

REFLECTING ON THE PAST WITH **A HOPE FOR THE FUTURE**

By Dr Ednin Hamzah, CEO, Hospis Malaysia

As always, the year creeps up on you. What were the significant events over the past year given that we are already about to herald in the new year and the challenges it brings? What are our reflections and thoughts for the coming year?

In 2017, 168,168 deaths were recorded in Malaysia (*Department of Statistics, Malaysia*) an increase of 5.3 from 5.1 per 1000 population from 2016. The figures for 2018 are likely to be of a similar magnitude. We know our main causes of death. Cerebrovascular and heart disease, infection and cancer as well as road traffic accidents dominate as in recent years.

For about 170,000 Malaysians, 2018 will be the last year of their life. Apart from the idiocy of sudden death from road traffic accidents, the vast majority will have spent most of the last year of their life navigating the health care system and its challenges but ultimately succumbing to their diseases. What was their experience? How responsive was the health care system to their needs?

How have we fared? Have we lost friends and family this year and how many loved ones are currently negotiating the challenges of dealing with a chronic disease? How do we feel about it and are there things that can be learnt in moving forwards?

There is significant evidence that may point to the experience of caring for those facing the last year of

*“Action without vision
is only passing time,
vision without action
is merely day dreaming,
but vision with action
can change the world.”*

- Nelson Mandela



life. The question, “Would I be surprised if a person would die in the next 12 months?” has been developed as a screening tool for palliative care. It suggests that if a doctor would not be surprised that a patient may succumb to an illness within the next 12 months, a referral for palliative care is indicated.

For many patients with cancer, heart failure, kidney failure and other organ failures, each failure with treatment may be life-threatening and brings greater suffering. Symptoms such as pain, fatigue, weakness, breathing difficulties, nausea, vomiting, as well as anxiety, depression, feeling a burden to others and loss of meaning in life, are common. Add to this is the significant burden of families trying to cope and care for an ill family member.

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“Malaysia’s achievement in Universal Health Care is defined as ensuring that all people can use the promotive, preventative, curative, rehabilitative and palliative care health services they need, of sufficient quality to be effective, whilst also ensuring that all people have the access to all services and do not incur financial hardship to pay for them”. – Minister of Health

There is a difference between the management of a disease and that of the symptoms of that disease. Most of the training of doctors is in disease management rather than symptom management. However, the training in palliative care emphasises assessment and management of symptoms that are not just physical but also social, psychological and spiritual or existential. Working collaboratively with doctors involved in disease management, the health and patient outcomes could be significantly improved.

This framework in healthcare management is nothing new and has been promoted through World Health Organisation policies for decades. There is increasing and significant evidence that implementing palliative care policies increases patient and family quality of life, decreases unnecessary suffering, improves patient satisfaction, potentially reduce healthcare costs and may extend quality of life.

Yet, less than 10% of the Malaysian population is able to access palliative care in Malaysia. In our 2016 survey, about 90% of Malaysians are not aware of palliative care.

In May 2018, a new government was elected in Malaysia. At a speech given to the Asian Strategy and Leadership Institute, the Minister of Health, YB Dr

Dzulkefly bin Ahmad said “Malaysia’s achievement in Universal Health Care is defined as ensuring that all people can use the promotive, preventative, curative, rehabilitative and **palliative care** health services they need, of sufficient quality to be effective, whilst also ensuring that all people have the access to all services and do not incur financial hardship to pay for them”.

Palliative Care has been available in Malaysia since 1991, started in the community by charitable organisations. Malaysia recognised it as a medical subspecialty since 2005 and several hospitals now have palliative care units. Whilst the government is slowly developing hospital-based services, most patients prefer to spend as much time as possible in the community. Charitable community services still depend on the goodwill of the community.

We may grieve for those we have lost in 2018 and reflect that many suffered in their battle with cancer, organ failures and other illness, the children as well as the elderly. What about 2019? Perhaps another 170,000 Malaysians will have to negotiate their final years. How will they fare? Are we going to give them the best chance not just in finding a way to treat their disease but also to alleviate their symptoms and suffering and assist their families in caregiving? Hindsight is only useful if it serves to improve the future. ■

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PALLIATIVE CARE MALAYSIA

an initiative by Hospis Malaysia

Website: palliativecare.my



PalliativeMY



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A PALLIATIVE CARE ASSESSMENT

By Dr Ednin Hamzah, CEO, Hospis Malaysia

"We are not ready to be referred for palliative care"

"But he is still having chemotherapy..."

"We are not giving up..."

"We are not that poor..."

"If you refer for palliative care, she will get depressed..."

The above are often statements that are often expressed when a referral for palliative care is discussed.

Patients and the public have become conditioned to the traditional way of how doctors approach patients. Patients are asked what's wrong and the responses from a list of lumps and bumps, pain, weight loss, bleeding etc. are elucidated. After the interrogation comes the measurement of blood pressure, pulse, temperature and then the prodding of the body. If you are unlucky, blood will be spilled and other investigations may follow.

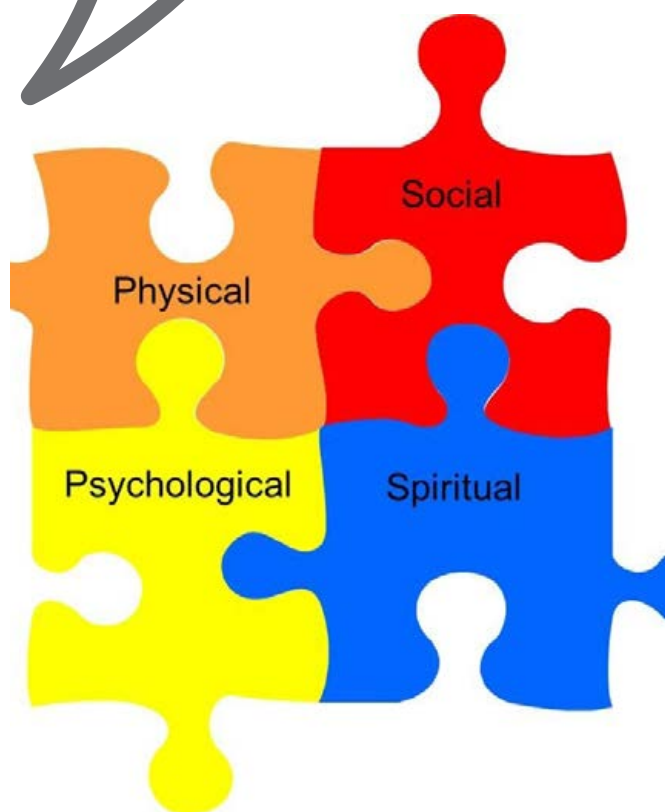
Having a palliative care assessment might be a little bit different as the focus is different.

The typical doctor looks mainly at health outcomes. Signs and symptoms of a disease are assessed, diagnosis of diseases made and treatment prescribed so that the patient will recover.

A palliative care assessment may come as a surprise as it seeks to understand how the patient is affected by the illness, and what are the physical, psychological, social and spiritual concerns that now affects the patient. Their understanding of the illness, treatment, care preferences and preferred outcomes are explored.

A central aspect is to understand the person, the values that are important and what truly matters. A palliative care assessment seeks to provide further clarity, offer other potential treatment options and outcomes that the patient may not have considered. Issues affecting the patient's loved ones and issues surrounding care giving should also be explored.

A palliative care assessment is about a person interested in another person and how an illness has impacted a life and starts a journey to discover what really is important as well as dealing with the illness.



No one chooses to be ill. A typical medical assessment is about a doctor interested in a disease. A palliative care assessment is about a person interested in another person and how an illness has impacted a life and starts a journey to discover what really is important as well as dealing with the illness.

Perhaps this is why the World Health Organisation is supporting palliative care being included as a country's Universal Health Care so everyone may benefit from it. ■



Photo Credit: The Worldwide Hospice Palliative Care Alliance

“Because I Matter” is this year’s theme for World Hospice and Palliative Care day. On the second Saturday of every October every year, the hospice and palliative care community around the world celebrate World Hospice and Palliative Care Day. It is a unified day of action which aims to share the vision to increase the availability of hospice and palliative care throughout the world by creating opportunities to speak out about the issues. It is also an event to raise awareness and understanding of the medical, social, practical and spiritual needs of people living with a life limiting illness and also the needs of their families. It also aims to raise funds to support and develop hospice and palliative care services around the world.

‘Because I Matter’ drives home the message that the centre of any care delivered should be the patient. And in the context of addressing the palliative care needs of any nation or community, the focus should be on the experiences of people affected by serious illnesses, looking at what matters most, including the often-overlooked financial

impact of palliative care needs on individuals and households. The theme also contains elements of human rights and justice, asking: *“If I matter, then why am I not getting the care I need?”*

This year is the centenary of Dame Cicely Saunders, founder of the modern hospice movement, and the theme aptly draws its wording from Dame Cicely’s iconic quote:

“You matter because you are you and you matter until the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die”

To mark this year’s World Hospice and Palliative Care Day, Hospis Malaysia launched the *“Speak Up – There Is An Elephant in the Room”* campaign, aimed at educating the public about acknowledging the needs of patients and their families and the gap in healthcare for people diagnosed with life-limiting illnesses.

For more information about this campaign, please see Page 6-7 or visit www.speakup.com.my. ■

FROM CAREGIVER TO PALLIATIVE CARE ADVOCATE – NORWATI BAHAR



My father didn't want to burden the family, despite us being there with him the whole time. He just felt more comfortable sharing his concerns about his pain with Stephanie, our palliative care nurse. She was always there to listen to him - his fears, hopes, dreams and about what will happen to his family after he's gone."

Wati's father, Pak Din was a man who loved life and knew how to make the most of it. He was a former police officer who led an independent life after retirement and the passing of his wife. That was why when he was referred to Hospis Malaysia after being told that his cancer had spread, he chose not to be moved back to hospital and be put on life support should the time come. And so the family started his journey with the illness with Hospis Malaysia's support. "We just wanted him to be comfortable and not suffer," Wati recalls. It started with Lilian, the first palliative care nurse who visited to assess Pak Din's condition. After that, Stephanie became the dedicated nurse to look after Pak Din.

To Wati and her family, Hospis Malaysia was more than just about medical support and pain management. Stephanie also provided Pak Din with psychological support, prepping him for what was to come. "She was always there to listen to him - his fears, hopes, dreams and about what will happen to his family after he's gone." "Stephanie would tell us that my father was always telling her how lucky he was to have his family around him," Wati continues.

2 years on, Wati continues to engage with Hospis Malaysia. In September, Hospis Malaysia was selected as a charity partner of Maybank's Group Finance Department for a two year CSR partnership. And during Maybank's 9th Global CR Day themed "Maybank

Cares - Impact, Engage & Empower" on 22 September, Wati and her colleagues organized the "Fun Run Challenge at Taman Rimba Kiara, KL. 250 Maybankers worked in teams to solve puzzles and riddles, including answering quizzes about Hospis Malaysia and palliative care. Thank you Wati, and your colleagues at Maybank's Group Finance Department. We look forward to a meaningful partnership together! ■



'SPEAK UP - THERE'S AN ELEPHANT IN THE ROOM': A CAMPAIGN TO ENCOURAGE CONVERSATIONS THAT MATTER



Aligning itself to this year's Global Theme for Hospice and Palliative Care Awareness "Because I Matter", Hospis Malaysia launched the "Speak up – There's an Elephant in the Room" Campaign to give a voice to patients and their families.

The diagnosis of a life-limiting illness such as cancer, organ failure, HIV/AIDS and certain degenerating neurological conditions can be devastating for the patient, and often to their loved ones. Often feelings of distress and sadness are suppressed or deferred as the family proceeds to work through the treatment and caregiving needs of the patient. Sometimes, denial of the life-limiting condition of the patient may set in, and the patient may find it difficult to discuss his/her feelings and what may matter most to them now that time may be limited.

Recognizing the importance of encouraging patients and their loved ones to speak up early in the patient's journey through the illness so that concerns are addressed, feelings acknowledged and goals of care are met, Hospis Malaysia initiated this campaign to acknowledge the 'elephant in the room' and encourage conversations to support families with loved ones suffering from a serious illness.

THE REASON BEHIND THE ELEPHANTS

"Our aim is to use the striking visuals of elephants in the campaign to give a voice to patients and families facing such situations and enable them to open up and discuss with their loved ones or to their healthcare providers what matters to them at this stage of their life. Facilitating these conversations is central to the

"A significant problem or controversial issue which is obviously present but ignored or avoided as a subject for discussion" – THE ELEPHANT IN THE ROOM AS DEFINED BY THE OXFORD ENGLISH DICTIONARY

work of our palliative care workers," said Datin Kathleen Chew, Chairman of Hospis Malaysia.

For patients, their caregivers and healthcare providers, the goal of this campaign is to create awareness of the importance of having open discussions about difficult issues such as prognosis, what to expect as the patient's health deteriorates, and what patients hope for with their care.

For the community, it speaks about the need to acknowledge the gap in healthcare for people diagnosed with life-limiting illnesses and to advocate for better and more accessible palliative care services for all when the need arises.

"An estimated 56,000 Malaysians require palliative care at the end of their lives each year, but less than 10 percent have access to it*. With Malaysians living longer, the need for palliative care to alleviate their suffering is expected to increase. The elephant in the room is too big to ignore, so our hope is that 'Speak Up' which brings together stakeholders from the private sector, the public sector, and NGOs, will help raise awareness amongst the public; and with greater mobilization of resources to ensure that palliative care becomes integrated into the nation's healthcare system, palliative care may one day be accessible to all in need"

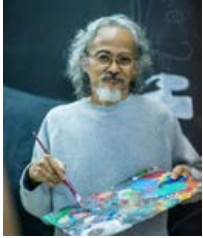
- Datin Kathleen Chew

* Palliative Care Needs Assessment – Malaysia 2016 (Hospis Malaysia)

THE SPARK OF AN IDEA, THE START OF A CAMPAIGN:

There was need to overcome the ‘elephant in the room’ - to bring the ‘elephant in the room’ to life so that Malaysians could start having conversations that matter.

THE ARTIST BEHIND THE CAMPAIGN: YUSOF GAJAH



A telephone call to explain the campaign, and a meeting to align our thoughts, and Yusof Gajah, Malaysia's foremost naïve art artist, and Malaysia's "Elephant Man" was on board!

And the 10 colourful elephant sketches forming the Cik Gajah Series was born!



FROM SKETCHES TO SCULPTURES



FINDING ADOPTERS FOR THE ELEPHANTS AND PARTNERS TO GIVE THE CAMPAIGN A GREATER VOICE

Donors from the private sector were approached to “adopt” an elephant each to fund the campaign, and to give the campaign a greater reach. Our partners from the non-government space were invited to join us in this call for greater access to professional palliative care.



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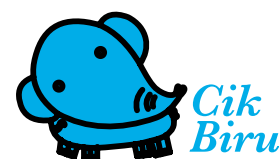
ANTHONY AND CHLOE TAN



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THE CAMPAIGN LAUNCH: 1 OCTOBER 2018



At the campaign launch In KLCC Explanade on 1 October 2018, our Guest of Honour, YB Hannah Yeoh, Deputy Minister of Women, Family and Community Development said: "The messages in "Speak Up" is poignant. The Malaysian population is aging. By 2035, almost 4 million people in the country will be over 65. I understand that the causes of death due to non-communicable diseases such as cancer and cardiovascular diseases is rising. The need for palliative care to alleviate the suffering of these very ill people therefore is expected to rise". She went to express: "Dealing with people with life-limiting illnesses is challenging. Many of us often will be at a loss as to how to care for our loved ones should they be inflicted. We will have many questions. Our loved one will have many questions. There will be much to be said, yet many of us will find it difficult to begin the conversations".



ELEPHANT INSTALLATION AT KLCC ESPLANADE: 1-14 OCTOBER 2018



WHAT'S NEXT IN THE PIPELINE?

Influencer Programme

While our adopters are busy crafting their own activations to support the campaign, we initiated a 6-month 'Influencer Programme' with four Key Opinion Leaders (KOLs), each a strong proponent of social causes in Malaysia, to help strengthen public awareness for the Speak Up campaign, and to drive public engagement and support for palliative care. Our KOLs will be sharing Hospis Malaysia's Speak Up cause with their followers. If you are a follower, check out what they have to say.



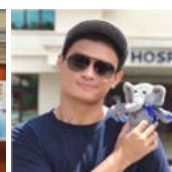
Daphne Iking



Sazzy Falak



Serena C



Figrie Dahari

For an update on what's going on with the "Speak Up – There's an Elephant in the Room" Campaign, check out www.speakup.com.my. ■

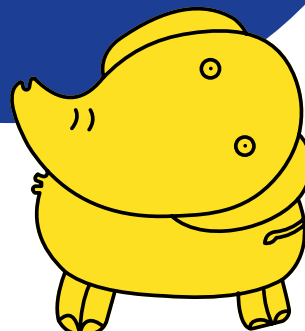
Support us at
www.speakup.com.my

Join us in our pledge to make quality
palliative care accessible to all in need.

Be a Hospis Malaysia donor.

Shop for our limited edition merchandise.

#speakupforpalliativecare



CHARITY BAZAAR: 11 NOVEMBER 2018, STELLA MARIS INTERNATIONAL SCHOOL, BUKIT DAMANSARA

It was a clear fine day. The location, in the quiet enclave of Bukit Damansara made it possible for continuous shoppers and supporters to arrive at the venue with minimal difficulty. There were 79 vendors, the biggest number yet at a Hospis Malaysia bazaar, and over 100 volunteers powering the bazaar from behind the scenes. These were all the makings of a memorable charity bazaar, and a day of fun!

As the bazaar opened at 9am, visitors strolling onto the school grounds were greeted by large inflatable castles and kids in bumper cars. Popular entertainers, a jolly clown and our delightful Pally the elephant, were on site to greet visitors. Both were crowd pleasers for kids, who were also kept amused by a magic show and balloon animal sculptures.

Those who sought pampering found the blind masseuse service a popular section. The biggest pull factor for almost everyone at the bazaar was the still the food! This was evident in long queues for popular Malaysian street food and how quickly the prawn noodles and rojak sellers sold out! Some food vendors came from as far as Ipoh and did not disappoint. People stood in lines and went back for seconds, filling their tummies with char koay teow, curry noodles, cendol, bubble tea and ice cream.

Shopping for bargains was definitely a high on everyone's list, and there was something for everyone. Shoppers bought quality dry foods and fresh produce at unbeatably low prices. There was homemade soaps and personal care products, home furnishings and décor, Christmas decorations and a gift for almost everyone during this festive period.. By 4pm, as visitors slowly trickled out of the venue, the skies opened up and a thunderstorm marked the end of the day's sales and festivities.

All in all, the 2018 bazaar is the biggest yet, in terms of venue size, number of vendors, volunteer support and number of visitors, young and old. Hospis Malaysia would like to thank everyone who played a hand in making the 2018 bazaar a success. The commitment and support shown is incredible and we are indeed grateful for those who came in support of palliative care and Hospis Malaysia. ■





Agromate Holdings: for choosing Hospis Malaysia as your CSR beneficiary.



RSM Malaysia: for the donation and support as our auditors for the last 10 years.



Malaysia British Society: for your donation in support of Hospis Malaysia in July.

thank you!



The Edge Education Foundation: for selecting us as a beneficiary of its 2018 Rat Race, and supporting the educational programmes run by Hospis Malaysia.



Persatuan Barah Selangor Dan Wilayah Persekutuan: for hosting the Cancer Society Charity Dinner & Dance Party and supporting Hospis Malaysia for the third year in a row.

Hospis Malaysia thanks donors for their generous contributions from July to November 2018:



Individuals who have made contributions to support our Donate-A-Brick Project.



Hong Leong Foundation: for sponsoring one of our palliative care nurses.

And to many more who have supported us!

THE QUARTER THAT WAS AT A GLANCE



DR LIM ZEE NEE DISCUSSING ADVANCE CARE PLANNING

Hospis Malaysia palliative care physician, Dr Lim Zee Nee spoke at a series of Advance Care Planning (ACP) Seminars organised by AGC Concept, and the World Cancer Congress 2018 about benefits of

having early conversations about care and treatment preferences either with their loved ones or with their healthcare provider. She highlighted that in the practice of palliative care, the healthcare worker will also explore with the patients their goals of care. They will work with the patients to uncover what's important to them as they journey through the illness, and how and where they want to be cared and who do they want to make decisions for them when they are no longer able to make decisions for themselves.

PALLIATIVE CARE AND CANCER SYMPOSIUM 2018



From left to right: Prof Jim Cleary – Director, WHO Collaborating Center of Policy & Communication in Cancer Care, USA, Dr Emmanuel Luyirika - Executive Director, African Association of Palliative Care, Prof Cynthia Goh – Chairperson, APHN, Prof Julia Downing – CEO, ICPCN, Dr Elizabeth Gwyther – CEO, Hospice Palliative Care Association of South Africa, Dr Ednin Hamzah - CEO, Hospis Malaysia and Dr Stephen Connor - Executive Director, WHPCA

Hospis Malaysia in collaboration with Asia Pacific Hospice Palliative Care Network (APHN) jointly organized a 1-day symposium preceding World Cancer Congress 2018 week. Palliative care experts from around the world presented case studies and updates in an effort to share and discuss significant evidence of the benefits of palliative care in cancer care. Tailored for physicians and nurses, topics spotlighted pain and

symptom control, efforts to reduce suffering, meeting patient goals of care and economic implications for countries in implementing palliative care programmes.

WORLD CANCER CONGRESS 2018

The World Cancer Congress 2018 held at KL from 1-4 October, was a major educational platform for the 3,000+ worldwide cancer and health experts who participated. The congress proved to be a venue for best practices sharing and learning experience for local healthcare professionals and organizations attending. Hospis Malaysia's Dr Ednin Hamzah and Dr Lim Zee Nee were guest speakers and we hosted a booth at the Global Village of the Congress to showcase the work of Hospis Malaysia in education and training, and public advocacy. Our "Speak Up – There's an Elephant in the Room" Campaign was highlighted at the booth.



Hospis Malaysia CEO, Dr Ednin Hamzah presenting his points at a debate during the Congress



Her Royal Highness Princess Dina Mired of Jordan, President-elect of the Union for International Cancer Control (UICC) at the Hospis Malaysia booth

HOSPIS MALAYSIA NURSE SPEAKS AT INTERNATIONAL SEMINAR ON PALLIATIVE CARE IN INDONESIA

Hospis Malaysia nurse, Nadiah Jaafar was invited to speak at a national seminar themed "Palliative Care: Issues and Challenges" in Jakarta in October. Her presentation on "Nursing Issues in Palliative Care" to approximately 600 Indonesian palliative care workers revolved around challenges faced by community palliative care nurses and coping strategies of delivering home-based palliative care. ■



Nadiah (in red baju kurung) with the organizing committee from Sint Carolus School of Health Sciences (STIK SC)

UPCOMING EVENTS IN 2019

JANUARY
**Registration for Run For A Reason (RFAR)
Standard Chartered KL Marathon 2019**
1-30 APRIL
Palliative Care Awareness Month 2019
27-28 APRIL
18th Annual HM Charity Treasure Hunt


RUN FOR A REASON ***RUN FOR HOSPIS MALAYSIA***



SIGN UP TO MAKE A DIFFERENCE!

Hospis Malaysia returns to the Standard Chartered KL Marathon (SCKLM) as the “Run For A Reason” charity beneficiary on 29 Sept 2019. Come be part of Malaysia’s signature marathon and support us in our efforts to help patients with life-limiting illnesses and their families.

- Registration opens in January 2019.
- To secure your spot for registration, email us at pr@hospismalaysia.org OR PM us on Facebook @HospisMY.
- Registration fee of RM150 entitles you to an SCKLM 2019 Race Pack plus an exclusive “Run For A Reason Hospis Malaysia / Standard Chartered KL Marathon” t-shirt.

**Speak
Up** there's an
elephant in
the room

*Let's start
conversations that matter.*

www.speakup.com.my

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