

## LIVING AND DYING IN PAIN, IT DOESN'T HAVE TO HAPPEN!

By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

*'We don't even ask happiness, just a little less pain', Charles Bukowski.*

**P**ain is the most dreaded of sensations experienced by all of us. Pain affects us in all manner of ways. Pain makes us scream or simply stay still in the hope that it goes away, to the piercing pain that hits us deep when we lose someone dear to us. Pain represents loss. Loss of control, loss of function and even loss of hope. Pain brings thoughts of death and dying to the extent that some may even be compelled to an argument that death is kinder to a life of enduring pain.

Despite the incredible advancements in healthcare, we are still somewhat blinded to the dealing with patients with pain. It is surprising that despite the sheer prevalence of pain affecting most patients, it is not a subject that receives much instruction



AHMAD YUSNI, EPA

*No one deserves to endure such pain in Malaysia or anywhere in the world*

in medical education. Surgeons, physicians, oncologists are experts in dealing with many of the diseases that define their specialty but pain management is an elusive skill often acquired as an aside.

A country's use of medicinal morphine and other similar drugs is often used as an indirect measurement of the level of pain and palliative care services in that country.

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## Are we so quick to give up on our loved ones?

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Yet Malaysia languishes in a ranking of 72 with a consumption of 0.7392 mg/capita when the world mean is 6.24 mg/capita (2014)<sup>1</sup>

Why is this? We have all the medications we need to reduce pain and we are producing increasing numbers of doctors and nurses. Yet, many patients in pain are not getting the pain relief they require. For patients with cancer and other debilitating diseases, they have to cope with other treatments, side-effects and try and live a life with pain. Families and loved ones feel helpless watching the suffering of the one they love so much.

In 2014, the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez said 'States also have an obligation to prevent pain and suffering that amounts to cruel, inhuman or degrading treatment.'

Mr. Méndez urged governments around the world to ensure full access to palliative care of all terminally ill, including older persons, and overcome all obstacles

that restrict availability to essential palliative care medications. "States should promote widespread understanding about the therapeutic usefulness of controlled substances and their rational use," he specified.

Healthcare systems which ignore the need to have accessible and good quality palliative care will never be able to effectively promote and protect the right to health and related human rights of their citizens," the UN Independent Expert on the right to health, Dainius Puras, said.

The central tenant of pain through torture is that by removing the act of torture, much of the pain will be relieved. Yet, with cancer and chronic pain, the pain will NOT go away without medication and other treatment. Yet some in society feel that assisted suicide is an answer rather than improving pain management and prescribing palliative care. Are we so quick to give up on our loved ones?

The central purpose of palliative care is to improve quality of life of patients and families by reducing

pain and suffering. Working with oncologists, physicians and other doctors who are experts in disease management, we are able to make a huge difference in reducing pain and suffering. Yet, despite having 25 years of palliative care in Malaysia, huge numbers of patients have unresolved pain.

A useful analogy is that of driving a car. The principle purpose of a car is to take us from point A to point B. But it is the comfortable seat, air-conditioning, good suspensions, brakes, and music that make that journey comfortable. Why can't we do the same in healthcare. The medication, chemotherapy, radiotherapy help to deal with the disease. It is the pain relief, social, psychological, emotional and spiritual support that makes fighting the disease not just bearable but meaningful. Good and effective palliative care does that. Is that too much to ask when someone is in pain? It really doesn't need to happen. ■

<sup>1</sup> [http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/global\\_morphine.pdf](http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/global_morphine.pdf)

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### HOSPIS MALAYSIA (223675-X)



2 Jalan 4/96, Off Jalan Sekuci,  
Taman Sri Bahtera, Jalan Cheras  
56100 Kuala Lumpur  
Tel: (03) 9133 3936  
Fax: (03) 9133 3941  
E-mail: [info@hospismalaysia.org](mailto:info@hospismalaysia.org)  
Website: [hospismalaysia.org](http://hospismalaysia.org)

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### PALLIATIVE CARE MALAYSIA

an initiative by Hospis Malaysia

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

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## HOW CAN THE PALLIATIVE CARE TEAM HELP ME COPE WITH MY PAIN?

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

**P**ain relief is possible. You do not have to suffer silently in pain.

Pain is a very individual experience. It can affect you in many ways, for example, disrupting your daily activities or making you feel emotional at times. It may also prevent you from having a meaningful relationship with your loved ones.

Pain relief is a priority for the palliative care team who comprises of a clinical team of doctors, nurses, pharmacist and allied healthcare professionals such as physiotherapist, occupational therapist.

The palliative care team will first take a full history of your pain. Some of the questions asked include:

- Can you describe your pain? How long have you been in pain? How severe is it? What makes it better? What makes it worse? How does your pain interfere with your lifestyle? What are the other symptoms you suffer from? What medications do you take for your pain-including medications purchased over the counter?

It is important that you describe your pain as fully as you can so that the palliative care team can work out the best treatment plan for you.

There are many causes of pain, including:

- **Cancer** - Cancer causes pain by destroying or growing into tissue near the cancer. As the cancer grows, it puts pressure on nerves, organs and bones, leading to pain.
- **Organ failures** - Heart failure, for example, may lead to chest pain due to lack of oxygen supply to the heart. Patients with chronic kidney failure may suffer from numerous painful syndromes affecting the joints and bones.
- **Treatment-related** - Cancer treatments such as radiotherapy to the head and neck, may lead to sore mouth and sore throat. Dialysis patients may suffer from cramps and headaches.
- **Co-existing medical illness**  
Pain can also be related to other medical illness such as osteoarthritis or diabetes causing nerve damage.



PHOTO BY SC SHEKAR

*The palliative care team will educate you on how to use pain medications and address your concerns*

From the assessment of your pain, the palliative care team will come up with a treatment plan. A treatment plan may include prescribing of pain medications, adjustment of home environment such as using the correct technique for transferring from bed to wheelchair to prevent pain, physiotherapy to improve mobility, review of medications by a pharmacist to prevent any adverse drug reactions as well as emotional or spiritual support to you and your family.

Selection of pain medications is based on the causes and the nature of the pain. There are many different types of medications available. Your palliative care team will be able to recommend pain medications that are suitable for you.

Based on the World Health Organisation's analgesic ladder, a palliative care team may prescribe opioids (e.g. morphine) and non-opioids (e.g. paracetamol) depending on the severity of your pain. Medications which enhance the effects of opioids and non-opioids will also be prescribed, for example, medications which specifically target nerve pain. The palliative care team will educate you on how to use the pain medications and address any concerns that you may have. You may be asked to keep a pain diary so that the team can follow up on your pain and adjust the treatment plan accordingly.

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Physical pain can sometimes escalate as a result of emotional or spiritual sufferings. It is important that you discuss any concerns or worries with the palliative care team in order for the team to better understand your pain and support you in the way you want.

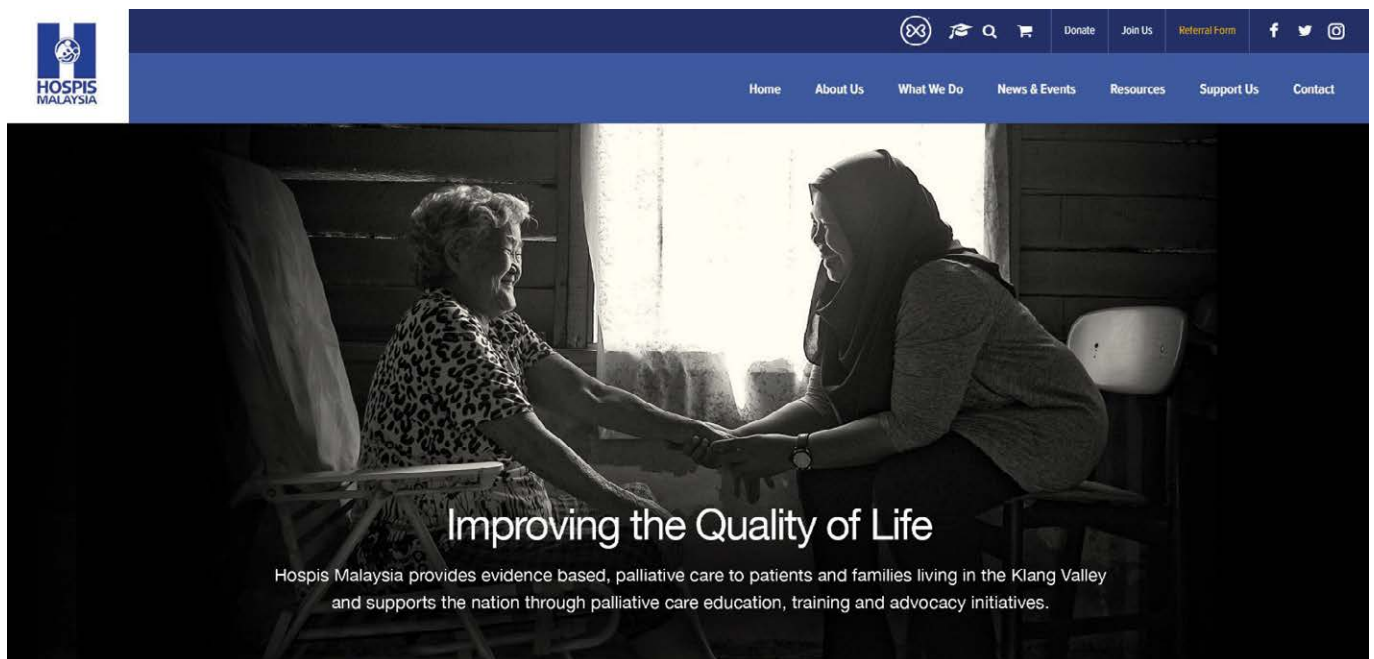
The palliative care team will ensure that pain reassessment and treatment continues, even at the

end of life. Oral pain medications can be changed to injections through a cannula placed just under the skin. This ensures that you are not being pricked repeatedly as it does not require access to one's blood vessels. In addition, your loved ones will be guided by the palliative care team in treating your pain should you choose to be in the comfort of your own home. ■

## ANNOUNCEMENTS

# ANNOUNCING THE LAUNCH OF OUR NEW WEBSITE

By Rini Vella, Advocacy & Media, Hospis Malaysia



**W**e are pleased to announce that our new and refreshed website is live!

You can find us at the same weblink: **[hospismalaysia.org](http://hospismalaysia.org)**

Our goal with this new website is to provide an easier way to find out more about Hospis Malaysia. The updated site includes changes to navigation, with drop down menus for both mobile and desktop. We have also improved the structure of our content, so you will get more from a quick read. There is a whole host of smaller but impactful changes, all to improve your experience when navigating the site.

We now have a more comprehensive 'What We Do' – if you would like to know more about Hospis Malaysia's three core pillars, then visiting this section can help. We will be constantly updating our content with helpful information, newsletters and upcoming events.

Our events section is now categorised separately under 1/" Training and Education" and 2/" Fundraising and Public Awareness Events"

In the 'Support Us' category, the upgraded Donation and Merchandise pages utilises an online payment gateway secured by e-GHL, aimed at making the process easier and secure for our donors.

With the technical support from creative agency Creative Juice and web developers SKYTOMATO, we have also created a host of new graphics and included a few user-friendly updates that have made the site easier to use, keeping our website relevant which ultimately enables us to better engage with the public.

We hope you like the changes, if you have any feedback or suggestions, please let us know via email [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org) ■

## THE NEED FOR GREATER PUBLIC AWARENESS

By Dennis Yap, Communications Manager, Hospis Malaysia



PHOTO CREDIT: MYTH STUDIOS

## LIVING & DYING IN PAIN, IT DOESN'T HAVE TO HAPPEN | PALLIATIVE CARE AWARENESS MONTH APRIL 2017



PHOTO CREDIT: RINVELLA

Palliative care is a specialised medical care which aims to improve the quality of life of adults and children living with life-limiting illnesses, such as cancer, organ failure, certain degenerative neurological disease, and HIV/AIDs.

The palliative care approach addresses the physical (pain and symptoms), social, psychological, spiritual issues and other problems faced by the patient and their families. Palliative care can be provided in the home, hospital, community clinic or nursing home by a team of qualified healthcare professionals.

### UNIVERSAL HEALTH COVERAGE & SUSTAINABLE DEVELOPMENT GOALS

Since the late 1960's, with the founding of the modern hospice movement by Cecily Saunders in the United Kingdom, interest in palliative care has been growing, together with encouraging signs of recognition by policymakers and influential bodies.

In December 2012, a resolution to progress towards Universal Health Coverage (UHC) was passed in the United Nations General Assembly<sup>1</sup>. The goal is to ensure that all people obtain the health services they need without suffering financial hardship. Within the framework of UHC, palliative care was recognised as an essential and needed health care service.

In May 2014, the WHO resolution to integrate hospice and palliative care into national health services was passed in the 67<sup>th</sup> World Health Assembly<sup>2</sup>. The resolution involves a set of standards and guidelines for palliative care, and the inclusion of palliative care in the health policies, budgets and healthcare education. Malaysia was a signatory to this resolution.

In September 2015, palliative care was recognised as an essential component of the Sustainable Development

Goals (SDG) under the UN Agenda 2030<sup>3</sup>. With these in place, policymakers are tasked to make more resources available for the delivery of palliative care in their national health systems.

### THE SCALE OF SUFFERING

Worldwide, it is estimated that over 40 million people each year require palliative care<sup>4</sup>. Of the 20 million that require palliative care at the end of life, it is estimated that 18 million people do not receive it<sup>4</sup>.

Echoing these findings, in Malaysia, estimates from a recently published palliative care needs assessment revealed that every year more than 56,000 people require palliative care at the end of their lives, with less than 10% receiving it<sup>5</sup>.

One of the key barriers to more people in need accessing palliative care services is the lack of awareness by the public. A public survey in 2016 revealed that over 90% of Malaysians are unaware about palliative care<sup>5</sup>.

By 2030, Malaysia will be an aging nation where the proportion aged 60 and above will make up 14% of the population<sup>6</sup>. In light of this, the urgency for palliative care to be delivered at some minimum standards, and as part of an integrated approach and a fundamental component of the continuum of care throughout the life course, is growing stronger.

Therefore, more support for public awareness initiatives to inform and educate the general public is important to drive the changes required at the national, community and provider levels.

### OPIOPHOBIA

As pain is one of the most common and distressing symptom that patients with a life-limiting illness will

face, pain management is integral in palliative care. Pain can be effectively controlled with the use of opioid medications, which are also the least expensive and simplest method of pain management.

Sadly, fears and myths of addiction, strict regulation, and inadequate training and understanding of the use of opioid medications among healthcare professionals, can limit access to oral morphine and other opioid preparations for pain management.

'Opiophobia' was coined to describe the unreasonable fear about the risks associated with opioids, which can arise in patients, family members, healthcare providers, and members of the public.

### PALLIATIVE CARE AWARENESS MONTH: APRIL 2017

To draw attention to this issue, the global theme "Living & Dying in Pain, It Doesn't Have to Happen", set by the Worldwide Hospice Palliative Care Alliance (WHPCA) has been adopted by Hospis Malaysia for a month-long public awareness campaign throughout April 2017.

This campaign aims to reach more Malaysians through strategic partnerships and collaborations with other hospices and palliative care organisations, and the involvement of selected private businesses, medical centres and learning institutions within the Klang Valley.

An array of events, exhibitions, public talks, and fundraising activities have been planned for the month of April 2017, targeted at the general public. Concurrently, on-going engagement with healthcare professionals will take place through a series of continuing medical education and training activities.

For the list of events occurring in April 2017, please see Page 12 or check out [hospismalaysia.org](http://hospismalaysia.org) ■

*One of the key barriers to more people in need accessing palliative care services is the lack of awareness by the public. A public survey in 2015 revealed that over 90% of Malaysians are unaware about palliative care*

### References:

1. United Nations. Draft Resolution (A/67/L.36) Global health and foreign policy, 6 Dec 2012.
2. WHO. 67th World Health Assembly: Resolutions & Decisions Annexes, 2014.
3. WHPCA. Universal access to palliative care must be an urgent priority to meet the new global goal on health and well-being, [thewhpc.org](http://www.thewhpc.org), 1 Oct 2015. Viewed 3 Mar 2017 <<http://www.thewhpc.org/resources/item/universal-access-to-palliative-care-must-be-an-urgent-priority-to-meet-to-new-global-goal-on-health-and-well-being>>
4. WHO. Global Atlas of Palliative Care at the End of Life, Jan 2014.
5. Hospis Malaysia. Palliative Care Needs Assessment 2016: Malaysia.
6. United Nations, Department of Economic and Social Affairs, Population Division (2015). World Population Ageing 2015.

## DEFINING A ROAD MAP AT HOSPIS MALAYSIA

By Rini Vella, Advocacy & Media, Hospis Malaysia

### MODERN PALLIATIVE CARE MOVEMENT CELEBRATES ITS 50TH ANNIVERSARY

A diagnosis of a life-limiting disease inadvertently affects everyone - the patient, their family, carers and healthcare providers alike. In the early 1960's in the United Kingdom, Dame Cicely Saunders established the modern discipline of palliative care and with it, revolutionised the way people with serious illnesses were treated. She introduced the idea that people who live with life-limiting illnesses (such as cancer, organ failure, AIDS/HIV) need dignity, compassion and respect in the care they receive.

This year marks the 50<sup>th</sup> anniversary of the modern palliative care movement.

Below are our three core development areas:



**Development area 1:  
Enhanced patient services**

Through our own patient services, we are looking at:

1. Increased and more effective patient contact,
2. Greater focus on improving quality of care,
3. Developing standards of care through quality and process indicators



**Development area 2:  
Improved training  
of healthcare professionals**

Work is under way to:

1. Increase capacity for training at all levels
2. Develop research with priorities in patient care
3. Create a teaching and research hub to bring together stakeholders for greater integration and coordination



**Development area 3:  
Increased public advocacy  
for better access**

In response to the public perception survey we conducted in 2015, we recognise the importance of greater public awareness of the benefits of palliative care, and will continue to mobilise resources to:

1. Improve public knowledge and perception in dealing with life-limiting illnesses
2. Advocate for the rights of patients and their families to have the option of accessing palliative care either in hospital or in the community (at home).
3. Effectively engage with policy makers and key stakeholders to advocate for the rights of these patients and families to be supported by healthcare workers, employers and medical insurance through supportive legislation.

### DEFINING A ROAD MAP AT HOSPIS MALAYSIA AFTER 25 YEARS

In 2016, Hospis Malaysia celebrated its 25<sup>th</sup> anniversary and recognised the need to define a road map and a set of guiding principles to help it achieve its goals and ultimately its vision.

We put together a set of tools to help us:

- We identified key areas where we could play a role in developing palliative care services in the country;
- We commit that our next phase of development will be about a nation coming together to alleviate the suffering of over 55,000\*1 people each year suffering from life-limiting illnesses, through more equitable access to quality palliative care.

1 Palliative Care Needs Assessment Report: Malaysia (2016)

## RAISING AWARENESS OF PALLIATIVE CARE AMONGST MEDICAL STUDENTS

By Rini Vella, Advocacy & Media, Hospis Malaysia

**23 March 2017** - The Asian Medical Students' Association (AMSA) is a representative organisation for medical students from across Asia, the Asia-Pacific and beyond who share knowledge and undertake activities and social services. As part of their project titled 'Dignity, Comfort & Support', the AMSA of International Medical University (IMU) partnered with Hospis Malaysia recently to raise awareness of palliative care among medical students across the Klang Valley.

Based on their research and readings in international medical papers, the AMSA of IMU organising committee, comprising first year medical students, felt it was essential that their fellow medical students be more aware of palliative care. "Not many medical students in Malaysia are aware of what palliative care is. We felt that they should," shares Soo Cher Pin, Chairman of the organising committee. "Palliative care is becoming increasingly recognised internationally as an essential element in medical care. Even then, emphasis that only cancer diseases need palliative care needs to shift. Studies show that there is a growing need to cater for patients with other diseases that may require palliative care such as organ failure, children with congenital issues as well as cardiovascular diseases. We researched for organisations providing palliative care, and contacted Hospis Malaysia to collaborate", adds Cher Pin.

Medical students from universities around the Klang Valley were invited to attend the event which contained our palliative care themed photo exhibition; palliative care themed games and activities aimed at improving palliative care knowledge, as well as a talk on palliative care presented by Dr Sylvia McCarthy, Medical Director of Hospis Malaysia. Besides raising awareness for palliative care, the organising committee fundraised for Hospis Malaysia through sales of our merchandise and collecting general donations.

An activity that stood out to visitors was the thought provoking board captioned 'If you were seriously ill, what's important to you?'. "The board aimed to encourage future medical professionals to think about and start asking questions about the type of care and quality of life their future patient's may or may not want when faced with an illness", says organising committee member Chew Xin Hui. ■



*"Not many medical students in Malaysia are aware of what palliative care is"*



## A DAY IN THE LIFE OF COMMUNITY PALLIATIVE CARE NURSES

By Rini Vella, Advocacy & Media, Hospis Malaysia

Every day is different for a community palliative care nurse. At Hospis Malaysia, our palliative care nurses are the frontline to our patients and their families and are trained to be independent clinicians. What does being a community palliative care nurse involve and how does it differ from basic nursing? To shed some light, our palliative care nurses Pam Ho, Vicky Pannirselvam, Mastura Mhd Rashid, Nadiah Jaafar and June Thow share a day in their lives as a community palliative care nurse.



Our palliative care nurses' day begins early in the morning as they tend to their personal obligations before starting their day at eight in the morning at Hospis Malaysia. "My work day starts at 8 am and ends at 5 pm, Monday to Friday. I also work on-call on a rotational basis which includes weekends. My patients' pain, symptoms and other issues do not stop when I finish work at 5 pm every day. They need a dependable service to cater to their emergency needs – our 24-hour emergency on-call service helps with that," shares Vicky.



Each morning the clinical team of palliative care doctors, nurses, a pharmacist and occupational therapist meets to discuss and find the most effective solutions to address each patient's needs. Our nurses will spend the rest of their day visiting and checking up on their patients. Some of their visits will be urgent to see patients who have become more unwell. Other visits are just to check up on how patients are doing or to meet with carers to discuss their concerns. Often a

phone call to inquire about the well-being of a patient and their family can go a long way to assuring them that we are a phone call away.

"My job aims to relieve the suffering of my patients. When I first meet my patients, they are often anxious and fearful about their condition and may have symptoms like pain or vomiting which are not controlled. My job is to talk to them, to understand their problems whether it is physical symptoms or the emotional distress that comes with having a serious illness. Then together, we work out a plan of how best to help reduce some of the suffering. I also need to anticipate what my patients may face as their illness progresses, so that we have a plan in place, shares Pam.

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She explains that her duties also require her to be an attentive listener and have the ability to communicate well, to address concerns of both her patients and their families.

“Palliative care in the community offers an entirely different type of nursing career than what we are used to in hospitals. In addition to the usual nursing duties, I have the unique opportunity to spend quality time with my patients, shares Mastura who was a hospital based nurse for four years before joining Hospis Malaysia. She explains that she is encouraged to teach her evidence-based palliative care skills through various training and educational channels.

“I feel confident conducting home visits alone. Doubts and questions are discussed under the guidance of Hospis Malaysia’s doctors at our morning meetings or via phone and every medical decision is made with confirmation from the doctors,” adds Nadiah.

“My duty as a community palliative care nurse includes on the ground training to caregivers of patients on how to handle basic and routine nursing care at home. I also need to be able to identify the cause of my patients’ pain, or other symptoms such as nausea or diarrhoea to be able to treat it. My knowledge of anatomy and physiology of a patient needs to be good, to be able to explain to the patient what is going on and to recommend the appropriate treatment” shares June.

Attracting the right nurses to be trained in palliative care who can work independently is an ongoing challenge at Hospis Malaysia. Over the years, we have been fortunate to benefit from support of the community to fund these nurses. More recently Yayasan Sime Darby (YSD) through its “YSD -Hospis Malaysia Palliative Care Home Visit Programme” supports the work of several of Hospis Malaysia’s palliative care nurses with a three-year commitment. ■

## JOB VACANCY

### PALLIATIVE CARE NURSE

**We are looking for dedicated and motivated nurses to join Hospis Malaysia’s multidisciplinary team of palliative care professionals.**

**Our ideal nurse will be knowledgeable and compassionate whilst having good communication skills. Training is provided on the job.**



**For more information, visit [hospismalaysia.org](http://hospismalaysia.org) or email us at [info@hospismalaysia.org](mailto:info@hospismalaysia.org)**

# PALLIATIVE CARE AWARENESS MONTH

## APRIL 2017

### CALENDAR OF EVENTS

DATE	EVENT												
APR 1 - 2	<p><b>WORKSHOP ON CLINICAL ETHICS IN PALLIATIVE CARE</b></p> <p>Venue: Hospis Malaysia Time: 9 AM – 5 PM</p>												
APR 3 – 13	<p><b>PALLIATIVE CARE AWARENESS AND CONTINUING MEDICAL EDUCATION ACTIVITIES WITH HEALTHCARE PROVIDERS</b></p> <table border="1"> <thead> <tr> <th>Date</th> <th>Time</th> <th>Hospital</th> <th>Event</th> </tr> </thead> <tbody> <tr> <td>April 3</td> <td>9am – 3pm</td> <td>Tung Shin Hospital</td> <td>Palliative Care Exhibition</td> </tr> <tr> <td>Apr 12 - 13</td> <td>9am – 3pm</td> <td>Sime Darby Medical Centre (SDMC)</td> <td>Palliative Care Exhibition</td> </tr> </tbody> </table>	Date	Time	Hospital	Event	April 3	9am – 3pm	Tung Shin Hospital	Palliative Care Exhibition	Apr 12 - 13	9am – 3pm	Sime Darby Medical Centre (SDMC)	Palliative Care Exhibition
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April 3	9am – 3pm	Tung Shin Hospital	Palliative Care Exhibition										
Apr 12 - 13	9am – 3pm	Sime Darby Medical Centre (SDMC)	Palliative Care Exhibition										
APR 13	<p><b>KUALA LUMPUR PIANO TRIO FUNDRAISER</b></p> <p>Venue: Wei Ling Gallery, Gardens Mall, Mid Valley City Time: 7.15 PM – 9.15 PM</p>												
APR 13	<p><b>PUBLIC LECTURE ON PALLIATIVE CARE</b></p> <p>Professor Bee Wee, National Clinical Director of End-of-Life Care, National Health Service, England</p> <p>Venue: Majestic Hotel, Kuala Lumpur Time: 6.30 PM - 9 PM</p>												
APR 19	<p><b>CAREGIVERS WORKSHOP: LOOKING AFTER PATIENTS WITH PRESSURE SORES AND CANCER WOUNDS</b></p> <p>Venue: Hospis Malaysia Time: 1-3 PM</p>												
APR 22	<p><b>HOSPIS MALAYSIA 16<sup>TH</sup> CHARITY TREASURE HUNT, KUALA LUMPUR - IPOH</b></p> <p>Flag off Venue: Bangsar Village</p>												

For inquiries, email [pr@hospismalaysia.org](mailto:pr@hospismalaysia.org) or visit [hospismalaysia.org](http://hospismalaysia.org)