

## THE PLACE OF PALLIATIVE CARE IN **CANCER CARE**

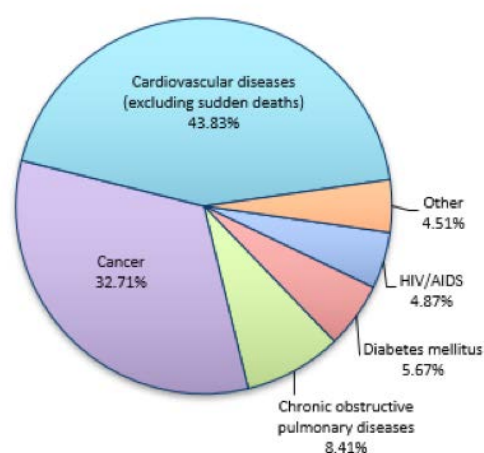
By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

Living well and being healthy is an aspiration that we all have. However, the likelihood is that many of us will be affected by serious illness during our lifetime and perhaps succumb to it. In 2016, the Department of Statistics listed the top 5 causes of death to be heart disease, pneumonia, stroke, road traffic accidents and cancers. Amongst these, the threat of cancer is never far from the public notion of suffering and death.

In Malaysia, the thrust of our National Cancer Control Programme has been prevention, early diagnosis, treatment and rehabilitation. In recent years, palliative care has joined this framework. However, many perceive that palliative care is only indicated when patients are incurable and terminal.

In 1986, the World Health Organisation published Cancer Pain Relief where a simple 3-step ladder was introduced to control cancer pain. Palliative Care services were key in implementing this framework. In 2005, the 58th World Health Assembly fully integrated palliative care into its resolution WHA58.22 to improve *Cancer Prevention and Control*. This resolution recognized palliative care as an essential component of comprehensive cancer care, equal to medical, surgical, and radiation oncology, and urged member nations to fully integrate palliative care into their national cancer control programs.

Causes of Death in Adults Needing Palliative Care at the End of Life



From Palliative Care Needs Assessment Report 2016: Malaysia

The Temel et al study in the New England Journal of Medicine in 2010, then showed not just quality of life improvements from the addition of palliative care to standard cancer care but that patients having palliative care early lived longer than those without palliative care. This has major implication in the delivery of palliative care early in the cancer diagnosis rather than the usual terminal phase of illness.

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***"... early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. "***

***- The Temel et al Study***

The 67th World Health Assembly resolution 67.19 'Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course' further makes the case for nations to provide palliative care in its healthcare system.

Cancer remains an emotive subject. There is hardly a day when cancer is not mentioned in the media in various contexts, from a famous personality afflicted with the disease, a breakthrough in the quest for cure or the bravery of a cancer survivor. In any case, we all know of someone touched by this disease.

Over decades of work, palliative care has accumulated a significant amount of evidence and experience in dealing with cancer. Pain relief and other physical effects, the social and psychological effects as well as the existential distress in living with cancer are areas that palliative care can make a difference to and add to potential survival benefits. There are also studies that indicate the financial benefits of palliative care.

A diagnosis of cancer is devastating. The effects are beyond the physical nature and extends to the psychosocial and spiritual. Hope is pursued and

wished for, yet the lauded advances in oncology which are mainly limited to expensive medications and technologies are either beyond the reach of most or only has marginal benefits. The way we approach cancer care needs to be modified to include not just the curative approach but also the palliative care concepts.

The inclusion of palliative care into national cancer control programmes will not change the number of patients diagnosed with cancer but it can reduce the suffering and improve survival of those affected by it.

In 2016, Hospis Malaysia published a needs analysis of palliative care in Malaysia as well as a public survey on understanding of palliative care. Each year we care for nearly 2000 patients with cancer, mainly towards the end of their illness. Many patients and families feel that palliative care makes a difference but to do so nationally requires a political willingness to have a paradigm shift. ■

***Hospis Malaysia will be participating in the UICC World Cancer Congress in October 2018 to advocate for improved palliative care as part of the national cancer control programme.***

#### **COUNCIL MEMBERS**

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#### **HOSPIS MALAYSIA (223675-X)**


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)  
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#### **PALLIATIVE CARE MALAYSIA**

an initiative by Hospis Malaysia

Website: [palliativecare.my](http://palliativecare.my)

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## HOW CAN HEALTHCARE PROFESSIONALS DEAL WITH **HOPELESSNESS AND SUFFERING?**

By Dr Lim Zee Nee, palliative care physician, Hospis Malaysia

Mr. H, who is dying from cancer, is not able to watch the World Cup matches with his sons in their favourite mamak store, knowing that this is his last World Cup. He had been a successful businessman, providing for his family of six, including his aging parents. He is afraid of being dependent on his wife because he does not want to burden her. He does not want to tell his aging parents about how little time he has left in this world. His sons are suffering silently, knowing that they are going to lose their father.

Is there hope amidst all these sufferings?

Hope is a rather complex concept. Hope is important in both living and dying and hope is said to be associated with a good sense of well-being and psychological state. An individual's hope changes throughout his illness journey. Hope can range from hope of being cured, to hope of spending good quality of time with family, hope for a better life for future generations, hope to not suffer in pain when one is dying, hope to have spiritual connection to God and so on and so forth.

Lack of hope, on the other hand, may lead to despair, meaninglessness, the desire to hasten death and possibly depression. Maintaining hope in the face of physical, psychological, social and spiritual challenges can be difficult.

It is understandable that most individuals still hang on to hope despite being aware that there is no cure for their illness and that time may be short. Mr. H hopes to see his sons getting married and hopes to see his grandchildren in the future. But, at the same time, he knows that he has little time. It does not mean that he is in denial.

As healthcare professionals, we have a duty to nurture hope and to maintain hope. It is also important for us not to give false hope and false reassurances. So, for example, if Mr. H hopes to see his sons getting married and have grandchildren and we know that prognosis is poor, having good communication skills is essential to deal with it. It is not helpful if we reassure Mr. H that everything is going to be alright or try to change the topic so as not to deal with difficult questions relating to end of life. What can we do? First of all, we can explore why it is important for Mr. H to see his sons get

*As healthcare professionals, we have a duty to nurture hope and to maintain hope. It is also important for us not to give false hope and false reassurances*



married and have grandchildren. By understanding the meaning of his hope in the context of his life, it will help us to see what hope means to him. Good communication is also about having open, honest conversation with Mr. H and his family in order for them to make realistic plans.

In general, healthcare professionals can also nurture hope by helping individuals set short attainable goals, supporting interpersonal connectedness, provide spiritual support and ensuring good symptom management. We need to be courageous to sit in the presence of suffering, not walk away from it, as well as understanding that there is no quick-fix formula to alleviate suffering.

## WORKSHOP ON COMMUNICATION SKILLS: 14-15 APRIL 2018

Facilitators:

- Dr Rebecca Coles-Gale, Clinical & Health Psychologist, Health & Care Professions Council (UK) & British Psychological Society
- Dr Sylvia McCarthy, Medical Director, Hospis Malaysia



Effective communication with a patient diagnosed with a serious illness is essential. If the illness is life-limiting, and the healthcare worker is tasked with “breaking the bad news”, the communication skills required to enable the healthcare worker to facilitate the conversations with the patient and family becomes paramount.

Throughout the care, it is equally as important for the healthcare worker to develop a therapeutic relationship with the patient and family. This is so that each party has the information that they need; for families to make informed decisions, and healthcare professionals to understand the patient and family’s preferences in developing goals of care.

This workshop discussed end-of-life communication guidelines for alleviating anxieties, encouraging situational control and promoting quality of life for patients. Participants learned to develop a framework that will facilitate and give structure to their communication process, through the influence and value of contemporary communication theories and models in palliative care. ■

If you’re a healthcare worker interested in attending one of our palliative care workshops for healthcare professionals, please check [www.hospismalaysia.org](http://www.hospismalaysia.org) to learn more.

## CAREGIVER’S WORKSHOPS

Being a family caregiver is an important responsibility, but despite this, many receive minimal training and support. To address this, our monthly free Caregiver’s Workshops are designed to assist caregivers with basic caregiving skills that will help them better manage their loved one’s symptoms and effects of illness at home.



### PERSONAL HYGIENE – JUNE 2018

Personal hygiene care is an intimate thing. In this workshop, Nurse Pooleen taught caregivers the basics on helping loved ones maintain their usual standards of personal hygiene in the areas of toileting, bathing and grooming as these are key to maintaining the self-esteem of any patient.

### HELPING PATIENTS WITH MOBILITY – JULY 2018

Being a caregiver to a loved one who has mobility issues presents a unique set of challenges, but it’s nothing that one can’t overcome with a little guidance from our occupational therapist, Raymond who demonstrated tips on assisting patients with limited mobility. ■



If you’re interested in attending an upcoming Caregiver’s Workshop, please send us an email at [education@hospismalaysia.org](mailto:education@hospismalaysia.org) to indicate your interest or to register.

## COLLABORATION PROVIDES HANDS-ON LEARNING FOR VISITING REGIONAL PALLIATIVE CARE TEAM

Training others to provide palliative care has always been a core aim of Hospis Malaysia. In addition to palliative care workshops which feature an international faculty of palliative care experts that attract healthcare professionals from across Malaysia, Hospis Malaysia's own clinical team provide training and support in palliative care for medical professionals from across the ASEAN region.

In 2016, The Department of Medical Services at the Ministry of Public Health in Thailand signed a Memorandum of Understanding (MOU) with Hospis Malaysia to enable healthcare professionals from Thailand to visit and learn from Hospis Malaysia on a continuous and sustainable basis via training, site visits, workshops and research opportunities.

Palliative care services in Thailand are still based in hospital type settings, which is where our most recent palliative care visitors hail from – the Surat Thani Cancer Centre in Southern Thailand. For one week, the team made up of a radiation oncologist, pharmacist, palliative care nurse and registered nurse, sat through morning reports with the Hospis Malaysia clinical teams, lectures with medical students, home visits with our nurses and took back with them a breadth of knowledge on Hospis Malaysia's model of care in the community.

When asked about their time spent learning with us – in the words of a member of the visiting Thai team: "Hospis Malaysia doctors and nurses are good role models for us to emulate back in Thailand". ■



Our visitors from Surat Thani Cancer Centre: Ms Pimonluck (registered nurse), Mrs Suvunna (palliative care nurse), Dr Darunee, (radiation oncologist) and Ms Tapanee Saisuwan (pharmacist)

## MINISTER RECOGNIZES UNIVERSAL HEALTH COVERAGE MAY HELP ACHIEVE "HEALTH FOR ALL"



Hospis Malaysia CEO, Dr. Ednin with Minister of Health, Dr. Dzulkefly

Dr Ednin Hamzah recently attended and spoke at ASLI's Healthcare Forum 2018 – "Sustaining Tomorrow's Healthcare, Empowering Today's Consumers".

At the forum, the Minister of Health, YB Dr Dzulkefly Bin Ahmad in his keynote address recognized WHO's definition of

Universal Health Coverage (UHC) which is "that all people can use the promotive, preventative, curative, rehabilitative and palliative healthcare services they need, of sufficient quality to be effective, while also ensuring that these services do not expose the user to financial hardship". He acknowledged that UHC represents a "foundational investment in human capital, and as a driver of sustainable economic growth and development"

The Minister also acknowledged the WHO recommendation that in order to achieve UHC, there must be a strong, efficient, well-run health system with proper financial planning, well-trained health workers and access to essential medicines and technologies (WHO 2000).

At the same forum, Hospis Malaysia's CEO, Dr Ednin Hamzah spoke about the need to support the most vulnerable in society – the very sick and the elderly. He reminded that the World Health Assembly Resolution 67.19 calls for the "Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course" and asked the question "What if your loved one's illness was not detected early? What if prevention was not possible? What if curative treatment is not possible? Is palliative care sufficiently integrated in our healthcare system to enable equal access to all in need when the need arises?"

Do we see a way forward for palliative care to be accessible for all in need? ■

## PALLIATIVE CARE AWARENESS MONTH – APRIL 2018

### BFM HEALTH AND LIVING LIVE: 7 APRIL 2018



Hospis Malaysia was a supporting partner of the BFM Health & Living LIVE event – a full-day health talk affair which had multiple panel discussions centred around the theme ‘Cost, Ethics & Care of Healthcare - A Future-Focused Health & Care System’. Hospis Malaysia’s Medical Director, Dr Sylvia McCarthy was a panellist for the session on ‘Quality End-of-Life Cancer Care’ which focused on the role of palliative care in supporting cancer patients and their families in maintaining quality of life and living with dignity despite the illness.

For many in attendance, palliative care was a new term and concept. So, using a large activity blackboard, we asked attendees of BFM Health & Living LIVE 2018 “If you were seriously ill, what would be important to you?”. A majority of the attendees said they wanted to know all their options, for their choices to be respected, to be cared for at home, near loved ones and to be able to maintain their dignity. ■



*We were joined by Jayanthi Palani and Muzdalifah Mohd Nasir from Yayasan Sime Darby (YSD). The philanthropic arm of the Sime Darby Group has been a strong financial supporter of the work of Hospis Malaysia.*

### ‘MUSIC & LAUGHTER’ - THE PHILHARMONIC SOCIETY OF SELANGOR’S 60TH ANNIVERSARY CONCERT: 14 APRIL 2018

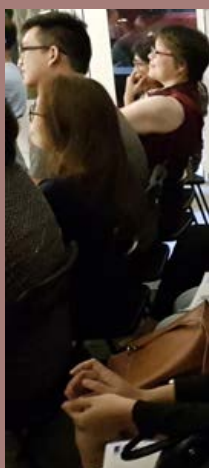
Hospis Malaysia was invited as a charity partner, in celebrating 60 years of music in the community, with the Philharmonic Society of Selangor at the KL Performing Arts Centre (KLPac). It was an occasion where music and fundraising brought people together in a commemorative event celebrating the community choir and palliative care.

In our increased efforts in public advocacy to bring greater public attention to the needs of Malaysians suffering from life-limiting illnesses, Hospis Malaysia is always grateful for the opportunity to come on board as a beneficiary partner for the Philharmonic Society of Selangor’s past concerts. This year, guests were serenaded with famous musical numbers from The Sound of Music and, The King and I, among others, as well as a dedicatory composition by Nick Choo to celebrate The Phil Choir turning 60. ■



### THE PAINKILLER SHOW – A NIGHT OF STAND-UP COMEDY BY ONE MIC STAND: 24 APRIL 2018

Palliative care and comedy aren’t two things that usually go together, but for one night only at The General Space in PJ, rib-tickling jokes were made, laughs were had and it was all in the name of charity. Big names in the local stand-up comedy scene (and some international) like Papi Zak, Kavin Jay and Rizal van Geyzel joined forces to help channel 100% of the proceeds that night for the palliative care efforts of Hospis Malaysia. The comedic night for charity was a big hit amongst One Mic Stand’s usual audience, most of whom, had never heard of Hospis Malaysia or palliative care before. It was a great opportunity for the Hospis Malaysia team that night to create awareness and share the work that Hospis Malaysia does in the community palliative care setting in the Klang Valley, as well as the training and education efforts that support over 1000 healthcare professionals in Malaysia. ■





**LOVE & CARE CHARITY WORKSHOP AND ART EXHIBITION: 27-29 APRIL 2018**



Curated by one of Hospis Malaysia's long-time supporters, Phillip Wong of Artseni Gallery, this exhibition was Phillip's novel way to support Palliative Care Awareness Month 2018. Through his philosophy that "Everyone Can Paint", Phillip managed to bring together 15 artists whose works were showcased in this charity exhibition, where 100% of proceeds from the sales of artwork were channelled to Hospis Malaysia.

Held at The Pod by EuGrow in Sunway Putra Mall, also the location for Phillip's Workshop, this event garnered the support and presence of Datin Ho Choy Meng, who officiated the launch of the exhibition, as well as support from philanthropist, Patron of Art and senior board member of the National Visual Arts Development Board, Dato' Haji Taib Ali and his wife, Dato' Zakiah Ibrahim. ■



PAST EVENTS

# 10TH ANNIVERSARY STANDARD CHARTERED KL MARATHON: 5-8 APRIL 2018



Almost 40,000 runners participated and celebrated the 10th edition of the Standard Chartered KL Marathon (SCKLM) this April. For Hospis Malaysia, it was great to be back for the 5th year in a row as an official charity partner, as SCKLM 2018 makes a conscious effort to help runners raise funds for some of Malaysia's charities.

For the first time, Hospis Malaysia also participated in the Race Entry Pack Collection & Expo at KLCC Convention Centre from 5-7 April with the aim of engaging with the thousands of runners and members of the public before Race Day. In addition to creating awareness about Hospis Malaysia's 'Elephant in the Room' Campaign, we also introduced the public to 'Pally', our palliative care mascot, which not only made its first public appearance during the Expo, but also found its way from KLCC to Dataran Merdeka via the LRT line just in time for the Kids' Dash on the evening of 7 April.

This year, 235 runners selected Hospis Malaysia as their beneficiary of choice in the Run For A Reason (RFAR) category. We were also delighted that three out of the top five fundraisers in the RFAR category ran for Hospis Malaysia. And just like them, there were many others who were just as passionate about raising funds for Hospis Malaysia and palliative care. Many had personal stories to share about how palliative care helped them at a time of need, while others supported Hospis Malaysia based on goodwill and running for those who could not.

Thank you to everyone who signed up to Run For Hospis Malaysia this year! Your support has been overwhelming. We hope to be elected once again as one of SCKLM's Charity Partners in 2019. And if we are – we will be in touch! ■



# 17TH ANNUAL TREASURE HUNT: 5-6 MAY 2018



While the main goal of a treasure hunt is 'finding the treasure', half the fun is embracing the journey, as our participants most certainly seemed to have done as they made their way to the Swiss-Garden Beach Resort Kuantan in support of our 17th Annual Treasure Hunt. Though there was serious mystery-solving and puzzle-cracking involved, we also got intel that some teams managed sneak stops along the way for snacks, and apparently even durian!



Flag off was at sharp 7:00 a.m. from M3 Mall in Gombak Setia by Hospis Malaysia's Council Member Ms Ho Chee Kit after a quick briefing by the Huntmasters YS Khong and Liew Kok Seng.



And by 3:00 p.m. at the final destination in Kuantan, stress and panic could be seen on the faces of team members who were running to the 'finish line', trying to beat the clock to avoid disqualification and to keep themselves in the running for the top prizes.



The dinner and prize presentation that evening brought everyone together like a large family reunion. Jokes were cracked by the Huntmasters at the many teams' expense. When the answers to the clues were finally shared, as usual, the majority of the participants lamented at how tricky the answers were. The race to win the all- expense paid holiday to Bangkok, the luxury stay at the Four Seasons Langkawi and several premium electrical and electronic items is always challenging. But as with all our past hunts, there were plenty of consolation prizes and no one left empty-handed.



We would like to thank everyone involved in making this signature fund raising event of Hospis Malaysia yet another success. Special thanks to our major cash and prize sponsors: Pestech International Berhad, LBS Bina Holdings Sdn Bhd, Rainbow Lighthouse Kindergarten, The Ark Group, SEIKO, Holiday Tours & Travel Sdn Bhd and BHP! ■





**21ST TEAM CHARITY GOLF** for choosing Hospis Malaysia as the beneficiary of the proceeds of your golf fundraiser.



**HOSPIS MALAYSIA DAY CARE VOLUNTEERS POP CORN FOR CHARITY**

A bunch of Hospis Malaysia day care volunteers organised a pop corn fundraiser at a kindergarten Sports Day recently in support of Hospis Malaysia.



**HEINEKEN MALAYSIA BERHAD** for the generous contribution.



Big thanks to Yin, Amy, Josephine, Helen, Lilly, Winnie and Sharon a.k.a. the 'Popperz' gang! For some people, volunteering is about giving. But for the likes of you, it is a way of living!



**PROFESSOR ANTHONY CUMMINS OF RCSI-PERDANA UNIVERSITY AND HIS MEDICAL STUDENTS** for actively

fundraising for us during Palliative Care Awareness Month 2018

**ARTIST DEDICATES PROCEEDS OF FIRST SOLO ART SHOW TO PALLIATIVE CARE**

Tan Kar Mern, a printmaker/artist who specializes in etching, screen-print and lithography, held her first solo art exhibition 'The Study of Life Adapting to the Chaos of Cityscapes' pledging 10% of the proceeds of the sale of her artwork to Hospis Malaysia.

While Kar Mern was contemplating where she could donate to help the less fortunate, she saw a few issues of Berita Hospis which her father had brought home from an event. Kar Mern says "I noted the amazing work Hospis Malaysia has done thus far. I am confident that Hospis Malaysia will use the donated money to make a difference!"

**DONORS OF DONATE-A-BRICK PROJECT**



*And to many others who have supported Hospis Malaysia!*



Launch of Tan Kar Mern's exhibition with architects Mustapha Kamal (far left) and David Teh (far right), the artist and Hospis Malaysia Chairman, Datin Kathleen Chew



World Cancer Congress  
Kuala Lumpur, Malaysia  
1–4 Oct 2018

Strengthen  
Inspire  
Deliver



## WORLD CANCER CONGRESS COMES TO KUALA LUMPUR

The World Cancer Congress (WCC) is a recognised biennial international conference which encourages knowledge transfer and best practices exchange amongst 3,500 public health experts from 150 countries.

It is an initiative of the Union for International Cancer Control (UICC), which aims to unite the cancer community, reduce the global cancer burden, promote greater equity and integrate cancer into the world's health and development agenda.

### A MAJOR EVENT IN THE GLOBAL CANCER CONTROL AGENDA

Dr Saunthari Somasundaram, President of National Cancer Society Malaysia and Chair of the 2018 WCC Host Committee expects “thousands of worldwide cancer and health experts to converge in KL to take advantage of this platform to further ‘Strengthen. Inspire. Deliver’ the global cancer control momentum.”

Studies estimate that 8.1 million people in Asia will die of cancer by 2020; of which 75% will not be able to face the huge medical care costs within their first year of diagnosis.

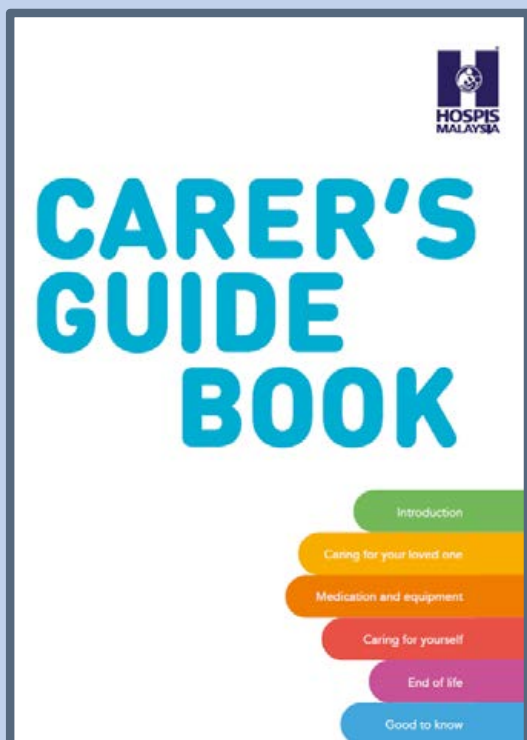
## HOSPIS MALAYSIA’S INVOLVEMENT IN WORLD CANCER CONGRESS 2018

The WCC programme is built around five thematic tracks that will provide the framework through which the global cancer community will deliver sessions covering the full spectrum of cancer control.

Hospis Malaysia’s CEO, Dr Ednin Hamzah will co-chair a track: “Maximising Quality of Life and Death and Empowering Patients and Caregivers”. The session will examine interventions to support patient engagement and survivorship in a variety of cancer care delivery settings. Another palliative care physician from Hospis Malaysia, Dr Lim Zee Nee will cover areas on legal, clinical and supportive care perspectives on advance care planning in her session on “Communicating Future Care Plans with Cancer Patients in Malaysia”.

Hospis Malaysia is also one of the sites for the WCC’s Institutional Visits, through which delegates will discover Hospis Malaysia’s work in community palliative care and the navigation of the culture of care in Malaysia.

In line with its increased push for greater public advocacy, Hospis Malaysia will also be launching its “Speak Up! There is an Elephant in the Room” campaign during the Congress week at KLCC Park. For more information, see next page.



## SPONSORS WELCOME!

Hospis Malaysia is seeking sponsorship for the printing of our revised and updated **Carer’s Guide Book**.

Contact us at [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org) or 03-9133 3936 ext. 203 / 207 (Suba / Carol) to find out how you can contribute!

# Speak Up

There's an Elephant in the Room

## JOIN US TO START CONVERSATIONS THAT MATTER.

When one has a life-limiting illness, it is often difficult to begin talking about what really matters. But what really matters is exactly what we need to talk about when time is limited. "Speak up" is a campaign to inspire patients and families to open up in the face of a life-limiting illness. It is through bringing up issues, unfinished business, and hopes and aspirations with your loved ones or with your healthcare provider, that issues that matter can be resolved, and hopes and aspirations redefined. Speaking up can be the beginning of a journey of a life well-lived despite the illness.

A series of 10 elephant sculptures in the Cik Gajah Limited Edition series by Yusof Gajah will be up for adoption to encourage people to "Speak Up".

And we'd like to invite you to be a part of it.

Contact Suba or Carol from our Communications Department at **03-9133 3936** ext. 203 / 204 or email [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org)



HOSPIS  
MALAYSIA

**CHARITY  
BAZAAR  
2018**

**DATE**  
Sunday, 11 Nov 2018

**TIME**  
9am - 4pm

**VENUE**  
**Stella Maris International School**  
7, Lorong Setiabistari 2, Bukit Damansara,  
50490 Kuala Lumpur.

**HOW YOU CAN HELP**

- Participate as vendor
- Donate items / prizes
- Purchase coupons

**CONTACT US AT:**  
+603 9133 3936 ext 204/207 (Carol / Kai Lee)  
+603 2182 8169 (Pragna)

**EMAIL:**  
[pr@hospismalaysia.org](mailto:pr@hospismalaysia.org)  
[carol@hospismalaysia.org](mailto:carol@hospismalaysia.org)  
[pragna@inyk.com](mailto:pragna@inyk.com)