HOSPIS MALAYSIA

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BERITA HOSPIS

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DO THOSE WITH LIFE-LIMITING ILLNESSES HAVE A VOICE?

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

> *"Without appreciation and respect for other people, true leadership becomes ineffective, if not impossible"*
> *– George Foreman*

As we grapple with the various crises that plague us, are our leaders equipped to steer us away from harm and into safe waters? Have they considered the needs of the vulnerable? The Covid-19 pandemic has continued to devastate us, and it augments the other economic, climate, health and human rights issues that affect everyone. Statistics are often quoted to justify the decisions that leaders make, yet every decision made may favour one side of the argument against others, often because they don't fit the narrative. Those that benefit rejoice and for the rest, there is dismay or perhaps it is a signal to raise their voices anew.

Where does the voice of palliative care belong in this narrative? What is the narrative, the facts, the voices, the champions for such a cause? And does this really matter for any or all of us?

Our Minister of Health's keynote speech at the launch of the Access to Cancer Treatment and Care Conference in October remarked that it is estimated that 49,000 people are diagnosed with cancer annually in Malaysia. According to the Malaysian National Cancer Registry, the percentage of cancer detected in stage 3 and 4 had increased from 58.7% to 63.7% from 2012 to 2016. For lung and liver cancers, the 5-year relative survival rate was only 11% and 12.8% respectively. With these low survival rates, should we be asking what can be done for the almost 80% who may not see it past the 5 years after diagnosis? Or those who didn't manage to be detected early enough, and present with late-stage cancer?

What about the corresponding figures for renal, heart and respiratory failure, dementia, stroke, where treatment that would return the person's condition to a picture of health is limited?

Malaysia is becoming an ageing society who will face a higher prevalence of co-morbidities. For when people live longer, the chances of being afflicted by a serious illness increases. For many therefore, getting old will mean having several illnesses requiring a diet of pills and more hospital visits. This will take time away from meeting people that matter and engaging in preferred activities.

What is the big picture? Can we accept that we are vulnerable beings and simply want to live a meaningful life and feel valued to others that matter to us?

There are 2 narratives. The first involves prevention and treatment. What can society do to prevent such

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ailments such as cancer and other diseases? There is also the clamour that various centres of excellence, coupled with learned specialists armed with the latest high-tech machines and drugs can do wonders for those afflicted with such diseases.

The second involves the voices of those who are and have been suffering from these very diseases for some time. They are those who are unable to voice out their pain, their debility of being bedbound, their difficulty breathing, their lost hopes, anxieties and depression. The families that struggle to care for an ill loved one and to cope with the thought of losing them.

Last weekend, we were referred a patient who was getting progressively more ill for a number of months. Within a couple of hours of receiving the referral, the patient passed away. This is not an uncommon scenario in palliative care – late referrals. Could the patient and family have benefitted from an earlier referral so that more could have been done to support this patient and his family as his condition was deteriorating? Is addressing how well a person lives until he dies such a difficult topic that it just doesn't get addressed? Will any of our leaders advocate for palliative care? Perhaps it will only be when they themselves require it, then it might already also be too late.

> The Lancet Commission in 2018 discussed the value of death and argues: "If we regard life as valuable at any price, and death as wholly bad, then poor decisions are likely to result. In the past few decades, medical science has rendered obsolete, centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die".

The statistics of the needs of palliative care patients are rarely publicised, nor how our country is managing their plight. For the majority of patients with advanced cancer, comfort and quality of life is paramount. Pain is of significant concern. So too is the want to be at home, which currently may not always be possible. The World Health Organisation has been strong advocates for palliative care to be part of universal health care. But is anyone listening?

"We all know someone who needs palliative care but only 1 in 10 people in need has access to it. We call on all countries to invest in palliative care, which everyone deserves", Dr Tedros Ghebreyesus - Director General, WHO

The Covid 19 pandemic has led to the popular narrative - 'follow the evidence'. There is evidence that early palliative care improves quality of life, reduce the burden on hospital admissions, reduce health care costs and extends survival. Yet, the willingness to include palliative care as a central pillar in healthcare is not there.

When do you need palliative care? There are many guidelines and they all suggest that palliative care is offered early in the diagnosis of a life-limiting illness and often in conjunction with disease modifying treatment that potentially could result in extension of life. When palliative care is only thought about when someone is dying, it is already too late for virtually anything that could make a significant difference.

The Director General of the WHO, Dr Tedros Ghebreyesus has advocated for greater investment in palliative care in every country. On World Hospice and Palliative Care Day in October, he tweeted "We all know someone who needs palliative care but only 1 in 10 people in need has access to it. We call on all countries to invest in palliative care, which everyone deserves". We have not seen our leaders advocating on the needs for palliative care in our country in the way that he has. Perhaps it is time for patients and families to speak up so that care is provided when it is needed, not when it is too late. ■

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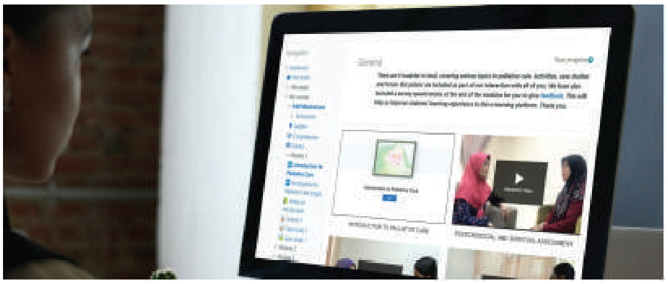
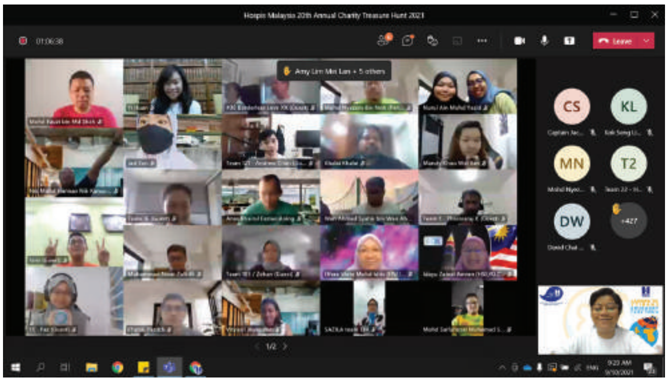
OPERATING IN THE EYE OF THE STORM – HOW HAVE WE FARED?

Patient care continues through the pandemic



Online teaching and training



Virtual fundraiser – Annual Charity Treasure Hunt 2021

Across the world, the Covid-19 pandemic swept through like a never-ending hurricane, leaving devastating effects on many it touched, while many others have been left to deal with its impact as it continues to ravage communities, and affect businesses. At Hospis Malaysia, it was important for us to rethink and adjust how we operate to ensure our services remained accessible during this very crucial time. While our responsibility to our patients who were the most vulnerable during these trying times was our utmost priority, it was also important to ensure that our education and training, and public education initiatives were maintained, albeit in different forms, when the pandemic proved to be protracted.

During the pandemic, our patients who by definition were those with significant co-morbidities, were considered the most vulnerable. With hospitals overwhelmed by Covid-19 patients, many were advised or opted to remain at home to stay safe. But with progressive illnesses, most patients' health conditions were deteriorating and therefore required ongoing medical attention. Our clinical team remained steadfast that the home visits had to continue, and the more symptomatic patients needed to be monitored closely. Equipped with appropriate PPEs and permits to travel, our palliative care team remained at full service, and the 24-hour emergency service proved to be an ongoing lifeline to many. More stable patients were contacted regularly, and families and caregivers were supported virtually where possible.

Teaching others to do what we do to enable better access to palliative care, has always been Hospis Malaysia's philosophy. But with the pandemic, physical teaching had to be curtailed, while lectures and tutorials very quickly switched online. The adoption of an e-learning platform enabled most factual content to be delivered virtually. And in the almost 2 years since the start of the pandemic, both teachers and students very quickly got up to speed with optimizing the various virtual platforms to conduct case discussions and reflections. Our training collaboration with the Asia Pacific Hospice and Palliative Care Network (APHN) has also enabled healthcare practitioners and allied healthcare workers to access high quality webinars facilitated by experienced practitioners from around the world.

Over the years, Hospis Malaysia has taken on the baton to lead the public awareness drive for palliative care nationally to educate and inform the public and communities about this very crucial layer of support for patients and families living with life limiting illnesses. While we have in recent years been increasingly utilizing digital platforms to promote our public awareness initiatives, the pandemic has indeed escalated our engagement with digital media. Due to the almost complete shutdown of physical engagements, our Palliative Care Awareness Months in April 2020 and 2021 went entirely digital, enabling us to reach perhaps a demographic we otherwise may have missed. We are also thankful for the collaborations with various e-commerce providers which once again provided access to an additional segment of supporters. Innovative supporters have also enabled us to run our signature Treasure Hunt event virtually as well as an e-Christmas Bazaar in 2020.

Perhaps as we emerge from the storm, the new norm may include a blend of physical and virtual engagements which may enable us then to reach a larger audience. For as they say – in every cloud, there is always a silver lining! ■

MYTH 3: IS PALLIATIVE CARE ONLY FOR CANCER PATIENTS?

This is Jennifer Nai's journey with our palliative care team. In 2017, she agreed for her story to be shared with a view that it would help others understand that palliative care can help patients suffering from other chronic illnesses, such as organ failure.

Jennifer with her mother

When we met Jennifer, she had just returned from her thrice-weekly dialysis treatment. Being positive and strong-willed, she shrugged off the effects of the treatment and put on a big smile. A petite 26-year-old, Jennifer giggled as she expressed here aspirations of becoming a nurse since she was young.

Jennifer was first diagnosed with Type 1 diabetes at the age of 12 and by 2016, her condition deteriorated with end stage renal failure. She was in and out of hospital and her experiences in the hospital were not always good. The constant readmissions to hospital caused substantial distress. It was then that she was referred to Hospis Malaysia when her goals of care were discussed with her and her family. Jennifer wanted to be cared for at home as much as possible and Hospis Malaysia was able to help her achieve her needs.

Throughout her illness, Jennifer had frequent attacks of uncontrollable vomiting which led to regular admissions to the hospital. The anxiety and distress would also then lead to bouts of breathlessness. With many years spent in and out of hospital, navigating treatment and care, Jennifer and her family were left with significant distress. The referral to a community palliative care provider such as Hospis Malaysia gave them direct access to its medical team and during those attacks, Jennifer was then treated in her home. Often, a sub-cutaneous line was inserted to enable a quick injection of medication and instructions were given to her mum for on-going dosages until her vomiting subsided. Over time, hospital visits reduced and her symptoms were better managed.

After all the time spent in and out of hospitals and coping with the illness, the palliative care team at Hospis Malaysia acknowledged and respected that Jennifer and her family had a certain level of knowledge about how she wanted to be cared for and how she wanted her illness to be managed. Jennifer and her mother, the primary caregiver were thankful that the team from Hospis Malaysia were not only able to reduce the physical impact from the illness but also took time to listen to their stories and focus on what mattered to Jennifer and what was important to support her needs.

Many people are unaware that palliative care can be available for those with serious progressive illnesses such as other late-stage organ failure, AIDS and progressive neurological conditions. Often, family members are left in despair not knowing how to handle the effect these serious illnesses will have on the patient – be it physical symptoms such as pain, nausea, breathlessness, insomnia, or emotional distress due to the inability to cope or not knowing what lies ahead. To know that good palliative care support can help to alleviate much of this distress and can be accessible to those suffering from other serious illnesses apart from cancer will help those in need to get the help that they require. ■

PLAYING A PART IN ADVANCING EQUITY IN ACCESS TO PALLIATIVE CARE

Inequity in access to palliative care has been a global dilemma for many years, with palliative care services developed with different intensity and modalities in many countries. Several studies have reported that a geographic variation in the availability and provision of palliative care services between and within countries exist and that a number of vulnerable groups still do not have access to these basic services.

Worldwide, more than 25.5 million people die each year with serious health suffering that requires palliative care including children, the homeless, people with physical or mental impairment, the prison population, those with HIV and TB, and the LGBTQ community.

Locally, despite a national strategy for palliative care development launched in 2019, access continues to be a challenge for many who live outside key cities, and quality of care remains uneven across different service providers, leaving more than 90% of the population's needs still unmet. The onset of the Covid-19 pandemic impeded any planned development within the government's agenda. In addition, lack of awareness is one of the biggest contributing factors. While many non-governmental organisations have made strides in advocating for access to good pain management being part of the human rights narrative and good palliative care being essential in the continuum of care for anyone with serious health-related suffering, they are constrained in services and geographical coverage by limited human and financial resources. Palliative care is still perceived by the majority as nursing care for the dying while some do not even know the existence of such services. Awareness is fundamental in educating the public on what is considered a human right and also in eliminating the myths surrounding palliative care so that there is equal access of these services to those in need.

In a multi-racial community, socio-cultural aspect plays a key role in shaping ideas and thoughts of an individual. Within some communities, death is not spoken openly and talks about it are seen as taboo. Progressive serious illnesses are viewed as a curse or a punishment and is left unspoken. In some instances, it is deemed shameful to voice out especially when they are illnesses related to gender, addiction or the much-feared disease such as AIDS. There are also those who associate death with failure, even within the healthcare fraternity. With many psychosocial needs at stake, there needs to be guidance from trained professionals and a change in belief systems to break the socio-cultural barriers which impedes equality in access to palliative care.

Let's start conversations that matter.

"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

SPEAK UP – THERE'S AN ELEPHANT IN THE ROOM is a campaign to encourage conversations that matter for patients living with life-limiting illnesses such as cancer, organ failure, HIV/AIDs and degenerative neurological conditions, and create awareness of how with good palliative care, patients' quality of life can improve.

Every year, 4 out of 10 Malaysians will require palliative care at the end of their lives*. Currently less than 10% have access to it.

SPEAK UP aims to:

- Empower patients and their families to have conversations that matter.
- Reduce the stigma of living with a life-limiting illness.
- Encourage the public to advocate for better access to quality palliative care.

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

For more information, visit **www.speakup.com.my**

AN INITIATIVE BY SUPPORTING

Starting conversations that matters – A campaign by Hospis Malaysia in 2018

With 30 years of service, Hospis Malaysia understands the complexities involved in advancing equity in access to palliative care. While it continues to provide support to those in need, it strives to overcome the challenges through education of healthcare workers and empowering the public through community awareness engagements. The "Speak Up- There's an Elephant in the Room" campaign was first introduced to empower those who are affected by serious progressive illness; providing them a space to voice out what truly matters to them and to reach out for support when they need it. Overtime, the idea evolved to become a symbolic figure of a friend in need during these difficult times.

This year, in line with advancing equity in access to palliative care, Hospis Malaysia introduced "Pally-Bank" which aims to encourage the public to "bank in" their thoughts about what matters, while saving up as a way to support the cause which aims to reach a wider community. ■

See Page 12 for the Pally Bank Story and how you can support Hospis Malaysia by owning your very own Pally Bank.

HOSPIS MALAYSIA 20TH ANNUAL TREASURE HUNT - TAKING HUNTERS AROUND THE WORLD IN CYBERSPACE

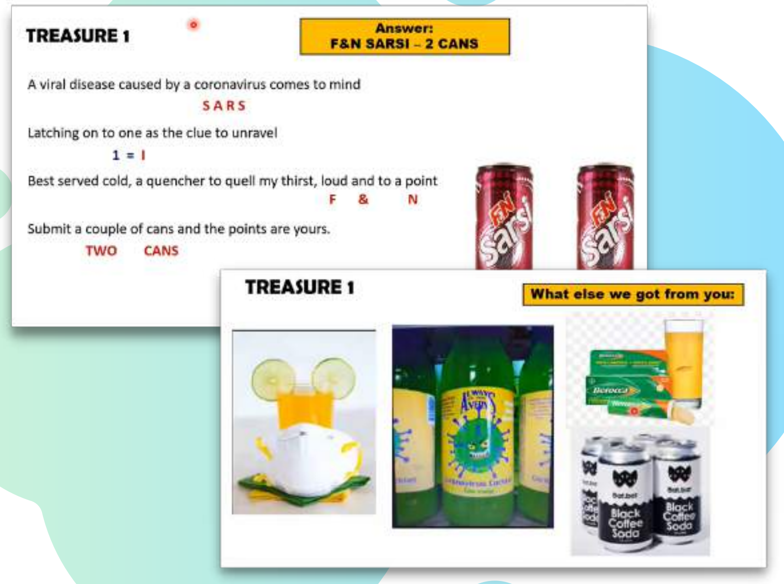
For a second year in a row, Hospis Malaysia held its Annual Charity Treasure Hunt virtually. This year the event attracted a record-breaking 150 teams joining from all around Malaysia!

This year's hunt was also significant as it was not only our 20th year running the event, it was also held on World's Hospice and Palliative Care Day (WHPCD) – a unified day to support hospice and palliative care around the world. The WHPCD theme this year: **"Leave No One Behind – Equity in Access to Palliative Care"** was aptly adopted by Hospis Malaysia to also commemorate our 30 years of service in the country with a 30th Anniversary tagline: **"Advancing Equity in Access to Palliative Care"**. While the main goal of treasure hunt is to find the treasure, our annual treasure hunt also serves as a platform to raise awareness on the benefits of palliative care and the importance of ensuring its access for all in need.

On the morning of 9th October, after a welcome speech and a virtual flag off by Miss Lim Wai Yee, Hospis Malaysia's Council Member, the hunters dived straight into three and half hours of hunting - traveling from some of the busiest cities in Asia, onto Europe, and ending their journey in the ethnic enclave of "Little Italy" in New York City. With a theme "Around the World with Hospis Malaysia" and inspired by the novel "Around the World in 80 Days" by Jules Verne, our brilliant hunt masters did not disappoint, brewing mind-boggling questions and clues for the hunters to decrypt.

It was also a new experience for Hospis Malaysia and our hunt masters from Euroscale, YS Khong and Liew Kok Seng catering to such large number of participants during the morning briefing on Microsoft Teams! Despite almost 2 years of conducting virtual activities, glitches did not elude us, as we realized technology still has its limitations. With almost everyone on camera, the Microsoft Teams meeting feature was overwhelmed, and the all-important Final Briefing slides was lost in translation – Huntmaster Kok Seng was unable to present! The problem was quickly solved when someone suggested that everyone turned off their camera, and everyone cooperated, switching off their cameras to give way to the Hunt Masters to present the briefing smoothly.

In a traditional motor hunt, our hunters would have to find the 'treasures' which are usually in a form of dry food and drinks they have to purchase. The same concept applies in the virtual hunt but instead of buying those items, participants have to submit photos of the treasures. With the internet being the source of finding these 'treasures' instead of hunting in local supermarkets in their route, our hunt masters were highly entertained by what the hunters came up with. For instance, the first Treasure item being two cans of F&N Sarsi drinks, but what was decrypted by the hunters ended up being products ranging from Corona-named drinks to a vitamin drink, and even a cocktail drink wearing a mask!



TREASURE 1

Answer: F&N SARSI – 2 CANS

A viral disease caused by a coronavirus comes to mind
SARS

Latching on to one as the clue to unravel
1 = I

Best served cold, a quencher to quell my thirst, loud and to a point
F & N

Submit a couple of cans and the points are yours.
TWO CANS

TREASURE 1

What else we got from you:

The Team Challenge received even more amusing submissions from our hunters as they had to figure out what was the 'tiny-winged creature' mentioned in our last Berita Hospis, draw the creature in "computer-mouse" size, and indicate the number of times this creature was mentioned in the article. Each team member must produce their own 'masterpiece' to contribute to the answer. While many teams managed to decrypt the clue correctly, which was eleven fireflies, there were also many teams with interesting interpretation – some drew butterflies, dragonflies and even our Palliative Care logo!

Answers and the virtual presentation of prizes were held the next day. Not surprising the regular hunters and supporters who paid their dues over the years deciphering with animated frustration Euroscale's cryptic clues came out tops. For as the Huntmaster shared with those who did not win a prize – "Try and try again for eventually you will outsmart us!" Winning teams walked away with luxury watches, smartwatches and smartphone accessories, and also our limited merchandise coming this December – Pally Bank!

We would like to thank everyone involved in making this signature fund raising event of Hospis Malaysia yet another success. Special thanks to our Diamond Sponsor - Blue Fortress Sdn Bhd who joined for the first time this year, our longtime supporters Pestech International Berhad and LBS Foundation, and a big thank you to our major cash and grand prize sponsors Bursa Malaysia, MBSB Bank Berhad, Great Eastern General (M) Berhad, Lonpac Insurance, Crowe Malaysia, AVEVA, and SEIKO. Not forgetting our goody bag sponsors Nestlé, LG Household and Healthcare Malaysia, and Amoy Canning.

For 20 years now, and still going strong, a big shout out to Liew Kok Seng and YS Khong from Euroscale for putting on a great show! Thank you!

FEATURE

"IT HELPS GIVE THE PATIENT QUALITY OF LIFE RIGHT FROM THE START."

"I was sacked by the helper," the late Datin Tan Chooi Hong joked when she talked about why she left her career as a nurse to become a full-time mum and wife. Such was her nature that even when she was diagnosed with pancreatic cancer. Datin Tan carried on positively. But was that enough to help her and the family navigate through the challenges of a life-limiting illness?

Here, Berita talks to Chew Beng Lin, daughter and caregiver to Datin Tan Chooi Hong who shares with us her family's journey in the last few years of her mum's life with the support from the palliative care team at Hospis Malaysia.

1. How did your mum and the family take to the news of the diagnosis at first?

She was devastated. It was an emotional roller-coaster ride for all of us. Then she did some soul searching and gradually, her spirit started to pick up. She was the patient but she was the one who gave us strength and encouraged us to work as a team to support her.

2. Did your mum know about palliative care even before she herself needed it? What about the family?

She roughly knew about palliative care from her time as a nurse, while my dad has been donating to Hospis Malaysia for many years. In their minds, palliative care was for the critically ill. When it happened, they had so much on their plate they couldn't quite give it much thought. I on the other hand, learned about palliative care from a book I read years ago. And I knew I needed to seek support from a palliative care provider right from the start. I initiated it and luckily, my parents were open.

3. Your mum didn't find death a taboo. How did the palliative care team further help in this aspect?

While we weren't afraid to talk about death as she was very open about it and had even mentally prepared us for what was to come, there were still issues and questions that skipped us. The nurse brought out many questions that neither my mother nor us would have thought of - like how she wanted things to be, how she wanted to be cared for and where she wanted to be towards the end. Would she want to be revived should anything happen? Who to make decisions when she couldn't anymore? Home care or hospital care? Burial or cremation? They were crucial questions. With all these questions addressed, it enabled us to just focus on what was important – our time together and how she wanted everything to be, right till the end.

Datin Tan and Dato' Chew (2020)

4. Your mum was very cheery and positive towards life despite her numbered days. Was it just the way she was?

She was by nature a very bubbly person. You would never think she was ill. But you know how something like cancer can break even the strongest and most jovial. But the support from the palliative care team reinforced her "positive vibes". Their presence "elevated her positivity". Knowing that they were there to support her as well as to support my dad and I while we were caring for her, gave her the confidence that we would be OK. It's like a ray of sunshine that the team would bring to the house whenever they came over. And my mum would look forward to their every visit.

6. Can you share with us what were the key things that you and the family found to be most helpful from the palliative care team?

It gave us the confidence to care for mum at home. They took away a lot of our stress as inexperienced caregivers. If my mum was unwell suddenly, I could call the emergency line any time and get advice almost immediately. There was no need to move my mum around and add to her discomfort. The other important thing was the emotional journey that the team helped us manage. They checked on how we were doing and if there was anything we wanted to address. My brother who works overseas could not be here with her most of the time. But he was very supportive of our decision to engage palliative care. And knowing that she was well looked after and we were well supported was comforting to him. I was also assured every now and then that it was ok to take a break from my caregiving duties.

7. Did you feel palliative care helped enhance your mum's quality of life?

The regular visits ensured that she was as comfortable as she could be. She could also see how we, as caregivers were supported. Without access to a palliative care home team, I think she would have had a lot more hospital visits. Mum was always mindful about how her condition would affect us and the to-ing and fro-ing to hospital would have added more stress to her and all of us.

8. What was it in our work that motivated your family to donate to Hospis Malaysia? Your mum did express that the funds be used to "support the good work of our nurses".

My dad has been a supporter of Hospis Malaysia for a long time without knowing that we would be in need of its service one day. And now having gone through it ourselves, we just want more people to benefit from Hospis Malaysia the way my mum and us as caregivers benefited. When a family member is diagnosed with a serious illness like cancer, it is not only that the patient's life will turn upside down. The lives of the people around the patient are also severely affected. It is good to know that there is this area of medical care which addresses the needs of both the patient and the caregivers and we want others to benefit from it.

9. In his thank-you note to us, your dad, Dato Chew wrote *"About six weeks after the surgery, she has her first dose of chemotherapy. As things turn out, this is when Hospis Malaysia comes into mind. We are told by well-meaning people that it is too early at this stage to engage with Hospis Malaysia as they usually come into the picture at the terminal stage. Admittedly, we, too, are not sure of when to seek help from Hospis Malaysia. Nevertheless, upon our request, the oncologist refers her to Hospis Malaysia on the first session of chemotherapy".*

Do you feel that early referral helped?

Definitely. The earlier the better. It helps give the patient quality of life right from the start. Palliative care prepares the patient for the journey, whatever the course it may take. She doesn't have to suffer emotionally and physically alone all the way. She should not seek help only near the end. It doesn't work well that way to wait till the critical stage. When you know what to do, you don't panic. And when we know what to expect, both the patient and everyone around are more at peace and mentally prepared. My mum and us were able to spend quality time with each other throughout. We can't recall any moment she complained against anybody or anything. She was always at peace with herself and others. The additional support just helped her be herself. ■

In early 2021, Datin Tan visited Hospis Malaysia with her family and made a generous donation to support our work. Her parting words with us during that visit: "I want your nurses to continue to be motivated and many more people to benefit from your good work."

From left to right: Dr Ednin Hamzah, Nurse Mastura, Dato Chew Swee Hock, Ms Chew Beng Lin, Datin Tan Chooi Hong, Dr Chew Guan Gae

WEBINARS - GOING VIRTUAL FOR HEALTHCARE PROFESSIONALS' CONTINUOUS LEARNING

Part of our goal in education and advocacy is to keep healthcare workers (and the public) abreast of the latest insights and updates on palliative care. In 2021, Hospis Malaysia continued to host and co-host webinars relevant to the current situation.

MARCH 2021: PRACTICING PATIENT CENTRED CARE IN THE COMMUNITY: BY HOSPIS MALAYSIA

This webinar aimed to address the importance of developing a patient-centred approach to palliative care and overcoming challenges to improve outcomes. The speaker, Dr Ednin Hamzah highlighted the significance of delivering palliative care in the community where practitioners see patients the way they want to be seen - in their own environment. When interviewed, a patient of Hospis Malaysia expressed: "The doctors understand cancer, they don't understand me". This was a powerful message to all practitioners, reinforcing the need to integrate communication skills, cultural competence and the ability to listen and understand what is important to the patient apart from pain and symptoms management.

MAY 2021: PSYCHOSOCIAL CARE: BY APHN IN COLLABORATION WITH HOSPIS MALAYSIA

The webinar, facilitated by Professor Dr Amy Chow from the Department of Social Work and Social Administration, The University of Hong Kong, discussed on psychosocial care in palliative care. The psychological, social and spiritual well-being of the patient were considered, reinforcing the need to reduce suffering within these dimensions as health is not just about the physical elements. Studies have shown that social determinant such as emotions, functional changes, cultural influences, social context, impact of illness on the person and the people around them and the spiritual domain plays a big part in the wellbeing and health of the individuals. Psychosocial care means looking into these factors and providing the best solution that would enhance the quality of life of the patients. A brief example of a psychosocial assessment was also presented during the webinar.

OCTOBER 2021: PALLIATIVE CARE IN A PUBLIC HEALTH CRISIS: BY HOSPIS MALAYSIA

The webinar, facilitated by Professor Bee Wee, National Clinical Director for End-of-Life Care, NHS England and NHS Improvement, UK reflected on the recent pandemic and the public health approach to palliative care. Prof Bee Wee highlighted that a public health strategy for palliative care offers the best approach for translating new knowledge and skills into evidence-based, cost-effective interventions that can reach everyone in the population. She emphasized that it must be incorporated by the governments and owned by the community as it involves the need for a policy under a national health plan that oversees education of healthcare professionals, public and media, and affordable drug availability and implementation through leadership, trained manpower and standard guidelines. In tackling the pandemic, Prof Bee Wee shared insights to practices in the UK.

An experience beyond norm

NOVEMBER 2021: CONVERSATION THAT VALUES WHAT MATTERS TO PATIENTS WITH SERIOUS ILLNESS – A NURSING PERSPECTIVE: BY APHN IN COLLABORATION WITH HOSPIS MALAYSIA

The webinar, facilitated by Associate Professor Sayaka Takenouchi from the Kyoto University Graduate School of Medicine discussed the challenges and opportunities to improve healthcare professionals' clinical practice of Advanced Care Planning (ACP) while enabling them to facilitate patient engagement in serious illness conversations successfully.

NOVEMBER 2021: THE RIGHTS OF PALLIATIVE CARE PATIENTS IN A PANDEMIC: BY HOSPIS MALAYSIA

The webinar was facilitated by Professor Ghauri Aggarwal, Head of the Palliative Care Department at Concord Hospital, Sydney and Dr Sumytra Menon, Co-Director for the Clinical Ethics Network and Research Ethics Support (CENTRES) initiatives in Singapore, through case studies presented the ethical concerns surrounding care during the pandemic. The facilitators provided valuable insights to patients' rights, ethical dilemmas and professional moral dilemmas (futility and the appropriateness of treatments) within the hospital systems they operated in.

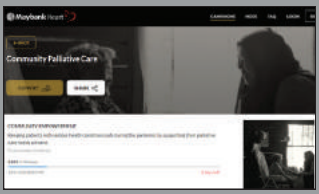
To access the recordings of the webinars, please email education@hospismalaysia.org for permission.

Thank you for your support!

Hospis Malaysia is grateful for the continuous support given by individuals and corporations throughout the year. Despite the Movement Control Order (MCO) which limited our community engagement and on-ground activation, we were able to reach out to the public and corporate organisations through our online initiatives and are thankful for their support.

During the period of August 2021 to November 2021, we would like to extend our thank you to:

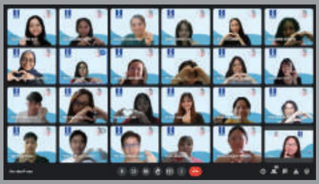
Wild Kombucha who in the month of November pledged RM1 for each sale to Hospis Malaysia alongside raising awareness on palliative care through a video they created. Check the video out on YouTube – Hospis Malaysia; Palliative Care: Myth or Facts?



MaybankHeart – Thank you for responding to our call during the Covid-19 pandemic and enabled us to raise funds through the MaybankHeart platform.

Xylem Sea – Our heartfelt gratitude to its staff who responded to our appeal for Personal Protective Equipment (PPE) through a fundraiser within the organization.

LG Household and Health Care Malaysia – For electing us as the sole beneficiary of your #Relaybersamajiayou #Journeyoflife initiative!



TAR University College – Thank you for your support in helping us raise funds and awareness through the Brains with Heart Campaign.

Prof Teoh Siew Li – Thank you for helping us raise funds through the "virtual mindful stretching activity".

Crawford and Company – Thank you for electing us as a beneficiary in your Global Days of Service event.

We also thank all our individual and corporate donors who have supported us in many ways!

Coming Up!

Jegadeva Fund – Look out for the sale of handcrafted work by Mrs Jegadeva this December. Proceeds from this fundraiser will be channeled to Hospis Malaysia for those in need. You may browse through the items at shorturl.at/jquN2 and place your order by WhatsApp: 012-5943987 if anything catches your eye.

ANNOUNCEMENTS

GET YOUR OWN PALLY BANK TODAY!

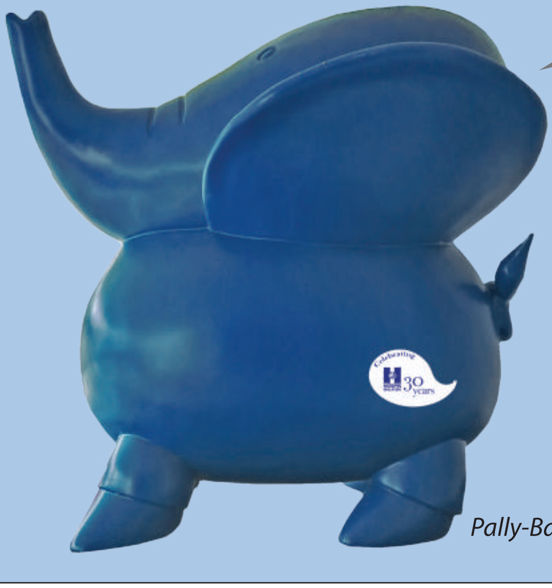
The life of Pally began when Hospis Malaysia understood the increasing need to advocate for patients and families living with serious progressive illnesses to be at the centre of any care they were receiving. The "Speak-Up – There's an Elephant in the Room" Campaign which was launched in 2018, enabled a safe space for those affected by serious progressive illnesses to voice out what matters to them when faced with these serious conditions, and not to suffer in silence.

Overtime, Pally the elephant evolved to become a symbolic figure of a friend in need during trying times and continues to develop its character as a way of raising awareness about issues that matter for these patients and their families. It is with this concept that the story of Pally was brought to life. You can read more about Pally on https://www.hospismalaysia.org/my-very-own-pally-bank/ .

Facilitating conversations that matter and ensuring that the needs of these patients and their families are addressed is central to the practice of palliative care.

Palliative care is defined as an approach that improves the quality of patients and their families through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

With more than 25.5 million people dying with serious health suffering that requires palliative care each year and less than 10% currently being able to access it, the need to support better access to palliative care has never been more urgent. We believe that the Pally Bank can be your inspiration to support the continued development of palliative care in Malaysia and around the world and improving its access to the millions who currently still do not have access. It can be a gift to a friend or a family member as a way of encouraging them to save and donate to the cause or a reminder that you can be one among the many changemakers to get the ball rolling towards the vision of "Leaving No One Behind; Equity in Access to Palliative Care".



Pally-Bank

This is what Pally has to say about its latest role.

"You can bank on me to always be there for you.

Keep your money in me so I can help you save up or donate it back to Hospis Malaysia, when you choose to do so one day.

If you are an e-saver, let me be the reminder to you to drop a RM or a penny into your e-wallet when you can. And if you can spare a moment, "bank in" with me your life wishes on social media (#pallybank #hospismalaysia) and share your posts as a means of letting your family and friends in on your hopes and thoughts.

I am Pally Bank, your pal today, tomorrow and in the future."

I am 18cm tall and 16cm wide. I am easy to handle and I assure you that I will be an awesome pal. Take me home with you by pre-ordering and introduce me to your circle of friends and family members. Log on to https://www.hospismalaysia.org/product/pally-bank/ to purchase, or scan

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