their personhood, and to share information about the patients we care for. In this way, we are using PHB to contribute to the effort of creating a person-centred culture in the organisation.”

For the patient, the PHB reminds them of their personhood, and the guiding questions serve as a tool for them to share more about themselves. Indicating their personal preferences allows patients and their family to gain a sense of control over their environment and feel empowered. The team directly engages the patients, if they are able and willing to share this information, and creates the PHB together. When it is not possible to engage the patient, the main caregiver steps in to co-create the PHB.

For the Care Team, it is a visual reminder that there is a unique human being behind the symptoms — to remember “who” it is they are caring for, beyond their illness. The team can also use it as a conversation starter to understand each patient’s preferences and provide personalised care. For nurses, the PHB enables them to offer caregivers practical advice

that is specific to the patient and allows caregivers to be involved, letting them know what the patient’s preferences are and act accordingly.

Clinical Pastoral Care Manager Joyce Cheah shared an example of how the PHB contributed in an unexpected way. “The patient had a very difficult relationship with her daughter, where any interaction invariably ended up in shouting matches, although they actually cared for each other deeply. The daughter was unsettled about her mother’s preferred place of death, as she felt that her mother would resent her if she let her die in the hospice.”

However, when Joyce managed to get a private moment with the patient the next day, she agreed to fill in her own PHB. The patient wrote: “I want you to know that I want to die simple [sic] with not many people around me....Happy to stay in hospice, new quiet

environment. Happy to die here.” This gave her daughter assurance, and whenever she had doubts, the team could direct her to the PHB to remind her of her mother’s wishes.

In spite of its many benefits, filling in the PHB has its challenges. Dr Tan shared, “We learned that not every team member has the tools to discuss the PHB and hence a list of prompters was created to guide staff through the process of creating the PHB. We hope to create a common language for all team members and to increase their confidence in filling in the PHB with patients and families. We also learned that the board is only as good as the effort put into creating it, and catching the right opportunity to do so is very important. For some patients who may be less expressive, engaging their family adds a lot of colour to their PHB and benefits the team immensely.”

From left: Understanding our patients’ personhood allows Assisi Hospice’s Care Team to care for them in ways aligned to their values, and hence allow them to maintain their dignity and quality of life; Examples of patients’ PHB



WORDS ASSISI HOSPICE PHOTOS ASSISI HOSPICE, FREEPIK

“WE TRY TO UNDERSTAND THEM, THEIR VALUES, AND WHAT MAKES THEM WHO THEY ARE.”

DR TAN SU-YEN



MEANINGFUL LAST MOMENTS

Through collaboration between SingHealth Community Hospitals (SCH) and HCA Hospice, a palliative patient was able to enjoy his favourite activity and find comfort during the end stage of his life.

“**L**ook at what I did!” exclaimed Mr W. His eyes sparkled with excitement as he proudly held up his masterpiece to the patient sitting beside him. Mr W was glad that he could still find peace and lose himself in his creativity during the final stage of his life.

KEEPING ACTIVE

Mr W suffered from metastatic appendiceal cancer, but despite his condition, he was a cheerful person with a pleasant disposition. After his retirement and diagnosis of cancer, Mr W began his palliative journey at Oasis@Outram, HCA's newest day hospice, where he spent many enjoyable hours indulging in his passion for arts and crafts.

Mr W had always been an artist at heart. Even in his ailing condition, he

found comfort and joy in creating beautiful masterpieces with his own hands. As his condition worsened, Mr W could no longer make his way to the elder day care centre by himself. Furthermore, his wife was unable to provide adequate care for him at home.

To address his health issues, he was admitted to Outram Community Hospital (OCH), part of SingHealth Community Hospitals (SCH), for inpatient palliative care in January 2023. As part of an ongoing collaboration between SCH and HCA, he resumed his routine at Oasis@Outram, where he continued to engage in his favourite activity and connect with his friends.


“The objective of this collaboration is to improve patients’ quality of life and fulfil their last wishes,” said Dr Sharon Harvinder, Senior Staff Registrar, Post-Acute & Continuing Care (PACC) at OCH. This is done via shared activities and the joint use of HCA and OCH facilities within SingHealth Tower so patients could improve their well-being through social activities such as table games, and simple arts and crafts.

“The proximity of Oasis@Outram to the OCH palliative ward within the same building also further enables both HCA and OCH teams to work together closely and creatively to improve patient-centred care,” said Dr Sharon.

CONTINUOUS INNOVATION

Pursuing innovation and expanding collaboration in palliative care increases the ability of healthcare teams to provide tailored, person-centred care to suit each patient’s goals, preferences, beliefs and values.

“Collaboration allows many parties to come together to exchange ideas and pool resources to improve quality of life for patients,” shared Dr Sharon.

Furthermore, building partnerships can help ensure that the patients’ wishes are respected and that they receive the best possible care throughout their journey. 



From opposite page (clockwise): Mr W’s passion in arts and crafts manifested in handmade bags and drawings; Dr Sharon is part of the OCH palliative team that supports the OCH-HCA collaboration



“COLLABORATION ALLOWS MANY PARTIES TO COME TOGETHER TO EXCHANGE IDEAS AND POOL RESOURCES TO IMPROVE QUALITY OF LIFE FOR PATIENTS.”

DR SHARON HARVINDER

OPENING GATEWAYS TO CONVERSATION

The unique preposition of co-locating childcare and eldercare has reaped benefits for all.

Aside from providing more opportunities for fun and laughter, what is the value of having an infant and childcare centre co-located within a nursing home? Is it too absurd to imagine little children as providers of palliative care?

The principal of St Joseph's Home Infant and Childcare Centre (SJHICC), Ms Imelda Anthony, shared a story involving the young children under her care.

Arriving in school early one morning, the children saw a bird lying dead on the playground. There were mixed reactions. Some squealed in disgust while others asked, "Why did it die? What could have happened to the bird?" Imelda gathered the children around and made it an opportunity to talk about death.

She explained, "Death is a natural part of life. The bird could have been seriously sick or hit itself against the wall. It's the same for us — we may fall sick or something

can happen to us too. As long as we are alive, death is inevitable at some point in time. When a person we love dies, we will feel sad and miss the person. That's normal."

The children and teachers prayed for the bird. They then gently picked up the carcass of the bird, wrapped it in a piece of cloth and buried it under the plants in the garden.

EMBRACING SMALL MOMENTS OF LIFE AS TEACHABLE MOMENTS ABOUT DEATH

As part of SJH philosophy, children are not shielded from topics of death and sickness. Children interact with elderly residents on a daily basis as part of their curriculum. Seeing residents with a urine catheter, rouse tube or lying motionless on the bed was not uncommon. The teachers embrace these small moments of life as teachable moments about death.

When death comes, our pastoral staff would set up a memorial

table with a lit candle for staff and residents to stop by for a prayer or moment of silence. Seeing the table along the walkway, teachers would take the opportunity to demonstrate how to pay respects to the deceased.

Starting early education on death and dying normalises this natural part of life — including the grieving process — and equips young children to be comforters and companions to others.

An edu-carer, lovingly known as Teacher Wen, who had worked at St Joseph's Home for three years caring for infants, left to nurse her illness when she was diagnosed with cancer. The SJH teachers took turns to call and check in on her and her family. Parents of the infants she cared for also gifted her with plants and fruits.

Although the children she cared for had just reached two or three years old, teachers would show them pictures of Teacher Wen and tell them that she took care of them when they were little. On her passing, teachers took extra care to inform the children and their parents as well.

CULTIVATING LITTLE COMFORTERS AND CARERS TO THOSE IN SUFFERING

When Louisa Chua, a senior teacher at SJHICC, admitted her father as a resident to SJH, a few of the current Kindergarten Two children met him. This visit was part of SJHICC's intergenerational experience, which included visiting residents every day and learning about music and nature alongside them.



This was the very reason behind Louisa's decision to choose SJH for her father. At the time of his admission, SJHICC had been in operation for two years. The intergenerational programme had become more established, with a timetable for children to visit residents and take specific subjects that involved them.

Louisa had seen how the children brighten up the residents' days. Having the children engaged in the same activities with the residents improved their alertness and participation, and she wanted her father to be able to have such experiences as well. After Louisa's father passed away in the Home, the children even created a card with handprints and kind words to comfort the family.

"My family enjoyed reading the notes from the children. It brought a smile to our faces despite the sadness of losing Dad. He would have loved seeing the messages because he really liked children," said Louise.

Children also encountered classmates with family members who passed away from illness. When a child enrolled in the Kindergarten Two class, known as Lei Lei, experienced the passing of his grandfather, he received support from his classmates through open and caring

conversations. On his first day back at school after the funeral, his classmate, Alexa, asked him, "How was the funeral? How are you now?"

CHILDREN ARE DOORWAYS FOR CONVERSATIONS AND GATEWAYS FOR HEALING

When children are unafraid of the topics surrounding death and illness, they become doorways for conversations. With open, honest and respectful dialogue, comfort and healing of the spirit is allowed to take place.

Mary, a resident who had her leg amputated, was a regular at the intergenerational programmes. The first time she met the children, they innocently asked her, "What

happened to your leg?" In the beginning, she gave short, curt responses such as, "I cut it off."

During subsequent visits, the teacher observed an increased openness and acceptance in the way she explained her amputation. When another child asked about her leg, she replied, "I got sick and in order to keep the sickness from spreading to the rest of my body, the doctors had to cut off my leg."

The conversation went on for about ten to fifteen minutes after that, with the conversation ending with the child looking over the amputation and asking, "Does it hurt?" And Mary replied, "It used to. Now, it no longer hurts." They both smiled at each other. ^{HL}



Top: Children and residents participating in an intergenerational puppetry programme, where they create paper puppets of themselves and rewrite endings of the classic "Tortoise and the Hare"; Left: The card made by the children for Louisa and her family



From far left:
Dr Grace Yang (middle)
with colleagues
Dr Shirley Neo (left) and
Dr Jamie Zhou (right);
Dr Raphael Lee (second
from right) and
his team handing
over patients

ASK THE EXPERTS

HARNESSING KNOWLEDGE, LINKING HANDS

Dr Grace Yang, Chairman of 8th Singapore Palliative Care Conference (SPCC 2023) Organising Committee, and Dr Raphael Lee, Chairman of SPCC 2023 Scientific Committee, share their thoughts on the palliative care sector, research and SPCC 2023.

Dr Grace Yang is Senior Consultant for the Division of Supportive & Palliative Care at National Cancer Centre Singapore, as well as Director of Research at SingHealth Duke-NUS Supportive & Palliative Care Centre. She is currently a Fellow of the Academy of Medicine, Singapore and in addition to her clinical work, she is also engaged in research projects pertaining to spirituality, health services research and quality of life.

Dr Raphael Lee is Consultant for the Department of Palliative Medicine and Supportive Care at Woodlands Health Campus. His

research interests include frailty, geriatrics and organ failures. Dr Lee has collaborated with Singapore Hospice Council (SHC) previously as a speaker for SHC's Multidisciplinary Palliative Care Forum, where he shared his experience and knowledge on frailty in palliative care and how it affects patients.

What led you to palliative care?

Dr Grace Yang (GY): I was drawn to the holistic approach of palliative care because I wanted to look at the patient as a whole person rather than a mere collection of body parts. Also, working in palliative care

allows me the privilege of journeying with someone as they go through the challenges of a serious illness.

Dr Raphael Lee (RL): Palliative care is very similar to my first speciality, geriatric medicine, in terms of its multidisciplinary and holistic approach and I view it as a continuum of care that I can deliver for my patients. I was heavily influenced by my grandmother whose values, love and guidance inspired me to care for older adults. The compassion and dedication of seniors, colleagues and the multidisciplinary team I worked with during my training were heartwarming and they all served

as role models for me in choosing palliative medicine eventually as my subspeciality.

How do you decide on a research topic?

GY: During the course of my clinical practice, I realised that in order to make a bigger impact, I needed to conduct research into models of palliative care service delivery so as to bring about system-level change in the delivery of care to patients.

RL: I decide on my research projects and collaborations based on both interest as well as identified needs. My current scope of work is in the areas of frailty, geriatrics and organ failures.

How does investing in research contribute towards delivering quality palliative care?

RL: Research establishes evidence to inform our medical practice and shape our clinical approach for decision-making that will enable us to provide quality and patient-centric care for our patients with life-limiting illness. On a larger scale, it can inform policy-making that will positively guide delivery and provision of palliative care.

The theme for SPCC this year is “Building Collaborative Communities”. Why is it important to encourage collaboration, inclusivity and open dialogue in this field?

GY: We all bring something different to the table — different skills, experiences and perspectives. We can do so much more when we work together!

RL: Multidisciplinary teamwork has always been one of the core tenets in the delivery of care for our patients. By being consultative, we can harness the expertise of each family group to synergise and provide holistic care for our patients. I have also been humbled by the rich learning experience each encounter brings and am grateful for the guidance and correction of my shortcomings that would not have been possible if not for my team.

What's new at SPCC 2023?

GY: We are expanding the content to include the wider palliative care community. In addition to topics such as pain management, we will be covering spiritual care and palliative care in the nursing home. We even have a special track for volunteers! We are also offering hospice visits, which will give participants a rare opportunity to both learn and explore possible collaborations.


What is one SPCC programme or workshop you are looking forward to?

GY: I am looking forward to the post-conference research development workshop in particular where an amazing expert panel will be giving guidance to young clinicians

aspiring to do research. Not only will we get to hear about potential research proposals from these young clinicians, but the expert panel will also each share their research experience. I am even more excited about the opportunity to network with the palliative care research community.

RL: I am looking forward to the plenary on collaboration across care settings as the topics involve my areas of interest, and learning from the esteemed speakers to better my own clinical practice.

What innovations or advancements are you hoping to see in the palliative care field in the near future?

GY: I hope that we as a palliative care fraternity will reach out and collaborate with others whose main area of work is not palliative care. There is so much we can learn from others. With all the outreach efforts by Singapore Hospice Council and palliative care organisations, public awareness of palliative care is increasing. Therefore, we should ride on the current wave of interest to collaborate and innovate in order to advance palliative care. 

SPCC 2023 takes place on 1-2 July at Marina Bay Sands Singapore.

“MULTIDISCIPLINARY TEAMWORK
HAS ALWAYS BEEN ONE OF THE
CORE TENETS IN THE DELIVERY OF
CARE FOR OUR PATIENTS.”

DR RAPHAEL LEE

SHOWING CARE AND SUPPORT FOR CAREGIVERS

The Palliative Care Centre for Excellence in Research and Education revealed key findings from its study into the effects of COVID-19 and inflationary pressure on family caregivers at Dover Park Hospice's "Empowering Caregivers as Partners in the Caregiving Journey" symposium on 6 April 2023.



KEY FINDINGS OF THE CAREGIVER STUDY

PROFILE OF THE MAJORITY OF SURVEYED CAREGIVERS

68%
female

79%
46-75 years old

61%
married

49 % employed full-time



6-7 hours per day on caregiving



42%
of caregivers are at risk of depression
Certain factors such as the lack of practical assistance and emotional support from family and friends, and caregivers' inability to have their spiritual and/or religious devotion needs met can increase the risk of depression in the respondents.



More than 60%
indicated that caregiving training would be helpful to their caregiving journey.



80%
of caregivers want greater financial assistance
The majority of the respondents were concerned about rising costs which may affect their ability to afford care for their loved ones and expressed the need for more financial incentives.



6 THINGS

TO DO TO SUPPORT THE CAREGIVERS

On average, respondents spend about seven hours a day caring for their loved ones and the majority have been caring for them for at least three years. Caregivers should be recognised for their efforts, contributions and being an important part of the community.

HOW CAN WE SHOW OUR SUPPORT TO CAREGIVERS?

1 PROVIDE INFORMATION AND RESOURCES

Look out for training courses, respite care programmes, and other helpful information, such as the palliative care resources on the Singapore Hospice Council (SHC) e-Library. Want to learn more about palliative care? Attend the SHC Palliative Care 101 course!

2 OFFER A LISTENING EAR

A kind word can make a difference. Let the caregiver know that you are there to provide emotional support.

3 CHECK IN REGULARLY

Remind caregivers to take breaks, eat regular meals and that caregiving can also be enjoyable and meaningful.

4 LEND A HELPING HAND

Offer practical help such as running errands or arranging for service providers to provide respite care so they may take a break with peace of mind.

5 PROVIDE ALTERNATIVE SPIRITUAL/RELIGIOUS SUPPORT

You can offer spiritual/religious support at the caregiver's convenience, especially if they are unable to leave the house or have limited time for these commitments.

6 ENCOURAGE THEM TO SEEK HELP

Caregivers may experience a range of emotions, including anxiety, depression and burnout. It is important for caregivers to prioritise their own mental health and seek help if needed.

"We are, will be, or will need caregivers at some point in our lives. It is a role that we should not be afraid of, but one that needs to be embraced."

DR LIEW LI LIAN, CEO OF DOVER PARK HOSPICE

By recognising the importance of caregiving and embracing the role of caregivers, we can build stronger and more caring communities, where everyone has the support they need to have the best quality of life at every stage.



Call Samaritans of Singapore (SOS) at 1800-221-4444 (24hrs) if you are thinking of suicide or harming yourself. If you know of someone who is in immediate harm, call Singapore Civil Defence Force (SCDF) at 995.

For financial assistance, check out www.aic.sg/financial-assistance

PALLIATIVE CARE CAREGIVER RESOURCES IN SINGAPORE

Common Caregiver Resources

<https://singaporehospice.org.sg/caregiver/>

Frequently Asked Questions on Palliative Care

<https://singaporehospice.org.sg/e-library/docs/faqs-palliative-care/>

Palliative Care Services in Singapore

<https://singaporehospice.org.sg/services/>

Talking to Someone Who is Dying

<https://singaporehospice.org.sg/dialogue/>

BRINGING OUT THE BEST CAREGIVER IN YOU



Tzu Chi home care team with Madam Tan and her daughter

Doctors, nurses and therapists come to mind when we think about receiving treatment for an illness, but the family caregiver is also critical to the team, providing day-to-day support to the patient such as administering medications, assisting with activities of daily living, providing emotional support, and even coordinating medical appointments and bills. They are often the first to notice changes in the patient's

condition and can alert the team to promptly address any issues.

Caregiving can be challenging and emotionally taxing. Over time, caregivers may experience stress, anxiety and depression, which can affect their well-being and ability to provide high-quality care. It is essential to support caregivers with community assistance and resources to ensure that they can continue to be the best caregiver to their loved ones.

Community assistance for caregivers includes respite care, counselling services, support groups and training programmes. Respite care gives caregivers a break from caregiving responsibilities, allowing them to rest and recharge. Counselling services offer emotional support and help caregivers manage stress and anxiety. Joining support groups can provide a sense of community and connection with other caregivers. They can also sign up for workshops to improve their caregiving abilities, such as managing symptoms and medication.

Besides the assistance offered by hospitals and hospices, SHC hosts an e-library on its website filled with free online resources such as booklets, brochures, videos and more.

It can be overwhelming to shoulder all the responsibilities of being a caregiver while dealing with the emotions that come with having a terminally ill loved one. Caregivers should know that they are never alone on their journey and that help is available to those who need it.

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