

SARAWAK – A MODEL FOR CAPACITY BUILDING BY EDUCATIONAL INTERVENTIONS

Sarawak stands out in Malaysia as a land of diversity. There are marked challenges in negotiating geographical terrain with a diverse rural population of myriad cultures, and a few urban sites. These create challenges for the delivery of healthcare, including palliative care. In line with other parts of Malaysia, local champions have initiated the introduction of palliative care in hospital and in the community through both the public and non-profit pathways.

Through visits to Sarawak over the years, attending and conducting workshops, Hospis Malaysia has witnessed the enthusiasm to deliver better care to the local community. Despite and perhaps because of its challenges, the Sarawak palliative care community has seen the pressing need to forge ahead with its plans for development of care, with help from national and international experts.

Dr Sharon Choo Yoke Ling, was a frequent attendee at several scientific meetings in Sarawak that incorporated palliative care themes in cancer control and pain management. She then entered specialist training in palliative medicine and spent her final 6 months of training at Hospis Malaysia. As she shared, her time at Hospis Malaysia allowed a better understanding of her challenges in developing palliative care in Sarawak. Today, she is the palliative care physician at Sarawak



Dr. Ednin Hamzah, CEO of Hospis Malaysia (third from the right) was invited to meet with Dr. Veronica Lugah, Director of Health for Sarawak (centre) in December 2024 to discuss further plans for the development and delivery of palliative care and treatment for the people of Sarawak. Also present were (from L to R) Dr. Dyana Nabila Mohd Nasir, Dr. Vivek Vijayan, Dr. Choo Yoke Ling, Palliative Medicine Specialist at Sarawak General Hospital and Dr. Azlee bin Ayub, Deputy Director of Health (Medical).

General Hospital, Kuching, and is spearheading the state's palliative care development initiative.

Over the years, Two Tree Lodge Hospice and the National Cancer Society of Malaysia in Kuching have

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Key factors in the development of palliative care have been the people of Sarawak.

also been strong partners in palliative care with Hospis Malaysia, sharing common principles and learnings. Dr Winnie Ling, an oncologist and founder of Two Tree Lodge Hospice has been a strong advocate for community palliative care.

The public health palliative care framework adopted by the World Health Organisation coupled with indicators in 2021 provides a useful template for development. As the then chair of the Asia Pacific Hospice Care Network, Dr Ednin Hamzah led a scoping visit to Sarawak in Nov 2022 to evaluate on a possible capacity building educational intervention by APHN. A Memorandum of Understanding between APHN and Sarawak was signed in April 2023 and Sarawak became the latest addition to the Lien Collaborative project with Dr Ednin as the APHN faculty lead.

Since then, Dr Ednin, together with palliative care nurses Mastura and Nadiah from Hospis Malaysia have been part of the training faculty, interacting, teaching and mentoring healthcare workers from Sarawak. The dedication, enthusiasm and commitment by the healthcare workers training to deliver palliative care under the programme have been impressive, which ever setting they are in.

Key factors in the development of palliative care have been the people of Sarawak. Alignment at various levels to develop palliative care services to serve the people where they need it, set the foundation. Essential medications have been made available across primary care clinics and healthcare staff have developed local initiatives in both education and service delivery. Dr Sharon Choo's personal leadership skills has been crucial in linking up the various strands of palliative

care activity throughout this vast land.

In between the Lien Collaborative workshops, Dr Ednin and Dr Sharon Choo have been visiting several primary palliative care services, observing healthcare workers practise what they have been taught during the various training modules. This allows adjustments in future training to improve both competency and hopefully patient outcomes.

There have also been opportunities for short term placements at Hospis Malaysia for healthcare workers if deemed that this would benefit them, and several have taken up these placements over the last several years.

The culmination of the efforts of the recent years to drive home the importance of developing adequate services, is the hosting of the 16th Asia Pacific Hospice Palliative Care Conference in Kuching from 23 – 26 April, 2025. The efforts of the palliative care leaders, supported by political will and community engagement signifies a desire to deliver the World Health Assembly resolution 67.19 which urges member states to strengthen palliative care as a core component of health systems, emphasizing primary health care and community/home-based care, and ensuring access to essential medicines.

Hospis Malaysia's vision is to provide access to the highest possible quality of an evidence-based approach to palliative care to everyone in need. It is our hope that enabling members of our clinical team to be part of the training faculty in Sarawak's capacity building initiative is the beginning of a broader partnership to deliver better access and better care to all in need. ■

COUNCIL MEMBERS

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Wai Lin

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HOSPIS MALAYSIA 2024 HIGHLIGHTS



PATIENT CARE SERVICES



1,184 patients referred to receive palliative care services



10,269 home visits made by our medical team within Klang Valley



110 emergency home visits made after hours



27,170 phone calls made to patients under our care



1,274 emergency calls received by our on-call medical team after hours

683 medical undergraduates taught



5 palliative care specialist trainees on 6-month training attachment

26 medical post-graduates taught with clinical attachments



125 healthcare workers attending palliative care workshops

268 participants in webinars organised



TEACHING & TRAINING



PUBLIC EDUCATION, COMMUNITY ENGAGEMENT & FUNDRAISING



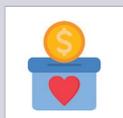
Palliative Care Awareness Month

reached 15.2K people organically, raising awareness of the importance of palliative care.



Palliative Care Pledge & Support

received 480 pledges, advocating for better access to palliative care and ensuring comfort, dignity, and support for those in need.



Fundraising Events

Over RM 900,000 was raised through:

- Kuala Lumpur Standard Chartered Marathon 2024
- Charity Bazaar
- Annual Motor Treasure Hunt



ONLINE PRESENCE & SOCIAL MEDIA ENGAGEMENT

Key Takeaways (Year On Year Comparison)



Website Growth:

+110% views
+21,719 users

Instagram:

+100% interactions
+300 followers

Facebook:

+30% interactions
+600 followers

Growth driven by diverse events, engaging social media, and awareness campaigns, attracting a global audience from Singapore, the U.S., Australia, the U.K., the Philippines, Indonesia, South Korea, India, and China.



Photo credit: <https://www.aphc2025.com>

Hospis Malaysia is proud to be featured at the 16th Asia Pacific Hospice Palliative Care Conference (APHC 2025), where we will present and showcase nine abstracts throughout the event.

This year’s conference, themed “Embracing Diversity, Empowering Communities,” underscores the importance of inclusive care models that cater to the diverse needs of patients, families, and communities facing serious illnesses.

Since its inception in Singapore in 1989, the Asia Pacific Hospice Network (APHN) has played a pivotal

role in advancing hospice care across Asia. Over the years, Hospis Malaysia has worked closely with APHN in expanding access to person-centred palliative care while driving innovation, research, and partnerships to further the field. Our participation in APHC 2025 reflects our dedication to improving patient care, fostering continuous learning, and sharing best practices across the region.

We are incredibly proud of our team for their dedication and contributions to palliative care. Their work not only enhances patient outcomes but also helps shape best practices in healthcare.

KEY HIGHLIGHTS OF HOSPIS MALAYSIA AT APHC 2025



DR. LIM ZEE NEE

Session: Oral Presentation: Session 14 – Symptomatology 2
Title: Follow-up of patients who were initiated with subcutaneous medications for symptom control at home – a descriptive study
Day: Conference Day 2 (Friday, 25-Apr-2025)
Time: 10.00am – 11.30am



NURUL NADIAH JAAFAR

Title: Sharing on Nurse Leadership
Day: Preconference (Wednesday, 23-Apr-2025)
Time: 9.00am – 1.00pm

HOSPIS MALAYSIA ABSTRACTS AT APHC 2025

AUTHORS

TITLE



Dr
Lim Zee Nee



Dr
Looh Wai Fong



Dr
Sylvia McCarthy

Home or Hospital? An Audit on the Preferred and Actual Place of Death in Community Palliative Patients



Nurul Nadiah
Jaafar



Dr
Punitha Krishnan



Low Su Jiun

Safety Calls for Restraints: Lessons from Community Palliative Care – A Case Series



Dr
Punitha Krishnan



Dr
Aishah Sabina

Shifting Towards Terminal Care? A Single-Centre Study on Late and Terminal Discharge Referrals to Community Palliative Care



Dr
Tan Pei Wen

After-Hours Service in a Community Palliative Care Service



Dr
Lim Zee Nee



Aidah Abdul
Hassan Chin



Norbazilah
Johari

The Use of Subcutaneous Medications for Patients Receiving Palliative Care at Home – Analysis of Prescribing Practices from Jan–Dec 2023



Dr
Lim Zee Nee



Aidah Abdul
Hassan Chin

From Concept to Community: The Evolution of a Programme Supporting Subcutaneous Use of Medications at Home



Dr
Lim Zee Nee



Aidah Abdul
Hassan Chin



Norbazilah
Johari

Follow-Up of Patients Who Were Initiated with Subcutaneous Medications for Symptom Control at Home – A Descriptive Study



Dr
Lim Zee Nee



Qaisara binti Idrus

Bridging The Gaps in Undergraduate Palliative Care Education in The Community: Evaluation of An Enhanced eLearning Based on Medical Students' Feedback



Dr
Ong Xin Wei



Low Su Jiun



Dr
Lim Zee Nee

Rehabilitative Palliative Care: Understanding Patient's Care Needs in Advanced Illness Who Wish to Be Cared for at Home



Dr
Sylvia McCarthy



Dr
Ednin Hamzah



SCAN TO LEARN MORE
ABOUT THEIR FULL ABSTRACTS.

THE HEART OF REHABILITATION AT HOSPIS MALAYSIA

For many living with serious progressive illnesses, losing the ability to move freely can feel as if vital parts of themselves have been taken away. Basic movements like walking to the dining table, stepping outside for fresh air, or even sitting up to greet their loved ones become daily struggles. At Hospis Malaysia, palliative rehabilitation is about restoring dignity, fostering independence, and enabling patients to embrace and cherish the time they have left.

Over the years, Hospis Malaysia has strengthened its rehabilitation services to better support patients and caregivers. The rehabilitation team, consisting of two physiotherapists and one occupational therapist, works closely with doctors and nurses to identify patients who would benefit from therapy. Rehab therapists take a holistic approach, integrating physiotherapy, occupational therapy, speech therapy, and, at times, even music and art therapy.

Rehabilitation focuses on optimising patient function and independence, ultimately easing the caregiver's burden. Our therapists assist with daily activities while prioritising patient comfort and caregiver support. This includes strength and balance training, fall prevention, pain management, and strategies for activity pacing and breathing control. They also recommend home modifications, provide assistive aids, and offer communication support for speech-impaired patients.

With the expansion of the rehabilitation team, the impact has been significant. In 2024, 172 patients received rehabilitative care, and as of February 2025, 78 patients have already benefited from therapy. With an increase in manpower this year, we anticipate that more patients will benefit from timely rehabilitation. The key challenge lies in healthcare providers recognising the potential of rehabilitation and recommending additional support before patients deteriorate.

Beyond therapy, human connections are at the heart of rehabilitation. Moments of trust, resilience, and even joy emerge through meaningful relationships. One patient's son (who wished to remain anonymous) shared his father's story:

"My father battled stage 4 cancer for several years. During his final months at home, he was under the care of Hospis Malaysia. As a stoic person, it was not easy for him to come to terms with his condition of being confined to a hospital bed most of the time. The rehab specialists played a very important role

during this period. They managed to get him to do some mobility exercises which helped, but even more crucial was their ability and willingness to just listen and talk to him when he was not up to it. Eventually they persuaded him to try using a wheelchair. One fine sunny morning, he was out in the garden with his granddaughter looking at the plants. Those photos are a wonderful memory of him, and we are very grateful to the rehab team for their role in making it happen."

Stories like these remind us that rehabilitation is not just about movement; it's about helping patients reclaim their sense of self, even in the final chapters of their lives.

As Hospis Malaysia continues to refine and grow its rehabilitation services, one thing remains certain; every patient deserves the opportunity to live fully, in whatever way they can, for as long as they can. ■



Our rehab specialist, Su Jiun, guided Aunty Liew Yen, who was diagnosed with lung cancer, in learning to stand and walk with support – a request she made to create lasting memories with her family.



As baby Gilbert recovered from the rare and aggressive Atypical Teratoid/Rhabdoid Tumor (ATRT), Su Jiun worked closely with his parents to help him learn to sit, crawl, and stand.

TRANSFORMING MND CARE: THE BENEFITS OF A COLLABORATIVE APPROACH TO CARE

Motor Neurone Disease (MND) is a progressive condition affecting movement, speech, swallowing, and breathing. While there is no cure, the right support can improve quality of life. Recognising this need, Hospis Malaysia (HM) and Universiti Malaya Medical Centre (UMMC) partnered in 2022 through a Memorandum of Understanding (MoU) to enhance care for individuals living with MND.

Prof. Dr. Nortina Shahrizaila at UMMC, who established Malaysia's first dedicated MND multidisciplinary team (MDT) clinic in 2016, recognised the limitations of hospital-only care. The addition of Hospis Malaysia's community palliative care in the MDT has strengthened trust among patients, families. The MDT which comprises of specialists in neurology, rehabilitation, and respiratory care, now includes community palliative care support – ensuring a seamless transition from hospital to home.

By integrating Hospis Malaysia's palliative care expertise, the collaboration bridges critical gaps in goals of care discussions, symptom management, end-of-life (EOL) planning, and caregiver support. "A smooth transition from hospital setting to home is key to this successful partnership, benefiting both patients and caregivers," shared Prof. Dr. Nortina.

Dr. Punitha Krishnan, Hospis Malaysia's palliative care doctor and team lead for the collaboration, shared that this partnership has significantly lessened hospital visits while providing essential out-of-hours support. She explained, "Patients and families see us as part of the team, ensuring continuity of care and easing the sense of abandonment. With out-of-hours care, we can address distressing issues anytime, reducing emergency hospital visits and admissions."

"Beyond patient care, this collaboration has fostered knowledge-sharing in managing respiratory difficulties, swallowing issues, spasticity, and communication techniques through innovative technologies. Recognising the importance of palliative rehabilitation in addressing some of these challenges, our clinical team works closely with our rehabilitation therapists to enhance support for our MND patients," she added.

LOOKING AHEAD

Since the start of the partnership, 63 patients have been referred to Hospis Malaysia for palliative care support in the community in the Klang Valley. Patients are typically referred within the same year or up to a year after diagnosis. Early referral to palliative care support is therefore recommended.

The MoU has been extended for another five years, reinforcing both organisations' commitment. On Hospis Malaysia's part, efforts are underway to monitor the quality of the care it delivers through tracking how well it is managing its patients' symptoms, good documentation, and crisis management planning. The collaboration also serves as a model for integrating palliative care into other specialties, such as geriatrics and paediatrics.

Prof. Nortina highlighted the broader vision of this initiative, "Ultimately, this is about building a community that looks after patients. It's not about individuals, but a collective effort across specialties."

The HM-UMMC partnership stands as a testament to the power of collaboration in transforming palliative care for MND patients, ensuring they receive compassionate, timely, and holistic support at every stage of their journey. ■



Caring Together: MND patients find comfort and support under the compassionate care of Hospis Malaysia

QUALITY CONVERSATIONS AS A KEY ELEMENT OF QUALITY PALLIATIVE CARE *WHAT DOES THE EVIDENCE TELL US*

Tuesday
7 January 2025

3.30pm - 4.30pm (MYT)

HOSPIS MALAYSIA SUPPORTING **PALLIATIVE CARE**

Participant list: Dr Nor Azian binti A Samad, Dr Ednin Hamzah, Dr Punitha (Hospis Malaysia), Peter Martin, Ronald Jo..., Siti Fathim..., Aidah Chi..., Ng San Sa..., Diah Ma... +38

Hospis Malaysia launched its 2025 events with an insightful webinar, "Quality Conversations as a Key Element of Quality Palliative Care: What Does the Evidence Tell Us?" in January. Moderated by Dr. Punitha Krishnan from Hospis Malaysia, the event featured renowned speaker Professor Peter Martin, an expert in clinical communication and end-of-life care.

Professor Martin highlighted that many patients perceive healthcare interactions as fragmented, rushed, and transactional, leaving them feeling uninformed and unsupported. Studies show that patient dissatisfaction often stems more from how they are spoken to than from the medical care itself. They would be looking for their clinical teams to listen more, confidently navigate difficult conversations, reinforce humanity in healthcare, and respect their unique perspectives.

Professor Martin underscored the vital role of skilled communication for palliative care practitioners dealing with patients with serious progressive illnesses in improving care outcomes. As in any communication between two parties, the lack of structure can delay meaningful conversations. He emphasised that communication is not an innate ability but a skill that requires training and refinement. To enhance communication, structured training programs should

be expanded to include techniques such as early agenda setting and recognising both verbal and non-verbal cues. Additionally, training in shared decision-making and ethical considerations is essential.

Clinicians with strong communication skills can quickly build trust, identify patient concerns, and facilitate shared decision-making. Moreover, skilled communicators are not only more effective in patient interactions but also more time-efficient.



Participants actively engaged throughout the webinar with Professor Peter Martin, an expert in clinical communication and end-of-life care, as they explored challenges and insights on effective and compassionate communication in palliative care.

Another significant challenge in palliative care is prognostic discordance – the gap between what patients believe about their illness and clinical reality. This issue can lead to misaligned expectations and emotional distress. Patients desire realistic yet hopeful discussions with their healthcare providers, guided by expertise that considers their cultural and personal values.

Echoing this, Dr. Ednin Hamzah, CEO of Hospis Malaysia, highlighted the risk of communication bias in end-of-life discussions, cautioning against imposing a predetermined way of dying without understanding individual patient priorities. Reinforcing Professor Martin's insights, he stressed the importance of shared decision-making that truly reflects patient needs.

As palliative care continues to evolve, fostering open, compassionate, and evidence-based communication will remain central to enhancing patient experiences. Moving forward, Hospis Malaysia remains dedicated to advancing quality palliative care by equipping healthcare professionals with the communication skills necessary to support patients with empathy, clarity, and respect. ■

KEY TAKEAWAYS: STRENGTHENING COMMUNICATION WITH PALLIATIVE CARE PATIENTS

- Increased communication training for healthcare providers.
- Encouraging patient participation in decision-making.
- Recognising and addressing prognostic discordance.
- Ensuring culturally and religiously sensitive care without stereotyping.
- Early shared agenda setting to align patient expectations and clinical goals.
- Using a balanced mix of open and directive questions.
- Attentively responding to verbal and non-verbal cues.
- Pausing to allow patient reflection.
- Validating emotions before presenting factual information.

HOSPIS MALAYSIA 24TH Annual Charity Motor Treasure Hunt

KL-MELAKA | 14-15 JUN 2025

Registration Ends: 14 May 2025
Per Pax:
Adult: RM350 | Kids: RM120
(age 12 & below)

*Corporate Sponsors Are Entitled To Complimentary Team Registration.

2025 MELAKA

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<https://rb.gy/wxupo6>

SUPPORTING THOSE NAVIGATING THE COMPLEXITIES OF LOSS

In December 2024, Hospis Malaysia hosted its annual Grief and Bereavement Care Workshop, a platform dedicated to enhancing healthcare professionals' ability to support those navigating the complexities of loss. Featuring returning speakers from Hong Kong University's Department of Social Work & Social Administration Head, Prof. Amy Chow, and Dr Margaret Suen, an honorary lecturer, the workshop offered enriching presentations, interactive discussions, and roleplay exercises designed to foster compassionate care.

Bereavement care is a key component of holistic patient care. Healthcare professionals often focus on patients, but after a patient dies, the bereaved also require attention. "Studies show that unresolved grief can lead to physical and psychological illnesses, placing additional strain on healthcare systems. By addressing grief early and effectively, healthcare professionals not only honour the deceased but also promote the well-being of families and communities, reducing the long-term demand for healthcare resources," said Prof Amy.

Prof Amy introduced a revised version of her ADAPTS model, which builds on a decade of development. First introduced in 2013, the ADAPTS framework has evolved to refine its bereavement care process, strengthen preparation work, and deepen contextual assessments. The model emphasises six domains: Anomalous Emotions, Dysfunctional Cognition, Adjustment Challenges, Physical Symptoms, Traumatic Responses, and Separation Distress. Each iteration has added dimensions to improve its application, moving

from individual-focused to family-inclusive care and integrating storytelling as a therapeutic tool.

The two facilitators also demonstrated the Empty Chair Technique, which can help bereaved individuals address unresolved feelings by engaging in a dialogue with the deceased (represented by an empty chair) and also with themselves as they switch seats and play the role of the deceased. The different techniques and tools shared by both speakers emphasised the importance of flexibility in care, as stated by Dr Margaret, "Grief is deeply individual; our approach must be just as unique."

Prof Amy then shared a moving example of her unconventional approach to grief care. She worked with a bereaved mother of two young children whose husband had died by suicide. Assessing the mother's high risk of suicide, Prof Amy spent six hours cooking with her to reignite her motivation to live. Years later, the mother called Prof Amy to share that one of her sons had been accepted into a medical program at Hong Kong University. Prof Amy, moved to tears, reflected on how that single intervention had saved not only the mother's life but also the lives of her two children. "Grief care is not about ticking boxes," she explained. "It's about creating meaningful, empathetic connections."

Workshops like this underscore the necessity of bereavement care training for healthcare professionals. As Dr Margaret highlighted, "Bereavement care is not optional; it is essential." Addressing grief comprehensively benefits not only the bereaved but also the broader healthcare system. ■



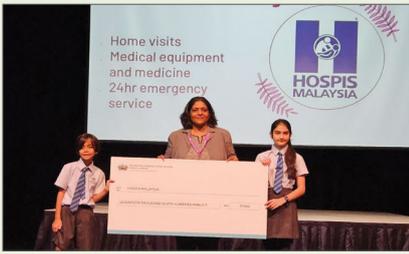
Prof. Amy Chow passionately re-introducing her innovative ADAPTS model. Her dedication to creating meaningful connections illustrates how healthcare professionals can effectively support grieving families.



Dr. Margaret Suen (left) highlighting the importance of personalized approaches in bereavement care, stating that "Grief is deeply individual." Her insights from the workshop underscore the vital role of compassion and flexibility in supporting the grieving.



We are grateful to our generous donors. Your contributions have made a profound impact on our mission, allowing us to continue providing care and support to those in need. Thank you for being part of the journey with us!



We are grateful to the *British International School KL* for your kindness and generosity. Your support makes a meaningful impact on our patients and their families.



A heartfelt thank you to *Da Ma Cai Community Aid Charity Programme* for your generous donation. Your support enables us to provide comfort and care to those facing life-limiting illnesses.



Thank you to *The Chinese Chamber of Commerce and Industry of Kuala Lumpur and Selangor (KLSCCCI)* for your invaluable support.



Thank you, *Vibrantline Sdn Bhd*, a subsidiary of Mitraland Holding (M) Sdn Bhd for your generous support through *Mitraland's Annual Donation Presentation*.



Fees due to *GO Communications* from Thriving Talents for a client project was donated to Hospis Malaysia.



" We cherish life through the lens, capturing moments that matter."

Raymond Ng

Our deepest gratitude to Raymond Ng from Ideabox Studio for donating his time & offering his photography services. Raymond has been dedicating his time and talent to capture precious moments of our patients and their families—moments that become cherished legacies.

Photography is more than just pictures. Raymond's work aligns with our mission to provide compassionate care, celebrate life, and offer comfort through the power of storytelling.

Thank you Raymond!





UPCOMING EVENTS

21 APR SYMPOSIUM: IMPROVING PATIENT-CENTRED PALLIATIVE CARE

23 - 26 APR ASIA PACIFIC HOSPICE CONFERENCE – KUCHING, SARAWAK

14 - 15 JUN ANNUAL CHARITY MOTOR TREASURE HUNT

4 - 5 OCT KUALA LUMPUR STANDARD CHARTERED MARATHON 2025

17 OCT VOICES FOR HOSPICES GALA DINNER



SCAN QR CODE
TO STAY UPDATED ON
UPCOMING EVENTS



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