KDN PP8369/10/2012(031405)



## THE BENEFIT OF PALLIATIVE CARE IS THROUGH EARLY REFERRAL

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

### Life is a journey, not a destination -**Ralph Waldo Emerson**

Your family is going on a week's holiday and you are too busy but make the effort to join them on the last day.

You want to see a movie but only got to see the last few minutes.

You want to get a new car but were told that you only need an old banger that may not even start...

A patient with cancer of the colon feels that he needs palliative care but was told by the oncologist that it is too early...

The family of a dying patient in hospital was asked by a 'helpful' palliative care doctor whether they want to take the patient home to die. A 'terminal' discharge could be arranged...

The journey of a patient starts NOT at the point of confirmation of a 'terrible' disease by some bespectacled, knowledgeable doctor that had skilfully broken bad news in a sensitive way. Her journey starts with the discovery of a symptom such as finding a breast lump, losing weight or coughing blood, and it is more sinister than realised.



CREDIT: PALLIATIVE CARE PHYSICIAN & CARTOONIST @NATHANAGRAY

The symptom itself coupled by fear and anxiety marks the long path for both patient and her family / caregiver, in the journey to finding both curative options as well as the relief of suffering. Hence the basis that palliative care should be introduced early in the course of a disease and palliative care intervention to be provided together with disease modifying

continues on page 2

S ISSUE	EDITORIAL The Benefit of Palliative Care is Through Early Referral PALLIATIVE CARE MYTHS & FACTS Myth & Facts	1	ADVOCACY Palliative Care Awareness Month TEACHING & TRAINING Grief and Bereavement Care Workshop, 17-18 December 2023	6 8	THANK YOU! UPCOMING EVENTS Kuala Lumpur Standard Chartered Marathon (KLSCM) 2024 – We are back for the 12th year as a charity beneficiary!	11
	FEATURE Strong Beliefs in Palliative Care Principles Drive Medical Student to Hospis Malaysia	4	PALLIATIVE CARE NURSING International Nurses Day 2024: "Our Nurses. Our Future. The Economic Power of Care", 12 May 2024	9	Upcoming Events for 2024	10

#### continues from page 1

treatment by an oncologist, physician, paediatrician, or whoever the patient's primary doctor is.

In countries with advanced palliative care development, there is integration of palliative care into its health system. Here, primary palliative care may be introduced by front line care delivery such as health clinics where basic symptom management, assessment of issues and clarification of goals of care discussions could be done. At the next level, general physicians in various specialties are trained to deliver general palliative care e.g. oncologists providing appropriate pain control.

It is only a small number of patients with complex needs that require specialist care that are referred to palliative care specialists who may reside in palliative care units in hospital or in the community.

There is numerous evidence of the benefits of palliative care. These include the relief of pain and suffering, reduce need for hospital stay, better quality of life and reduce healthcare expenditure. The Temel study (Temel et al. NEJM 2010) that looked at early integration of palliative care in the management of non-small cell lung cancer even showed a higher survival for patients receiving palliative care.

"The common message is that to derive the greatest benefit to palliative care, patients need to receive such care early in the course of their illness."

Since 1997, Hospis Malaysia has been providing palliative care in the community and advocating for earlier referral and integration with other medical services. We were part of a multidisciplinary team approach at Universiti Malaya Medical Centre, working with breast surgeons and oncologists in managing advanced breast cancer and we are now working with the Department of Neurology in managing motor neurone cases. Both examples of early integration of palliative care. However, by and large, the referrals from our hospital colleagues have become later with nearly 40% of all cases referred to us, hardly surviving for a week. It is unfortunate that the development of hospital palliative care seems to have resulted in much later referrals to community services that creates a significant level of distress to patients, caregivers and families, resulting in greater demand on community services to stabilise the patient at home in their last few days or sometimes hours. And one may ask – while the patient did pass away at home, was it peaceful at the end, and was she able to spend quality and meaningful time with her loved ones? For isn't that what palliative care is about – improving quality of life?

Rather than engaging in the promotion of 'terminal discharge' policies, we hope that healthcare systems' decision makers will engage with relevant stakeholders to address gaps in services and policies so that we look at appropriate transitions in care delivery between institutions so that both derive benefits to all parties. For many patients, these transitions in care could be much improved with better communication. In other cases however, even though a patient may want to go home for end-of-life care, this may not be possible if insufficient resources to support quality services in the community were available, and the outcome could then be devastating for all.

The journey through advanced cancer and other similar diseases could lead to all manner of suffering for the patient, family and caregiver. The additional layer of support from palliative care could bring significant benefit if introduced at the start. Perhaps like watching a movie, if we start from the beginning, would we not benefit more from it?

2024 marks the 10th anniversary of the World Health Assembly resolution 67.19 'Strengthening palliative care as a component of comprehensive care throughout the life course'. Hospis Malaysia supports the integration of early palliative care into Malaysia's health system rather than simply its use in 'terminal discharge policies'.

#### **COUNCIL MEMBERS**

**Chairman:** Dato' Kathleen Chew Wai Lin

Secretary: Dr Chong Su-Lin

Treasurer: Dr Ong Hock Chye *Members:* Ms Lim Wai Yee Professor Dr Khoo Ee Ming Mr Chan Yee Hon Mr Irvin Menezes

#### **HOSPIS MALAYSIA (199101013363)**

2, Jalan 4/96, Off Jalan Sekuci, Taman Sri Bahtera, 56100 Kuala Lumpur
Tel: (03) 9133 3936 Fax: (03) 9133 3941
E-mail: info@hospismalaysia.org
Website: hospismalaysia.org
HospisMY
HospisMalaysia
Hospis Malaysia

### PALLIATIVE CARE MYTHS AND FACTS MYTH & FACTS

Myth: Only the person who is ill can benefit from palliative care.

FACT: Palliative care is designed to also help the patient's family and the people close to him. If someone close to you has a serious progressive illness, it can have a big impact on you.

Palliative care is a multidimensional approach that aims to provide comfort, support, and relief to individuals and their families who are dealing with serious progressive illnesses. Contrary to the widespread misconception that palliative care is exclusively beneficial to the patient, it also extends its support to the loved ones of the person who is ill. This is particularly relevant when considering the emotional, psychological, and social impact that such illnesses can have on caregivers and family members.

Caregivers often face immense stress and challenges as they navigate the complexities of providing care for their loved ones.

They may have to cope with the emotional turmoil of witnessing the decline in their loved one's health, while simultaneously managing their own emotional wellbeing. Additionally, caregivers are often responsible for coordinating medical appointments, managing medications, and providing hands-on care, which can lead to exhaustion and burnout.

Palliative care recognizes the importance of addressing the needs of caregivers and family members, offering them crucial support during this difficult time. By providing resources, guidance, and emotional assistance, a palliative care practitioner can help to alleviate the burden on caregivers and enhance their ability to cope with the challenges they face. This may include training on caregiving, offering counselling services or providing education on self-care techniques to help them maintain their own well-being.

#### **9 SYMPTOMS OF CAREGIVER BURNOUT**

Are you a caregiver?

Take care of your physical and mental health. Check these 9 symptoms to recognise in time if you are suffering from burnout syndrome:



"There are only four kinds of people in the world — those that have been caregivers, those that are caregivers, those who will be caregivers, and those who will need caregivers." - Rosalynn Carter

As we celebrate Palliative Care Awareness Month 2024 in April themed "Compassion Communities", it is essential to recognize the vital role that palliative care plays in supporting not only the patients but also their families and caregivers. By understanding the true nature of palliative care and its benefits, we can work together to ensure that everyone who needs this compassionate, holistic approach receives the support they deserve.

### FEATURE STRONG BELIEFS IN PALLIATIVE CARE PRINCIPLES DRIVE MEDICAL STUDENT TO HOSPIS MALAYSIA

We sat down to ask her why....

Jasmine Palm, a 23-year-old medical student from Germany, recently conducted her research on undergraduate palliative care education in Malaysia. Here, she shares her experience and insights gained during her time in the country and at Hospis Malaysia.

# Can you tell us a bit about yourself and your background in medicine?

I am a 5th year medical student at RWTH Aachen University in Germany. In Germany, we undergo 6 years in undergraduate medical school. My passion for palliative care grew steadily after having completed a one-month internship at a palliative care ward in Germany, and a lot of optional courses on palliative care at university. It is such an important medical field and I really like the principles of it.

In Germany, to receive our "Dr." title, we have to perform research and write a thesis about it. It is not mandatory, but most students choose to do it this way. It is comparable to a PhD, but is not as extensive. This is why I chose to write my thesis about a topic related to palliative care.

## How did you hear about Hospis Malaysia and what is its relevance to your research?

My supervisor, Dr. Frank Elsner, is passionate about palliative care education. Some of his research projects have involved investigating the status of undergraduate palliative care education in various countries, such as Germany, Austria, China, Israel and Nigeria. When I expressed interest in conducting a research, he suggested a similar project abroad, but we were not sure which country to pick at first. Then at an international conference in June 2023, he met Dr. Ednin Hamzah, Hospis Malaysia's CEO, and the idea of conducting my research in Malaysia was discussed and Dr Ednin agreed to host me at Hospis Malaysia!

### What made you choose Malaysia for your research?

Honestly, before Professor Elsner's suggestion, I wasn't familiar with Malaysia! But the idea of broadening my horizons by experiencing a new culture was very appealing, especially while solo traveling. When I reached out to Hospis Malaysia, their team, particularly Dr. Ednin, Dr. Zee Nee, Dr. Sylvia, and Dr. Punitha, were incredibly supportive and enthusiastic about



Jasmine is part of a growing international community of healthcare workers choosing to spend time at Hospis Malaysia

collaborating, and that solidified my decision. Their dedication to palliative care advocacy and education was truly inspiring.

## Can you tell us a bit about your research project and your collaboration with Hospis Malaysia?

Our project, titled "International Medical Education in Palliative Care – Research on Medical Student Education Outcomes – IMEP-Malaysia," investigates the current state of palliative care education in Malaysian medical schools. We contacted all medical faculties to identify key personnel involved in the curriculum. These individuals participated in surveys and interviews to provide insights. The data will be analysed to create a comprehensive picture.

Our primary aim is to explore the current landscape of palliative care education in Malaysian medical schools. We hope we have included all institutions for a representative outcome and will perform a qualitative analysis of all collected data and summarize the findings in a paper. The final analysis will be published in a medical journal to raise awareness about palliative care education, highlight existing strengths and identify areas for improvement.

We await the findings of your research. But in the meantime, can you share some of the key takeaways from your time spent at Hospis Malaysia, as your host?

Apart from conducting my research, I also had the opportunity to shadow some of their nurses and doctors as they conducted their patient visits, and sit in on some of their lectures and tutorials. The need for increased public awareness about palliative care and the importance of



Jasmine is seen here with members of Hospis Malaysia's clinical team and the proverbial 'elephant in the room'.

equipping medical students with the skills to provide compassionate care are some of the key takeaways. Hospis Malaysia's dedication to patient care leaves a lasting impression, and my time here broadened my horizons by exposing me to a new culture and the importance of palliative care education.

From the peaceful and calm atmosphere at the centre, to friendly and empathetic staff, and to well-structured training and e-learning modules, every aspect of Hospis Malaysia motivates active learning and student engagement.

I am very impressed with how much time and effort is put into constant education of the staff and that everybody tries their best to uphold the quality of care. I am truly impressed by their experience and their knowledge when I followed them around on home visits. They know and understand their patients, take as much time as they need and try to help where they can. I learned so much about cultural and religious aspects that need to be considered when taking care of terminally ill patients in Malaysia. Most interesting to me was learning about collusion and how to deal with it.

And not only staff, but also medical students and qualified doctors also benefit from excellent education

at Hospis Malaysia. I had a look at the e-learning module which seemed very interesting. Prof. Frank Elsner, who visited Hospis Malaysia for a couple of days, was surely impressed when he clicked through it. I also had the chance to sit in on a day of medical student education and I think this debriefing session was very well-structured. One could see how much thought and effort went into the building of this program. The focus was put on engaging the students, motivating them to take part actively and thinking about their own experiences. I think this is a good way to make students remember something. If they just listen to a lecture, it doesn't stick with them.

To add to this, the communications team's creative campaigns, like the "Elephant in the Room" initiative, showcased their active work in raising public awareness about this vital field.

Hospis Malaysia's strong network of connections is also commendable. They collaborate with various institutions, not just within Malaysia, but around the world, demonstrating their commitment to knowledge sharing and advancing the field of palliative care both locally and globally. I am very happy I ended up at Hospis Malaysia, I think it couldn't have turned out any better!





April 2024 is Hospis Malaysia's 9th Annual Palliative Care Awareness Month (PCAM 2024). This campaign serves to highlight the plight of everyone whose lives have been affected by the diagnosis of a serious progressive illness. *Palliative care* aims to *improve the quality of life* of patients and their families by identifying and addressing the physical and emotional suffering of people living with serious progressive illnesses. The Ministry of Health, Malaysia estimates that every year more than 100,000 people require palliative care. By another measure, people affected by serious health-related suffering can exceed 220,000 each year, and this number is expected to double by 2030 when the Malaysian population reaches an aged population. And currently only approximately 10% have access to this very crucial area of healthcare.\**National Palliative Care Policy & Strategic Plan 2019 - 2030 by MOH, Malaysia*.



Such misunderstanding and stigma regarding palliative care may be perpetuated by those who falsely believe they understand its meaning. It is imperative therefore that public health education is needed to increase knowledge about palliative care, promote its early integration and counter false assumptions.

### This year's PCAM 2024 theme is "Compassionate Communities: Together for Palliative Care"



Compassionate communities care for people, assist people to live in the place they call home, connect people to services, and raise awareness about the quality of life issues for those people facing serious illnesses. The 'true meaning' of *compassion* is to *recognise the suffering* of others and actually *take action to help*.

Let us *come together as a community* and make a meaningful impact. As everyone deserves to live well and live their final days with dignity.



As a community, our patients and their families have joined us to share their stories to highlight the benefits of a referral to palliative care.

### TIJANI'S STORY

#### **Seeking Hospital Comfort At Home**



Tijani with her mum, Norra

"It is difficult as I am not able to do the things I used to do – I cant go for walks in the park as I get tired easily. I enjoyed my job as a social media manager but I can no longer work. But at least I get to spend time at home, being with mum, sleeping in my own bed, be with my cats, and seeing my brother and

# friends whenever they feel like visiting", the late Tijani Batrisyia shared.

Her mum, Norra expressed how important it was for *Tijani* to be able to take her pain and other medication by injectables at home, as her fluid intake by mouth was difficult. Wi th co mprehensive co mmunity palliative care support, Tijani's symptoms were managed at home, and her psycho-social wellbeing improved as in her own words she "found hospital comfort at home"

## SHU HUA'S STORY

### **Trust To Guide Us At Home**



Shu Hua at home

"I was an emotional yo-yo when I found out about my motor neurone disease (MND). I was 30 years old with 2 young kids. How was I going to cope? I don't want to be a burden to my family". This was how Shu Hua felt when she was diagnosed with MND. She was aware that her condition was going to deteriorate, and struggled to find meaning in life.

A referral to community palliative care has alleviated much of Shu Hua and her husband's concerns about coping at home where she wants to be, and has helped her deal with her worries. Shu Hua now has significant mobility issues but she has found with regular visits by the palliative care team, her pain and insomnia problems have been addressed, she knows how to deal with her breathlessness, and her husband has been taught how to care for her.

"When my hospice nurse visits, she gives me space to voice my concerns. She does not judge, and may not have a solution for everything. But this means a lot to me, as I trust her, and can express my emotions to her, and this is what I need to help me through each day".

Join us to advocate for better access to evidence-based palliative care, so that we can work with our policy makers to ensure that it is fully integrated into our healthcare system. Pledge to support equal access to palliative care:





Prof. Amy Chow with her team from The University of Hong Kong (HKU) - Margaret Suen, Dr Jiao Keyuan, Jade Leung & Ng Yong Hao

The goal of Hospis Malaysia's yearly Grief and Bereavement Care Workshop is to equip attendees with the necessary tools and knowledge to offer empathetic care and support to those who have experienced loss. Through engaging presentations, interactive discussions, and practical exercises, this workshop creates a safe and supportive environment for healthcare professionals to gain a deeper understanding of the complex emotions and challenges associated with grief and bereavement. By the end of each workshop, our participants often leave with valuable insights into the various aspects of grief and bereavement, enabling them to provide compassionate care and contribute positively to the healing journey of those navigating the grieving process.

We caught up with the esteemed facilitators from the Department of Social Work & Social Administration, The University of Hong Kong (HKU) at the Grief and Bereavement Workshop and delved into their insights on what they consider important and crucial for anyone looking to support individuals going through the grieving process:

### Prof. Amy Chow, Head and Professor, Department of Social Work & Social Administration, HKU, on the ADAPTS Model

While bereavement is a universal life event, grief reactions are diversified and can manifest in different

aspects. Most of the current bereavement care follows a one-size-fits-all method; the ADAPTS model is a tailored approach for focusing on personalized needs. ADAPTS is the acronym for Anomalous Emotions, Dysfunctional Cognition, Adjustment Challenges, Physical Symptoms, Traumatic Responses, and Separation Distress. This model has been found to be more effective and efficient with better intervention outcomes

### Mr Ng Yong Hao, PhD student discussing Compassionate Communities

In compassionate communities, everyone has an important role to support people experiencing dying, death, and bereavement. Within each community, one can assume there is already a certain level of death and grief literacy. We should start on the premise that everyone possesses some knowledge, skill, and/or value of death and grief, and collectively the community of people can address the complex experiences of dying, death, and bereavement.

### Dr. Jiao Keyuan on Assessment

Adopting the public health model, there are three levels of bereavement care: universal care for everyone, selective care for the high-risk group, and indicated care for the high-distress group. To deliver the right care to the right person, risk assessment and outcome assessment are important. A bereavement risk assessment tool can assist in prioritizing cases, while an outcome assessment tool can help identify the primary goals for intervention.

# Ms. Jade Leung, PhD student discussing Caregrieving

Beyond the traditional conceptualisation of the term 'Caregiving', 'Caregrieving' is a relatively new word that highlights the duality of the journey for those who are caring for their dying loved ones. When supporting the caregrievers, we should be sensitive to the oscillations they experience during their coping process and mindful of the importance of pacing ourselves with our patients and their families.

### Ms. Margaret Suen, PhD student discussing Pre-Death Bereavement Care

Conspiracy of silence during final days and regret on unexpressed messages such as apology, forgiveness, appreciation, and love may hamper both the deceased in the closure and the bereaved in post-

### PALLIATIVE CARE NURSING

## INTERNATIONAL NURSES DAY 2024: "OUR NURSES. OUR FUTURE. THE ECONOMIC POWER OF CARE", 12 MAY 2024



International Nurses Day held yearly on May 12th, marks the anniversary of Florence Nightingale's birth and serves as an opportunity to recognize the vital role nurses play in healthcare systems worldwide and to appreciate their dedication, professionalism, and resilience. This year's International Nurses Day theme "Our Nurses. Our Future. The economic power of care," is a testament to the immense value and impact nurses have in our society. Their dedication, hard work, and compassionate care contributes to the well-being of individual health outcomes and to the overall economic well-being of our communities.

Nurses are central figures in Hospis Malaysia as they are the key providers of comfort, relief from pain, and symptom management to our patients with serious progressive illnesses. Guided by our palliative care doctors, and supported by our pharmacists, physiotherapist and counsellor, they ensure that our patients receive holistic care that addresses their physical, emotional, social, and spiritual needs. Hospis Malaysia nurses are not just nurses. Not only do they work with the doctors to manage the patients' symptoms, but they also help our patients and families navigate their treatment options. By offering a listening ear and empathy, they are fostering a sense of hope and well-being with their patients

Each nurse advocates for patients, ensuring that their preferences, values, and goals are considered in the decision-making process. They facilitate communication among healthcare providers, patients, and families, promoting a shared understanding of the patient's needs and care plan.

Lastly, our nurses contribute greatly to the education and training of future healthcare professionals, specifically a new generation of doctors in Malaysia, by sharing expertise and experiences to enhance the quality of care provided to patients.

"The Hospis Malaysia nurse goes beyond the scope of traditional nursing roles – she is trained to assess the patient's needs holistically and deliver care where it is needed."

International Nurses Day 2024 highlights the economic power of care that nurses hold, and their crucial role in shaping the future of healthcare. In palliative care, our nurses demonstrate their dedication and expertise by providing compassionate, holistic care to patients and their families. Their work is essential in improving the quality of life for all individuals facing serious progressive illnesses and ensuring that they live their final days in comfort and with dignity.

continues from page 8



Workshop facilitators with Hospis Malaysia CEO Dr Ednin Hamzah and participants at the end of the workshop

death bereavement. Pre-death bereavement care, including Advance Care Planning discussion on EOL care, facilitates intrapersonal and interpersonal communication through meaning-making, e.g., life review is crucial to post-death bereavement. ■

### UPCOMING EVENTS KUALA LUMPUR STANDARD CHARTERED MARATHON (KLSCM) 2024 – WE ARE BACK FOR THE 12<sup>TH</sup> YEAR AS A CHARITY BENEFICIARY!



HOSPIS MALAYSIA is proud to once again be chosen for the 12th consecutive year, as a charity beneficiary of the prestigious Kuala Lumpur Standard Chartered Marathon (KLSCM)! We are grateful for being recognised and valued as a charity partner. It is a testament to the impact we have made in the lives of those we serve, as well as the trust and confidence placed in our mission!

Over the years, the **Run For A Reason (RFAR)** collaboration has not only raised vital funds for Hospis Malaysia but also fostered a sense of shared purpose among participants, encouraging them to make a positive difference in society through their passion for running.

To all who have chosen to Run For A Reason this year, *thank you for signing up to run for Hospis Malaysia*. Over the next several months we will be reaching out to you with more news about our work, which we hope you will share with your friends, colleagues and relatives who will further donate in support of your run, and in support of our work as a charity. So, look out for our RFAR emails, Facebook & Instagram posts!



MISSED OUT ON SIGNING UP BUT YOU WOULD STILL LIKE TO SUPPORT US?

### If you are a corporate, you can still sign up through the Corporate Challenge!

### HOW CORPORATE CHALLENGE WORKS:

- Companies must be based in Malaysia to participate.
- Companies must register minimum 3 runners in a team to participate.
- Companies can register as many teams as they want under different team names.
- Runners will run in the 10km Cruise category.
- The company with the lowest aggregate 'net time' of the first 3 finishers will be declared the winner.
- Tax-exempt receipts will be given for all Corporate Challenge donations.

*Find out more on*: https://www.kl-marathon.com/charity/corporate-challenge/about/ or *email us* at *pr@hospismalaysia.org* to discuss your interest.



Our donors' kindness and compassion play a vital role in our mission to provide exceptional palliative care to those in need. We would like to extend our heartfelt gratitude, to our valued supporters from December 2023 to March 2024:

**IOI** Foundation for selecting Hospis Malaysia as one of its beneficiaries of its Bargain Basement Proceeds Giving.





Pan Malaysian Pools Sdn. Bhd. for their donation through the Da Ma Cai Annual Community Aid Charity Programme.

Magnum Foundation for their contribution which will make a significant difference in the lives of our patients and their families.

**TEAM LEWIS Foundation** for adopting Hospis Malaysia as a cause to support through their global impact initiative.

Mitraland Group for selecting Hospis Malaysia as a beneficiary of their charity fund-raising drive in celebration of the Group's 25th Anniversary & Annual Dinner.

Tatler Asia for selecting Hospis Malaysia as a Tatler Ball Charity Beneficiary.

Mercedes-Benz Malaysia Sdn Bhd for their support via their Mercedes-Benz Grants for Good charity programme.



AAL

MITRALAND





The Chinese Chamber of Commerce & Industry of Kuala Lumpur & Selangor for the Ang Pow Giving in conjunction with Chinese New Year.



Tenaga Nasional Berhad (TNB) for their contribution in conjunction with their Women in Leadership Seminar & Women's Day celebration.



TatleAsia





Hopsis Malaysia Nurses with Rotary PJ award & vouchers

The Rotary Club of Petaling Java for recognising the work that Hospis Malaysia does in the community and honouring our nurses with the RCPJ Vocational Service Award Vocational Service Award and contribution of grocery vouchers.

11

## **UPCOMING EVENTS**

APR	PALLIATIVE CARE AWARENESS MONTH
27 - 28 APR	HOSPIS MALAYSIA 23RD ANNUAL CHARITY MOTOR TREASURE HUNT
29 - 30 JUN	WORKSHOP: DEVELOPING RESILIENCE IN MANAGING CHALLENGING CLINICAL SITUATIONS
5 - 6 OCT	KUALA LUMPUR STANDARD CHARTERED MARATHON 2024

