

THE HOSPICE LINK

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**Giving voice
to young grief**

**Die-logues to
raise awareness**

**Palliative
care for
all ages**



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now available as
animated audiobooks

When I first shared that I was joining the Singapore Hospice Council a year ago, reactions from friends and peers were mostly in the vein of: "huh, so depressing leh," "you sure boh?" and "so sad!" I remembered that my thoughts were "why not?" and that palliative care and hospice work are important, impactful and meaningful. While I was undeterred — not knowing better — I had no ammunition to rebut my dear detractors that the work was neither sad nor depressing.

One year on, after working alongside the palliative care family of dedicated healthcare professionals, policymakers, partners and stakeholders, I set out to convince others of the value of palliative care and share the critical work of the Singapore Hospice Council.

Not attempting to mask the subject many have deemed taboo, most of us are "future patients" and "future caregivers" who will need palliative care sooner or later. Death knocks on everyone's doors regardless of age, wealth or status. Some deaths may be sudden or traumatic, but more often, many of us have a runway to benefit from palliative care before our eventual demise.

We hope that our readers will benefit from the authentic stories and personal experiences in this issue of *Hospice Link*. In this issue, Dr Norhisham bin Main from Ng Teng Fong General Hospital discussed his career and how he supports our council's mission of advancing education in palliative care to the Malay-Muslim community (page 16).

I would like to share a quote from Dame Cicely Saunders, founder of the modern hospice movement, "You matter because you are you, and you matter to the last moment of your life."

Start today and make every moment count until the very last.

Sim Bee Hia
Executive Director
Singapore Hospice Council

I would like to share a quote from Dame Cicely Saunders, founder of the modern hospice movement, "You matter because you are you, and you matter to the last moment of your life."

Below: Dame Cicely Saunders, founder of the global hospice movement, 1996



Caring for young children of palliative patients

In palliative care, we not only provide care and comfort to patients, but give support to patients' families too, not forgetting the young children.



Alice (name has been changed) is in her 40s and has been diagnosed with breast cancer. She is under the care of Assisi Hospice's Home Care service. Her youngest daughter, Brenda (name has been changed) is six years old. Alice and her husband did not speak to their daughter about her condition as

they felt that she was too young to understand. However, Assisi Hospice's medical social worker Ms Ooi Yinn Shan noticed that Brenda was in distress.

She said, "When our Home Care nurse and I visited the family, Brenda came to us and asked, 'Is she in pain? Is she dying?' I also noticed her tearing."

Alice's husband was initially reluctant for Yinn Shan to reach out to Brenda. He thought his daughter was too young to experience any distress or grief. After highlighting the impact of psycho-emotional pain on Brenda, Yinn Shan convinced Alice's husband to allow her to reach out to Brenda. Yinn Shan started play therapy with Brenda, using selected play materials like balls and dolls. This facilitated the development of a safe relationship for Brenda to fully express and explore her

feelings, thoughts, experiences and behaviour through play.


Yinn Shan shared, "All children need help and support to manage strong emotions, especially children dealing with challenges like a family member who is sick, a death in the family or other traumatic events. Children develop their ability to identify and name emotions through plenty of practice. Recognising and naming emotions help children understand their feelings and lay the groundwork for managing emotions. It is easier for children to practise through play when they are relaxed before their emotions get too intense."

Throughout the four sessions with Brenda, Yinn Shan found that Brenda was interested in art and referred Brenda to Assisi Hospice's art therapist, Ms Vivian Wong, for further intervention. Vivian facilitated a session where Alice and Brenda worked on an artwork together. Brenda chose to paint a

Opposite page (bottom): Pink box with gems and beads made by Alice and Brenda; Right: Alice added a "Sweetheart" sticker to express her love for her daughter

box in her favourite colour — pink — and decorated it with gems and beads. Alice showed her love for her daughter by working alongside and using similar materials, finally adding a sticker with the word "Sweetheart". Alice shared that she was glad for the session as it had been a long time since

she shared a fun activity with Brenda.

The process of creating art together provided space for Alice to preserve her role as a doting mother to Brenda and allowed Brenda to receive a gift and the attention she needed. Brenda's father was more receptive to art therapy sessions for her after observing the process and exchanges that took place. This paved the way for further assessment of needs and formulation of appropriate interventions to support Brenda. 



Insight from a medical social worker and art therapist

Yinn Shan and Vivian share their experiences and challenges working with young children of palliative patients.

What are the common challenges when working with young children of patients?

Yinn Shan: Most people assume that young children are too young to know what is happening, so adults tend to assume that avoiding the topic is beneficial for the child. However, children are observant and can see and sense the changes around them. For young children, losing their parents is painful, and early engagement can allow them to process their emotions and have a good closure.

Vivian: Children's grief may be under-addressed as adults around them base their assessment of how the children are coping on what they observe instead of trying to understand how they truly feel. Parents may send the children away to a friend or relative's house to "protect" them from seeing their loved one being critically ill or dying. Children who are losing someone who is their attachment figure may experience anxiety at the prospect of losing their sense of security and safety.

What are the common issues that these children may face?

Yinn Shan: They may face adjustment difficulty with changes in their daily routine, family environment, and grieving family members. Preschool children understand the concept of death and will experience loss, abandonment, and insecurity if a significant person is missing. They may also have issues processing grief and other emotions as they struggle to express their feelings in words.

Vivian: As young children do not respond to grief the same way adults do, or lack the emotional language to articulate how they truly feel, adults often can't understand the impact of serious illness or death of a loved one on them. Younger children who do not understand the concept of illness and death may see these events as reversible or believe that they are a result of their negative thoughts or behaviour. Therapeutic interventions should cater to the child's needs based on factors such as developmental age, maturity, attachment to the patient and relationship with surviving caregivers.

How does counselling and art therapy help?

Yinn Shan: Play therapy is one of the more effective counselling methodologies for engaging young children. It provides a psychological buffer between children and their problems, so that they feel safe. Play provides children with an outlet for self-expression, increasing knowledge of self and relieving stress by establishing successful strategies for addressing concerns and coping.

Vivian: Art therapy helps a child to articulate aspects of experiences or difficulties that need attention. Sensory materials such as clay is a versatile medium which allows for different complex feelings to be expressed in a safe way, facilitating the discharge of energy and pent-up emotions through movements such as pounding, squeezing, pinching and ripping, but also has a calming effect when the art process involves rolling, moulding and smoothening. Creating a piece of tangible artwork together brings loved ones together and strengthens connections between them.



WORDS ASSISI HOSPICE PHOTOS ASSISI HOSPICE, FREEPIK

Giving voice to young grief

The tumultuous journey of losing a parent often creates immense emotional upheaval for children and the surviving parent. Project Kindle, one of HCA's newest initiatives, aims to give voice to these children, and support young families in coming to terms with death and dying.

Little Brendon's misconceptions surrounding his mother, Madam A's condition might not have come to light in a timely manner if the HCA psychosocial team had not engaged him in conversation and ascertained his understanding of the situation.

"Children are often the 'silent grievers', often overlooked when the adults in the family are overwhelmed with the patient's physical care and may not have the awareness or emotional capacity to support the children's grief," explained HCA Medical Social Worker Koh Yuqi.

Research has shown that there is often a gap in parents' understanding of their children's emotional state and ability to cope. "When interviewed, parents almost always said that their kids were fine, but this was not the case when the children shared their thoughts," Yuqi explained.

This could stem from denial of the difficult reality, or a subconscious instinct to protect their children from the emotional impact.

Supporting young families, and children less than 18 years old, in coming to terms with the impending loss and grief, is the primary focus of Project Kindle, a new initiative spearheaded by Yuqi and HCA Senior Palliative Care Nurse Nicole Peng.



Left to right: Creating art is often therapeutic for children, and helps them to express their grief and feelings; Medical Social Worker Wang Yuqi (far right) with her colleagues from HCA Psychosocial Services team

LIGHT OF HOPE

There is a heart-warming anecdote behind the name of the project. "As parents, we will always say that our children are the light of our lives," Yuqi said. "Through our efforts, we hope to bring some light to these families and also to raise awareness of the struggles they go through."

Ascertaining the children's understanding of illness and death is often one of the first steps for the HCA team, after obtaining parental consent to engage them. It is common for children to harbour misconceptions about the situation or hear about erroneous beliefs from their friends. Through the medium of art, HCA's art therapist will explore their feelings and thoughts with them, setting the stage for further intervention.

"In little Brendon's case, we tapped on our doctor and nurse to share with him about cancer, helping him to understand that his mother's illness was not his fault in any way," Yuqi shared. "We also assessed the family's coping ability, in relation to Madam A's care needs, and ensured she was supported emotionally."

KEEPING HAPPY MEMORIES

A key focus of Project Kindle lies in bereavement support and continuity

of care for surviving family members. "After Madam A passed on, our art therapist provided guidance to the children's father on their grief management," Yuqi says.

Witnessing their mother on her deathbed had caused some stress for Brendon and his sister. "Children can be sensitive to the emotional needs of adults, and become protective of them," Yuqi shared. "Our art therapist observed that Brendon felt uncomfortable talking about his late mother, for fear of upsetting his father."

But as the well-known proverb says: "Shared joy is a double joy; shared sorrow is half a sorrow." Brendon's reticence gradually faded away as the family participated in activities together, upon the encouragement of HCA's art therapist.

"Doing things together as a family brought them closer and also encouraged them to express their grief," Yuqi explained. "Madam A's children also created memory books to remind them of the happy memories they had shared with their late mother."

These memory books provided Brendon and his sister with a creative outlet to express their love and longing for their mother, and

enabled them to recall happier memories with her, instead of dwelling on sad times when her health was deteriorating.

THE FUTURE AHEAD

The death of a loved one changes family dynamics irrevocably. Bereaved families often benefit from longer-term support as they navigate new routines and roles. "We discussed childcare and work arrangements with the father, as well as looking for an alternative caregiver during the transition," Yuqi said. "We also referred them to other community stakeholders, like the Family Service Centre and Social Service Office, for long-term support."

Project Kindle is a budding initiative with big objectives for the future, all with the primary goal of supporting young families. "The families we worked with have taught us a lot, motivating us to create the project," Yuqi said. "Presently, in the local context, there is no formal framework to support these families. We aim to build capability within our team, and also come up with a proper curriculum and training programme." ¹

*Brendon is not his real name

WORDS HCA HOSPICE PHOTOS HCA HOSPICE, FREEPIK

Listening and learning

There is a lesson to be learnt from every patient, and it helps to have an open heart and a patient ear.



“Palliative care is about adding meaning to patients’ remaining time with us. When we make a positive impact, these are the memories patients reflect on at the end of their lives,” shared Assistant Nurse Clinician Kimberly Lim.

These patients are a part of Yishun Health’s Ageing-in-Place programme, a service that supports patients in their care transitions from hospital to home through home visits and tele-support. Since Kimberly started her journey as a community nurse in 2012, she has provided palliative care to patients of different ages from 40 to over 100 years old. To Kimberly, each of these patients has a story that offers lessons that have enriched her perspective.

LEARNING WHAT MATTERS MOST

News that the end of life is approaching could at times renew

one’s sense of priority for what matters most.

Kimberly recalls a heart failure patient in her 60s, for example, who kept herself busy with gardening, and arts and crafts every day, and even made the effort to keep up with current affairs on the radio. She had a strong sense of purpose for what mattered to her — not being a burden to her sister, whom she lived with.

With independence at the top of her mind, the care team assisted her to apply for a walking aid and reduced the swelling she experienced so she could be as mobile as possible. A medical social worker also facilitated her application for financial assistance. The lightening of the financial burden offered a great deal of comfort to her in her last days.

LISTENING WITH THE HEART

Kimberly reflected that her younger patients were often more communicative about their wishes and plans. This also extended to their interest to understand the details of their condition. In contrast, the family members of older patients were often the key decision-makers, especially if the elderly patients were non-verbal as a result of their medical conditions.

However, this did not mean that older patients did not have goals or preferences. Kimberly recalls her oldest palliative care patient — a then 102-year-old gentleman. When she visited him at home, she saw that he had a bad temper and refused to cooperate with his family members. As the patient was on nasogastric (NG) feeding tube and on tracheostomy tube for breathing, he could not communicate verbally. To understand his views, Kimberly

News that the end of life is approaching could at times renew one’s sense of priority for what matters most.

therefore made observations of his behavior, and had several conversations with his family members. She then realised that he was upset about being moved out of his home to live with his son. What mattered most to him was spending more of his remaining time at home, where he had memories with his late wife, whom he still missed dearly.

Kimberly and her colleagues then facilitated conversations with his family so that he was able to spend more time at his own home, giving him the motivation and hope to keep going. In this case, it was crucial to listen with not just the ears, but also the eyes and heart.

LIFTING UP TO CARRY ON

When a loved one nears the end of life, family members are often affected not just emotionally, but also where the practical aspects of life are concerned. This is doubly so when a patient is at the prime of his life.

One of Kimberly’s palliative care patients was a man in his 40s who had experienced a sudden heart attack, leaving him unable to communicate and dependent on full-time care with minimal chance of recovery. He was the sole breadwinner and at the time, was thinking about starting a family. For his wife, this meant not just the profound loss of a loved one, but



Opposite page: Assistant Nurse Clinician Kimberly Lim is always ready to extend advice and assistance, and bonding with her community nursing team (right)



also of shared goals and dreams. It also caused an upheaval in her life with the shift from being a housewife, to breadwinner and caregiver. For the first time, she was faced with the prospect of searching for work that could pay the bills and support them.

“We really needed community social support — counselling support and an ongoing social worker — to journey together with the family, and help his wife to plan for the future,” shared Kimberly. “This is a unique aspect of care for patients at this age.”

After years of experience as a community nurse, Kimberly has been confronted with numerous

difficult situations. “There were times when I was at a loss. But, just by going through this journey with the patients and their families reassured them that they are not alone. They have someone to hold their hand and listen to them,” Kimberly said.

As every case is unique, Kimberly has gained new and broader perspectives in the process of walking with her patients. “Providing palliative care has enriched my life,” she explained. “I experience different moments of my patients’ lives together with them, and each experience prepares me to manage my future patients.”



From wellness to wholeness

St Luke's Hospital launches a Palliative Care Symposium to reinspire compassionate care among individuals, teams and organisations.

Participants at the inaugural Palliative Care Symposium organised by St Luke's Hospital have gained greater insight into how to practise "compassion as a way of life" and were thankful for the "affirmation in the palliative work we all do".

The symposium themed "Wellness to Wholeness" was held at One Farrer Hotel on 22 November 2022. About 150 participants from the healthcare and community care sector came together to learn, network

and exchange knowledge and experiences in providing whole-person care from an international panel of experts.

Grief therapist Ms Liese Groot-Alberts, Asia Pacific Hospice Palliative Care Network & Hospis Malaysia Faculty Member, in her keynote presentation, highlighted compassion as a "deep awareness of the suffering of another, coupled with the desire to relieve it. It is love in action, with the purpose to heal".

While whole-person compassionate care through

caring for the patient's clinical, social and emotional needs seeks to improve a patient's overall well-being and health outcomes, spiritual care is an integral aspect that is sometimes overlooked.

In her workshop, registered nurse Ms Joan Marston, Global Ambassador for the International Children's Palliative Care Network, and Executive Committee of Palliative Care in Humanitarian Aid Situations and Emergencies (PallCHASE), emphasised the need to identify what gives meaning, purpose and joy to patients' lives, and helping them fulfil basic spiritual needs such as love, faith, hope, integrity and beauty. For most patients, strengthening one's spirituality can influence key outcomes, such as improved quality of life and better healthcare decisions.

Likewise, the same care should also be extended to healthcare professionals in Singapore, to empower them to better care for patients and meet the care needs of a rapidly ageing population.


Acknowledging the increased reports of compassion fatigue and burnout in the sector, Ms Groot-Alberts shared how practices such as setting clear boundaries, having clear and honest communication, making healthy compromises, and being open-minded and flexible can help to build cohesive and supportive relationships for a sustainable care team. She encouraged healthcare workers to continue showing compassion by establishing authentic relationships, practising unconditional acceptance and active listening. By building a trusting relationship with patients and their families, healthcare professionals can better identify care needs and usage of appropriate methods of care, leading to better patient outcomes.

Beyond hospital walls, it is also crucial to provide assistance for those with serious illnesses through a network of community-based services working collaboratively with the care team. Psychotherapist and medical social worker Dr Katie Eastman, Adjunct Professor of Antioch University, N.E. Graduate School, touched on key elements



of compassionate communities, which include care delivery across settings based on a shared plan, and communication between patient, family and caregivers on tracking outcomes. Such methods can increase efficiency and effectiveness, as well as improve coordination of care.

As Associate Professor Tan Boon Yeow, Chief Executive Officer of St Luke's Hospital said in his welcome address, "We journey with every individual who comes through our ward till their final days. We see how our patients pass in peace as

their final wishes were fulfilled. However, our work to care does not end with patients leaving the ward. We will continue to engage the patients' loved ones through grief and bereavement support, and memorial service." In 2017, St Luke's Hospital opened its dedicated palliative ward and has since served more than 500 patients, regardless of race, language or religion. Through sharing of experiences and best practices, the symposium hopes to reinspire and reinforce the concept of compassionate care as the bedrock and foundation of the hospital's capacity to serve. 

WORDS ST LUKE'S HOSPITAL PHOTOS ST LUKE'S HOSPITAL
GETTY IMAGES SIGNATURE VIA CANVA.COM



Above: Guest-of-Honour A/Prof Kenneth Mak (Director of Medical Services, Ministry of Health, Singapore) in his virtual Opening Address; Left: End-of-life care experts during the panel discussion (left to right): Mr Ken Ross (President of Elisabeth Kübler-Ross Foundation), Ms Joan Marston, Dr Chong Poh Heng (Vice Chairman of Singapore Hospice Council, Medical Director of HCA Hospice Limited), Ms Liese Groot-Alberts and A/Prof Tan Boon Yeow

Regardless of age

Death is not the prerogative of the old, and neither is the need for palliative care. It happens to the youngest and the best of us.

Singapore's population is ageing rapidly — one in four will be 65 years and older by 2030. In data published in June 2021 by the Singapore Department of Statistics: Singaporeans enjoy the third longest life expectancy in the world at an average of 83.9 years, yet the years spent in ill health has increased to 10.6 years. With ageing comes increased prevalence of serious illnesses such as cancer, ischemic heart diseases and stroke, which are the top causes of death in Singapore.

At the virtual 7th Singapore Palliative Care Conference on 8 December 2021 organised by the Singapore Hospice Council (SHC), Guest-of-Honour Minister for Health Ong Ye Kung spoke about the rising importance of palliative care for a rapidly ageing Singapore population. That the desire of the caregivers to ensure all avenues of recovery for the patient diagnosed with a terminal or life-limiting illness have been explored, which may culminate in the end of life in a hospital or hospice, and the desire

of the patient to spend the remaining time and dying in the comfort of home will have to converge. While ramping up the training of palliative care professionals and palliative care capacity in the healthcare institutions are part of the Ministry of Health Singapore's National Strategy for Palliative Care, supporting caregivers and expanding home palliative care are also part of the plan.

There is a standard of palliative care set out by the World Health Organization, that states: "Palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well."

PALLIATIVE CARE FOR THE AGED

Many people do associate palliative care more with the elderly who are suffering from life-limiting or terminal illness, and frequently, mistakenly, think it is synonymous with hospice care. The misperception is that one



Every palliative patient has their own needs and concerns, hopes and dreams, love and hate — yes, even the youngest ones — and should not be treated as just a case number to be looked in upon as part of the ceaseless round of duty.

WORDS ANNE LOH PHOTOS FREEPIK

has given up hope when a patient is receiving palliative care, which is not the case. Patients with the afore-mentioned illnesses are eligible for palliative care, as are those with dementia, kidney disease and liver disease, to name a few.

Palliative care is not about letting the patient languish however. As HCA Hospice Limited (HCA) Medical Director Dr Chong Poh Heng, who is Vice-Chair of SHC, put it in Season 3 Episode 7 of the Institute of Policy Studies (IPS) On Diversity Podcast titled "Palliative Care for the Young and Old", it is about

bringing back “the fervour to live” after one’s life has been turned upside down when diagnosed with a serious illness.

Although, where palliative care for the aged is concerned, family members and caregivers, as well as the patients themselves, expect a deterioration of their condition, according to St. Andrew’s Community Hospital Senior Resident Physician Dr Karen Liaw, who also said that it is a common concern that less than optimal care is rendered.

This is, and definitely should not be the case, said Dr Liaw, although she pointed out that many caregivers of elderly palliative care patients feel that they have to advocate for their loved ones. She gave a case in point, “We are currently caring for a 97-year-old patient who has advanced dementia. Her main caregiver is her son who is in his late 60s. While he acknowledges that she is elderly and will eventually deteriorate, he reiterated multiple times in the first phone call and during the care team’s first home visit that he will not agree to anything that would deprive his mother of treatment. We realised he had an unhappy experience during his mother’s previous hospitalisation, where he had the misperception that the medical team did not want to

resuscitate his mother in the event of deterioration because she is old.

“The care team will address the family’s concerns by engaging them in discussions regarding the patient’s values and what matters most to them,” said Dr Liaw.

PALLIATIVE CARE FOR ADULTS

While palliative care for the elderly is particularly challenging because the patient could be having a life-limiting illness in addition to concurrent chronic disease that needed to be addressed at the same time, palliative care for teens and adults presents a more complex need for psychosocial and spiritual support.

Adults in their prime, and especially those who are the main breadwinners of the family, are more likely than not wont to rail against their “fate” or ask the existential question: “why me?” If they are married with young children, the palliative care situation compounds, as their caregiver would be stretched physically, financially, emotionally as well as mentally.

Recognised as a Leader of Good at the President’s Volunteerism & Philanthropy Awards 2021, Dr Chong, a general practitioner turned palliative care professional, is advocating for more caregiver leave as well as a change from “the medicalisation of death and

dying”. It goes beyond morphine, he said in his podcast, to even non-medical interventions.

Many adult palliative care teams thus swing into legacy-building, morale-boosting and connection-making activities in a bid to fulfil any last wishes of the adult patients so that they do not have any regrets or leave any unfinished business, and are able to leave with peace of mind.

PAEDIATRIC PALLIATIVE CARE

Dr Chong, who founded Star PALS, a palliative service for children and minors up to 19 years old, under HCA, published “A good death in the child with life shortening illness: A qualitative multiple-case study” with Catherine Walshe and Sean Hughes in *Palliative Medicine* December 2021. While current literature comparing dying at home or in palliative care has mixed views of individual impact, the study states, it is certain that the perceptions of a good death in adults with life-limiting illness may not apply to children. The study concluded that “the priorities of the child should become central”, caregivers learning to let go would result in “minimised overall suffering” and a supportive familial environment brings the most comfort.

On the IPS podcast, Dr Chong said that palliative care for young people who are still studying extends beyond the immediate family. He recounted times when he had to visit the school in advance of a returning student undergoing care in order to prepare the classmates and teachers on what to expect and also to inform them of the eventual final farewell that would take place.

Indeed, paediatric palliative care has improved by leaps and bounds since KK Women’s & Children’s Hospital Head of Service Associate Professor Chan Mei-Yoke published the “Paediatric Palliative Care in Singapore” chapter in the book *Pediatric Palliative Care: Global Perspectives* (SpringerLink, 2021) 10 years ago.

“There has been vast improvement but it can be improved further! Some physicians and families still feel that being referred to palliative care means that we are giving up on the child or that it is a failure on the part of the physicians,” said A/Prof Chan. “I see these situations very often when I was training

Palliative care is a universal and human right. We all deserve a good death that gives us the dignity to leave well on our own terms.

in paediatric oncology. Paediatric palliative care is not just for end-of-life, it should be integrated into the continuum of care of children the moment they are diagnosed with life-threatening or life-limiting disease.”

Paediatric palliative care has always been difficult to broach, A/Prof Chan pointed out, because parents don’t want to face the possibility that treatment has failed and death is the only possible outcome, resulting in late referrals by physicians. “Active treatment aiming at cure (however slim) can carry on in parallel with comfort supportive palliative care,” she said.

Managing the family’s expectations is crucial as the progression of disease in children is not as predictable as for adults. Furthermore, the whole family has to be involved. “Palliative care also has to take the whole family unit into account and provide support not just for the child-patient but also the parents, siblings, grandparents and, in the Singapore context, the foreign caregivers too, who are often forgotten!” said A/Prof Chan.

STARTING THE CONVERSATION

As Minister Ong pointed out, “We need to discuss the sensitive issue of deaths more openly and more honestly. This is probably the most important thing we need to do. It has to happen within families, between patients and doctors, and amongst members of our society and healthcare fraternity.”

SHC runs outreach programmes in the form of PC101 training (page 18), roadshows, library exhibitions and has both online (page 24) and hard-copy resources such as this magazine, to name a few. Its member organisations (page 2) also run independent outreach programmes on Advance Care Planning.


Lyn Che, a pastoral care staff from St Joseph’s Home, shared, “We raise awareness through inviting the children from the Infant and Childcare Centre and our volunteers to get to know our residents. Through conversations with residents or when residents they know pass away, the children and youths become exposed to the topic of death and dying, and are open to learning about it.”

In particular, A/Prof Chan pointed out that there are ongoing efforts to raise the profile and need for paediatric palliative care to administrators in hospitals, the Ministry of Health and the government, “The concentration is more on the elderly than the children at the moment.”

TAILORED PALLIATIVE CARE

As it says on the SHC website: “Palliative care can be provided at home, in nursing homes, hospices, specialist clinics, general and community hospitals, catering to every patient’s needs.”

It is essential that we build a palliative care structure, both institutional and community, that caters to all as individuals, regardless of age. It is not just about the pain relief, the management of symptoms, the repair of wounds and the comfort of the physical self. Every palliative patient has their own needs and concerns, hopes and dreams, love and hate — yes, even the youngest ones — and should not be treated as just a case number to be looked in upon as part of the ceaseless round of duty. Everyone can find a situation that suits them financially, emotionally, and comfortably.

This is why palliative care cannot be cookie-cutter. Palliative care is a universal and human right. We all deserve a good death that gives us the dignity to leave well on our own terms. 

83.9
YEARS

AVERAGE LIFE
EXPECTANCY
IN SINGAPORE
(BOTH GENDERS)

ONE
IN FOUR

WILL BE

65

YEARS AND
OLDER BY 2030

3RD

RANKING OF
SINGAPORE’S LIFE
EXPECTANCY
IN THE WORLD

10.6
YEARS

SPENT IN
ILL-HEALTH

SINGAPORE’S LIFE
EXPECTANCY IS
EXPECTED TO REACH

85.4
IN 2040





Die-logues to raise awareness

Dr Norhisham bin Main shares about his palliative care career and offers insight into how we can open up die-logues among healthcare professionals and the Malay community.

Dr Norhisham bin Main is the Head of Division & Senior Consultant, Division of Supportive Care & Palliative Medicine, Department of Medicine at Ng Teng Fong General Hospital. He also serves as the current Vice-Chairman of the Chapter of Palliative Medicine Physicians (2022-2024) of the Singapore College of Physicians. Dr Norhisham is also President of the Muslim Healthcare Professionals Association, dedicated to building a network of healthcare professionals who practice medicine guided by Islamic principles.

Dr Norhisham has supported Singapore Hospice Council (SHC) as a council member from 2016-2022 and continues to offer his time and

expertise as a valued consultant to the organisation. With more than 10 years of experience in the palliative field, Dr Norhisham has intimate knowledge of the growth of palliative care in Singapore. This past January, Dr Norhisham graciously volunteered his time to conduct a session of Palliative Care 101 at An-Nur Mosque.

What does Live Well, Leave Well mean to you?

To me, Live Well, Leave Well is very much about living life to the fullest, where one enjoys the various facets of life. Health allows us to pursue our dreams and do what is important to us. Health allows me to connect with others, build relationships, learn

and play. Being healthy is not about physical health alone. It includes being spiritually, mentally, and emotionally healthy too.

What inspired you to join this field?

I had the opportunity to work with Professor Pang Weng Sun and Dr James Low years ago. They not only showed me how to care for the elderly in good health but also how to care for them when they were deteriorating and dying. The palliative and hospice nurses were most inspiring in their passion, devotion, and love, to support and care for their patients. Importantly, they made seemingly difficult tasks simple and doable while putting the patient at the centre of it all.

Below: Dr Norhisham bin Main conducting a session of Palliative Care 101 at An-Nur Mosque

Why do you think conducting community outreach programmes such as SHC Palliative Care 101 course is important?

Most of our patients live in the community. There is so much that our community has been doing and could potentially do. During the pandemic, our community rallied to help others so willingly. With such outreach programmes, we can enable and empower them even more so that they can achieve more for the benefit of patients in the community.

What aspects of palliative care are most misunderstood or underrepresented in the Malay community?

The common myth that palliative care is only about end-of-life care and dying is also found in the Malay community. It does not help that healthcare professionals tend to label palliative care as care that only starts when there are no treatment options or when treatment is withdrawn. We know today that palliative care can and should be provided alongside active curative treatment. Active

treatment focuses on cure and return to health while palliative care focuses on symptom control so patients can go through treatments without too much significant loss in quality of life.

To what extent is the patient's religious or spiritual beliefs considered during their care?

Religious and spiritual beliefs can shape treatment preferences and influence decisions. It is a potential source of strength and resilience that helps patients and their families cope with what may be a difficult journey in illness.

Share a memorable incident with us.

A family chose to withhold information from a patient. When I saw the patient, he hinted that he was aware that he had a serious illness and that he was deteriorating. He shared that his wife for whom he was a caregiver was a priority for him. He also wanted his children to know that he was glad that they have stepped up to care for her in his illness. He understood that they did it out of their own fears and their love for him in not wanting to upset him. He did not hold it against them and shared his love for them. Unfortunately, he deteriorated that same night and died the next morning. His family heard that he had passed a message to me

for them. I shared what he told me and assured them that he still loved them. They acknowledged his love for them.

Has the level of awareness of palliative care increased over the years?

Yes, though it can still be improved. There are myths and fallacies; however, more people are aware of and seek resources on palliative care. There are those in need of palliative care in Singapore who do not know how to access it, so it is important that we have resources in the community for this. SHC's Palliative Care 101 programme aims to increase these community resources for palliative care.

To what extent are healthcare professionals more comfortable talking about death and dying?

Not all healthcare professionals are comfortable with dying and death itself, let alone talking about it. Our experiences with dying and death and our attitudes towards death vary at different stages in life.

How can more people be made comfortable talking about death and dying in Singapore?

It helps to talk to a loved one, an elder or a faith leader when we find the topic of death and dying difficult. A safe space to talk about it without being judged is important; therefore, choosing someone we trust matters too.

What advice do you have for them?

I would advise them to reflect and examine what makes it difficult or fearful. One should also think about times when they have seen others have a good peaceful death and how it was possible. End-of-life conversations may be difficult but having open conversations on it helps us to understand more, allows us to know what a seriously ill person wants, and strengthens bonds through open honest conversations.

What do you hope to see in the palliative care sector in the next 10 years?

I hope to see palliative care become more accessible and seamless, so that those who need it can receive it. 🌟



INTERVIEW: SINGAPORE HOSPICE COUNCIL

Never too early to talk about palliative care

Find out more about end-of-life care matters at the Palliative Care 101 Course conducted by Singapore Hospice Council.

There is no doubt that it is uncomfortable to talk about death and dying. Such conversations are avoided or put off until one encounters a life-limiting illness. According to a 2019 nationwide study carried out by Singapore Management University¹, 53% of Singaporeans are comfortable discussing issues concerning their own death, but only 1 in 3 respondents were comfortable discussing death with someone with a life-threatening illness. As part of its ongoing efforts to raise awareness for quality palliative care and to normalise end-of-life dialogues, Singapore Hospice Council (SHC) launched the Palliative Care 101 (PC101) course in English and Mandarin for members of the public.

The free course aims to educate attendees on the multidisciplinary aspects of palliative

care in Singapore and encourage people to begin thinking about their own attitudes towards death and their willingness to converse with family or loved ones. The course also addresses myths and misconceptions, such as the cost of hospice care and when to engage palliative services. Participants will walk away with a more holistic understanding of what quality palliative care is and practical tips on starting die-logues with friends, family, and members of their community.

Since its launch, SHC has partnered with organisations such as Nanyang Polytechnic, Raffles Institution, NUS - Project Happy Apples, Society of Sheng Hong Welfare Services (Life Point) and An-Nur Mosque to spread awareness across different ages and backgrounds. Interested agencies, institutions and corporations can invite SHC's trained speakers to conduct the talk at their preferred




Left and below: Free resources available at PC101 sessions; a PC101 session at An-Nur Mosque



location. Since the launch, more than ten sessions have been conducted and over 400 attendees have completed the course.

Participants who wish to play a greater role in advocating for the cause and have completed the PC101 training course are eligible to become SHC Ambassadors. Ambassadors are encouraged to engage with at least 20 persons over a period of two years, starting end-of-life conversations and sharing about palliative care using SHC Outreach Kits.

Starting conversations with loved ones is the first step towards normalising this taboo topic. A lack of openness on issues surrounding death and dying can lead to compromised care and support at the end of life. SHC hopes to equip Singaporeans with the right knowledge and practical tools to help them think about the matters important to them and what it means to leave well.

The next PC101 session will be held in May 2023. Interested parties can visit SHC's website to find out more and sign up for their preferred session. 

¹SMU study shows Singaporeans are more comfortable discussing end-of-life matters. SMU Newsroom. (2019, October 5). Retrieved February 20, 2023, from <https://news.smu.edu.sg/news/2019/10/05/smu-study-shows-singaporeans-are-more-comfortable-discussing-end-life-matters>



From far left to right: The start of a PC101 session; Invited PC101 session with Pallipals x Project Gift of Song students with Dr Mervyn Koh; Attendees participating in interactive SHC Conversation Cards section of SHC PC101

World Cancer Day Carnival 2023

Cancer and palliative care awareness headline this annual public event.

On 4 February, Singapore Cancer Society (SCS) presented the annual World Cancer Day Carnival 2023 in collaboration with National Cancer Centre Singapore (NCCS), National University Cancer Institute, Singapore (NCIS), Singapore Hospice Council (SHC), Woodlands Health Campus (WHC) and other major partners.

Over 1,000 people attended the event held in Kampung Admiralty, which was graced by Guest-of-Honour Mayor of North West District Alex Yam.

The event aims to raise public awareness and catalyse government action so that the public can gain access to life-saving cancer treatment as universal for all, regardless of personal circumstances.

While we live in an era of awe-inspiring advancements in cancer prevention, diagnosis, and cure, many of us who seek cancer care should know that palliative care services can be engaged concurrently to complement treatment plans.

CANCER TALKS AND AWARENESS

On the cancer awareness side, both NCC and NCIS fielded Dr Han Shuting and Dr Gloria Chan respectively to give a talk in both Mandarin and English on "Prevention and Screening of Colorectal Cancer". NCC not only brought a mega inflatable of the colon to have a big "show and tell" about polyps growth, but also lung cancer and cancer

Above: SHC Ambassador Ms Helen Ding sharing palliative care information with a member of the public; Right: Goodie bag for booth visitors who participated in the interactive activities



8TH SINGAPORE PALLIATIVE CARE CONFERENCE

BUILDING COLLABORATIVE COMMUNITIES

1-2 JULY 2023 • MARINA BAY SANDS SINGAPORE

SINGAPORE PALLIATIVE CARE CONFERENCE

is a biennial conference that brings together a community of healthcare professionals, community service providers, industrial partners, scientists, educators, caregivers and volunteers, for a rich learning and networking experience.

Come join us at the in-person conference to engage and learn from our stellar line-up of local and international experts and leaders, including:



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REGISTRATION FEES

CATEGORIES	UNTIL 14 APR	
	EARLY BIRD FEES	REGULAR FEES
Doctor	SGD720	SGD800
Doctor (Low & Lower Middle-income countries)	SGD500	SGD560
Non-Doctor	SGD400	SGD450
Non-Doctor (Low & Lower Middle-income countries)	SGD285	SGD315
Student/Volunteer (Non-Clinicians)	SGD100	SGD100



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Below: The hospice booth set up by SCS, WHC and SHC

trivia games as ways to bring serious facts across to the public in a light-hearted way. NCIS presented a colorectal cancer game and taught breast self-examination.

PALLIATIVE CARE RESOURCES

Educating the public on palliative care resources available in Singapore is part of the broader ongoing nationwide effort to decrease the care of terminally ill patients in acute hospital settings. To help the public better understand the scope of caring for patients in palliative care, SCS Hospice Care team, together with SHC and WHC palliative team jointly set up a hospice booth to provide information on palliative educational resources, the availability of homecare services and Advance Care Planning. The public was also given a three-question survey to identify their attitudes on death and dying in the

The event aims to raise public awareness and catalyse government action so that the public can gain access to life-saving cancer treatment as universal for all.

Singapore context, and two-thirds of those surveyed preferred to pass away at home.

SHC took this opportunity to continue spreading awareness on the easy accessibility of hospice resources, as well as promote various educational workshops and community outreach events organised by the organisation. At the same time, SCS stepped in to inform the public on the various services that the public can tap on such as the Living-well Programme fund and tuition for needy kids.

The WHC palliative team, meanwhile, engaged the public in conversation starters about end of life by inviting participants to spin a wheel of conversation starters to initiate meaningful chats on death and dying and identify baseline knowledge of the public.

The World Cancer Day Carnival 2023 came to a successful close and it is hoped that people took away with them useful skills and knowledge about cancer prevention and palliative care resources that they will be able to build on in the future. 🌟



WORDS SINGAPORE CANCER SOCIETY

"COURAGE TO CARE" PHOTO COMPETITION

CLOSING DATE: 9 JUNE 2023

Join us to recognise our **palliative care healthcare professionals** for their **courage, dedication and compassion** in caring for patients and caregivers.

Capture their warmth, love and care you have witnessed above and beyond their duty.

Submit your photographs to the "Courage to Care" photo competition today and stand a chance to win attractive prizes!

SCAN THE QR
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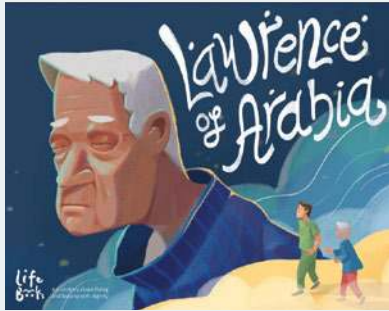


Terms and conditions apply.
For more information, visit bit.ly/SPCC2023photocompetition

Enquiries: email info@singaporehospice.org.sg or
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In conjunction with

SHC Life Books are now available as animated audiobooks



Each book in Singapore Hospice Council's (SHC) Life Book series is an inspiring true story that is sure to tug at your heartstrings. Follow therapy aide Michael Lewis as he recounts a memorable patient playfully nicknamed "Lawrence of Arabia" or laugh with Melisa as she looks back on how her sassy



grandmother kept her spirits up while receiving palliative care. Allow teenage gamer Zach to bring you into his world as he battled cancer with Dr Jane and her palliative care team.

These amazing stories are brought to life with soulful narration and instrumental



accompaniment by final-year students from Republic Polytechnic's Diploma in Sonic Arts.

Watch the animated audiobooks on the SHC YouTube channel. Download the Life Books series for free from the SHC website. It is available in English, Chinese, Malay and Tamil.

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Upcoming Events

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 to find out about the next session.

Date: May 2023
Venue: TBC

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

Visit SHC's exhibition booth at libraries across Singapore to find out more about hospice care, how to get started on end-of-life planning, and why conversations on death and dying are essential.

Date: 1 March - 27 April
Venue: Sengkang Public Library, Level 4 Foyer, 1 Sengkang Square, Unit #03-28, Singapore 545078

Date: 2 May - 30 June
Venue: Woodlands Regional Library, 900 South Woodlands Drive #01-03 Singapore 730900



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