

## CENTERING HEALTHCARE WHERE IT IS WANTED – COMPASSIONATE COMMUNITIES

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

What if...

Madam Tan with breast cancer had an appointment at the hospital but their car couldn't start. Encik Hassan has chronic lung disease and his wife who is also aging, is exhausted after years of looking after him. Mrs Devi, a single mother caring for her son with leukaemia needs to run to the hospital to collect his drug prescription but is unable to leave his side to go.

Healthcare tends to look at illness as a pathological process that causes harm to the body and looks at medical management using medical intervention. And if it is recognised that there are social and psychological concerns, these issues tend also to be dealt with using a medical framework.

A nation may want to highlight its medical stature through the recognition of its centres of excellence such as the National Heart Institute and the National Cancer Centre for cardiology and cancer treatment services. Is it not possible that potentially the most impactful centre of excellence is not centred on a concrete structure with state-of-the-art equipment but rather a wide residential area where the community lives, breathes and dies?



Source credit: ehospice

When a person feels unwell, it is natural that they may first try self-medication, and if it becomes worrying, they may then seek medical attention. The more affluent may want to seek the best perceived opinion from a private medical centre whilst others may go to

*continues on page 2*

IN THIS ISSUE	EDITORIAL		Empowering Communities to Embrace Palliative Care: World Hospice and Palliative Care Day 2023	5	PAST EVENTS	Empowering Compassionate Communities: Gotong Royong 2.0	10
	Centering Healthcare Where It Is Wanted – Compassionate Communities		1		Ethics in Palliative Care Workshop (2-3 December 2023)	11	
	ADVOCACY		KLSCM		THANK YOU!	11	
	Palliative Care Support Roadmap 2023		3	11 Years Strong: Hospis Malaysia Continues to Make Strides In KLSCM	6		
	TEACHING AND TRAINING		FEATURE			UPCOMING EVENTS	
	Transforming Care & Advancing Paediatric Palliative Medicine in Malaysia		4	Dignity and Comfort: Haris Ibrahim's Journey with Palliative Care	8	Upcoming Events for 2024	12
	Looking for Hope in Humanitarian Crises - Recognising the inherent wisdom within communities		4				

*“Death is a social event with a medical component, not a medical event with a social component.” Professor Allan Kellehear*

the nearest Klinik Kesihatan (community health clinic) to see a family physician. For those seeing the family physician, if the problem is not settled, this may lead to consulting a specialist at a government hospital.

Surveys across the world has demonstrated that most patients prefer to be cared for in the community. For years, the family doctor or physician was the main source of care, dealing with the children to the parents, from childhood ailments to chronic disease ...and in many countries such as the United Kingdom, in palliative care and end of life care.

Malaysia is a signatory to the World Health Assembly Resolution 67.19: ‘Strengthening palliative care as a component of comprehensive care throughout the life course’. In most developed healthcare settings, the family physician is best placed to provide much of the palliative care that anyone in a family requires. Only if the palliative care needs are complex or become complex, will the patient perhaps then be referred to hospital for treatment or if an in-patient service is available, for respite care.

Family medicine doctors are trained to be the family physicians, and should have the skills to deal with most illnesses affecting a patient. They should also be looking at the caregiving the family requires when a member of the family is unwell. In many countries, palliative care skills are part of the basic competency of the family physician. So, the skills of communication, basic symptom control and psychological distress should well be within the ability for the family physician to resolve.

Let us not forget, each of us reside within a community that comprises of multiple social networks. These

social networks came to life in many areas of Malaysia during the Covid-19 pandemic. If these social networks could be harnessed and be partnered with health and palliative care expertise, it would create a formidable resource that can be called upon to manage and maintain many patients in the community, where they want to live their lives.

This year, the theme for World Hospice and Palliative Care Day is *Compassionate Communities: Together for Palliative Care*. In about 19 countries around the world, such communities exist. It has been our shared culture and traditions that have taught us how to live and how to manage death. Compassionate communities help normalise death, dying and improve the capacity for caring. For many communities and countries, it also reduces the burden on hospital admissions.

As befits an ageing society and a higher incidence of non-communicable diseases, palliative care should be a cornerstone of a nation’s health care policy rather than an add on. Transforming the culture of care from monolithic institutions of healthcare to the bosom of the community will bring long term benefits. There will always be a need for specialised hospital-based palliative care, but these are for a small proportion of society.

Madam Tan could have someone take her to the hospital, Encik Hassan could have some volunteers give his wife some respite and someone could go to the hospital to collect her son’s prescription for Mrs Devi. These and so much more could be done through a network of caring human connection. Unlocking the richness of this social capital is the key. And the sooner we realise that we share a common goal, the faster we may benefit from them. ■

#### COUNCIL MEMBERS

**Chairman:**

Dato’ Kathleen Chew  
Wai Lin

**Secretary:**

Dr Chong Su-Lin

**Treasurer:**

Dr Ong Hock Chye

**Members:**

Ms Lim Wai Yee  
Professor Dr Khoo Ee Ming  
Mr Chan Yee Hon  
Mr Irvin Menezes


#### HOSPIS MALAYSIA (199101013363)


2 Jalan 4/96, 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)

 [HospisMY](https://www.facebook.com/HospisMY)

 [HospisMalaysia](https://www.instagram.com/HospisMalaysia)

 [Hospis Malaysia](https://www.youtube.com/HospisMalaysia)

# PALLIATIVE CARE SUPPORT ROADMAP 2023

As a community palliative care provider, Hospis Malaysia touches the lives of many who have voiced the importance of being cared for at home where family and friends are, and spending the limited time they may have left, in the community where they have built their lives. When a person is unwell, it is likely they will want to seek medical attention. The question often is – where do they go? In Malaysia, often if one is very unwell, he will immediately go to a hospital, where many are doing the same, and as such waiting times may be long, and the hospital may be a distance away. And if you were to be admitted, it may be difficult for your loved ones to visit regularly.

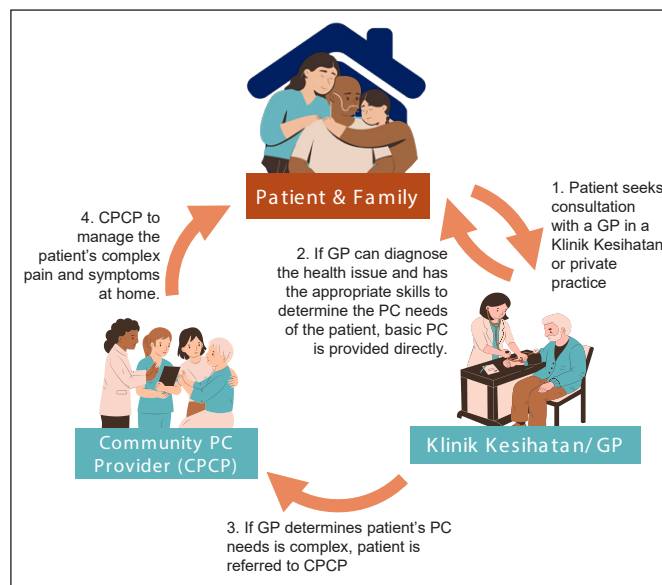
Imagine if there was an ability for that person to first see a medical doctor in a clinic nearby. And the doctor has sufficient training, experience and perhaps already knows him and his healthcare history, to attend to his basic medical needs. And if he were experiencing pain and other physical and psychological symptoms related to a serious illness, the doctor has sufficient skills and medication to address some of his basic palliative care needs. Could that be a preferred option for the patient and his family?

In conjunction with World Hospice and Palliative Care Day 2023 this year, where the theme is “Compassionate Communities – Together for Palliative Care”, Hospis Malaysia highlighted the option of bringing healthcare back to communities. And more importantly, bringing palliative care availability back into the community.

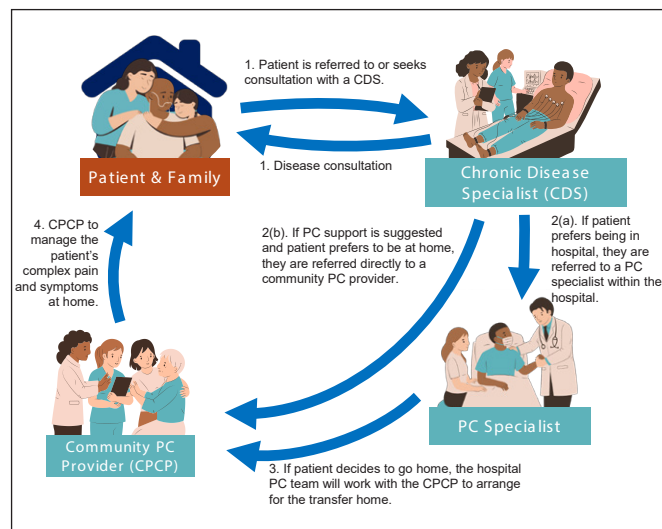
It offers a patient the option of being treated and cared for at home or in hospital, respecting one of palliative care’s most fundamental tenets – the patient’s choice of place of care.

In the next column are illustrations of the potential pathways someone with a serious illness may take – both pathways offer the possibility for the patient to be cared for at home. ■

**Pathway 1** - The patient’s illness and palliative care (PC) needs remain at the community level and is managed between their General Practitioner (GP) and the community palliative care provider.



**Pathway 2** - The patient seeks consultation with a chronic disease specialist (CDS) and requires palliative care (PC)



Please scan or click on the QR code to view the patient’s full palliative care journey. The link is: [https://hospismalaysia.org/wp-content/uploads/2023/10/WHPCD\\_Road-Map.png](https://hospismalaysia.org/wp-content/uploads/2023/10/WHPCD_Road-Map.png)

## TRANSFORMING CARE & ADVANCING PAEDIATRIC PALLIATIVE MEDICINE IN MALAYSIA

In September, Hospis Malaysia in partnership with University of Malaya, hosted the Inaugural Paediatric Palliative Care Symposium facilitated by a faculty of internationally renowned paediatric palliative care professionals\*. Attended by over 70 doctors, nurses and allied healthcare workers from across the region, the symposium focused on Narrative Medicine, a holistic and interactive approach to palliative care that emphasizes empathy and compassionate care. The symposium aimed to enable healthcare providers with palliative care experience and interest to foster collaborations to advance the field by informing policy decisions, developing guidelines, and training the next generation of healthcare professionals in paediatric palliative care.

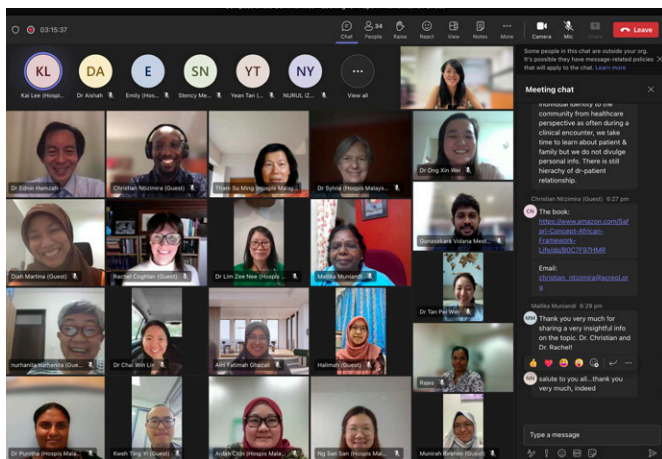
As Dr Chong Lee Ai, the symposium lead shared “I hope with the takeaways from this inaugural event, more healthcare providers will be ready and prepared to care



for the children and families who need palliative care as so much more can be done to support them”. ■

*\*Liese Groot-Alberts, Chaplain Jenny Busch, Brian Carter, Alex Mancini, Komal Tewani, Azanna Ahmad Kamar, Rita Charon, Yukie Kurihara*

## LOOKING FOR HOPE IN HUMANITARIAN CRISES - RECOGNISING THE INHERENT WISDOM WITHIN COMMUNITIES



In an inspiring 2-hour webinar, two prominent palliative care experts cited examples in communities they have worked in and insisted on the importance of recognizing the inclusion of family and communities and empowering them to support the work of palliative care professionals.

Rachel Coghlan<sup>1</sup>, a seasoned advocate for palliative care in humanitarian emergencies, highlighted the importance of utilizing existing resources and social networks to address complex health and social care issues. She stressed the need for intuition, emotions,

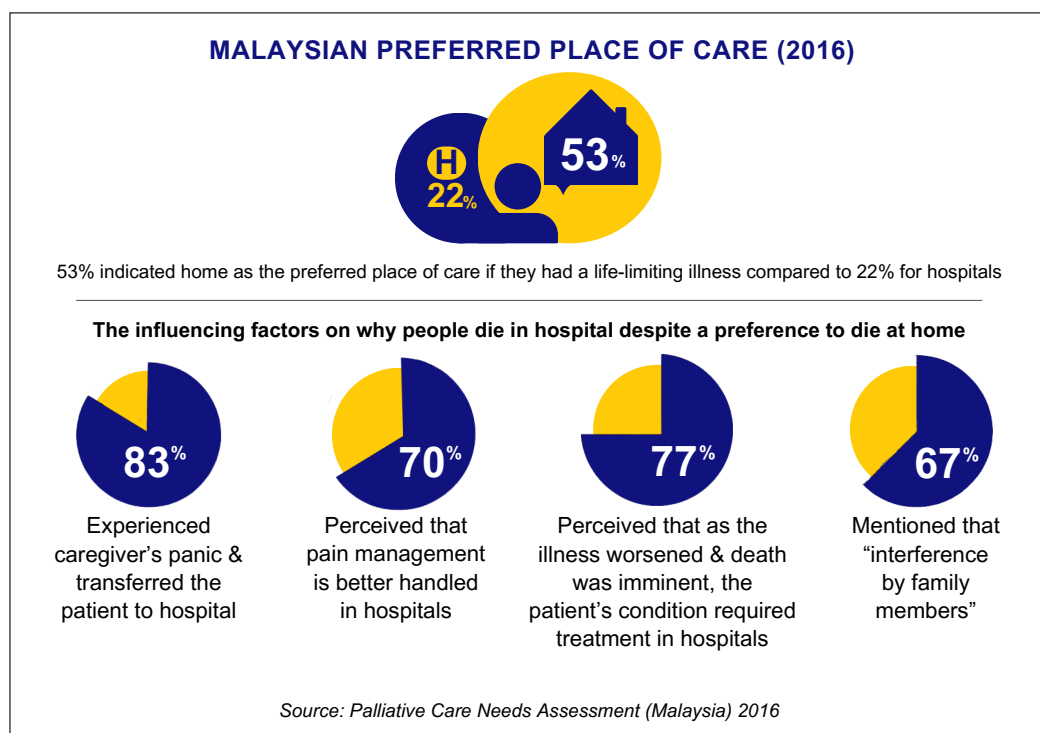
and acknowledging local traditions and narratives, and emphasized the need to integrate community and family-centred approaches into healthcare systems.

In his discussion, Dr Christian Ntizmira<sup>2</sup> explained the concept of Ubuntu, an African philosophy deeply rooted in culture which permeates every aspect of medicine. Ubuntu goes beyond treating symptoms and diseases; it involves caring for the whole person, taking into account their social, cultural, and spiritual dimensions. Dr Ntizmira's statement, “When you are well, you belong to yourself. But when you are sick, you belong to your family,” highlights the importance of recognizing the role of family and community in healthcare. ■

1. Rachel Coghlan is from the Centre for Humanitarian Leadership, Deakin University, Australia and a Fulbright Scholar at the Center for Humanitarian Health, Johns Hopkins University, USA.
2. Dr. Christian Ntizmira is a Palliative care physician and the Founder/Executive Director of the African Center for Research on End-of-Life Care (ACREOL), an organization dedicated to promoting socio-cultural equality in end-of-life care in Africa.



# EMPOWERING COMMUNITIES TO EMBRACE PALLIATIVE CARE: WORLD HOSPICE AND PALLIATIVE CARE DAY 2023



World Hospice and Palliative Care Day (WHPCD) is a unified day of action to celebrate and support hospice and palliative care around the world. The theme for WHPCD 2023, "Compassionate Communities: Together for Palliative Care," highlights the importance of working together to strengthen community involvement in supporting palliative care delivery. It recognises that when communities develop a sense of compassion, they will work together to care for people, assist people to live in the place they call home, connect people to services, and raise awareness about end-of-life issues.

In recent years, hundreds of compassionate communities have developed all around the world. It is believed that palliative care working alongside compassionate communities multiplies the ability to respond to the needs of the most vulnerable.

At this year's WHPCD in October, Hospis Malaysia participated in an event organised by the Malaysian Hospice and Palliative Care Council (MHPCC). As a leading palliative care provider in the community, this year's theme reinforces our belief in building care in the community where there is an abundance of inherent resources which can be harnessed, and where care is the most needed.

With a gathering of a large number of the country's palliative care professionals involved in the



*Dr. Mohamed Iqbal bin Hamzah, Director of Medical Practice Division, Ministry of Health (MOH) visiting Hospis Malaysia's WHPCD booth with MOH officials*

development of services, and officials from the Ministry of Health, it was a poignant time to remind all who attended that the ethos behind palliative care is its patient-centred approach, and the journey for someone with a serious progressive illness often begins at home. We reminded participants at the event that a public survey conducted in 2016 amongst the Malaysian public continues to hold true in Malaysia and across the world – that with the right support, most people prefer to be cared for at home, and most prefer to spend their last days at home. ■

## 11 YEARS STRONG: HOSPIS MALAYSIA CONTINUES TO MAKE STRIDES IN KUALA LUMPUR STANDARD CHARTERED MARATHON (KLSCM) 2023

The Kuala Lumpur Standard Chartered Marathon (KLSCM) is one of Hospis Malaysia's most important fund-raising and public awareness platforms. For little more than a decade now, Hospis Malaysia has been actively involved as a charity partner. This annual event serves as a powerful platform, for individuals and corporates who share a common goal of combining their passion for sports and running with supporting a meaningful cause. Individuals raise funds through their network of friends, colleagues and relatives while corporates support a charity such as Hospis Malaysia while encouraging their internal stakeholders to participate. And in so doing, sow the seeds of awareness about the importance of palliative care support should the need arise.

This year, over 400 runners pledged their support for Hospis Malaysia through the Run for a Reason (RFAR) category. We are grateful for the extra effort many of them made to raise a minimum of RM500 to qualify for the exclusive 2023 RFAR T-shirt and in addition earned themselves a bonus KLSCM 2023 limited edition plush toy specially designed by Hospis Malaysia for the event. Ardent supporters of the run and for Hospis Malaysia were thrilled to add this year's plush toy to their set of 4 since 2019.



Photo courtesy of our regular supporter, Dragon Pang

Funds raised goes towards our very crucial and core service - patient care. With approximately 1700 patient referrals a year, our domiciliary care service remains the single largest service in the country. This service includes regular home visits which involves comprehensive assessment of the well-being of the patient, treatment of pain and other physical symptoms, psycho-social care, and caregiver training to cope with the care of the patient at home. As







patients can go into distress due to their symptoms at any time, an emergency call service is also availed to all patients. All at no charge.

Leveraging on the platform to improve public awareness is also key to Hospis Malaysia' engagement in KLSCM. This year, the atmosphere at the Expo in KL Convention Centre and race days at Dataran Merdeka was filled with energy and enthusiasm. It was heartening to see people genuinely interested in learning more about palliative care, as volunteers handed out informational materials to educate the crowd about its significance.

As KLSCM enters its next milestone, we would like to thank the organiser, Dirigo Event for their unwavering belief in Hospis Malaysia being a worthy charity partner. And through the beliefs of our runners, Hospis Malaysia has managed to yet again touch the lives of countless individuals and their families. Our presence in this signature sports event serves as a reminder that every step taken, every stride made, truly matters when it comes to creating a better world for those in need. ■

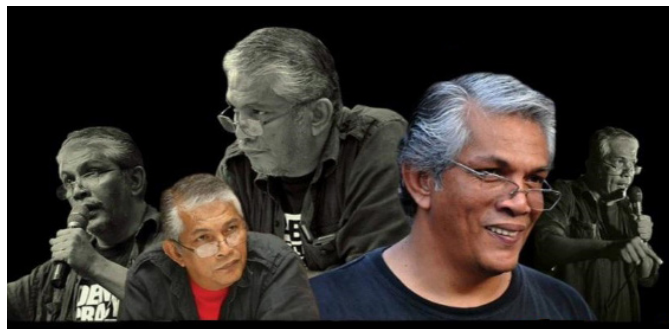
## Our champion runner this year: Renee Ahmad Aziz

"I am truly blessed to have friends who took the trouble to wake me up at 5a.m. and go with me to Dataran Merdeka, and brought balloons and water for me at the start line. And ran most of the way with me taking photos and videos and generally just let me know that I am not alone on this journey..."

**(Renee Ahmad Aziz is a cancer patient who is still undergoing treatment and has been referred for palliative care)**



## DIGNITY AND COMFORT: HARIS IBRAHIM'S JOURNEY WITH PALLIATIVE CARE



**INTRO: A successful lawyer and well-known social activist, Haris Ibrahim was “a towering Malaysian who gave up life’s comforts for the betterment of the country,” as remembered by Ashok Kandiah, his law firm partner. When Haris suffered a major health setback, he found himself having to navigate one of life’s toughest challenges. We caught up with his brother Encik Adam Ibrahim and sister-in-law Puan Firoza for an insight into Haris’ journey in the last year of his life.**

“It was a great shock to him,” Pn. Firoza recalled. For a man committed to the pursuit of a better Malaysia for all, it was a huge blow to Haris to see bleak days ahead upon a Stage-4 lung cancer diagnosis. “But he concealed his feelings well and didn’t appear depressed to us, though we sensed he was at some point,” En. Adam added.

While Haris knew death was inevitable, he didn’t rule out treatment to buy some time to attend to his personal and professional matters. One of his wishes was to continue his work for as long as possible. He also wanted to be in control of all arrangements and decisions regarding his care and circumstances, with home care being his preference. Being informed about his prognosis and how much time he had left was therefore important.

When Haris was referred for palliative care, En. Adam felt that it probably crossed his brother’s mind that time was limited and this was the final step to the end. But again, Haris didn’t fully display his feelings and continued to look at other avenues with the hope of staving off the disease, so that he could continue with his work and deal with unfinished business. So, with what little the family knew about Hospis Malaysia at that point, they got in touch with the organisation.

The referral turned out to be a valuable step in the journey. “For a start, the palliative care team was very

attentive to Haris’ needs and choices. We received a lot of advice about treatments including alternative ones from well-meaning people and it became quite confusing. There were times when we questioned whether the different treatments complemented each other and if they were doing him any good. The team from Hospis Malaysia provided clear advice on all the issues. Although not in complete agreement with alternative treatments, they accepted that this was Haris’ choice and was always ready to assist,” En. Adam said. This laid a solid foundation of trust between the family and the team, which did not waver till the end.

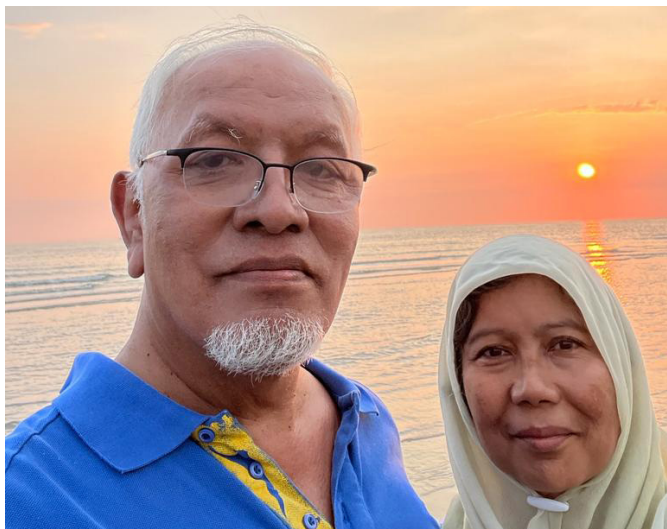
As the disease progressed, the team helped Haris in pain management and end-of-life care. They provided medications and guided the family on how to manage the discomfort and other symptoms as well as what to expect. “They also taught us how to administer some of the medications. In fact, Haris’ caregiver benefited from the support too. From his updates to the team, they’d discuss next steps together so he’d know what to do,” Pn. Firoza highlighted.

Haris made it clear that it wasn’t death that he feared. “He was very courageous in that sense,” Pn. Firoza commented. It was the prolonged suffering of pain and other symptoms and being a burden to the family that he was more concerned with. “He suggested several times to go to the hospital so as not to trouble the family. But we assured him that there was no issue of burden, especially when spending his last days at home was his preference,” En. Adam shared.

Managing Haris’ condition at home and thus, fulfilling his wish, was made viable with the support from Hospis Malaysia. More than just bringing comfort to Haris, the team also saw the family through their anxiety, fear, uncertainty and grief. As echoed by Pn. Firoza, “The home visits became a sort of lifeline for us, as it lessened the stress for everyone. Haris was always cheerful when the team came by. We all looked forward to their visits. When you know what to expect, it makes the whole process much easier to bear, especially in the active dying stage when it would’ve been so easy to panic.”

Haris wanted to make the most of each day in the company of his family, relatives and friends. Once his pain was better managed, he got to do exactly that, albeit within constraints. Not only did he get to carry out his daily routine and receive the many visitors





*Haris's brother, Encik Adam Ibrahim and sister-in-law, Puan Firoza Burhan*

coming to the house almost daily, he even managed to travel locally a few times to have a change of scenery.

Before he passed away in August 2023, true to his character as a man of integrity, Haris instructed the family that the balance of the funds raised from the public for his care be donated to Hospis Malaysia



*Encik Adam and Puan Firoza with Mr Arthur Toh, who initiated the crowdfunding for En Haris' treatment, seen here during a visit to Hospis Malaysia to donate the balance of funds raised*

for their unstinting medical, emotional and moral support. In En. Adam's words, "It was pure gratitude. Haris also wanted the same assistance he received to be extended to others in similar situations. We're glad we got to fulfill his wish." ■

## ETHICS IN PALLIATIVE CARE WORKSHOP (2-3 DECEMBER 2023)

*Workshop facilitators:*

*Dr Sumytra Menon, Deputy Director of National University of Singapore's Centre for Biomedical Ethics & Co-Director of the Clinical Ethics Network + Research Ethics Support (CENTRES).*

*Associate Professor Chan Mei Yoke, Senior Consultant in Paediatric Haematology / Oncology and the Chair of the Hospital Clinical Ethics Committee in KK Women's and Children's Hospital (KKH), Singapore*

Here's what first-time participants had to say about this workshop:

Dr Justine Wong from Kasih Hospice shared "I found it extremely thought-provoking with robust discussions surrounding challenging situations. The 'Four Box Method', is something I will certainly use as a framework to make objective decisions in ethical dilemmas. In my opinion,

this workshop is as important as a Basic Life Support course, and should be compulsory for all healthcare practitioners."

Clinical Psychologist Jefferson Ng from National Cancer Society Malaysia (NCSM) expressed that "Practicing clinical ethics requires more than the mechanics in executing it; rather, it involves the humanistic understanding of the beneficence and autonomy of each individual patient, knowing that they have a voice to be heard in any medical circumstances." ■





## EMPOWERING COMPASSIONATE COMMUNITIES: GOTONG ROYONG 2.0



Great Eastern General Malaysia (GEGM) recently collaborated with Hospis Malaysia for its annual employee volunteerism programme with aims to give back to the community and make a positive impact on society. More than 40 staff members including several Senior Management Team members donated two Saturdays of their time, to spruce up portions of Hospis Malaysia's exterior walls and performed an annual spring clean of our medical equipment storage rooms.

On both Saturdays the team broke up into smaller groups to spring clean and reorganize our medical equipment storage rooms, and stripped old paint off selected exterior walls, and prime and painted them in between inclement weather.

At the closing of the 'Gotong-Royong', Mr. Dennis Tan, Head of Human Capital at GEGM, expressed "GEGM's volunteerism program is a testament to our company's commitment to social responsibility and dedication to making a positive impact on society, especially to an organisation such as Hospis Malaysia that serves the community by doing noble work to serve those in need. Through this CSR, we are now educated on the importance of access to palliative care when the need arises. This is something that almost all of us are learning for the first time". Also present were, Madam Kherk Teng Teng, Head of Human Resources and Mr. Teo Chun Seng, Head of Risk Management who echoed the words of Mr Tan by adding "With this newfound palliative care awareness, our employees feel a sense of accomplishment as not only were they able to give back to society through their volunteering but in return they were able to educate themselves about the benefits of this very crucial area of healthcare which many of us are unaware of, but may touch most of us at some stage in our lives".

Thank you to GEGM for choosing to support Hospis Malaysia. We appreciate the time and dedication your volunteers have shown. ■







Hospis Malaysia consistently seeks to increase our reach in the community by encouraging collaborative partnerships for public awareness and fundraising. We are grateful for support from the following individuals and organisations this past June to November:

Syarikat Ong for their generous donation and pledge to support for the next 3 years.



Harlow's & MGI for their continuous support.



Bread Lab's Straightforward Sourdough initiative which gives back to the community (by enriching people's lives with good bread!) while spreading awareness about palliative care.



The family of the late Haris Ibrahim for their donation of funds raised by friends and supporters for his treatment.



Alia Ainuddin for choosing Hospis Malaysia as this year's beneficiary of her yearly birthday fundraiser tradition.



Cancer Centre @PHKL for rallying a group of runners with doctors, staff and patients in support of Hospis Malaysia for Run For A Reason in KLSCM 2023.



**ARE YOU KEEN TO COLLABORATE WITH HOSPIS MALAYSIA FOR YOUR CSR EVENT?**



The trend in corporate volunteerism is shifting towards more strategic and impactful initiatives. We understand that companies are recognizing that volunteerism is not just a philanthropic activity, but also a way to build brand, engage employees, and contribute to the community's social and economic development. Hospis Malaysia welcomes those who wish to contribute by volunteering time and resources. Volunteering can take many forms; from organizing fundraising events to providing professional services or offering employees as volunteers to assist with administrative tasks or event support.

**Email [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org) to discuss your interest to volunteer. ■**



**UPCOMING EVENTS 2024**



**PALLIATIVE CARE AWARENESS MONTH**  
*April 2024*

**CALLING FOR COLLABORATION**

Be Our Palliative Care Awareness Month (PCAM) Partner

**THE SKY IS THE LIMIT!**  
 Some ideas on how to support us:



**Just For Fun**  
 Yoga/ Baking/ Trivia Night /  
 Birthday Fundraisers

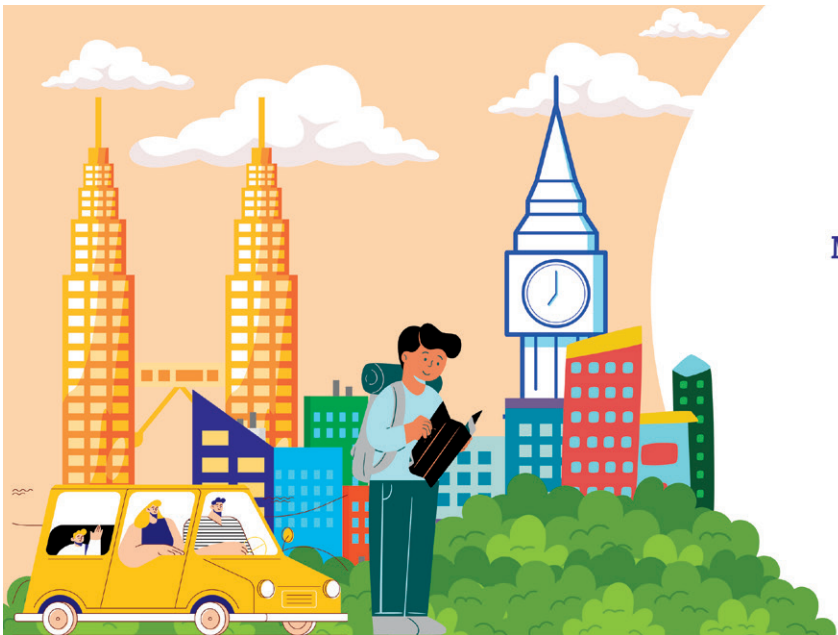


**Corporate**  
 Employee Engagement



**Services**  
 Energy Healing / Coaching

Register your interest to be our PCAM partner at [tinyurl.com/HMPCAM2024](https://tinyurl.com/HMPCAM2024)



**23<sup>rd</sup> CHARITY MOTOR TREASURE HUNT**

**SAVE THE DATE**  
 27-28 APRIL 2024

Where are we going?  
 Sign up to find out:



[tinyurl.com/HMTH2024](https://tinyurl.com/HMTH2024)