

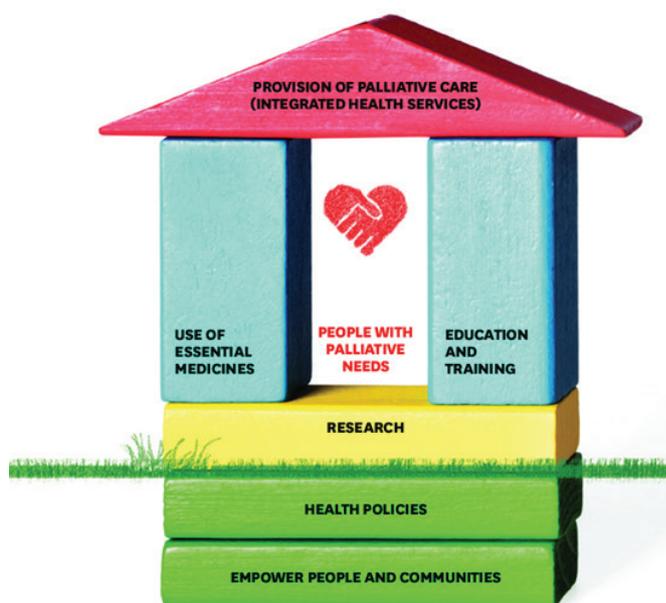
## DOES MALAYSIA HAVE MUCH TO LEARN FROM GLOBAL PALLIATIVE CARE?

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

Palliative Care was introduced in Malaysia formally in the early 90s with the inauguration of services from Hospis Malaysia and the National Cancer Society, Penang Branch. Since then, Malaysia has established palliative medicine as a subspecialty under internal medicine and a Ministry of Health National Palliative Care Strategy was published in 2019.

Somehow though in the various iterations of global benchmarking that looks at factors around death, dying and palliative care, Malaysia has seen a constant decline compared to many of our Asian neighbours. In the 'Cross Country Comparisons of Expert Assessments of Quality of Death and Dying 2021, Malaysia ranked 62 out of 81 countries, ranking above Ethiopia, but below Sudan.

Palliative Care is now a significant area of healthcare activity in the region. The WHO Public Palliative Care framework which uses a model of a house has the patient at the centre with education and training as key components. Its foundation consists of policies, empowering communities and research. Only then can the 'roof' be placed – provision of palliative care services.



Palliative Care services made their mark in Malaysia in the 1990s from community services before the Ministry of Health commenced services that focussed on hospital based palliative care. Today, with over 30 years of palliative care activity, perhaps it's time to

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ask - what is the state of our palliative care 'house'? Are there strong policies that are patient-centred and empower communities so that much of care delivery need not require hospital care? Is education provided not just for specialist physician training but also nurses, allied health at basic and intermediate level as well as opportunities for caregiver training in the community? Are essential medicines easily available when needed both in hospital and in the community? And is both pertinent and reliable data collected and analysed that may aid further research and development? And does anyone care?

Providing community palliative care remains challenging for Hospis Malaysia, as it is for others as there is a lack of synergy in the health system that facilitates transitions in care, especially in terms of hospital referrals to community palliative care. Hospis Malaysia tries to create its own palliative care environment through delivering a patient service supported by the provision of medication and medical equipment and the training of caregivers, as well as training of health professionals and public advocacy in the community. As an organization we have in recent years also created networks with other patient-based medical organisations to form a community of care for groups of patients with specific conditions who require palliative care support.

A key factor in the development of Hospis Malaysia is its interaction with our international colleagues, both individuals and organisations. Learning, sharing and benchmarking from palliative care professionals and institutions from the United Kingdom, Singapore, Australia, Hong Kong, New Zealand and elsewhere are key factors. Hospis Malaysia is a key member of the Asia Pacific Hospice Palliative Care Network and the rest of the global palliative care movement.

Earlier in the year, Hospis Malaysia arranged for our physiotherapist to be attached at Dover Park Hospice, Singapore followed by a visit by our CEO. In October, a team from Dover Park Hospice visited Hospis Malaysia and discussed many issues from service delivery, education, quality indicators, to funding and research. We have also strengthened our relationship with the University of Sydney, participating in a research project with a wish for further collaborations moving forward.

The experience that Hospis Malaysia has acquired over 30 years of work is recognised regionally and globally. Whilst others have come to Kuala Lumpur both to teach, share and learn, Hospis Malaysia staff have also been invited to share our knowledge and skills in different countries.

Members of our clinical team have participated in notable meetings at the World Bank Asia Pacific Health Financing Forum, the Indonesian International Cancer Conference where there were meetings with the nations' ministry of health and academic community, the World Cancer Congress in Geneva and the World Health Organisation working group meeting in Memphis.

Through building greater connections regionally and beyond, Hospis Malaysia hopes to further develop innovative ways to ensure our staff continue to develop and our services continue to improve despite the many challenges that we face. We do this because we acknowledge that there is much knowledge and skills to be learnt from and best practices to be shared with our international colleagues. Equipped with this, we hope that national policies will be supportive to enable us to help others to build capacity, which in turn will enable us as a country to provide quality palliative care that our community deserves. ■

#### COUNCIL MEMBERS

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#### HOSPIS MALAYSIA (199101013363)

2, Jalan 4/96, Off Jalan Sekuci, Taman Sri Bahtera,  
56100 Kuala Lumpur

Tel: (03) 9133 3936 Fax: (03) 9133 3941

E-mail: [info@hospismalaysia.org](mailto:info@hospismalaysia.org)

Website: [hospismalaysia.org](http://hospismalaysia.org)

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**A YOUNG HEART, A BIG IMPACT: YAO SERN'S INSPIRING JOURNEY FOR HOSPIS MALAYSIA**



We extend our heartfelt gratitude to Tan Yao Sern, a remarkable 14-year-old student from The British International School of Kuala Lumpur, for his extraordinary fundraising initiative, “Easing Life’s Final Journey,” supporting Hospis Malaysia. In just two months, Yao Sern raised over RM62,000—far surpassing his initial target of RM25,000. His commitment to honouring his late father through this effort not only provides significant financial support but also raises essential awareness about the importance of palliative care.

Thank you, Yao Sern, for your inspiring efforts!

Read Yao Sern’s blog here: <https://www.simplygiving.com/easing-life-s-final-journey-hospis-malaysia>

**Our heartfelt gratitude also goes out to:**

- **Tan Kien Eng:**  
For his inspiring ‘Blue Light, Sleep Deprived’ Art Exhibition, which beautifully bridged the worlds of art and awareness to make a significant contribution to our cause.
- **Dato’ Henry Barlow:**  
We are deeply appreciative of your generosity in encouraging your guests to support Hospis Malaysia in lieu of gifts during your 80th birthday celebration!
- **Selangor St Andrews Society:**  
Thank you for selecting Hospis Malaysia as a beneficiary of the KL Highland Games.
- **Harlow’s and MGI:**  
We are grateful for your continued commitment to Hospis Malaysia through your charitable efforts.
- **Jing Lian Ge Buddhist Association:**  
Your generous donation of medical supplies!
- **PIKOM:**  
We appreciate your choice of Hospis Malaysia as one of the beneficiaries of your Invitational Golf and Charity Drive 2024.
- **YB Tan Kok Wai (MP Cheras):**  
For your ongoing support of our cause.
- **Students from YTL International College of Hotel Management’s Diploma in Hotel Management and Culinary Arts (Batch 7/22 & 9/22):**  
For raising funds while showcasing your culinary skills.

**Thank you**  
all for your invaluable contributions  
and for standing alongside us in our  
mission.

**Together,**  
your contributions make a positive  
difference in the lives of those we  
serve!

## HEALTHCARE ETHICS – WHY ARE THEY IMPORTANT?

### A DAUGHTER’S REFLECTIONS:

My father had heart failure, but we were never fully informed of the seriousness of his condition. False hope was given (stents, then bypass surgery) despite knowing his heart was too weak.

Months passed between appointments, adding to uncertainty and frustration.

Three days before his death, he showed signs of serious decline (vomiting, inability to eat, chest pains). At the hospital, we learned his kidneys were failing, and doctors recommended dialysis.

I knew that it wasn’t appropriate given his condition, and with what I knew about palliative care, I felt symptom control and supportive care was what was needed, but this was never mentioned. The doctors proceeded with plans for dialysis, ignoring signs that his heart was too weak.

My father died during sedation for dialysis as they prepared to insert the tubes. They had already created vascular access in his neck and arms – again, extremely unnecessary for someone who was dying. Only my mother was present; she trusted the doctors and was unaware he was dying. When I asked the doctor over the phone why they decided to go with dialysis despite his heart being too weak, the doctor said it could prolong his life, and she repeatedly insisted that the family had agreed to dialysis, a discussion that never occurred. My father, in pain and desperate, likely agreed to the procedure without fully understanding what it entailed.

I felt dismissed when I raised concerns about the procedure. The truth is that my father was dying but it was not conveyed until it was too late. He passed away in hospital, and we were unable to be at his side.

**Discussions about ethical issues around end-of-life care often spark debates and families looking back and wondering if things could have been done better for their loved one, if they had better support from their healthcare providers (HCPs). Underpinning this is the sphere of healthcare ethics and why it is an important framework which guides HCPs when they are aligning their healthcare decisions with their patients’ values.**

do. Over time, certain principles of healthcare ethics and methodologies have developed to help HCPs address ethical dilemmas in a consistent manner, grounded in frameworks that are generally acceptable.

In September, Hospis Malaysia organized its regular 2-day workshop on “Clinical Ethics in Palliative Care”, focusing primarily on issues faced by palliative care practitioners.

Facilitated by two prominent figures in this area of work, Dr Sumytra Menon from the Centre for Biomedical Ethics, Yong Loo Lin School of Medicine, National University of Singapore and Dr Chan Mei Yoke from the KK Women’s & Children’s Hospital Singapore, the workshop anchored discussions on the four primary ethical principles that have gained widespread acceptance in healthcare:

- Beneficence - requires that HCPs promote the patient’s best interest
- Non-maleficence – the HCP has a duty to minimize harm
- Justice - requires that HCPs treat like cases alike
- Respect for Persons/Autonomy – reminds that while the professional may know more about medicine, the patient is the one who knows best their own interests and values, and whether certain risks are worth the purported benefits.



*Facilitator Dr. Chan Mei Yoke guiding participants through complex ethical dilemmas in end-of-life*

Healthcare is not just about applying scientific knowledge to the care of patients. It is also about taking into account the values the patient holds. However, sometimes it is unclear what these values are, and people’s values may vary. HCPs make ethical decisions every day when caring for patients. Sometimes, they may face challenges in deciding what is the right thing to

The workshop also presented case studies to help participants better appreciate the importance of patient consent, and what the guidelines are with regards to a patient's capacity to give consent. Discussions were also rife around collusion which describes how family members collude with the healthcare system to moderate or hide disclosure of the patient's condition, and why this may not be in the best interest of the patient.

Patient confidentiality and why this is paramount in any patient-HCP relationship to enable the building of trust was also a key discussion topic.

Healthcare ethics is particularly important when it comes to end-of-life (EOL) issues. The stakes are high as it is literally life and death. Emotions run strong. Technology and scientific advancement have changed attitudes towards death. There is a necessary reminder that death is NOT a failure of the HCP, and the goal of medicine is to prevent an untimely death, not delay the inevitable. Is a discussion weighing beneficence vs maleficence necessary here?

Other common EOL ethical issues/dilemmas which has attracted significant debate globally such as withdrawing and withholding treatment, physician-assisted suicide and euthanasia were also key areas covered with case studies presented to help participants better understand the differences. ■



*Engaging minds and fostering discussions at our Ethics in Palliative Workshop - where every voice matters!*



*Our dedicated facilitators lead an insightful discussion, empowering participants to apply ethical principles in their work*



*Dr. Sumytra emphasizes the importance of proper Advance Care Planning in palliative care, highlighting how it empowers patients to express their values and treatment preferences. Open conversations about goals of care ensure compassionate support aligned with patients' wishes.*



*Empowered minds, inspired hearts! Wrapping up an incredible weekend of growth and insight. Thank you to all the passionate participants for making this journey so meaningful!*



## CELEBRATING COMMUNITY SPIRIT: CHARITY BAZAAR UNITE



The recently held Hospis Malaysia Charity Bazaar at Stella Maris International School in Bukit Damansara was a success by many accounts. Despite a rainy week leading up to the event, the day blossomed into a beautiful celebration, uniting a diverse crowd committed to supporting our cause.

The bazaar showcased the vibrant creativity of our community, featuring a wide collection of handmade crafts, delicious local and international cuisine, and unique items generously donated by local businesses and artisans. The lively atmosphere transformed the bazaar into a celebration of compassion and togetherness, providing shoppers with a delightful experience while contributing to a meaningful cause.

We extend our heartfelt gratitude to everyone who made this bazaar possible—our dedicated vendors, donors, enthusiastic visitors, tireless volunteers, and the Hospis Malaysia team. A special thank you goes to the sponsors of the Lucky Dip prizes, which included





## PAST EVENTS

# BE THE COMMUNITY FOR PALLIATIVE CARE!

a 10th Gen iPad as the top prize! and our amazing vendors who generously donated proceeds of their sales to support Hospis Malaysia. Your contributions were pivotal in turning this bazaar into a success!

Dato Kathleen Chew, Chairperson of Hospis Malaysia, expressed her appreciation: "We are incredibly thankful for the overwhelming support we received. This bazaar is a testament to the positive impact we can have on patients facing serious health-related challenges. By providing care right where it matters most - at home - this community gathering holds meaningful significance."

Thanks to the generous contributions of visitors who purchased coupons to spend, we raised almost RM200,000! These funds will play a crucial role in enhancing our vital services, including patient care, education, training, and advocacy efforts. We remain steadfast in our vision that no patient or family should face the challenges of life-limiting illnesses—such as cancer, late-stage organ failure, dementia, Alzheimer's disease, and motor neuron disease alone.

As we reflect on the success of this bazaar, we look forward to continuing our mission of support and care with renewed enthusiasm. Thank you for being a part of the Hospis Malaysia family!



## WORKING WITH OTHERS TO SHARE EXPERIENCES AND BEST PRACTICES

As an organization constantly looking at innovative ways to improve itself, Hospis Malaysia welcomes the opportunity to work with others to explore collaborations and to share best practices.

In October, we welcomed several groups of visitors – Nurse Bung Hui Na from Hospital Sibü, Sarawak, Dr Christiannie Tay from Palliative Care Association of

Kota Kinabalu (PCA KK), Nurse Jay Balante from the University of Sydney, and a team from Dover Park Hospice Singapore.

We share some of the exchanges we had with each of them, to gather their thoughts about their respective visits:

### **NURSE BUNG HUI NA, FROM HOSPITAL SIBU, SARAWAK**

Hui Na, a palliative care nurse selected to train as a “Master Trainer” and to be involved eventually in training other healthcare workers under the Sarawak palliative care services development programme, spent 2 weeks attached to the palliative care team at Hospis Malaysia. Here, she reflects on her experience and lessons she picked up:

*“When I follow a nurse on their home visit, I see how they deal with the complexities of the patient and family’s emotional and physical needs when they are in their own home setting. I observe first-hand how they initiate difficult conversations about prognosis, treatment options, and end-of-life care.*

*I am now aware of why a physical examination of the patient during each visit is important, as this provides the nurse with information which she can then share with the doctor (her team lead), and together they formulate a care plan for the patient.*

### **JAY BALANTE - NURSE ACADEMIC AND PHD STUDENT FROM UNIVERSITY OF SYDNEY**

Jay Balante spent 2 weeks with Hospis Malaysia’s nurses to investigate the role of cultural values in shaping the approaches of internationally educated nurses in palliative care. Here he shares some initial thoughts about his time with the team at Hospis Malaysia:

*“Research is essential as it equips clinicians with up-to-date knowledge. It bridges the gap between theoretical understanding and practical application. It is about applying this knowledge effectively to enhance patient outcomes.*

*Malaysia has a diverse cultural landscape, and it offers a unique perspective on care practices. Hospis Malaysia is particularly known for its holistic approach, which reflects the rich mix of traditions in Malaysian society. This creates a special environment where traditional practices and modern palliative care come together, making it an ideal place for my research and a fantastic opportunity to learn how culture shapes care.*

*I am impressed by the team’s dedication and empathy. They genuinely connect with patients and their families, making sure that every interaction feels meaningful and is tailored to their needs. My findings will eventually be made available in my research publication”.*



*Bung Hui Na (third from right) and Jay Balante (far right) during their time at Hospis Malaysia.*



The Dover Park team spent three days with Hospis Malaysia to exchange insights on community palliative care and operational practices. They praised Hospis Malaysia's resourcefulness and the adaptability of its nurses in meeting challenges.

### DOVER PARK HOSPICE, SINGAPORE (DPHS)

The team from DPHS comprising of their Medical Director, Head of Home Care, Head of Social Work & Psychosocial Services, Director of Nursing, Nurse Manager of Home Care, and Head of Admin, Operations & Facilities and Patient Services spent 3 days with various teams of Hospis Malaysia with the objective of gaining insights on Hospis Malaysia's work.

The DPHS team were particularly interested in understanding care delivery of community palliative care in Malaysia, and sharing practices around patient intake procedures, care coordination, resource management and integration of community and volunteer services. Practices around access of

medications and commonly used medications, strategies used to engage key stakeholders, and Hospis Malaysia's education initiatives were also discussed.

While each of our teams parted with a common understanding that much can be gained from greater collaboration on patient care and stakeholder engagement, here is what our visitors from DPHS had to say:

*"The organization's level of resourcefulness and creativity in carrying out their duties is impressive".*

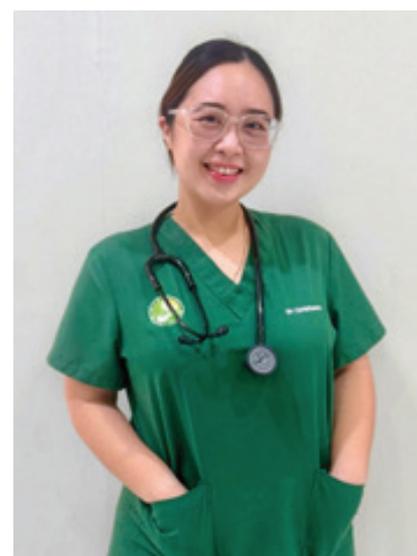
*"Despite facing resource and human constraints, I am impressed with the adaptability of the nurses to fulfil multiple roles"*

### DR CHRISTIANNIE TAY, PCA KK

Dr Christiannie is the Resident Medical Officer at PCAKK. She requested to spend time at Hospis Malaysia to observe and learn about our service delivery. We asked her about her key takeaways from the 2 week attachment:

"There is so much emphasis on the holistic, patient-centred approach to care, and respecting patients' values. I have seen the importance of good communication and how care is tailored to individual patient needs in a home setting. The nurse I was attached with engaged with her patients professionally and with deep empathy, which left a lasting impression on me.

I'm also impressed by how committed the team is to continuous education and skills development, which I now see as a critical component of improving care for patients".



Dr. Christiannie gained invaluable insights during her two-week attachment at Hospis Malaysia, highlighting the power of a holistic, patient-centered approach and the importance of continuous education in enhancing care delivery.

## PAST EVENTS

# CELEBRATING 12 YEARS OF IMPACT: HOSPIS MALAYSIA AT KLSCM 2024'S "RUN FOR A REASON"



Hospis Malaysia proudly celebrates its 12th year as a charity beneficiary of the Kuala Lumpur Standard Chartered Marathon (KLSCM) 2024, a milestone marked by our successful participation in the "Run for a Reason" (RFAR) initiative. This year, more than 400 enthusiastic runners and almost 40 volunteers rallied behind Hospis Malaysia, making everyone's involvement in the event a powerful testament to our work in palliative care delivery and development in the country.

A highlight of this year's KLSCM was the remarkable fundraising efforts of our participants, who together raised over RM400,000 to support our vital services. This achievement also includes generous contributions from companies participating in the Corporate Challenge. Their unwavering commitment and generosity play a crucial role in advancing our mission to deliver palliative care to patients facing serious illnesses where they need it most – in their own homes, as well as essential support for their families during difficult times.

Over RM1 million was collected through the Run for a Reason platform for the 4 charity partners. We are thrilled to collaborate alongside other organisations in this collective endeavour, demonstrating the immense power of community support and unified action.

The funds raised will enable Hospis Malaysia to continue offering compassionate care through regular contact and home visits where our clinical team will assess, treat symptoms where needed, and counsel patients and their families accordingly. Medicines and medical supplies are dispensed when required, all at

no charge. Our mission is to ensure that no one faces serious health-related suffering alone, as much of it can be treated and addressed, so that everyone can live the last phase of their lives with comfort and dignity.

We extend our heartfelt gratitude to all the KLSCM 2024 runners, donors, and volunteers. Your enthusiasm and dedication empower us to continue our essential work, ensuring that we can deliver the high-quality care that every patient deserves. Together, we're not just running a marathon; we're forging a path towards a more compassionate future. Thank you for being part of this incredible journey!



*Volunteers from Oracle rallying to raise awareness for Hospis Malaysia.*



*Behind every great event, there are dedicated volunteers making it happen. Thank you for your hard work and passion!*



Familiar faces and friendly smiles—regular RFA runners stopping by to say 'Hi!' It's all about community and connection.



Runners united in spirit, creating a vibrant wave of hope and support. Not just moving feet but elevating hearts and making a lasting impact.



The energy was electric at Dataran Merdeka! Every stride was fueled by determination and compassion as runners came together for a common goal.

# Annual Charity Motor Treasure Hunt

2025



MELAKA, 14 - 15 JUN



Gear up, adventurers!  
A thrilling new quest  
awaits you!

## UPCOMING EVENTS

7 JAN

WEBINAR:  
"QUALITY CONVERSATIONS AS A KEY ELEMENT OF QUALITY PALLIATIVE CARE; WHAT DOES THE EVIDENCE TELL US" - Prof Peter Martin, Professor Of Clinical Communication & End-Of-Life Care, Deakin University School Of Medicine.

21 APR

SYMPOSIUM: IMPROVING PATIENT-CENTRED PALLIATIVE CARE

23 - 26  
APR

ASIA PACIFIC HOSPICE CONFERENCE – KUCHING, SARAWAK

MAR/APR

*\*to be confirmed*

WORKSHOP:  
PALLIATIVE CARE NURSING WORKSHOP

MAY/JUN

*\*to be confirmed*

COMMUNICATION SKILLS IN PALLIATIVE CARE

14 - 15  
JUN

ANNUAL CHARITY MOTOR TREASURE HUNT



SCAN QR CODE  
TO STAY UPDATED ON  
UPCOMING EVENTS