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BERITA HOSPIS

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REFLECTIVE LEARNING – WHY ARE INTERNATIONAL COLLABORATIONS IMPORTANT?

The growth and development of Hospis Malaysia is significantly influenced by our international connections. From the formative years, Dr Robin Teoh and Dato Peter Mooney brought their background and experience in family medicine and law from countries afar, to augment others in setting up Hospis Malaysia in 1991. The foundation of the clinical team through the stewardship of Dr Ednin Hamzah and Dr Sylvia McCarthy with international experience coupled with 3 nurses all trained overseas are key contributing factors in the development of a unique culture of care and reflective learning.

Over the years, palliative care colleagues from Singapore, Australia, Hong Kong, United Kingdom, New Zealand and elsewhere were common visitors to Hospis Malaysia. Organisations such as the Asia Pacific Hospice Palliative Care Network (APHN) as well as the International Association of Hospice and Palliative Care (IAHPC) shared their resources to assist in education, training which supported capacity building.

Many became lifelong friends and what was gained was not just professional related knowledge and skills but also values, both personal and organisational that has shaped Hospis Malaysia's identity. A key element is the desire to have services that meets the patient and



caregiver goals though ideally, we should strive to go beyond those expectations. For some, it is fine to be 'good enough' but often with a little bit of extra effort, we can be better.

Since then, international collaboration has been part of the process of how Hospis Malaysia continues its evolution and learning to meet global standards.

continues on page 2

ш	EDITORIAL	
SSU	Reflective Learning — Why Are International Collaborations Important?	1
S IS	EDUCATION Hospis Malaysia Palliative Care Symposium 2025 Brings Global Visionaries Together	3
THIS	FEATURE Reigniting Purpose and Possibilities: Hospis Malaysia at APHC 2025	4
Z		

SPECIAL In Their Own Words: A Royal Visit that Amplifies Patients' Voices	
and Call for Equitable Palliative Care	6
PAST EVENTS	
Engines Roared, Hearts Soared: A Look Back at Our 2025 Treasure Hunt	8
ADVOCACY	
Our People in the Spotlight	10
THANK YOU	11
UPCOMING EVENTS	12

continues from page 1



Dr Ednin with WHO Working Group on Palliative Care at the World Innovation Summit for Health in Oatar

In the Global Atlas of Palliative Care 2020 (WHPCA/WHO), Hospis Malaysia was cited as one of the models of service delivery in the publication. The frequent connections to international palliative care colleagues allow learning in both directions and arguably to improve patient care in our local Malaysian context.

In April 2025, the APHN Atlas of Palliative Care in the Asia Pacific Regions was published by the Atlantes Global Observatory of Palliative Care ("the Atlas"). Hospis Malaysia's CEO, Dr Ednin who has been active in international palliative care since 1998 was part of its development and the Atlas marks the first time that a mapping of regional palliative care is done using the WHO palliative care indicators. The Atlas is available (free download) at https://aphn.org/the-aphn-atlas-of-palliative-care-in-the-asia-pacific-regions-2025/.

The data for Malaysia could certainly be looked at from either a half full or half empty perspective. There is undoubted progress in the development of policy, recognition of its importance and a generalised provision of palliative care. However, it also indicates that Malaysia could do more in improving education and training in medical and nursing schools, the building blocks to improving access. Indicators also highlight that access to essential medicines in rural areas is patchy and there is much room to increase palliative care research activity to enable policy makers to make informed decisions on service development and resource allocation.

The Atlas highlights the state of palliative care in the South-East Asia Region and the Western Pacific Region, providing a detailed analysis of resources, policy gaps and opportunities. It is with this baseline analysis that countries such as Malaysia then reflect on the quality of the data used to evaluate the various indicators and work on how the indicators can be improved on. For example, the indicators show that there is a need to look at the distribution of the various aspects of palliative care across the country and evaluate why better results may be obtained in some areas or domains, if we work on the challenges to close the gaps.

The Atlas offers regional data that when reflected on, can help us look at ways for further improvement and especially from our neighbours such as Singapore, Thailand, Philippines, Taiwan and others. National development is not necessarily only about the economic resources of a country. In fact, in many countries, leadership attributes of the palliative care community and its stakeholders can play an even more crucial role as innovative ways for development can be nurtured. The Atlas unfortunately does not measure the inherent leadership factors that could be a key factor in development.

At Hospis Malaysia, we look at the array of indicators and how it may be used to guide our role in not just providing patient care but also to support other national parameters such as education, research and advocacy. We welcome collaborative opportunities that may assist in this development that are founded on evidence and patient-based or community-based care.

The national standards for palliative care in Malaysia is due to be published in coming months. We await its adoption and subsequent evaluation, and urge stakeholders to examine its link to patient outcomes. This may assist Malaysians who may ask 'will I get the care that I want when I need it?'

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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
Website: hospismalaysia.org

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EDUCATION

HOSPIS MALAYSIA PALLIATIVE CARE SYMPOSIUM 2025 BRINGS GLOBAL VISIONARIES TOGETHER

On 21st April 2025, Hospis Malaysia welcomed over 60 passionate healthcare professionals, policymakers, advocates, and thought leaders from across the globe to our auditorium in Kuala Lumpur for the Palliative Care Symposium 2025: Improving Palliative Care Delivery Systems Through Person-Centred and Community Engagement.

The day-long gathering was more than just an exchange of ideas – it was a powerful reminder of our shared belief that palliative care is a human right for all.

We were especially honoured to have **Dato' Indera Dr. Nor Azimi binti Yunus**, Deputy Director-General (Medical), Ministry of Health Malaysia, deliver the opening speech. Her reaffirmation of the Ministry's commitment to WHA Resolution 67.19 and its enduring partnership with Hospis Malaysia was a meaningful endorsement of our shared mission.

From there, the conversations deepened. **Dr. Julie Ling** from the World Health Organization emphasised the importance of building strong, collaborative care networks, while **Prof. Carlos Centeno** highlighted the need to balance data-driven quality indicators with compassion — offering practical insights for palliative care professionals and unveiling the *APHN Atlas of Palliative Care in Asia Pacific*, co-authored with Hospis Malaysia CEO, Dr. Ednin Hamzah.

Dr. Emmanuel Luyirika reminded us that policy is not just intent; it's action. Strong, well-crafted policies unlock resources, drive investment, and lay the groundwork for sustainable, system-wide change. blueprints for real change — strong policies drive action and build healthier communities.

Dr. Sabrina Bajwah challenged conventional care models by listening directly to ILD patients, showing that the best solutions often begin by asking better questions. Similarly, **Prof. Nancy Preston** demonstrated how involving patients and caregivers in research leads to more compassionate, relevant care design.

Dr. Rachel Coghlan reminded us that dignity and presence lie at the heart of palliative care – whether in conflict zones or quiet hospital rooms – and **Dr. Diah Martina** reinforced the need for evidence-based, culturally grounded policymaking to support sustainable care in complex national contexts.



Our distinguished speakers with Hospis Malaysia CEO, Dr Ednin Hamzah (fifth from left), and Guest of Honour, Dato' Indera Dr. Nor Azimi binti Yunus, Deputy Director-General (Medical), Ministry of Health Malaysia (fifth from right).



The audience listens attentively as one of our speakers shares their insights.



Dato' Indera Dr. Nor Azimi binti Yunus, with Ministry of Health officers and Hospis Malaysia staff.

We were also inspired by the work of **Prof. Srivieng Pairojkul** and her team in Thailand, whose people-first approach is paving the way for broader access to care within the country's universal health system. Her work reinforces a powerful truth that real systems change only happens when rooted in compassion and cultural relevance.

For Hospis Malaysia, hosting this symposium was more than an honour – it was a reaffirmation of our commitment to collaboration, compassion, and community.

We are deeply grateful to all who participated. To continue the learning, presentation videos and session summaries are available upon request. Kindly visit https://hospismalaysia.org/palliative-caresymposium-2025.

REIGNITING PURPOSE AND POSSIBILITIES: HOSPIS MALAYSIA AT APHC 2025

Held from 24th to 26th April 2025 at the Borneo Convention Centre Kuching (BCCK), the Asia Pacific Hospice Palliative Care Conference (APHC) 2025 welcomed over 1,200 healthcare professionals, many from across the region and beyond.

Hospis Malaysia was proud to be prominently featured – presenting nine abstracts, joining panel discussions, and hosting a dedicated exhibition booth that highlighted our community-based model of care.

A key highlight of the conference was the launch of the APHN Atlas of Palliative Care in Asia Pacific, authored by Prof. Carlos Centeno and co-authored by our CEO, Dr. Ednin Hamzah. The Atlas revealed several important findings, including the state of palliative care development in Malaysia. Check out a snapshot of key findings in the graphic on the right.

Another central theme echoed throughout the conference was the importance of community engagement in complementing care – ensuring a more holistic, person-centred approach that supports not only patients but their caregivers as well.

We sincerely thank everyone who visited our booth – your enthusiasm for our gamified online learning programme and interest in collaboration were truly encouraging. A special thanks as well to YB Datuk Michael Tiang Ming Tee, Sarawak's Deputy Minister for Public Health, Housing and Local Government II, for honouring us with his visit.

Beyond the presentations and booth, perhaps the most meaningful takeaway came from our own team who returned not just more informed, but deeply inspired.

SMAPSHOT

PALLIATIVE CARE (PC) IN MALAYSIA

FROM APHN ATLAS OF PALLIATIVE CARE IN THE ASIA PACIFIC REGIONS 2025

Based on WHO Framework for Palliative Care Development Framework Ratings: 1 = Emerging | 2 = Progressing | 3 = Established | 4 = Advanced

A. Empowerment of People & Communities

- Existence of groups to promote PC patient rights the biggest are MHPCC & Hospis Malaysia.
- Advanced care planning-related policies. National Advance Care Planning (ACP) program launched; clinical guidelines developed.



Government funds cover only 10% of NGO/ hospice operational costs → financial gaps remain. B. Policies 3 National PC plan e Responsi Health (N Developer

- National PC plan or strategy National PC plan exists; not yet evaluated.

 Responsible PC authority in Ministry of
 - Responsible PC authority in Ministry of Health (MoH) National PC Services Development Committee.
 - Inclusion of PC in basic health package at primary care level – 308 domiciliary teams and expanding under 2021–2025 Strategic Plan.

C. Research

- PC-related research articles few peerreviewed PC research publications with local authorship.
- Existence of PC congresses or scientific meetings regular national PC conferences held (at least once every 3 years).



D. Essential Medicines

- Opioid consumption (2020–2022): 295 S-DDD* below regional average of 558.5 S-DDD.
- Overall, opioid access remains limited across primary care, especially in rural settings.
- Primary care has good access to non-opioids and Tramadol, but limited morphine use due to low prescribing confidence by providers.

*S-DDD = Daily Doses for Statistical Purposes Per Million Inhabitants Per Day.

E. Education & Training

- Only 5 of 32 medical schools mandate PC training
- None of the 33 nursing schools include PC in core curriculum
- Hospis Malaysia provides PC education at 5 institutions (e.g UM, UTM); developing programs for nurses/allied health professionals.
- PC is a recognised subspecialty (3-year training) under Internal Medicine by MOH.



Service density 1.41 specialised PC services per 100,000 population.

Geographic coverage Generalised but urban-focused.

F. Provision for PC Services

483+ total palliative care teams including:

- 59 hospital-based teams
- 30 NGO teams mostly community-based care none in Perlis and only 1 in Penang.
- 197 of 265 primary care clinics home care teams.
- 6 paediatric PC services progressing.



We are honoured to receive YB Datuk Michael Tiang Ming Tee, Sarawak's Deputy Minister for Public Health, Housing and Local Government II (Public Health & Housing) at our booth.

REFRAMING CONVERSATIONS FROM ACP TO REAL-TIME CARE

One of the most widely discussed topics was Advance Care Planning (ACP) and its limitations. Several sessions challenged whether ACP, in its current form, truly supports patients during the realities of serious illness as the patient's wishes and preferences may change over time, and especially as the illness progresses. Instead, there was strong advocacy for real-time Goals of Care (GOC) conversations – those rooted in patients' current experiences and evolving values.

This message resonated deeply with our team members including nurses Norbazilah Johari, Low Ker Yong, Nurul Nadiah Jaafar, and pharmacist Chua Hui Ming, who attended the Serious Illness Conversation (SIC) workshop. They praised the session for providing a clear 'compassionate framework' for exploring what matters most to patients, and for emphasising shared decision-making over clinical assumptions.

PUTTING THE PATIENT FIRST

A strong theme across the conference was the need to centre care around the person, not just the condition. Presentations by global leaders such as Dr Libby Sallnow and Dr Sean Morrison highlighted the emotional, spiritual, and relational dimensions of care – reaffirming what Hospis Malaysia already strives to deliver.

Our physiotherapists, Low Su Jiun and Kiren Darshiny M Ravi, reflected on how this applies in rehabilitation – allowing patients to make choices that may carry risks such as moving independently despite fall concerns – because living meaningfully often matters more to them than living cautiously. These reflections are a reminder that effective care isn't about removing risks, but about balancing safety while respecting autonomy and enabling dignity.

FINDING REHABILITATION VOICE IN PALLIATIVE CARE

Although rehabilitation wasn't a key focus at the conference, this prompted meaningful reflection for our rehab team, who saw the lack of visibility for physiotherapists in palliative care as an opportunity to grow and advocate for the role of rehab in improving quality of life. Conversations with therapists from Brunei and Japan highlighted shared struggles in gaining early referrals and recognition reinforcing their commitment to develop evidence-based outcomes and raise awareness of palliative rehabilitation.

GLOBAL CONNECTIONS, LOCAL IMPACT

Throughout the three-day conference, the team made



Dr Punitha Krishnan shared how her MSc journey at King's College London shaped her growth both personally and professionally. Today, she's leading Hospis Malaysia's MND project in collaboration with UMMC, driving forward compassionate, evidence-based palliative care.

meaningful connections with peers from Singapore, India, Taiwan, Bangladesh, Hong Kong, and Australia. For Ker Yong and others, this highlighted the diversity of palliative care models across the region – and reinforced how unique Hospis Malaysia is in its commitment to home-based, community-driven care.

INSPIRED TO GROW

Each team member returned with renewed energy and purpose. The experience also deepened team connection. Many noted that spending time outside the usual work routine – engaging with ideas, each other, and the broader palliative care community – allowed for richer conversations and stronger bonds.

As one of them reflected, "This wasn't just about gaining knowledge. It was about reminding ourselves why we do this work and how we can keep doing it better."

Together, they return not just with learnings, but with leadership – to help shape the future of palliative care in Malaysia.

IN THEIR OWN WORDS: A ROYAL VISIT THAT AMPLIFIES PATIENTS' VOICES AND CALL FOR EQUITABLE PALLIATIVE CARE



Our Guests of Honours present were KDYMM SPB Raja Permaisuri Agong Raja Zarith Sofiah (middle), YABhg. Dato' Seri Dr. Wan Azizah Dr. Wan Ismail, Wife of the Prime Minister (third from left), YB Dato' Lukanisman bin Awang Sauni, Deputy Minister of Health (third from right), YBhg. Datuk Abd Shukor bin Mahmood, Senior Deputy Secretary-General, Prime Minister's Department (second from left), YBhg. Dato' Sri Suriani binti Dato' Ahmad, Secretary-General, Ministry of Health (second from right), Dato' Kathleen Chew, Chairman, Hospis Malaysia (left), and Dr. Ednin Hamzah, Chief Executive Officer, Hospis Malaysia (right).

In conjunction with the 2025 Official Birthday Celebration of KDYMM Yang di-Pertuan Agong, Hospis Malaysia had the honour of receiving KDYMM Seri Paduka Baginda Raja Permaisuri Agong, Raja Zarith Sofiah, at our centre in early June. Her Majesty's visit was deeply meaningful – not only to our patients and their families, but also to the broader cause of palliative care advocacy in Malaysia. The occasion was witnessed by some 80 guests from various organisations.

Warm and gracious, Her Majesty spent time with seven of our patients – including two children – and their families, as well as two caregivers, who were eager to share their stories. Her genuine compassion, and her willingness to listen was a powerful act of validation for those navigating life-limiting illnesses.

During her visit, Her Majesty acknowledged the importance of making palliative care more accessible – especially within community settings, where most patients prefer to receive care. Her remarks deeply resonated with the lived experiences of those in our care, many of whom voiced concerns about affordability, limited access to essential medications, and the lack of

IN THEIR OWN WORDS







Norlina Non & Michael Tan

Norlina Non, referred to Hospis Malaysia in 2019 with advanced cancer, shared how home support for managing her pain and symptoms let her enjoy meaningful time with family.

Similarly, Michael Tan, 65, living with heart failure, continues to live well with our support—welcoming a grandson, babysitting, and proudly walking his daughter down the aisle.

Tan Shu Hua

Tan Shu Hua, 43, who lives with motor neurone disease and faces significant mobility challenges, shared how comprehensive palliative care at home helps manage her symptoms while offering a safe space and guidance to prepare her and her family for the journey ahead.





Mahalinggam Karpayah

Mahalinggam Karpayah, 76, lived with progressive supranuclear palsy (PSP) and chronic myeloid leukaemia. Over two years with Hospis Malaysia, his wife Jeyanthi Annamalai shared how the team, including rehab therapists, helped manage his condition, avoid unnecessary hospital visits, and made her feel supported throughout the long caregiving journey.

Samsul Kamal Ali Budin

Samsul Kamal Ali Budin, 50, living with lung cancer, is grateful for his early referral to Hospis Malaysia in 2023. He emphasised that palliative care doesn't mean giving up hope, as he continues treatment while receiving support to manage his symptoms and maintain quality of life.



IN THEIR OWN WORDS







Gilbert M. Spykerman

Gilbert M. Spykerman's parents shared their gratitude for the care and support received from Hospis Malaysia since in July 2024, following his diagnosis of a rare cancer, Atypical Teratoid/Rhabdoid Tumor (ATRT). With successful treatment and ongoing rehabilitation from our physiotherapist, Gilbert is now thriving as a growing toddler.

Muhammad Azrul

Born with a genetic disorder, 8-year-old Muhammad Azrul has been under Hospis Malaysia's care since infancy. His parents shared with Her Majesty how ongoing medical and psychosocial support for their son—and themselves—has helped ease their journey and reduce unnecessary hospital admissions.





Datuk Idris Abdullah

Datin Fathiah Abdul Rahman witnessed first-hand the impact of comprehensive palliative care provided by Hospis Malaysia for her late husband, Datuk Idris Abdullah, over three years. Despite affording private care, she deeply valued the 24/7 medical support from the team — including after-hours visits — which made a vital difference.

Wilfred Gasper

Rosie Gan also echoed the same reflections about Hospis Malaysia's care for her late husband, Wilfred Gasper who had late-stage dementia. She shared: "not only did they support my husband, they were also always mindful about how we were coping as caregivers."



adequate palliative support beyond urban areas. Collectively, our patients underscored the urgent need to raise public awareness and expand community-based palliative care across Malaysia, ensuring equitable access to quality care for all.

The visit was also graced by the presence of other Guests of Honour including YABhg. Dato' Seri Dr. Wan Azizah Dr. Wan Ismail, wife of the Prime Minister and YB Datuk Lukanisman Awang Sauni, Deputy Health Minister. Their presence signals potential for stronger collaboration between the public and private sectors, and brings hope that palliative care will receive the national attention it urgently deserves.

As our CEO, Dr. Ednin Hamzah, noted in his speech, "We must never forget that we are caring for people – not just treating diseases. One day, any of us could be in their place. When that time comes, how would we want to be treated?"

At Hospis Malaysia, we continue to advocate for palliative care as a holistic, multidisciplinary approach that enhances quality of life from the point of diagnosis. It is not merely end-of-life care, but a vital support system throughout the course of a serious illness. Our 24-hour emergency service, for instance, ensures that patients can have their symptoms managed at home, minimising distress and reducing unnecessary hospital admissions. Our message is simple but urgent: Palliative care is for everyone – young or old, at any stage of a serious illness.

We are deeply thankful for Her Majesty's generous donation which will further support our ongoing efforts. Her visit has shone a national spotlight on the importance of equitable, person-centred palliative care, and strengthened the voices of those who need it most.



PAST EVENTS

ENGINES ROARED, HEARTS SOARED: A LOOK BACK AT OUR 2025 TREASURE HUNT



The thrill was back in full force as our Annual Charity Motor Treasure Hunt kicked off from Bangsar Village—made possible by our generous venue partner. With a hearty breakfast fuelling our teams for the journey ahead, the spirit of adventure was palpable.

The convoy set its sights on Melaka, with every team arriving safe and sound—no disqualifications, no mishaps, just smooth sailing through a day bursting with energy and community spirit.

The competition heated up, but one team rose above the rest—congratulations to Armchair Hunters, who defended their title in spectacular fashion!























We extend a heartfelt thank you to our sponsors for powering this unforgettable experience. Your support not only propels the event forward but builds cherished memories year after year. Newcomers, veterans, and master clue-crackers alike—your passion and participation have shaped this signature event. As we rev up for our landmark 25th Treasure Hunt next year, brace yourselves for another chapter of adventure, camaraderie, and surprises along the way.

It's more than an anniversary—it's a celebration of the community we've built, the memories we've created,

and the adventures that still lie ahead. We can't wait to see you there for more fun, tougher challenges, and unforgettable moments.

A huge thank you to every participant, partner, and supporter for helping the hunt thrive year after year. Let's make history together, and keep the spirit of discovery rolling strong.

Scan the QR code or click on it to view the Treasure Hunt 2025 Photo Album.

OUR PEOPLE IN THE SPOTLIGHT

RESEARCH PUBLICATION LED BY OUR MEDICAL DIRECTOR ON COPD & PALLIATIVE CARE

In May, after more than 2 years of study, our Medical Director, Dr Lim Zee Nee and her co-authors from Department of Primary Care Medicine and Department of Medicine, Faculty of Medicine, Universiti Malaya; the Usher Institute,



Dr Lim Zee Nee Medical Director, Hospis Malaysia

University of Edinburgh, UK; and Hospital Pusrawi, Kuala Lumpur, saw the publication of their study project "Exploring the disease experience and supportive care for people with very severe chronic obstructive pulmonary disease in Malaysia: a multiperspective qualitative study" in the Journal of Global Health.

The study is a multiperspective qualitative exploration of the lived experiences and supportive care needs of people with very severe chronic obstructive pulmonary disease (COPD) in Malaysia. It reveals that in Malaysia, palliative care services and access to them for individuals with severe organ failure remain almost non-existent. Awareness among both the public and healthcare professionals is still low, and palliative care for non-malignant conditions like COPD remains underrepresented in the literature.



This publication is a vital step forward in highlighting the gaps, and advocating for more equitable, personcentred care for all.

Scan or click on the QR code to read the full study.



SPEAKING FROM THE HEART: NURSE NADIAH CHAMPIONING EMPATHY, ADVOCACY, AND CULTURAL INSIGHT IN HOME-BASED PALLIATIVE CARE

In June, our very own nurse Nurul Nadiah Jaafar was a plenary speaker at the CNSA & ICCN 2025 Congress in Adelaide, organised by the Cancer Nurses Society of Australia (CNSA) and the International Society of Nurses in Cancer Care (ISNCC).

In her presentation titled "Care Beyond Symptoms: Nursing, Advocacy and Culture in Home-Based Palliative Care," Nadiah offered a grounded perspective on what it means to deliver palliative care with empathy and purpose while reflecting on the emotional realities of care and the role of nurses in navigating complex clinical settings.

Many in the audience felt her talk resonated well with the congress's theme "Global Voices, Local Actions: From Inspiration to Implementation", demonstrating how compassionate care can make a difference to patients and their families.

OUR CEO SPEAKING ON BFM - A CALL FOR INCREASED PALLIATIVE CARE TRAINING

In early July, our CEO Dr Ednin Hamzah was interviewed by BFM 89.9 about the need for increased training in palliative care for doctors. He was joined by Niensi Atarah Akiu, a community palliative care nurse from Two Tree Lodge



Dr Ednin Hamzah CEO, Hospis Malaysia

Hospice, Kuching echoing a similar gap in nurses' training.

Dr Ednin described palliative care as an evolving specialty aimed at improving the quality of life for patients with serious illnesses. And with Malaysia's ageing population and rising incidence of noncommunicable diseases (NDCs), the need for palliative care is greater than ever. He reminded that with NCDs, apart from managing the illness, there is also a need to address how the illness is affecting the patient whether it is in the form of physical or emotional pain, or spiritual and psycho-social distress.

In his words - "We must move beyond the diseasecentric model of care and help healthcare professionals



become better communicators, better listeners, and better humans. It's time to give palliative care the attention it deserves – in every classroom, every ward, and every patient interaction. Because every person deserves to live and die with dignity".

Scan or click on the QR code to listen to the full BFM interview here.

Your generous support helps us deliver comfort, care, and dignity to those who need it most.



With gratitude to:

- Chuan Huat Resources Berhad
- Malaysian Institute of Human Resource Management (MIHRM)
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- Selangor and Kuala Lumpur
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- The Truly Loving Company (TLC)



A Legacy of Compassion Lives On: The Ripple Effect Continues We deeply thank Visaghan Shanta Mohan and Pranava Shanta Mohan for their steadfast support of Hospis Malaysia through The Ripple Effect 5.0, in loving memory of their late neighbour and family friend Jegadeva, who fondly called our nurses 'angels who walk among us'. Special appreciation to Shivanee Selvaratnam fom Asia Weaves and Raja Singham from Brickfields Asia College for championing this fundraiser.

